CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with and carers of people diagnosed with:

CARDIAC AMYLOIDOSIS + OTHER FORMS OF AMYLOIDOSIS

Volume 3 (2020), Issue 1

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PEEK study process information

Volume	3
Issue	1
Reference	Centre for Community-Driven Research (CCDR). Personal Experience Expectations and Knowledge (PEEK) study: People diagnosed with and carers of people diagnosed with cardiac amyloidosis and other forms of amyloidosis. Volume 3, Issue 1 (2020)
CCDR research team	Catherine Holliday, Anne Holliday, Lara Baker, Klair Bayley, Ishka Bless, Vanessa Brunelli, Josephine Byrne, Katriona Christiansen, Eve Houghton, Jenny Hutton
Recruitment start date	15 July 2019
Recruitment end date	8 October 2019
Were there breaks in recruitment?	Yes. This was due to summer bushfires, followed by floods and then Covid-19
Recruitment re-start date	15 April 2020
Recruitment final end date	22 June 2020
Length of time for recruitment	163 days
Data analysis commencement	23 June 2020
Final report completed	29 August 2020
Number of participants	34
Total amount of interview time	30 hours 39 minutes 13 seconds
Average interview time	59 minutes 19 seconds

Summary of results

Executive summary

There were 36 participants in the study from across Australia, 28 diagnosed with amyloidosis, and eight carers to people with amyloidosis. The majority of participants were from Queensland and New South Wales, and most lived in major cities, they lived in all levels of advantage. Most of the of participants identified as Caucasian or white, aged mostly between 65 and 74. Half of the participants had completed some university, and most were retired.

Participants in this PEEK study were most commonly diagnosed with ATTR, either hereditary or wild type. Most of the participants also had other health conditions they had to manage, approximately 44% of the participants had anxiety and/or depression.

This is a patient population that experienced fatigue as the most common symptom leading to diagnosis. They most commonly had five or six diagnostic tests to get their diagnosis, and were diagnosed more than a year after first noticing symptoms. They had out of pocket expenses for their diagnosis, but usually the cost wasn't a significant burden. Most participants felt they had enough emotional support and information from healthcare professionals at the time of diagnosis.

This is a patient population that experienced excessive weight loss, breathlessness and tiredness as key symptoms leading to their diagnosis. Half of the participants described seeking medical attention relatively soon after they started experiencing symptoms.

This is a study cohort that described knowing nothing or very little about their condition prior to diagnosis.

This is a patient population that had conversations about treatment where multiple options were presented. They mostly took quality of life, efficacy of treatment, and side effects into consideration when making treatment decisions, their decision making had not changed over time. They commonly did not have many discussions about biomarkers and were not sure if they had any.

This is a group who felt they were treated with respect throughout their experience. They were most commonly treated for ATTR-CM with loop-acting diuretics, and doxycycline; and were most commonly treated for AL amyloidosis with melphalan and dexamethasone. Half of this study population made lifestyle changes following diagnosis, and most used complementary therapies to manage their amyloidosis

Most of the participants in this study population reported having discussions about clinical trials with their clinician and though only one had taken part in a clinical trial. Participants in this study would be willing to participate if there was a suitable trial for them.

This is a patient population that described mild side effects as fatigue and diarrhoea. They described severe side effects as pain, neuropathy, nausea and vomiting.

Within this patient population, most participants adhered to treatment at the advice of their clinician or as long as it was prescribed. They felt that evidence of stable disease and an improvement in general well-being were needed to feel like treatment was effective.

This is a patient population that primarily needed the advice of their clinician as well as information about side effects, scientific evidence and clinical advice or expertise in order to feel comfortable trying new treatments.

The cohort was split between people who did not need support to have treatment at home, and those who needed the support from family or friends, regular check-ups from a GP or nurse, and someone to call if they had a question or issue.

Participants in this study had excellent knowledge about their condition and treatments, an excellent ability to adhere to treatments and communicate with healthcare professionals, excellent recognition and management of

symptoms, and a very good ability to manage the effects of their health condition on emotional well-being, social life and healthy behaviours.

This is a patient population that primarily accessed information through the internet, books, pamphlets and newsletters as well as from specific health charities. They found information from reliable sources and from their doctors helpful, and preferred to get information by talking to someone. They were most receptive to information at the time of diagnosis.

The participants in this PEEK study had very good communication, navigation and overall experience of care coordination. They mostly experienced positive communication from health care professionals with holistic, two way, and supportive conversations.

This is a patient population that experienced support and care from family and friends, through hospital or clinical settings, peer support and charities though some reported the challenges of finding or accessing support.

This is a patient population where their condition had an impact on their mental and emotional health, and it had a negative impact on their quality of life. The participants in this PEEK study had moderate levels of anxiety in relation to their condition. They managed their general health by understanding their limitations.

This is a group who would most like to control heart and lung symptoms. The most important aspect for making decisions about their own treatment was medication safety, and they thought that decision-makers should consider quality of life when making decisions about treatment for people with amyloidosis.

This is a patient population that would like future treatments to be more affordable, and more effective.

This is a study cohort did not have any recommendations for information about their condition, but want more access to support services. They would like health professionals to have more knowledge of their condition.

This is a patient population that felt grateful for healthcare staff and the entire health system in general.

This is a patient population that wanted to tell patients and families in the future that they should seek peer support and join support groups, as well as seeking and accepting support in general.

Section 1 Summary: Introduction and methodology

About this condition

Amyloidosis is a heterogeneous disease, where amyloid deposits form and accumulate in tissues and organs of the body. It can be acquired or hereditary, localised or systemic. The amyloid deposits can accumulate in the heart, kidneys, spleen, nerves, and blood vessels [1].

Participants

To be eligible for the study, participants needed to have been diagnosed with ATTR-CM or AL amyloidosis, or be a carer to someone diagnosed with either condition, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Initial recruitment commenced in July 2019 to October 2019 and recommenced April 2020 to June 2020.

Personal Experience, Expectations and Knowledge (PEEK): Study position

In this PEEK study, 28 people diagnosed with amyloidosis, and 8 carers to people with amyloidosis throughout Australia participated in the study that included a qualitative structured interview and quantitative questionnaire. This study in amyloidosis is therefore the largest mixed methods study reported in an Australian population, and it includes the most patient interviews worldwide. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Section 2 Summary: Demographics

Participants

- In this PEEK study, 28 participants with amyloidosis, and 8 carers to people with amyloidosis were recruited into the study, 14 females (38.89%) and 22 males (61.11%), aged mostly between 55 and 74 (n=27, 75.00%), and most participants identified as Caucasian/white (n=33, 91.67%).

- Participants were most frequently from Queensland (n=14, 38.89%), New South Wales (n=11, 30.56%), and Western Australia (n=6, 16.67%). Most participants were from major cities (n=27, 75.00%) and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) with 25 participants (69.44%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 11 participants (30.56%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Baseline health

- The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, where a higher score denotes better health or function.

- The **"SF36 Role functioning/emotional"** scale measures how emotional problems interfere with work or other activities. On average, any emotional problems of the participants in this study slightly interfered with work or other activities. The **"SF36 Emotional well-being"** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, the participants in this study participants felt happy and calm most of the time, and anxious and depressed a little of the time.

- The **"SF36 Physical functioning"** measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities for participants in this study moderately limited. The "**SF36 Role functioning/physical"** scale measures how physical health interferes with work or other activities. On average, physical health of the participants in this study interfered quite a bit with work or other activities.

- The **"SF36 Social functioning"** scale measures the limitations on social activities due to physical or emotional problems. On average for the participants in this study, social activities were slightly limited

- The "SF36 Role Energy/Fatigue" scale measures the amount of energy or fatigue. On average the participants in this study had moderate energy/fatigue, that is, felt tired some of the time and had energy some of the time.

- The **"SF36 Pain"** scale measures the amount of pain, and how pain interferes with work and other activities. On average, the participants in this study had moderate pain.

Section 3 Summary: Symptoms and diagnosis

Symptoms

- Participants had between zero and 13 symptoms (median = 5.00, IQR = 3.00), most commonly three to four symptoms (n=6, 21.43%) (Table 3.1). The most common symptoms for all participants were fatigue (n=18, 64.29%), being short of breath (n=16, 57.14%), limb weakness (n=16, 57.14%), and light-headedness (n=16, 57.14%).

- The median quality of life was between 1.00 and 4.00, for all of the symptoms listed in the questionnaire, this is in the "Life was very distressing" to "Life was average" range. Median quality of life for the most common symptoms (fatigue, short of breath, light-headedness, and limb weakness) was between 3.00 and 4.00, in the life was a little distressing.

Symptoms leading to diagnosis

- In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was excessive weight loss (n=8, 22.22%). There were seven participants (19.44%) who described experiencing breathlessness and four participants (11.11%) who described having tiredness. A final four participants (11.11%) identified a specific physical sensation, such as numbness or tingling in their fingers or toes, which led to their diagnosis.

- When discussing symptoms leading to their diagnosis, participants described how soon after experiencing symptoms they sought medical attention. There were five participants (13.89%) that described having symptoms and not seeking medical attention initially but recognising the importance of those symptoms in hindsight. An additional three participants (8.33%) also mentioned having symptoms and not seeking medical attention initially, but they provided no reason for this.

- Overall, 18 participants (50.00%) described having symptoms and seeking medical attention relatively soon. There were eight participants (22.22%) that described having symptoms and not seeking medical attention initially, and a final five participants (13.89%) that described having no symptoms or not noticing them prior to diagnosis.

- There were nine participants (25.00%) that described a diagnostic pathway that required appointments with a general practitioner and two or more specialists. There were also nine participants (25.00%) who described receiving a diagnosis following referral from their general practitioner to a specialist. A final six participants (16.67%) described receiving diagnosis following a specialist ordering tests. They made no mention of a GP referral.

- When discussing symptoms, overall participants had either a strong recollection of symptoms (69.44%) or describes not experiencing any symptoms prior to diagnosis (11.11%).

Diagnostic tests

- Participants had between one and 11 diagnostic tests, most commonly five to six tests (n=11, 39.29%) (Median = 6.5, IQR = 3.25) (Table 3.5, Figure 3.5). The most common diagnostic tests were blood tests (n=23, 82.14%), electrocardiogram (n=18, 64.29%), and echocardiogram (n=16, 57.14%).

Time from symptoms to diagnosis

- Participants most commonly had more than a year between noticing symptoms and being diagnosed (n=11, 42.31%), followed by between 6 months and a year (n=7, 26.92%). There were five participants (19.23%) that had noticed symptoms between one and six months before getting diagnosed, and three participants (11.54%) that had less than one month.

Time from diagnostic tests to diagnosis

- The majority of participants waited between 2 and 3 weeks (n=8, 28.57%) or more than 4 weeks (n=8, 28.57%).

Diagnosis provider and location

- The diagnosis was given most commonly by the haematologist (n=9, 32.14%), followed by a cardiologist (n=7, 25.00%). The diagnosis was most commonly given at a specialist clinic (n=28, 67.86%).

Understanding of disease at diagnosis

- Participants were asked in the structured interview how much they knew about their condition at diagnosis and the reason for their level of knowledge. There were 15 participants (41.67%) that gave no specific reason for their level of knowledge. There were eight participants (22.22%) who said they came to understand their condition more over time and through lived experience, and four participants (11.11%) described knowing very little about their condition at diagnosis, but that they were aware of family history with the condition.

- Overall, there were 27 participants (75.00%) that described knowing nothing or very little at diagnosis and these were the most common themes. There were three participants (8.33%) who noted that they knew good amount about the condition at diagnosis.

Emotional support at diagnosis

- Almost half of participants (including carers) had enough support (n=17, 47.22%), 6 participants (16.67%) had no support, and 13 participants (36.11%) had some support but it wasn't enough.

Information provided at diagnosis

- The majority of participants had enough information (n=20, 71.43%) at diagnosis. There were eight participants (28.57%) that had some information but not enough, and there were no participants that had no information at all at diagnosis.

Costs at diagnosis

- There were 12 participants (42.86%) who could recall the out of pocket expenses at diagnosis. There were eight participants who had no out of pocket expenses at diagnosis (28.57%), two that spent between $100 and $500 (7.14%), four who spent between $500 and $1000 (14.29%), and two who spent more than $1000 (7.14%) in out of pocket expenses

- In the follow-up question about the burden of costs at diagnosis, for 12 participants (60.00%) the cost was either slightly significant or not significant at all. For 5 participants (25.00%) the out of pocket expenses were somewhat significant, and for 3 participants (15.00%), the burden of out of pocket expenses were moderately significant.

Genetic tests and biomarkers

- The majority of participants had no conversation about biomarker/genomic/gene testing that might be relevant to treatment (n=17, 60.71%). There were three participants who brought up the topic with their doctor (10.71%), and eight whose doctor brought up the topic (28.57%).

- Over half of the participants (not including carers) have not had any testing but would like to (n=15, 53.57%). There were a total of 10 participants that had the test, either paying for it themselves (n=5, 17.86%), or not paying out of pocket (n=5, 17.86%). Three participants did not have the test and had no interest in having one (10.71%).

- The majority of participants were not sure if they had specific biomarkers (n=15, 53.57%), there were five that stated they had no biomarkers (17.86%), and eight that were able to name specific markers that they had.

Understanding of prognosis

- Participants were asked in the structured interview to describe what their current understanding of their prognosis was. There were 15 participants (41.67%) that described that they had a discussion about prognosis, and there were 14 participants (38.89%) did not mention having discussions about prognosis.

- Overall, 18 participants (50.00%) described having a clear understanding of their prognosis and 11 described having an unclear understanding (30.56%).

- There were two main themes that were equally reported, including participants describing their prognosis in relation to the specific medical interventions they need to manage their condition (n=9, 25.00%) and relating their prognosis to a specific timeframe that they are expected to live (n=9, 25.00%). There were eight participants (22.22%) that described their prognosis in relation to poor outcomes or as a terminal condition and five participants (13.89%) that understood their prognosis as positive and their condition as manageable.

Section 4 Summary: Decision-making

Discussions about treatment

- Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common response from participants was that it was difficult to remember/other response (n=14, 38.89%) which was closely followed by multiple treatment options were discussed which was described by 13 participants (36.11%). Six participants described discussing one treatment option (16.67%) and three participants described no treatment options being discussed (8.33%).

- Among participant who discussed multiple treatment options, five described participating in decision-making (13.89%), four described not participating in the decision-making process (11.11%) and four described being told what to do without discussion (11.11%). Three participants described being presented with no options because no therapies were available (8.33%). Out of those who were presented with one option three participants described being told what to do without discussion (8.33%) and two participants described some but very little discussion (5.56%).
- Some participants described discussions of specific treatments. Six participants described discussing the option of a stem cell transplant (16.67%), while four participants described discussing the option of a liver transplant (11.11%). Other participants described being presented with the option of chemotherapy (n=3, 8.33%), Green tea extract (n=3, 8.33%), Velcade or dexamethasone (n=3, 8.33%) and Bone marrow transplant (n=2, 5.56%).

Decision-making

- Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was quality of life as part of multiple aspects that they consider when making decisions about treatment and this was described by 13 participants (36.11%). This was followed by efficacy as part of multiple aspects they consider (n=9, 25.00%); side effects as part of multiple aspects they consider (n=9, 25.00%); the long term impact and side effects of treatment as part of multiple aspects they consider (n=7, 19.44%), taking the advice of their clinician as part of multiple aspects they consider (n=6, 16.67%), considering the potential impact on their family or dependents as part of multiple aspects they consider (n=5, 13.89%), survival benefit as part of multiple aspects they consider (n=5, 13.89%) and taking the advice of their clinician as the only aspect they consider (n=5, 13.89%).

Changes in decision-making

- Participants were asked if the way they made decisions had changed over time. There were 15 participants (41.67%) that felt the way they made decisions about treatment had not changed over time, and 12 participants (33.33%) that described decision-making changing. Nine participants (25.00%) were unsure/other or gave no response.

- Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed and/or assertive (n=7, 19.44%). Three participants described their decision-making changing over time as they are more aware of their health, responsibilities and/or limitations (8.33%) Other participants described changing over time as they are more accepting of their condition and choices available (n=1, 2.78%), they are more focused on how treatment impacts their family and dependents (n=1, 2.78%), they are more cautious and considered (n=1, 2.78%) and they are more focused on quality of life or the impact of side effects (n=1, 2.78%).

- Among participants who described no change in the way they make decisions the most common response was that this was because they had always been informed/assertive (n=7, 19.44%) followed by those who did not mention any reason (n=4, 11.11%). Other responses were that there had been no change because they always took the advice of clinicians (n=2, 5.56%) and because they have had no treatment options to choose from (n=1, 2.78%).

Section 5 Summary: Treatment

Main provider of treatment

- The haematologist was the main provider of amyloidosis treatment for the majority of participants (n=19, 67.86%).

Access to healthcare professionals

- All participants had access to a general practitioner (n=28, 100.00%) and the majority had access to a cardiologist (n=26, 92.86%), and haematologist (n=24, 85.71%) for the treatment of their amyloidosis.

Respect shown

- The majority of participants indicated that they had been treated with respect throughout their experience (n=31, 86.11%), five participants (13.89%) participants felt they had been treated with respect with the exception of one or two occasions, there were no participants who felt they weren't treated with respect.

Healthcare system

- The majority of participants had private healthcare insurance (n=23, 82.14%), five participants (17.86%) asked if they want to be treated as a public or private patient. The majority of participants had not been asked if they had private health insurance (n=15, 53.57%). Throughout their treatment, equal numbers of participants were treated as a public patient (n=11, 39.29%), or private patient (n=11, 39.29%), and most commonly in the public hospital system (n=13, 46.43%) (Table 5.4).

Affordability of healthcare

- The majority of participants never cancelled their appointments due to cost (n=23, 82.14.00%), while four (14.29%) participants rarely had to cancel appointments. Almost all participants (n=27, 96.43%) never had any trouble paying for prescriptions.

Cost of amyloidosis

- Almost all participants never or rarely found it difficult to pay for basic necessities such as housing food and electricity (n=25, 89.29%). There were two participants (7.14%) had to pay for additional carers for themselves or their family. Participants spent between $0 and $1400 per month on amyloidosis. The amount spent was extremely significant or moderately significant burden for 4 participants (14.29%), five found it somewhat significant (17.86%), and 19 participants found costs slightly or not at all significant (67.86%).

Changes to employment status

- Half of the participants (n=18, 50.00%) of this PEEK study were retired at the time of the amyloidosis diagnosis. There were six participant (16.67%) that quit their job, and four (11.11%) reduced their work hours.

- There were 25 (89.29%) participants with a main partner or carer, 13 partners or main carers (46.43%) did not have a job or were retired at the time of diagnosis, seven (25.00%) had no change in employment status, and three (10.71%) quit their job.

Reduced income due to amyloidosis

- A third of participants (32.14%) had a reduced family income due to amyloidosis. Participants noted a drop in monthly income of between $100 to over $5,000 per month. For 18 of these participants (54.54%), the burden of this reduced income was extremely or moderately significant.

Treatment

- The most common drugs taken for *ATTR-cardiac* subgroup were loop-acting diuretics (n=8, 44.44%), followed by doxycycline (n=7, 38.89%), and Diffusional (n=5, 27.78%).

- The most common treatment for *AL-amyloidosis* subgroup was Melphalan and Dexamethasone (50.00%).

Surgery

- There were five participants that had surgery, four participants had a single surgery for amyloidosis, and one patient had four or more surgeries. The types of surgeries that participants had include pacemaker related surgeries, liver transplant, defibrillator fitting, and carpal tunnel surgery.

Lifestyle changes

- Nearly half of the participants made no lifestyle changes (n=13, 46.43%). The most common lifestyle changes were exercise (n=12, 42.86%), and diet (n=9, 32.14%).

Complementary therapies

- There were 24 participants (85.71%) that used some form of complementary therapies to manage their amyloidosis. The most common complementary therapies used were exercise (n=18, 64.29%) and dietary supplements (n=13, 46.43%), and for ATTR-cardiac participant, half weighed themselves daily (n=9, 50.00%).

Clinical trials

- There was a total of 26 participants (92.86%) that had discussions about clinical trials, either by bringing up the topic themselves (n=5, 17.86%) or their doctor bringing up the topic (n=21, 75.00%).

- There was a single participant (3.57%) who had taken part in a clinical trial, and 22 (78.57%) who would like to take part in a clinical trial if there was a suitable one.

Description of mild side effects

- In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common description of ‘mild side effects’ was in relation to a specific symptom as an example (n=19, 52.78%). The most common specific side effects given as an example was fatigue and/or tiredness (n=7, 19.44%) followed by diarrhoea (n=4, 11.11%). Another description of ‘mild side effects’ was those that can be self-managed and do not interfere with daily life (n=15, 41.67%).

Description of severe side effects

- In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of ‘severe side effects’ given was a specific side effect given as an example (n=17, 47.22%). The most common specific side effect given was pain (n=6, 16.67%), followed by neuropathy/sensory disturbance (n=4, 11.11%) and nausea or vomiting (n=4, 11.11%). Other descriptions

of 'severe side effects' included those that impact everyday life/ability to conduct activities of daily living (n=12, 33.33%). Four participants described coping with all side effects (11.11%).

Adherence to treatment

- Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common theme described was adhering as per the advice of their specialist or as long as its prescribed (n=16, 44.44%). Participants also reported not giving up on any treatment (n=6, 16.67%) and adhering to treatment for a specific amount of time (n=5, 13.89%).

What needs to change to feel like treatment is effective

- Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 11 participants (30.56%) was needing to experience evidence of stable disease or no disease progression. This was followed by needing to experience an improvement in general wellbeing (n=9, 25.00%).

Information needed to be confident in new treatments

- Participants were asked to describe what information would be needed to be confident in a new treatment. The most common response from17 participants (47.22%) was needing the advice of their clinician followed by 14 participants (38.89%) was needing to know about side effects to feel confident about trying a new treatment. There were 11 participants (30.56%) that reported needing scientific evidence and this was followed by needing to conduct their own research (n=9, 25.00%); needing to know about efficacy (n=9, 25.00%) and needing to know the overall benefits (n=8, 22.22%).

Support needed for treatment at home

- Participants were asked to describe what support they would need if they were having treatment at home. The two most common responses were participants not needing support (n=8, 22.22%) and needing support from their friends or family (n=8, 22.22%). There were seven participants that reported needing regular check-ups with a GP or nurse (19.44%) and this was followed by needing someone to call if they have a question or issue (n=4, 11.11%). Four participants described needing training and education on how to administer treatment.

Section 6 Summary: Information and communication

Access to information

- In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 20 participants (55.56%) was through the internet in general. This was followed by books, pamphlets and newsletters (n=15, 41.67%) and information from specific health charities (n=12, 33.33%). There were eight participants (22.22%) that described accessing information through their treating clinician and seven participants (19.44%) that described accessing information through Facebook and/or social media. Other types of information accessed included other patients' experiences (n=4, 11.11%) and primarily through journals or research articles (n=4, 11.11%).

Information that has been helpful

- In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 12 participants (33.33%) was information from reliable source, and this was followed by talking to their doctor or specialists (n=7, 19.44%). There were six participants (16.67%) that described health charities as being helpful and six (16.67%) that described information that's easy to understand as being helpful. Other types of information described as being helpful included information about what to expect (n=5, 13.89%), information specific to their condition (n=5, 13.89%) and other people's experiences (n=4, 11.11%).

Information that has not been helpful

- In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response by 18 participants (50.00%) was that no information was not helpful, and this was followed by GP and specialists as being not helpful (n=5, 13.89%).

Information preferences

- Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone app. Overall, the most common theme was talking to someone (n=10, 27.78%). There were seven participants (19.44%) that described a preference for talking to someone plus online information. There were also seven participants (19.44%) that described online information as their main preference.

- There were 12 participants (33.33%) whose rationale for their preference was simply a personal preference or gave no strong rationale for their preference. Among those who gave a rationale for their preference, seven (19.44%) described it as due to being able to digest information at their own pace and six (16.67%) described it as due to being able to, or having time to, ask questions.

Timing of information

- Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was from the beginning/diagnosis (n=12, 33.33%) and this was followed by participants describing being receptive to information a specific amount of time after (n=7, 19.44%). There were six participants (16.67%) that described being receptive to information after the shock of diagnosis.

Partners in health

- The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score.

- The **"Partners in health: knowledge"** scale measures the participants knowledge of their health condition, treatments, their participation in decision-making and taking action when they get symptoms. Participants in this study had excellent knowledge about their condition and treatments.

- The **"Partners in health: coping"** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). Participants in this study had very good ability to manage the effects of their health condition on emotional well-being, social life and healthy behaviours.

- The **"Partners in health: treatment"** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. Participants in this study had an excellent ability to adhere to treatments and communicate with healthcare professionals.

- The **"Partners in health: recognition and management of symptoms"** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. Participants in this study had excellent recognition and management of symptoms.

Information given by health professionals

- Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=27, 75.00%), disease management (n=26, 72.22%), and disease cause (n=22, 61.11%) were most frequently given to participants by healthcare professionals, and information about psychological/social support (n=8, 22.22%), and complementary therapies (n=4, 11.11%) were given least often.

Information searched independently

- Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. Information about disease management (58.33%) disease cause (55.56%), and treatment options (55.56%) were most often searched for independently by participants. Psychological/social support (27.78%), and hereditary considerations (30.56%) were least searched for.

Information gaps

- The largest gaps in information, where information was neither given to patients nor searched for independently were for psychological/social support (n=21, 58.33%), hereditary considerations genes or genomic biomarker information (n=21, 58.33%), and complementary therapies (n=20, 55.56%). Participants were given most information either from healthcare professionals or independently for disease management (n=16, 44.44%), and treatment options (n=15, 41.67%). The topic that was most searched for independently following no information from health professionals was complementary therapies (n=12, 33.33%).

Most accessed information

- Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. Across all participants, information from the hospital or clinic where treated was most accessed, followed by information from non-profit or charities or patient organisations.

My Health Record

- My Health Record is an online summary of key health information, an initiative of the Australian Government. Eleven participants (39.29%) had accessed "My Health Record". There were 15 (53.57%) who had not, two participants did not know what it is (7.14%), and four participants (4.00%) were not sure. Of those that had accessed "My Health Record", five participants (45.45%) found it good or
- acceptable, six participants (54.54%) found it poor, or very poor.

Section 7 Summary: Care and support

Care coordination

- The **"Care coordination: communication"** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, the participants in this study scored in the middle of the scale, indicating that participants had moderate communication with healthcare professionals.

- The **"Care coordination: navigation"** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, the participants in this study had good navigation of the healthcare system.

- The **"Care coordination: total score"** scale measures communication, navigation and overall experience of care coordination. On average, participants in this study had very good communication, navigation and overall experience of care coordination.

- The **"Care coordination: care coordination global measure"** scale measures the participants overall rating of the coordination of their care. On average, participants in this study rated their care coordination as very good.

- The **"Care coordination: Quality of care global measure"** scale measures the participants overall rating of the quality of their care. On average, participants in this study rated their quality of care as excellent.

Experience of care and support

- In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most frequent description of care and support was family and friends (n=19, 52.78%). This was followed by receiving support through a hospital or clinical setting (n=14, 38.89%); through face-to-face peer support (n=10, 27.78%); through charities (n=7, 19.44%). There were seven participants that described finding or accessing support as challenging (19.44%).

Section 8 Summary: Quality of life

Experience of quality of life

- In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 19 participants (52.78%) that described a negative impact on quality of life and seven participants (19.44%) that felt that there had been minimal impact on their quality of life. The most common themes in relation to having a negative impact on quality of life included a reduced capacity for physical activity (n=15, 41.67%) and emotional strain on family or a change in relationship dynamics (n=13, 36.11%). There were also eight participants (22.22%) that described a negative impact as they are unable to travel or need to adapt significantly in order to travel. In addition, six participants (16.67%) described a negative impact as a result of fatigue, and another six (16.67%) noted a negative impact due to reduced social interaction. There were four participants (11.11%) that described a negative impact on their quality of life due to an inability to work or needing to make changes with their work.

Impact on mental health

- In the structured interview, participants were asked to share any impact on their emotional and mental health as a result of their condition. The most common theme that participants reported was experiencing at least some impact on their mental and emotional health (n=20, 55.56%). There were also seven participants (19.44%) that described experiencing no impact on their mental and emotional health overall.

Regular activities to maintain mental health

- In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common way that participants reported managing their mental and emotional health was by using coping strategies such as remaining social, making lifestyle changes or having hobbies (n=10, 27.78%). There were nine participants (25.00%) that described the importance of physical exercise in maintaining their mental health and seven (19.44%) that described the importance of family and friends in this endeavour. Other common themes included consulting a mental health professional (n=6, 16.67%), experiencing an impact but not using any activities to maintain their mental health (n=5, 13.89%) and not doing any activities to maintain their mental health as they have experienced no impact (n=4, 11.11%).

Regular activities to maintain health

- In the structured interview, participants were asked to share some of the things they needed to do every day to maintain their health. The most common way that participants reported managing their health was by understanding their limitations (n=15, 41.67%). There were 10 participants (27.78%) that described staying physically active and nine (25.00%) that described the importance of complying with treatment. Other common themes included maintaining a healthy diet (n=7, 19.44%) and the importance of self-care, for example getting more rest or seeking support for housework (n=5, 13.89%).

Impact on relationships

- In the structured interview, participants were asked whether their condition had affected their personal relationships. The most common themes in relation to impact on relationships was participants describing their relationships with family being strengthened (n=6, 16.67%) and experiencing changing dynamics in their relationships due to added anxiety, exacerbations and/or physical limitations (n=6, 16.67%).

- Overall, there were nine participants (25.00%) that described a negative impact on relationships, eight participants (22.22%) that reported a positive impact on relationships and seven participants (19.44%) that

felt that relationships had not been impacted. There were also five participants (13.89%) who noted an impact on their relationships but did not feel it was positive or negative overall.

Burden on family

- In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Where participants described there was no additional burden, this was primarily described in general terms, with no specific examples provided (n=11, 30.56%). On the other hand, where participants felt there was an additional burden, this was primarily described in relation to the additional mental or emotional strain placed on their family (n=7, 19.44%), the extra household duties and responsibilities their family needed to take on (n=6, 16.67%) and as a burden in general, with no specific examples (n=4, 11.11%).

- Overall, there were 16 participants (44.44%) that felt there was an additional burden and 11 participants (30.56%) that reported no additional burden.

Experience of anxiety related to disease progression

- The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Overall the participants had a mean total score of 33.19 (SD = 9.92), which corresponds to moderate levels of anxiety.

Section 9 Summary: Expectations and messages to decision-makers

Expectations of future treatments

- In the structured interview, participants were asked what their expectations of future treatments are. The most common theme was participants expected treatments to be more affordable (n=18, 50.00%), followed by the expectation that future treatments would be more effective (n=8, 22.22%). There were six participants (16.67%) that recommended future treatments should have fewer or less intense side effects and four participants (11.11%) that called for future treatments to be less invasive.

Expectations of future information

- Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was participants having no recommendations or feeling satisfied with the information currently available (n=7, 19.44%), and this was followed by the expectation that future information would be easier to understand (n=6, 16.67%). There were five participants (13.89%) that recommended more information to inform the community and decision-makers about the condition. There were also four participants (11.11%) who suggested future information provide more details about new treatments and trials and four participants (11.11%) that called for more details about the specific classification of their condition.

Expectations of future communication with healthcare professionals

- Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will involve health professionals having a better knowledge of the condition (n=13, 36.11%), and this was followed by no recommendations or participants feeling they had experienced good communication (n=10, 27.78%).

Expectations of future care and support

- Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was more access to support services in future (n=8, 22.22%), and this was followed by participants having no recommendations or being satisfied with the care they have received (n=6, 16.67%). There were four participants (11.11%) that recommended future care and support involving more peer support such as support groups and four participants (11.11%) that called for care and support to include more long-term condition management or care planning.

What participants are grateful for in the health system

- Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was participants expressing feeling grateful for the entire healthcare system (n=13, 36.11%). This was followed by those who were grateful for healthcare staff (n=10, 27.78%), low cost or free medical care through the government (n=10, 27.78%), timely access to treatment (n=5, 13.89%) and access to private healthcare/insurance (n=4, 11.11%).

Symptoms and aspects of quality of life

- Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported for participants with

ATTR-cardiac were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and arm and leg symptoms (e.g. numbing, tingling, weakness, pain).

- The most important aspects reported for participants with AL amyloidosis were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and kidney symptoms (fatigue, loss of appetite and swelling in feet, ankles or legs).

Values for decision-making

- Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were 'How safe the medication is and weighing up the risks and benefits', and 'The severity of the side effects'. The least important were 'The financial costs to me and my family'.

Values for decision-makers

- Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values were quality of life for patients, and access for all patients to all treatments and services; the least important was economic value to government.

Time taking medication to improve quality of life

- Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n=19, 67.86%) would use a treatment for more than ten years for a good quality of life, even if it didn't offer a cure.

Message to decision-makers

- Participants were asked, 'If you were standing in front of the health minister, what would your message be in relation to your condition?'. The most common message was that treatments need to be affordable (n=10, 27.78%). This was followed by the message that there should be more clinical trials and/or new treatments (n=8, 22.22%), that there should be improved access to support and care (n=6, 16.67%), the need to take the condition seriously (n=5, 13.89%), the need to invest in professional development so that clinicians better understand the condition (n=5, 13.89%) and finally, to invest in research, including the effort to find new treatments (n=4, 11.11%).

Section 10 Summary: Advice to others in the future

Advice to other patients and families in the future

- In the structured interview, participants were asked what advice they would give to other patients and their families. Six themes emerged as a result, the most frequent of which was that newly diagnosed patients should seek peer support or join support groups (n=9, 25.00%), followed by advice to seek and accept support in general (n=8, 22.22%). Other themes that emerged were to do research and ask questions (n=6, 16.67%), to find the best medical support for you which may include seeking a second opinion (n=5, 13.89%), try to stay positive (n=4, 11.11%) and finally, to be aware of your own body and trust your instincts (n=4, 11.11%).

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Section 1

Introduction and methods

Section 1 Introduction and methodology

About this condition

- Amyloidosis is a heterogeneous disease, where amyloid deposits form and accumulate in tissues and organs of the body. It can be acquired or hereditary, localised or systemic. The amyloid deposits can accumulate in the heart, kidneys, spleen, nerves, and blood vessels [1].

Participants

- To be eligible for the study, participants needed to have been diagnosed with ATTR-CM or AL amyloidosis, or be a carer to someone diagnosed with either condition, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Initial recruitment commenced in July 2019 to October 2019 and recommenced April 2020 to June 2020.

Personal Experience, Expectations and Knowledge (PEEK): Study position

- In this PEEK study, 28 people diagnosed with amyloidosis, and 8 carers to people with amyloidosis throughout Australia participated in the study that included a qualitative structured interview and quantitative questionnaire. This study in amyloidosis is therefore the largest mixed methods study reported in an Australian population, and it includes the most patient interviews worldwide. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Introduction

Amyloidosis is a heterogeneous disease, where amyloid deposits form and accumulate in tissues and organs of the body. It can be acquired or hereditary, localised or systemic. The amyloid deposits can accumulate in the heart, kidneys, spleen, nerves, and blood vessels [1].

There are two types of transthyretin amyloidosis, the more common is the wild type, the other is an inherited transthyretin mutation[2,3]. Amyloid light-chain (AL) amyloidosis is the most commonly diagnosed type of amyloidosis.

Risk factors include advanced age, male gender, family history, having dialysis, and African descent[2,3].

Amyloidosis is a rare disease; the number of cases is not known in Australia. The incidence in Queensland was estimated at 10 cases per million per year in people aged 20 years or older[4].

The median age for a wild type transthyretin amyloidosis diagnosis is 79, though can be found in people in their forties. It is predominantly a disease found in males, with approximately 96% of cases reported in men[5]. The median age for inherited transthyretin amyloidosis diagnosis is 67, and the proportion of males to females is approximately 70:30[5].

Symptoms of amyloidosis depend on the tissues and organs affected, they are often mistaken for other more common diseases[2,3]. Symptoms of wild type and hereditary transthyretin amyloidosis include fatigue, shortness of breath, swelling of feet and legs, heart palpitations, slow heart rate that can cause dizziness or blackouts, chest pain, sleep problems, unintentional weight loss, carpel tunnel syndrome, nerve pain, and blood in urine[2,3].

General symptoms of amyloid light-chain amyloidosis include loss of appetite, fatigue, unintentional weight loss, and weakness. When the heart us involved, swollen ankles, and being short of breath. The symptoms when the kidneys are involved include swollen ankles, frothy urine, and high cholesterol[2,3].

When there is nerve involvement, symptoms can include tingling in fingers and toes, and diarrhoea. Bruising, especially around eyes occurs with blood vessel involvement, diarrhoea from gut involvement, and swollen tongue when the tongue is involved[2,3].

Personal Experience, Expectations and Knowledge (PEEK)

Personal Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

Methodology

Participants

To be eligible for the study, participants needed to have been diagnosed with transthyretin amyloidosis or amyloid light-chain amyloidosis, or be a carer to someone diagnosed with either condition, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Initial recruitment commenced in July 2019 to October 2019 and recommenced in April 2020 to June 2020.

Ethics

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS_Q4_03).

Data collection

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, www.zoho.com/survey). Participants completed the survey from July 2017 to August 2018.

There were four researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included in the transcript. All transcripts were checked against the original recording for quality assurance.

Interview data was collected from July 2019 to June 2020.

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)[6], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)[7], the Short Fear of Progression Questionnaire (FOP12)[8], and the Partners in Health version 2 (PIH)[9]. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by registered nurses, who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

Questionnaire analysis

Statistical analysis was conducted using R included in the packages "car", "dplyr" and "ggplot2" (R 3.3.3 GUI 1.69 Mavericks build (7328)). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by participant type, gender, age, location of residence, education status and Socio-economic Indexes for Areas (SEIFA). Global scales and subscales were calculated according to reported instructions[6-9].

The **Location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics[10].

The level of social advantage of participants was evaluated by postcode using the Socio-economic Indexes for Areas (**SEIFA**) accessed from the Australian Bureau of Statistics[11].

Where participants list other conditions, these were classified by the Classification of Diseases 11th Revision[12].

For comparisons by Participant type, and **Age**, a one-way analysis of variance (ANOVA) analysis was conducted. A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. Where the assumptions for the one-way ANOVA were not met, a Kruskal-Wallis rank sum test on care was conducted with post-hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used. Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

Structured interviews analysis

Content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into MaxQDA. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in MaxQDA. The minimum coded unit was a sentence with paragraphs and phrases coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. Where a theme occurred less than four times it was not included in the study results, unless this result demonstrated a significant gap or unexpected result.

Participants that did not take part in the structured interviews after completing the survey have been coded as no response, with results calculated accordingly. Non-responses have not been included in the in the study results.

Data analysis and final reporting was completed in August 2020.

Position of this study

A search was conducted in Pubmed (June 24, 2020) to identify transthyretin amyloidosis or amyloid light-chain amyloidosis quality of life or patient experience studies of adults that had been conducted in the past ten years in worldwide (Table 1.1). Meta-analysis studies, studies conducted in developing countries, and studies of less than five participants were excluded.

There were 32 studies identified that collected patient self-reported data. There were three studies using qualitative methods of between 10 and 18 participants[13-15], and 28 studies using quantitative methods of between 10 and 1,739 participants[5,16-44], and one mixed methods study of 10 interviewed participants with 341 participants completing questionnaires[45,46]. There were eight international studies[16-21,28,30,34], eight in the USA[22-24,32,35,37,41,43-45,47], six in Portugal[13,14,26,27,33,40], two in France[15,29], two in the UK[5,36], and one each in, Japan[25] and Sweden[42]. One international study included participants from Australia[28].

There were ten drug trials[16-20,25,28,30,32,34], five studies focused on quality of life[5,35,37,41,44], three nutrition studies[31,36], two studies each focused on distress[33,43], liver transplants[27,42], disease characterisation, [21-24], and a single study each focused on anxiety and depression[38], coping strategies[39], diagnosis[45,47], education[15], genetic screening[40], pharyngo-laryngeal involvement[29], stigma[13], and urinary tract dysfunction[26].

There were 28 people diagnosed with amyloidosis, and 8 carers to people with amyloidosis from throughout Australia that participated in this PEEK study. This included a qualitative structured interview and quantitative questionnaire. This study in amyloidosis is therefore the largest mixed methods study reported in an Australian population, and it includes the most patient interviews worldwide. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Author, Year	Location	Number of participants	Design	Focus	PEEK Section							
					2: Health status, co-morbidities, health-related quality of life	3: Diagnosis experience, information, support and costs	4: Decision making and healthcare professional discussions	5: Treatment, healthcare system use and access, economic implications	6: Information, communication and self-management	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9 Expectations, preferences and messages
McCausland et al, 2018[47], Bayliss et al, 2017[45]	USA	10 (interviews), 341 (questionnaire)	Mixed	Diagnosis		x						
Théaudin et al, 2014[15]	France	8 plus 2 carers	Qualitative (Interviews)	Education	x				x	x	x	
Oliveira et al, 2017[14]	Portugal	18	Qualitative (Interviews)	Health self-management				x	x	x	x	
Mendes et al, 2017[13]	Portugal	11	Qualitative (Interviews)	Stigma							x	
Smorti et al, 2012[38]	Italy	32	Quantitative	Anxiety and depression	x	x					x	
Waddington-Cruz et al, 2018[21]	International	172	Quantitative	Characterisation of disease	x							
Coelho et al, 2013; [22]; Wixner et al, 2014[23]; Maurer et al, 2016[24]	USA	1739	Quantitative	Characterisation of disease	x							
Smorti et al, 2014[39]	Italy	34	Quantitative	Coping strategies							x	
Lopes et al, 2018[33]	Portugal	209	Quantitative	Distress		x						
Wright et al, 2018[43]	USA	78	Quantitative	Distress							x	
Coelho et al, 2012 [16]; Keohane et al, 2017[17]	International	290	Quantitative	Drug	X							
Merlini et al, 2013[18]	International	21	Quantitative	Drug	x							
Coelho et al, 2013 [19]	International	86	Quantitative	Drug	x							
Barroso et al, 2017 [20]	International	75	Quantitative	Drug	x							
Adams et al, 2018[28]	International	225	Quantitative	Drug	x							
Berk et al, 2013[30]	International	130	Quantitative	Drug	x	x						

Author, Year	Location	Number of participants	Design	Focus	PEEK Section							
					2: Health status, co-morbidities, health-related quality of life	3: Diagnosis experience, information, support and costs	4: Decision making and healthcare professional discussions	5: Treatment, healthcare system use and access, economic implications	6: Information, communication and self-management	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9 Expectations, preferences and messages
Maurer et al, 2018[34]	International	441	Quantitative	Drug	x							
Ando et al, 2016[25]	Japan	10	Quantitative	Drug	x							
D'Souza et al, 2019[32]	USA	31	Quantitative	Drug	x							
Valdrez et al, 2014[40]	Portugal	111	Quantitative	Genetic screening		x						
Lane et al, 2019[5]	UK	158	Quantitative	Health related quality of life	x	x						
Sanchorawala et al, 2017[35]	USA	574	Quantitative	Health related quality of life	X							
Shu et al, 2016[37]	USA	1226	Quantitative	Health related quality of life	x							
Warsame et al, 2017[41]	USA	302	Quantitative	Health related quality of life	x							
Yarlas et al, 2019[44]	USA	172	Quantitative	Health related quality of life	x							
Telles-Correia and Moreira, 2014[27]	Portugal	10	Quantitative	Liver transplant							x	
Wixner et al, 2015[42]	Sweden	77	Quantitative	Liver transplant	x	x						
Caccialanza et al, 2012[31]	Italy	150	Quantitative	Nutrition	x							
Caccialanza et al, 2015 [31]	Italy	143	Quantitative	Nutrition	x							
Sattianayagam et al, 2013[36]	UK	110	Quantitative	Nutrition	x							
Bartier et al, 2019[29]	France	95	Quantitative	Pharyngo-laryngeal involvement	x							
Gomes et al, 2014[26]	Portugal	23	Quantitative	Urinary tract dysfunction	x						x	

Abbreviations and terminology

AL amyloidosis	Amyloid light-chain amyloidosis
Amyloidosis	Refers to transthyretin amyloidosis or amyloid light-chain amyloidosis
ANOVA	Analysis of variance (ANOVA). This is used to analyze the differences among group means in a sample.
ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
ATTR	Transthyretin amyloidosis
CCDR	Centre for Community-Driven Research
dF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
f	The F ratio is the ratio of two mean square values, used in an ANOVA comparison. A large F ratio means that the variation among group means is more than you'd expect to see by chance.
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
p	Probability value. A small *p*-value (typically ≤ 0.05) indicates strong. A large *p*-value (> 0.05) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a group digger from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to relative socio-economic advantage and disadvantage. This is developed by the Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find 6significantly different means following an ANOVA test.
W	The W statistic is the test value from the Wilcoxon Rank sum test. The theoretical range of W is between 0 and (number in group one) x (number in group 2). When W=0, the two groups are exactly the same.
X^2	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square distribution. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance.

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Section 2

Demographics

Section 2 Summary: Demographics

Participants

- In this PEEK study, 28 participants with amyloidosis, and 8 carers to people with amyloidosis were recruited, 14 females (38.89%) and 22 males (61.11%), aged mostly between 55 and 74 (n=27, 75.00%), and most participants identified as Caucasian or white (n=33, 91.67%).

- Participants were most frequently from Queensland (n=14, 38.89%), New South Wales (n=11, 30.56%), and Western Australia (n=6, 16.67%). Most participants were from major cities (n=27, 75.00%) and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) with 25 participants (69.44%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 11 participants (30.56%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Baseline health

- The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, where a higher score denotes better health or function.

- The **"SF36 Role functioning/emotional"** scale measures how emotional problems interfere with work or other activities. On average, any emotional problems of the participants in this study slightly interfered with work or other activities. The **"SF36 Emotional well-being"** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, the participants in this study participants felt happy and calm most of the time, and anxious and depressed a little of the time.

- The **"SF36 Physical functioning"** measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities for participants in this study moderately limited. The "**SF36 Role functioning/physical"** scale measures how physical health interferes with work or other activities. On average, physical health of the participants in this study interfered quite a bit with work or other activities.

- The **"SF36 Social functioning"** scale measures the limitations on social activities due to physical or emotional problems. On average for the participants in this study, social activities were slightly limited.

- The **"SF36 Role Energy/Fatigue"** scale measures the amount of energy or fatigue. On average the participants in this study had moderate energy/fatigue, that is, felt tired some of the time and had energy some of the time.

- The **"SF36 Pain"** scale measures the amount of pain, and how pain interferes with work and other activities. On average, the participants in this study had moderate pain.

Demographics

In this PEEK study, 28 participants with amyloidosis, and 8 carers to people with amyloidosis were recruited (Table 2.1). There were 14 females (38.89%) and 22 males (61.11%), aged mostly between 55 and 74 (n=27, 75.00%), and most participants identified as Caucasian/white (n=33, 91.67%). One participant with ATTR-CM, one participant with AL amyloidosis (cardiac) and three carers were unwell or unable to complete a full telephone interview.

Participants were most frequently from Queensland (n=14, 38.89%), New South Wales (n=11, 30.56%), and Western Australia (n=6, 16.67%). Most participants were from metropolitan areas (n=27, 75.00%) and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), with 25 participants (69.44%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 11 participants (30.56%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

Of the participants with amyloidosis (n=28), half had completed some university (n=14, 50.00%), and most were retired (n=17, 60.71%). The eight carers in the study cared for spouses (n=7, 87.50%), and grandchildren (n=1, 12.50%). The demographics of participants are listed in Table 2.2.

Table 2.1: Participants and diagnosis

Participants and diagnosis	Number (n=36)	Percent
AL Amyloidosis with cardiac involvement	7	19.44
AL Amyloidosis with other involvement	3	8.33
ATTR - wildtype or hereditary	18	50.00
Carer to AL Amyloidosis	6	16.67
Carer to ATTR - wildtype or hereditary	2	5.56

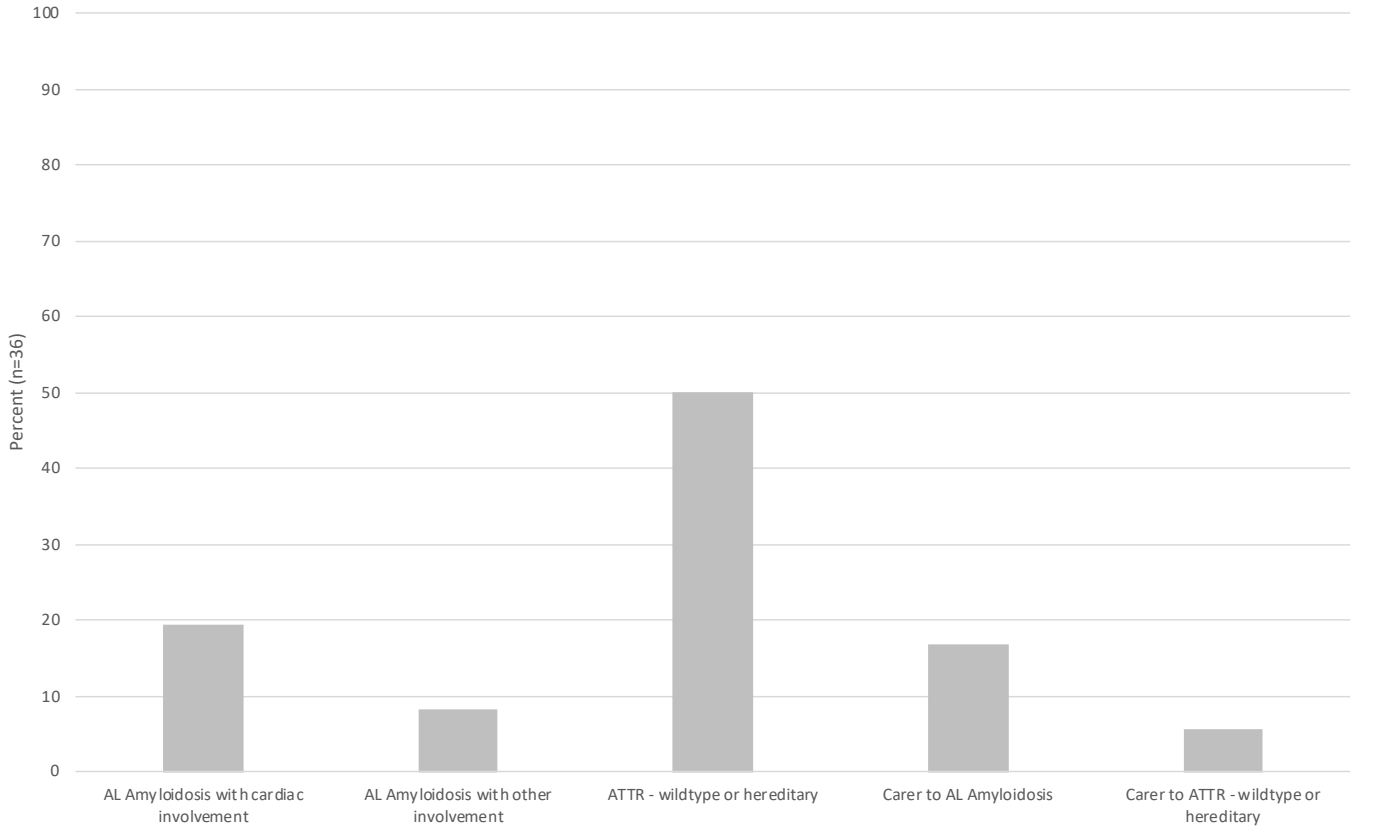


Figure 2.1: Participants and diagnosis

Table 2.2: Demographics

Demographic	Definition	Number (n=36)	Percent
Gender	Female	14	38.89
	Male	22	61.11
Age	25 to 34	1	2.78
	55 to 64	8	22.22
	65 to 74	19	52.78
	75 and older	8	22.22
Location	Metropolitan	27	75.00
	Inner regional	8	22.22
	Outer regional	1	2.78
State	Queensland	14	38.89
	New South Wales	11	30.56
	Western Australia	6	16.67
	Victoria	3	8.33
	South Australia	2	5.56
Socio-Economic Indexes for Areas (SEIFA)	1	0	0.00
	2	2	5.56
	3	2	5.56
	4	1	2.78
	5	3	8.33
	6	3	8.33
	7	1	2.78
	8	11	30.56
	9	2	5.56
	10	11	30.56
Race/ethnicity	Caucasian/white	33	91.67
	Other	3	8.33
Education (n=28)	High school degree or equivalent	5	17.86
	Some college but no degree	3	10.71
	Trade	6	21.43
	Associate degree	1	3.57
	Bachelor degree	5	17.86
	Graduate degree	8	28.57
Employment	Retired	17	60.71
	Employed, working part time	5	17.86
	Disabled, not able to work	2	7.14
	Disabled, not able to work, Retired	1	3.57
	Employed, working full time	1	3.57
	Employed, working part time, Full/part time study	1	3.57
	Not employed, looking for work	1	3.57
Carer status	Grandchildren	2	5.56
	Spouse	7	19.44
	I am not a carer	27	75.00

Other health conditions

Participants with amyloidosis noted between zero and 11 other health conditions that they had to manage, with a median of three (Table 2.4). In the online questionnaire, participants selected the conditions that they had from a list (Table 2.3), and they had the option to specify other conditions (Table 2.5). The most commonly reported conditions were arrhythmias (n=15, 53.57%), sleep problems or insomnia (n=11, 39.29%), and anxiety (self or doctor diagnosed) (n=10, 35.71%).

Participants listed other conditions they had. These were coded according to the International Classification of Diseases 11th Revision and grouped according the ancestor chapter. The most common were diseases of the musculoskeletal system or connective tissue (n=4, 14.29%), followed by diseases of the circulatory system (n=3, 10.71) (Table 2.5).

Table 2.3: Other health conditions

Other conditions	Number (n=36)	Percent
Sleep problems or insomnia	11	39.29
COPD	5	17.86
Depression (Self or doctor diagnosed)	8	28.57
Depression (Self diagnosed)	6	21.43
Depression (Diagnosed by a doctor)	5	17.86
Anxiety (Self or doctor diagnosed)	10	35.71
Anxiety (self diagnosed)	9	32.14
Anxiety (diagnosed by a doctor)	5	17.86
Hypertension	8	28.57
Diabetes	1	3.57
Arrhythmias	15	53.57
Chronic pain	9	32.14
Chronic heart failure	6	21.43
Angina	3	10.71
Other conditions	11	39.29

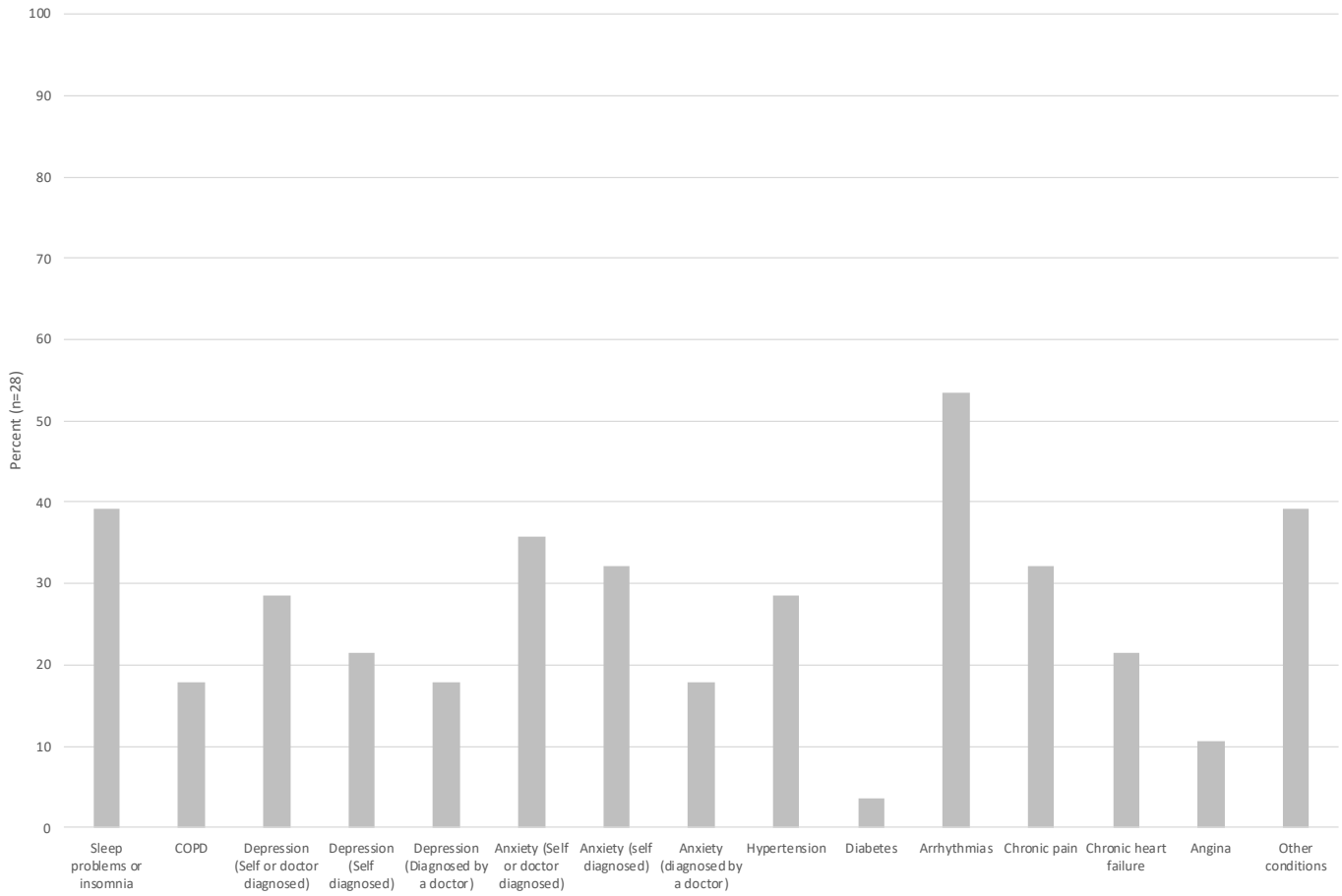


Figure 2.2: Other health conditions

Table 2.4: Number of other health conditions

Number of other conditions	Number (n=36)	Percent
No other conditions	5	17.86
1	3	10.71
2	2	7.14
3	5	17.86
4	4	14.29
5	3	10.71
6	3	10.71
7	1	3.57
8 or more	2	7.14

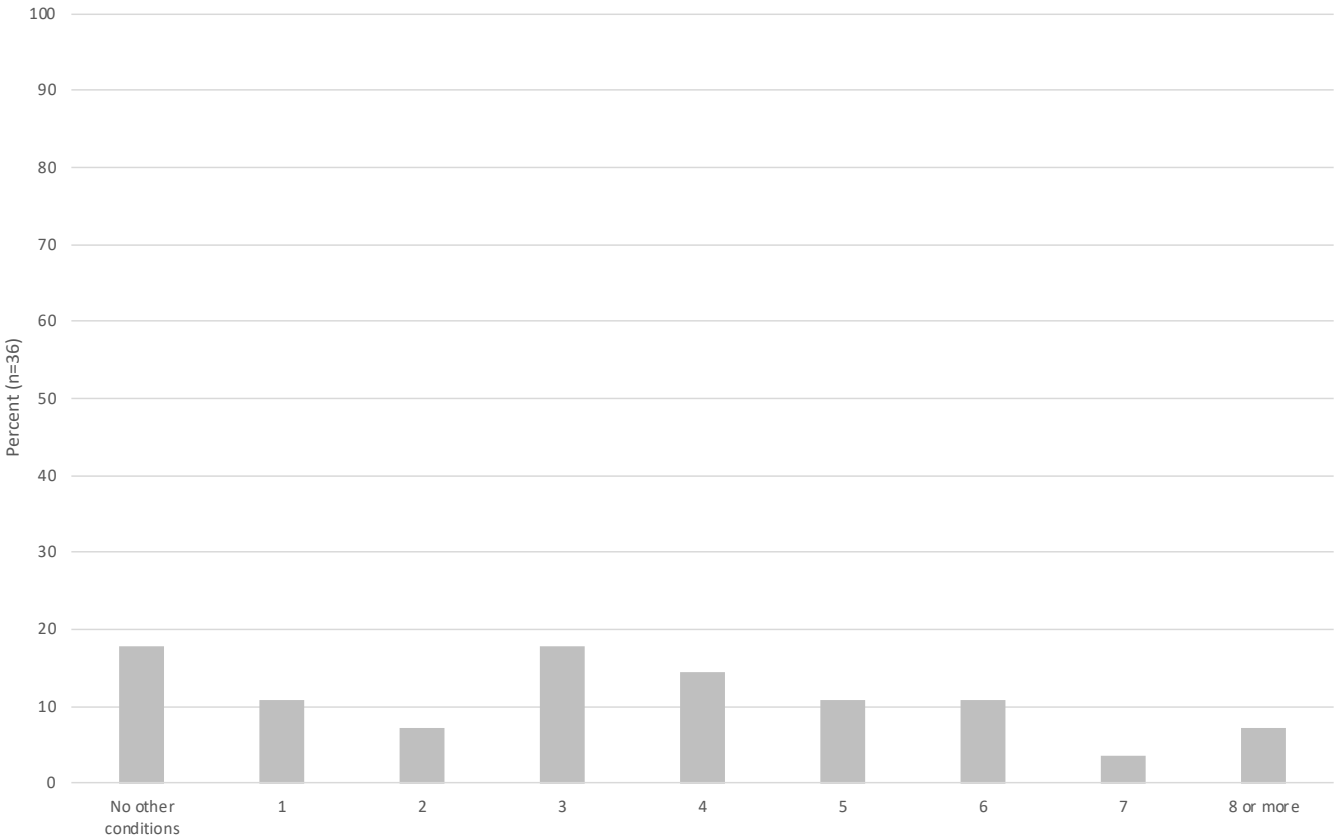


Figure 2.3: Number of other health conditions

Table 2.5: Participant specified other conditions

Type of other conditions	Number (n=36)	Percent
Diseases of the musculoskeletal system or connective tissue	4	14.29
Diseases of the circulatory system	3	10.71
Diseases of the genitourinary system	2	7.14
Diseases of the nervous system	2	7.14
Conditions related to sexual health	1	3.57
Diseases of the respiratory system	1	3.57
Diseases of the visual system	1	3.57
Endocrine, nutritional or metabolic diseases	1	3.57
Neoplasms	1	3.57

Subgroup analysis

Subgroup analysis are included throughout the study and the subgroups are listed in Table 2.6.

Participant type were grouped according to diagnosis; *ATTR-cardiac* group include participants diagnosed with hereditary or wild type ATTR (n=18, 50.00%). *All cardiac* includes all participants diagnosed with amyloidosis that have cardiac involvement, this group includes participants diagnosed with AL amyloidosis and ATTR (n=25, 64.44%). The *AL amyloidosis* subgroup includes all participants diagnosed with AL amyloidosis, including any organ involvement (n=10, 27.78%). The final participant type are *Carers* to people with any type of amyloidosis (n=8, 22.22%).

Comparisons were made by **gender**, between *Males* (n=22, 61.11) and *Females* (n=14, 38.89%). The **Location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in a major city, *Metropolitan* (n=27, 75.00%) were compared to those living in regional/rural areas, *Regional or remote* (n=9, 25.00%).

Participants were grouped according to **age,** with comparisons made between participants *Aged 55 to 64* (n=8, 22.86%), *Aged 65 to 74* (n=19, 54.29%), and *Aged 75 or older* (n=8, 22.86%). One participant was aged in the 25 to 34 year-old age bracket and was excluded from age comparisons.

Education status was collected only for participants diagnosed with amyloidosis (n=28). Comparisons were made by **education** status, between those with a university qualification, *University* (n= 14, 50.00%), and those with trade or high school qualifications, *Trade or high school* (n=14, 50.00%).

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au). SEIFA scores range from one to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of seven to 10, *Higher SEIFA* (n=25, 69.44%) compared to those with a mid to low SEIFA score of one to six, *Mid to low SEIFA* (n=11, 30.56%).

Table 2.6: Subgroups

Subgroup	Definition	Number (n=36)	Percent
Participant type	ATTR-Cardiac	18	50.00
	All cardiac	25	69.44
	AL amyloidosis	10	27.78
	Carer	8	22.22
Gender	Male	22	61.11
	Female	14	38.89
Location	Regional or remote	9	25.00
	Metropolitan	27	75.00
Age	Aged 55 to 64	8	22.86
	Aged 65 to 74	19	54.29
	Aged 75 or older	8	22.86
Education	Trade or high school	14	50.00
	University	14	50.00
Socio-Economic Indexes for Areas (SEIFA)	Mid to low SEIFA	11	30.56
	Higher SEIFA	25	69.44

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.7. Where the scale has a normal distribution, mean and SD are used as a central measure, otherwise the median and IQR are used.

The overall scores for the cohort were in the second highest quintile for **"SF36 Role functioning/emotional"** (Median = 66.67, IQR = 66.67), "SF36 Emotional well-being" (Median = 76.00, IQR = 20.00), and "SF36 Social functioning" (Median = 62.50, IQR = 40.63) indicating good emotional role functioning, emotional well-being, and social functioning.

The overall scores for the cohort were in the middle of the scale for **"SF36 Physical functioning"** (Median = 52.50, IQR = 57.50), **"SF36 Energy/Fatigue"** (Mean = 43.33, SD = 25.41), **"SF36 Pain"** (Mean = 59.58, SD = 24.39), and **"SF36 General health"** (Mean = 46.81, SD = 22.46) indicating moderate scores.

The overall scores for the cohort were in the second lowest quintile for **"SF36 Role functioning/physical"** (Median=25.00, IQR =100.00), and **"SF36 Health change"** (Median=37.50, IQR =25.00) indicating poor physical functioning role, and worse health compared to a year ago.

Comparisons of SF36 have been made based on **Participant type** (Figures 2.4 to 2.12, Tables 2.8 to 2.11), **Gender** (Figures 2.13 to 2.21, Tables 2.12 to 2.13), **Age** (Figures 2.22 to 2.30, Tables 2.14 to 2.15), **Education,** (Figures 2.31 to 2.39, Tables 2.16 to 2.17), **Location** (Figures 2.40 to 2.48, (Tables 2.18 to 2.19),and **SEIFA** (Figures 2.49 to 2.57, Tables 2.20 to 2.21).

Table 2.7: SF36 summary statistics

SF36 scale (n=36)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	53.47	31.82	52.50	57.50	0 to 100	3
Role functioning/physical	37.50	43.30	25.00	100.00	0 to 100	2
Role functioning/emotional	62.04	41.52	66.67	66.67	0 to 100	4
Energy/Fatigue*	43.33	25.41	45.00	35.00	0 to 100	3
Emotional well-being	72.44	17.44	76.00	20.00	0 to 100	4
Social functioning	60.76	28.99	62.50	40.63	0 to 100	4
Pain*	59.58	24.39	55.00	32.50	0 to 100	3
General health*	46.81	22.46	45.00	41.25	0 to 100	3
Health change	40.28	24.11	37.50	25.00	0 to 100	2

*Normal distribution, use mean and SD as central measure. Possible range 0-100

Comparisons of SF36 scales by participant type

Participant type groups participants according to diagnosis. The *ATTR-cardiac* group includes participants diagnosed with hereditary or wild type ATTR (n=18, 50.00%). *All cardiac* includes all participants diagnosed with amyloidosis that have cardiac involvement, this group includes participants diagnosed with AL amyloidosis and ATTR (n=25, 64.44%). The *AL amyloidosis* group includes all participants diagnosed with AL amyloidosis, including any organ involvement (n=10, 27.78%). The final participant type are *Carers* to people with any type of amyloidosis (n=8, 22.22%).

Boxplots of each SF36 scale by participant type are displayed in Figures 2.4 to 2.12. Summary statistics are displayed in Tables 2.8 and 2.10.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.8). A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test (Table 2.9).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.10). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal-Wallis test (Table 2.11).

A one way ANOVA test indicated a statistically significant difference in the **"SF36 General health"** scale between groups, $F(3, 57) = 4.84$, $p = 0.0046$ (Table 2.8). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the *Carer* subgroup (Mean = 66.88, SD = 14.62) was significantly higher compared to participants in the *ATTR-cardiac* subgroup (Mean = 36.11, SD = 18.52, $p = 0.0043$); and participants in the *Carer* subgroup (Mean = 66.88, SD = 14.62) was significantly higher compared to participants in the *AL amyloidosis* subgroup (Mean = 50.00, SD = 23.45, $p = 0.0106$).

A Kruskal-Wallis test indicated a statistically significant difference in the **"SF36 Role functioning/physical"** scale between groups ($\chi^2(3) = 15.03$, $p = 0.0018$). Wilcoxon rank sum tests between groups indicated that participants in the *Carer* subgroup (Median = 100.00, IQR = 31.25), scored significantly higher than participants in the *ATTR-cardiac* subgroup (Median = 0.00, IQR = 18.75, $p = 0.0054$); and participants in the *Carer* subgroup (Median = 100.00, IQR = 31.25), scored significantly higher than participants with participants in the *All cardiac* subgroup (Median = 0.00, IQR = 25.00, $p = 0.007$).

"SF36 Role functioning/physical" measures how physical health interferes with work or other activities. On average, participants in the *Carer* subgroup scored higher than participants in the *ATTR-cardiac* and *All cardiac* subgroups. This indicates that physical health did not at all interfere with work or other activities for participants in the *Carer* subgroup, compared to extremely interfered with work or other activities for participants in the *ATTR-cardiac* and *All cardiac* subgroups.

The **"SF36 General health"** measures perception of health. On average, participants in the *Carer* subgroup scored higher than participants in the *ATTR-cardiac* and *AL amyloidosis* subgroups. This indicates that participants in the *Carer* subgroup reported good health, compared to participants in the *ATTR-cardiac* subgroup who reported poor general health, and participants in the *AL amyloidosis* subgroup who reported moderate general health.

Table 2.8: SF36 by participant type ANOVA test and summary statistics

SF36 Scale	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Energy/Fatigue	ATTR-cardiac	18	50.00	37.22	26.25	Between groups	2063.00	3	687.70	1.02	0.3890
	All-cardiac	25	69.44	37.80	26.85	Within groups	38293.00	57	671.80		
	AL amyloidosis	10	27.78	46.00	28.07	Total	40356.00	60			
	Carer	8	22.22	53.75	17.68						
Pain	ATTR-cardiac	18	50.00	50.42	22.23	Between groups	3588.00	3	1196.10	2.29	0.0878
	All-cardiac	25	69.44	53.60	22.35	Within groups	29747.00	57	521.90		
	AL amyloidosis	10	27.78	70.00	23.00	Total	33335.00	60			
	Carer	8	22.22	67.19	25.62						
General health	ATTR-cardiac	18	50.00	36.11	18.52	Between groups	6066.00	3	2022.00	4.84	0.0046*
	All-cardiac	25	69.44	40.00	21.94	Within groups	23825.00	57	418.00		
	AL amyloidosis	10	27.78	50.00	23.45	Total	29891.00	60			
	Carer	8	22.22	66.88	14.62						

*Statistically significant at p<0.05

Table 2.9: SF36 by participant type post hoc Tukey HSD test

SF36 General health	Subgroup	Difference	Upper	Lower	p adjusted
General health	All-cardiac -ATTR-cardiac	3.89	-12.84	20.61	0.9268
	AL amyloidosis - ATTR-cardiac	13.89	-7.45	35.23	0.3217
	Carer - ATTR-cardiac	30.76	7.77	53.75	0.0043*
	AL amyloidosis - All-cardiac	10.00	-10.24	30.24	0.5622
	Carer - All-cardiac	26.88	4.90	48.85	0.0106*
	Carer - AL amyloidosis	16.88	-8.79	42.54	0.3129

*Statistically significant at p<0.05

Table 2.10: SF36 by participant type Kruskal-Wallis test and summary statistics

SF36 Scale	Group	Number (n=36)	Percent	Median	IQR	C^2	dF	p-value
Physical functioning	ATTR-cardiac	18	50.00	32.50	47.50	7.17	3	0.0667
	All-cardiac	25	69.44	35.00	55.00			
	AL amyloidosis	10	27.78	60.00	58.75			
	Carer	8	22.22	82.50	43.75			
Role functioning/physical	ATTR-cardiac	18	50.00	0.00	18.75	15.03	3	0.0018*
	All-cardiac	25	69.44	0.00	25.00			
	AL amyloidosis	10	27.78	25.00	93.75			
	Carer	8	22.22	100.00	31.25			
Role functioning/emotional	ATTR-cardiac	18	50.00	66.67	100.00	0.66	3	0.8829
	All-cardiac	25	69.44	100.00	100.00			
	AL amyloidosis	10	27.78	100.00	58.33			
	Carer	8	22.22	66.67	16.67			
Emotional well-being	ATTR-cardiac	18	50.00	72.00	15.00	5.51	3	0.1380
	All-cardiac	25	69.44	72.00	16.00			
	AL amyloidosis	10	27.78	82.00	12.00			
	Carer	8	22.22	76.00	12.00			
Social functioning	ATTR-cardiac	18	50.00	62.50	46.88	4.11	3	0.2494
	All-cardiac	25	69.44	62.50	37.50			
	AL amyloidosis	10	27.78	75.00	50.00			
	Carer	8	22.22	68.75	28.13			
Health change	ATTR-cardiac	18	50.00	25.00	25.00	4.79	3	0.1881
	All-cardiac	25	69.44	25.00	25.00			
	AL amyloidosis	10	27.78	50.00	25.00			
	Carer	8	22.22	50.00	12.50			

*Statistically significant at p<0.05

Table 2.11: SF36 by participant type post hoc pairwise Wilcoxon rank sum test

SF36 Scale	Subgroup	ATTR-cardiac	All-cardiac	AL amyloidosis
SF36 Role functioning/physical	All-cardiac	0.4415	-	-
	AL amyloidosis	0.0564	0.1259	-
	Carer	0.0054*	0.007*	0.2561

*Statistically significant at p<0.05

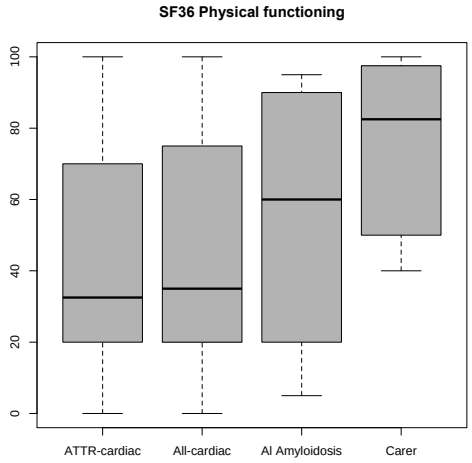


Figure 2.4: Boxplot of SF36 Physical functioning by participant type

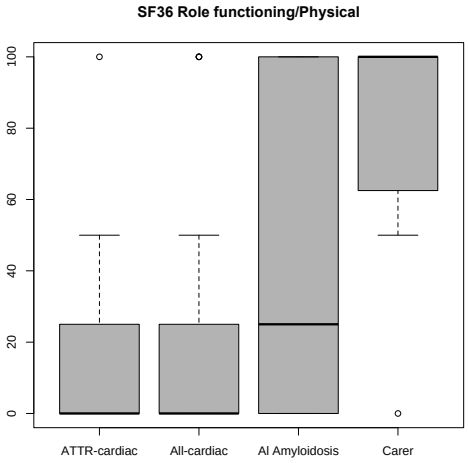


Figure 2.5: Boxplot of SF36 Role functioning/physical by participant type

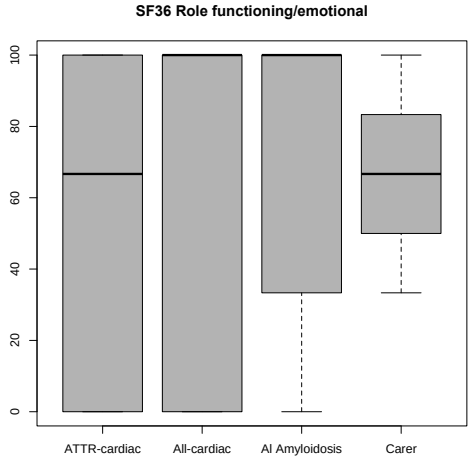


Figure 2.6: Boxplot of SF36 Role functioning/emotional by participant type

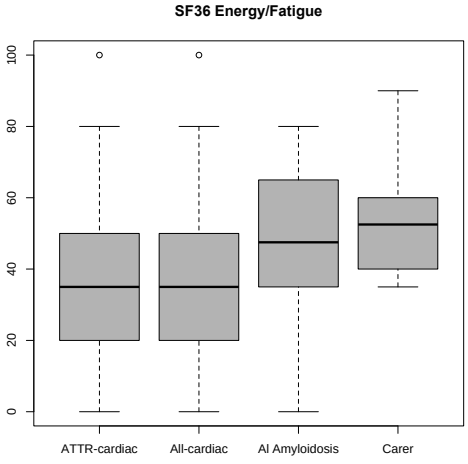


Figure 2.7: Boxplot of SF36 Energy/fatigue by participant type

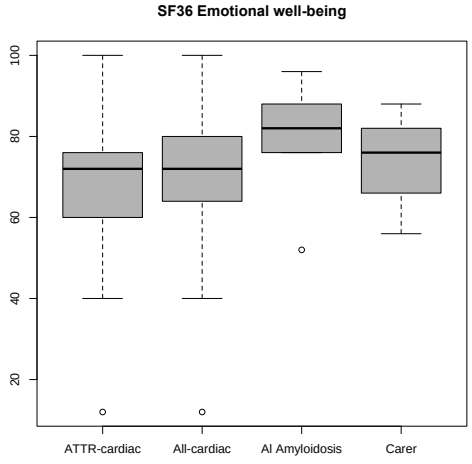


Figure 2.8: Boxplot of SF36 Emotional well-being by participant type

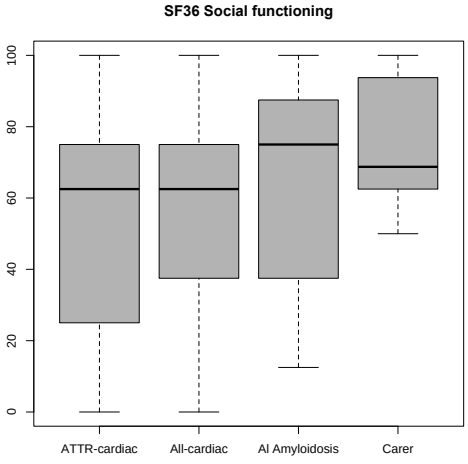


Figure 2.9: Boxplot of SF36 Social functioning by participant type

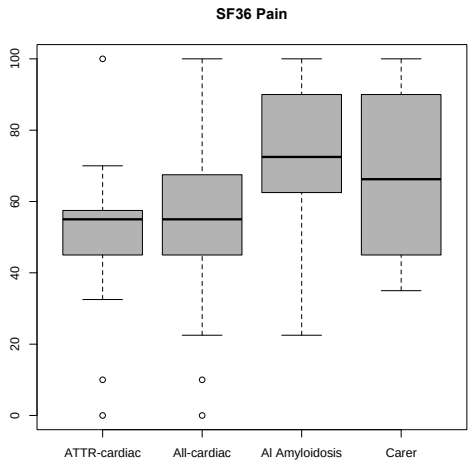


Figure 2.10: Boxplot of SF36 Pain by participant type

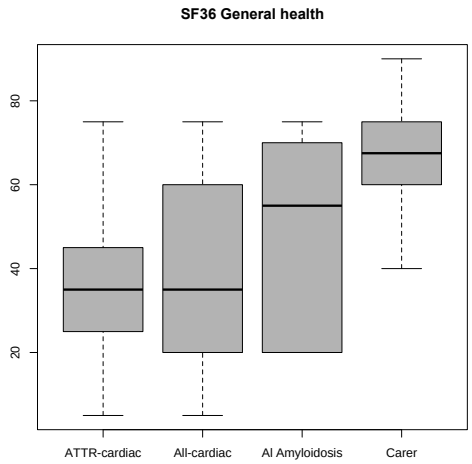


Figure 2.11: Boxplot of SF36 General health by participant type

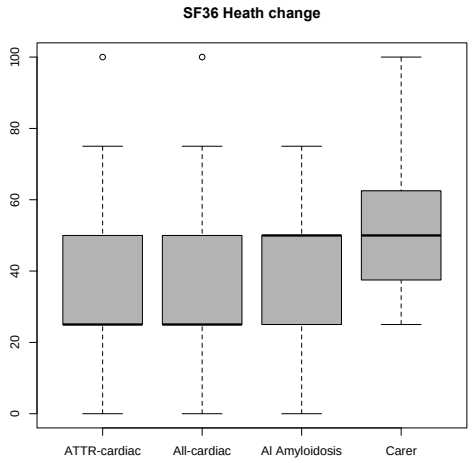


Figure 2.12: Boxplot of SF36 Health change by participant type

Comparisons of SF36 scales by gender

Comparisons were made by **gender**, between *Males* (n=22, 61.11) and *Females* (n=14, 38.89%).

Boxplots of each SF36 scale by **gender** are displayed in Figures 2.13 to 2.21, summary statistics are displayed in Tables 2.12 to 2.13. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.13).

A two sample t-test indicated that the mean score for the **"SF36 General health"** [t(34) = -2.63, p = 0.0128] was significantly higher for participants in the *Female* subgroup (Mean = 58.21, SD = 22.33) compared to participants in the subgroup *Male* (Mean = 39.55, SD = 19.75).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **"SF36 Physical functioning"** [W = 85.00, p = 0.0256] was significantly higher for participants in the *Female* subgroup (Median = 77.50, IQR = 46.25) compared to participants in the *Male* subgroup (Median = 40.00, SD = 40.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **"SF36 Role functioning/physical"** [W = 86.50, p = 0.0198] was significantly higher for participants in the *Female* subgroup (Median = 87.50, IQR = 93.75) compared to participants in the *Male* subgroup (Median = 0.00, SD = 25.00).

"SF36 Physical functioning" measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, *Female* participants scored higher than *Male* participants. This indicates that physical

activities were slightly limited for *Female* participants, compared to moderately limited for *Male* participants.

"SF36 Role functioning/physical" measures how physical health interferes with work or other activities. On average, *Female* participants scored higher than *Male* participants. This indicates that physical health did not at all interfere with work or other activities for *Female* participants, compared to extremely interfered with work or other activities for *Male* participants.

The **"SF36 General health"** measures perception of health. On average, *Female* participants scored higher than *Male* participants. This indicates that *Female* participants reported moderate health, compared to *Male* participants who reported poor general health.

Table 2.12: SF36 by gender summary statistics and two sample t-test

SF36 Scale	Group	Number (n=36)	Percent	Mean	SD	t	dF	p-value
Energy/Fatigue	Female	14	38.89	52.50	24.00	-1.78	34	0.0841
	Male	22	61.11	37.50	25.06			
Pain	Female	14	38.89	67.68	22.31	-1.63	34	0.1133
	Male	22	61.11	54.43	24.74			
General health	Female	14	38.89	58.21	22.33	-2.63	34	0.0128*
	Male	22	61.11	39.55	19.75			

*Statistically significant at p<0.05

Table 2.13: SF36 by gender summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 Scale	Group	Number (n=36)	Percent	Median	IQR	W	p-value
Physical functioning	Female	14	38.89	77.50	46.25	85.00	0.0256*
	Male	22	61.11	40.00	40.00		
Role functioning/physical	Female	14	38.89	87.50	93.75	86.50	0.0198*
	Male	22	61.11	0.00	25.00		
Role functioning/emotional	Female	14	38.89	66.67	58.33	145.00	0.7684
	Male	22	61.11	83.33	91.67		
Emotional well-being	Female	14	38.89	78.00	8.00	107.50	0.1331
	Male	22	61.11	72.00	18.00		
Social functioning	Female	14	38.89	62.50	46.88	111.00	0.1626
	Male	22	61.11	62.50	37.50		
Health change	Female	14	38.89	50.00	25.00	113.00	0.1612
	Male	22	61.11	25.00	25.00		

*Statistically significant at p<0.05

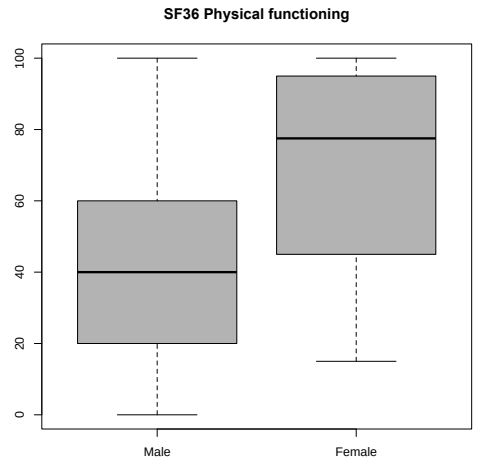


Figure 2.13: Boxplot of SF36 Physical functioning by gender

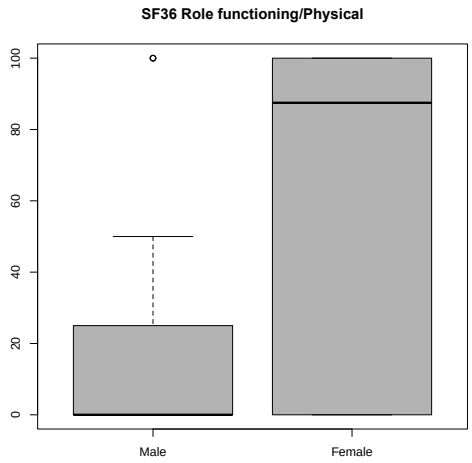


Figure 2.14: Boxplot of SF36 Role functioning/physical by gender

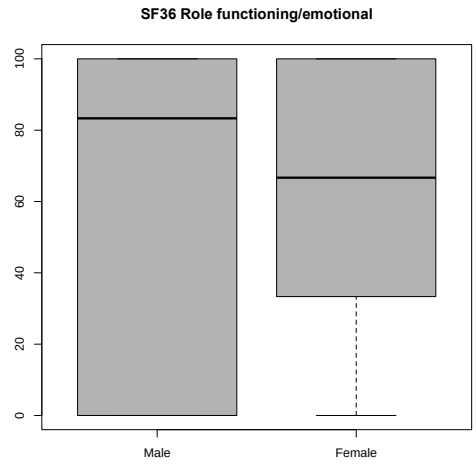


Figure 2.15: Boxplot of SF36 Role functioning/emotional by gender

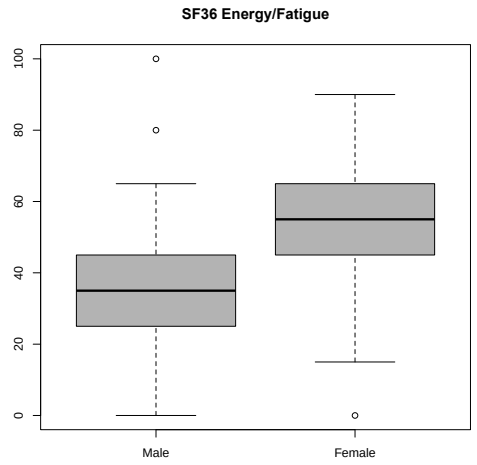


Figure 2.16: Boxplot of SF36 Energy/fatigue by gender

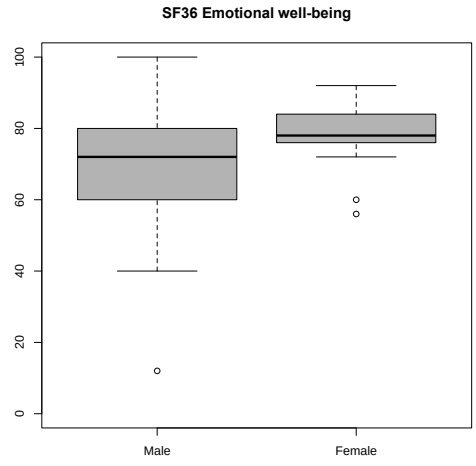


Figure 2.17: Boxplot of SF36 Emotional well-being by gender

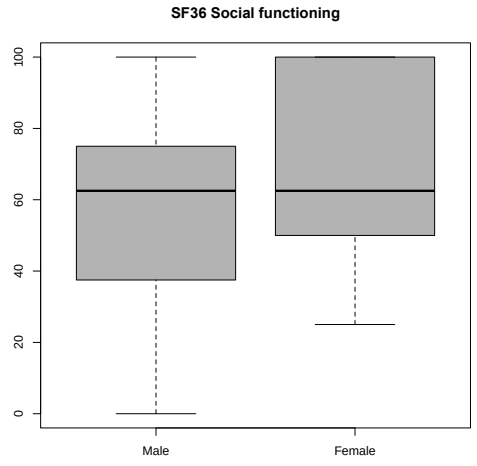


Figure 2.18: Boxplot of SF36 Social functioning by gender

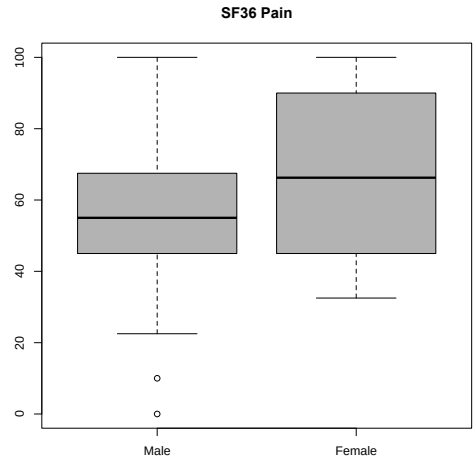


Figure 2.19: Boxplot of SF36 Pain by gender

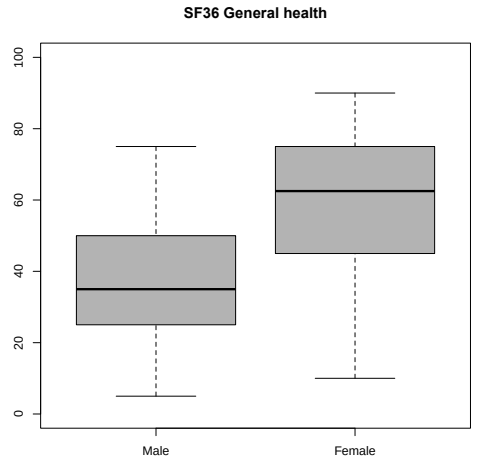


Figure 2.20: Boxplot of SF36 General health by gender

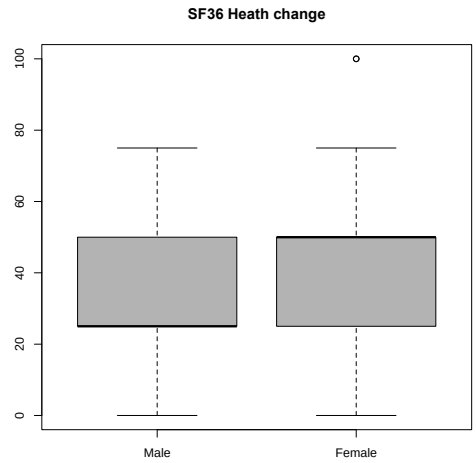


Figure 2.21: Boxplot of SF36 Health change by gender

Comparisons of SF36 scales by age

Participants were groups according to **age,** with comparisons made between participants *Aged 55 to 64* (n=8, 22.86%), *Aged 65 to 74* (n=19, 54.29%), and *Aged 75 or older* (n=8, 22.86%). One participant was aged in the 25 to 34 year old age bracket and was excluded from age comparisons.

Boxplots of each SF36 scale by **age** are displayed in Figures 2.22 to 2.30. Summary statistics are displayed in Tables 2.14 and 2.15.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.14).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.15).

No significant differences were observed between participants in the subgroups *Aged 55 to 64*, *Aged 65 to 74*, and *Aged 75 or older* for any of the SF36 scales.

Table 2.14: SF36 by age ANOVA test and summary statistics

SF36 Scale	Group	Number (n=35)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Physical functioning	Aged 55 to 64	8	22.86	48.13	33.69	Between groups	1827	2	913.30	0.88	0.4250
	Aged 65 to 74	19	54.29	60.53	32.01	Within groups	33263	32	1039.50		
	Aged 75 and older	8	22.86	44.38	31.33	Total	35090	34			
Energy/Fatigue*	Aged 55 to 64	8	22.86	38.13	31.05	Between groups	439	2	219.60	0.35	0.7090
	Aged 65 to 74	19	54.29	46.84	21.36	Within groups	20229	32	632.20		
	Aged 75 and older	8	22.86	45.63	27.44	Total					
Emotional well-being	Aged 55 to 64	8	22.86	65.50	26.87	Between groups	548	2	274.10	0.87	0.4290
	Aged 65 to 74	19	54.29	75.37	11.72	Within groups	10100	32	315.60		
	Aged 75 and older	8	22.86	72.50	19.18	Total					
Social functioning	Aged 55 to 64	8	22.86	48.44	28.69	Between groups	1696	2	847.80	0.98	0.3870
	Aged 65 to 74	19	54.29	65.79	29.71	Within groups	27724	32	866.40		
	Aged 75 and older	8	22.86	60.94	29.46	Total					
Pain	Aged 55 to 64	8	22.86	61.88	20.60	Between groups	112	2	55.80	0.09	0.9170
	Aged 65 to 74	19	54.29	60.53	24.90	Within groups	20488	32	640.30		
	Aged 75 and older	8	22.86	56.88	30.14	Total					
General health	Aged 55 to 64	8	22.86	39.38	22.11	Between groups	2655	2	1327.50	2.98	0.0651
	Aged 65 to 74	19	54.29	55.53	19.85	Within groups	14263	32	445.70		
	Aged 75 and older	8	22.86	36.88	23.14	Total					
Health change	Aged 55 to 64	8	22.86	37.50	23.15	Between groups	1341	2	670.30	1.14	0.3320
	Aged 65 to 74	19	54.29	46.05	26.70	Within groups	18766	32	586.50		
	Aged 75 and older	8	22.86	31.25	17.68	Total					

Table 2.15: SF36 by age Kruskal-Wallis test

SF36 Scale	Group	Number (n=35)	Percent	Median	IQR	C^2	dF	p-value
Role functioning/physical	Aged 55 to 64	8	22.86	50.00	62.50	1.41	2	0.4939
	Aged 65 to 74	19	54.29	25.00	100.00			
	Aged 75 and older	8	22.86	0.00	43.75			
Role functioning/emotional	Aged 55 to 64	8	22.86	33.33	75.00	2.89	2	0.2360
	Aged 65 to 74	19	54.29	100.00	50.00			
	Aged 75 and older	8	22.86	83.33	75.00			

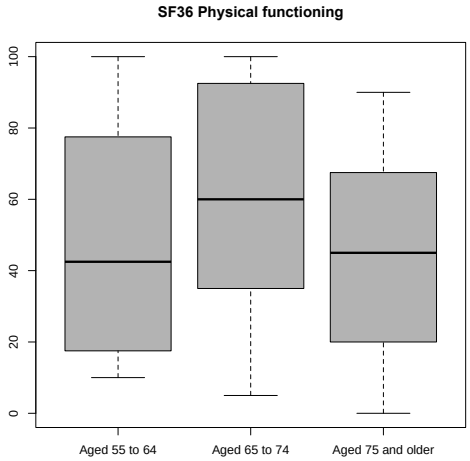


Figure 2.22: Boxplot of SF36 Physical functioning by age

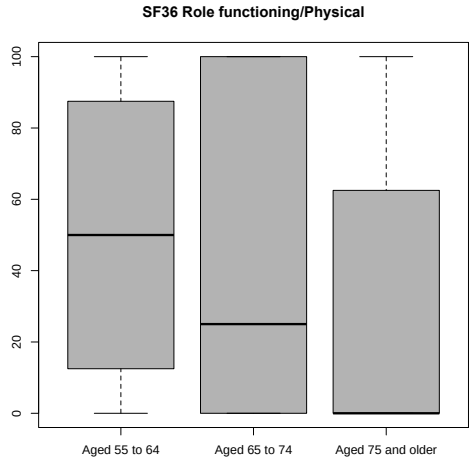


Figure 2.23: Boxplot of SF36 Role functioning/physical by age

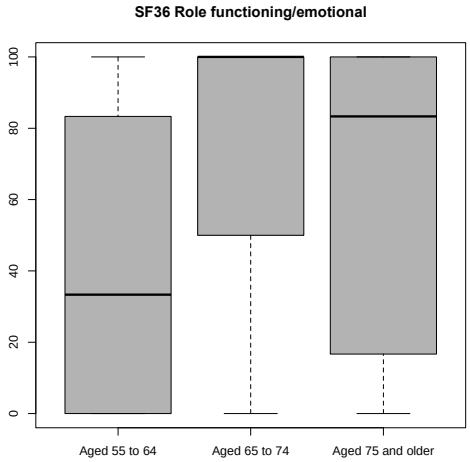


Figure 2.24: Boxplot of SF36 Role functioning/emotional by age

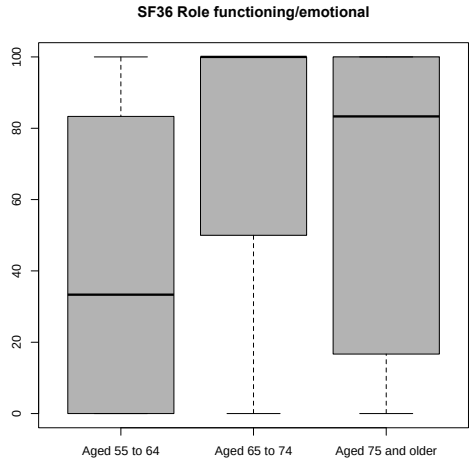


Figure 2.25: Boxplot of SF36 Energy/fatigue by age

Figure 2.26: Boxplot of SF36 Emotional well-being by age

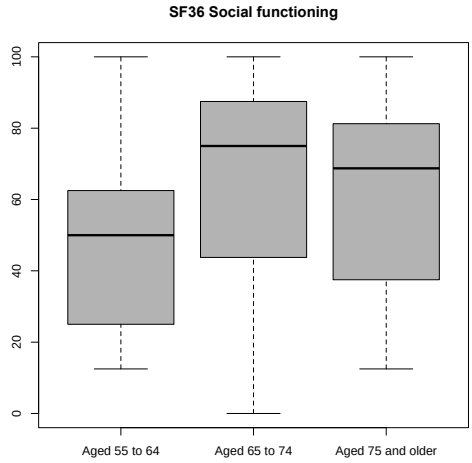


Figure 2.27: Boxplot of SF36 Social functioning by age

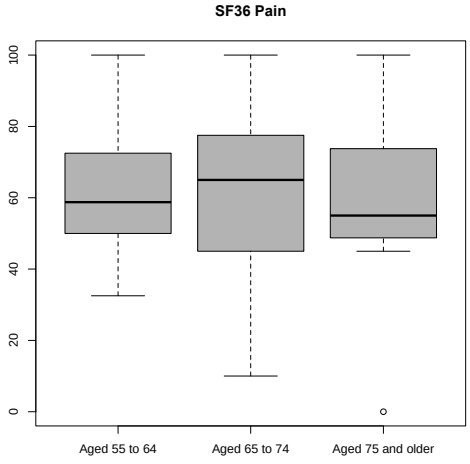


Figure 2.28: Boxplot of SF36 Pain by age

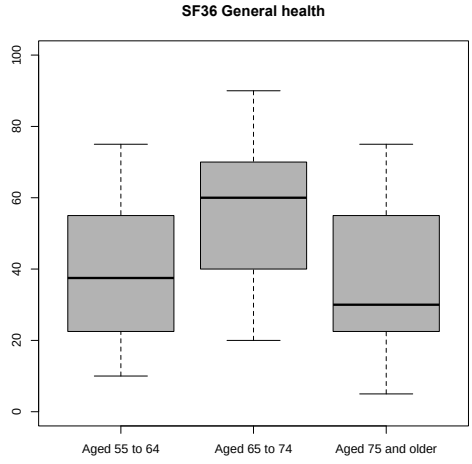


Figure 2.29: Boxplot of SF36 General health by age

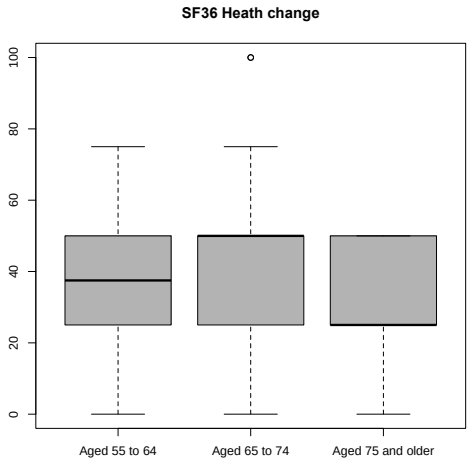


Figure 2.30: Boxplot of SF36 Health change by age

Comparisons of SF36 scales by education

Education status was collected only for participants diagnosed with amyloidosis (n=28).

Comparisons were made by **education** status, between those with a university qualification, *University* (n= 14, 50.00%), and those with trade or high school qualifications, *Trade or high school* (n=14, 50.00%).

Boxplots of each SF36 scale by **education** are displayed in Figures 2.31 to 2.39, summary statistics are displayed in Tables 2.16 to 2.17. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.16), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.17).

No significant differences were observed between participants in the *Trade or high school* subgroup compared to those in the *University* subgroup for any of the SF36 scales.

Table 2.16: SF36 by education summary statistics and two sample t-test

SF36 Scale	Group	Number (n=28)	Percent	Mean	SD	t	dF	p-value
Physical functioning	Trade or high school	14	50.00	48.21	30.86	0.15	26	0.8832
	University	14	50.00	46.43	32.78			
Energy/Fatigue*	Trade or high school	14	50.00	44.29	28.00	0.77	26	0.4472
	University	14	50.00	36.43	25.83			
Social functioning	Trade or high school	14	50.00	58.93	33.77	0.38	26	0.7047
	University	14	50.00	54.46	27.56			
Pain	Trade or high school	14	50.00	61.25	25.94	0.84	26	0.4087
	University	14	50.00	53.57	22.31			
General health	Trade or high school	14	50.00	45.71	18.90	1.17	26	0.2516
	University	14	50.00	36.43	22.82			

Table 2.17: SF36 by education summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 Scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Role functioning/physical	Trade or high school	14	50.00	0.00	25.00	87.50	0.6081
	University	14	50.00	12.50	43.75		
Role functioning/emotional	Trade or high school	14	50.00	83.33	91.67	94.00	0.8591
	University	14	50.00	100.00	91.67		
Emotional well-being	Trade or high school	14	50.00	74.00	27.00	103.50	0.8173
	University	14	50.00	76.00	14.00		
Health change	Trade or high school	14	50.00	37.50	25.00	111.00	0.5372
	University	14	50.00	25.00	25.00		

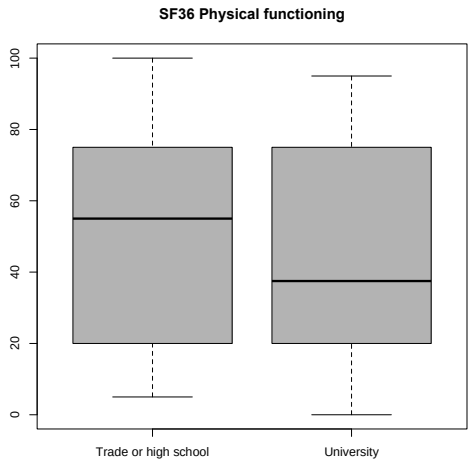


Figure 2.31: Boxplot of SF36 Physical functioning by education

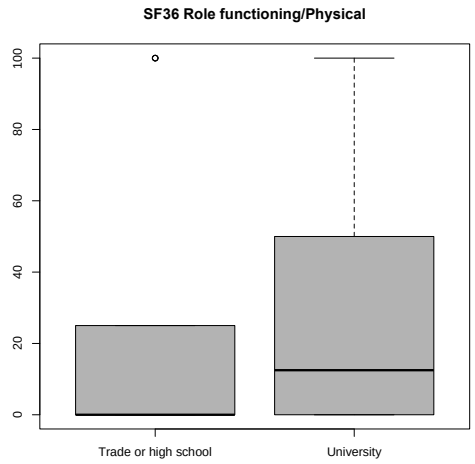


Figure 2.32: Boxplot of SF36 Role functioning/physical by education

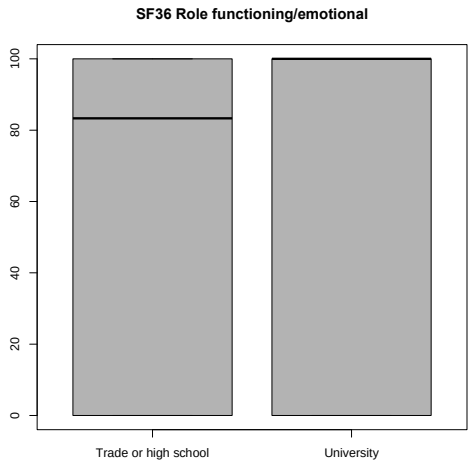


Figure 2.33: Boxplot of SF36 Role functioning/emotional by education

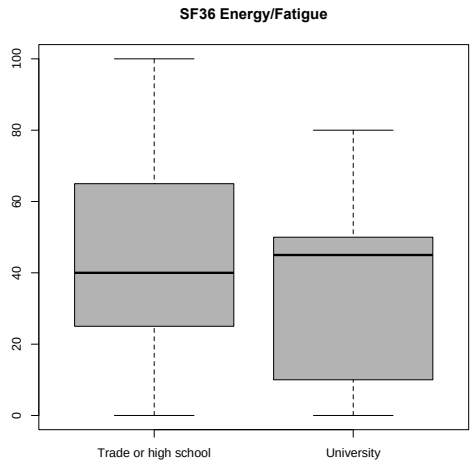


Figure 2.34: Boxplot of SF36 Energy/fatigue by education

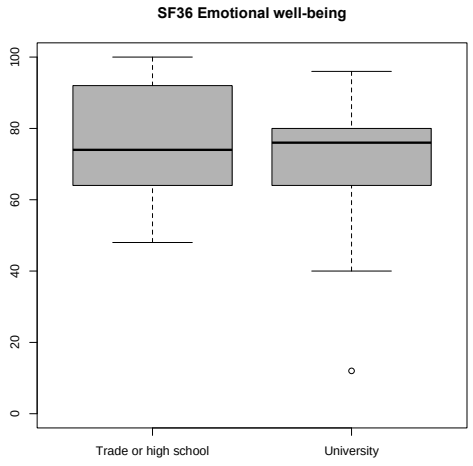


Figure 2.35: Boxplot of SF36 Emotional well-being by education

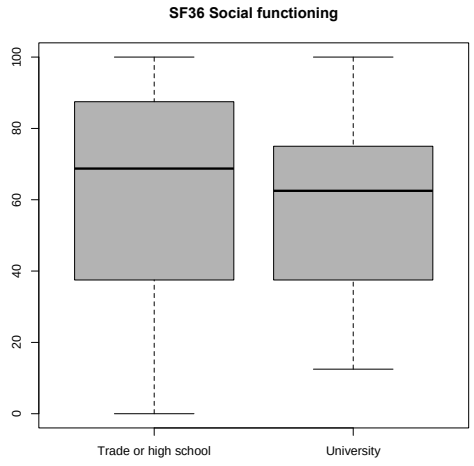


Figure 2.36: Boxplot of SF36 Social functioning by education

Figure 2.37: Boxplot of SF36 Pain by education

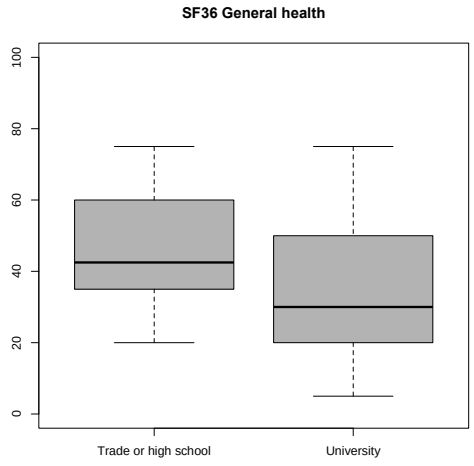


Figure 2.38: Boxplot of SF36 General health by education

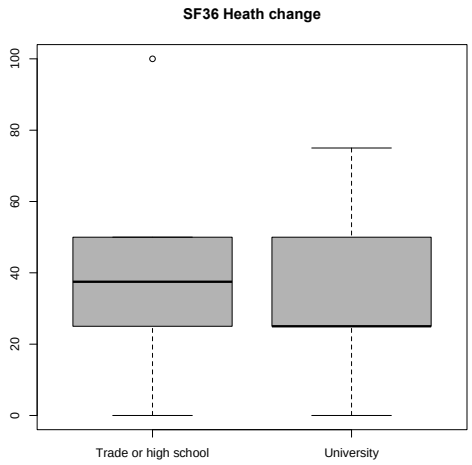


Figure 2.39: Boxplot of SF36 Health change by education

Comparisons of SF36 scales by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas, accessed from accessed from the Australian Bureau of Statistics. Those living in a major city, *Metropolitan* (n=27, 75.00%) were compared to those living in regional and rural areas, *Regional or remote* (n=9, 25.00%).

Boxplots of each SF36 scale by **location** are displayed in Figures 2.40 to 2.48. Summary statistics are displayed in Tables 2.18 to 2.19.

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.18), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.19).

No significant differences were observed between participants in the *Metropolitan* subgroup compared to those in the *Regional or remote* subgroup for any of the SF36 scales.

Table 2.18: SF36 by location summary statistics and two sample t-test

SF36 Scale	Group	Number (n=36)	Percent	Mean	SD	T	dF	p-value
Physical functioning	Regional or remote	9	25.00	58.89	29.77	0.58	34.00	0.5630
	Metropolitan	27	75.00	51.67	32.82			
Energy/Fatigue	Regional or remote	9	25.00	51.67	21.79	1.14	34.00	0.2619
	Metropolitan	27	75.00	40.56	26.29			
Pain	Regional or remote	9	25.00	57.78	23.86	-0.25	34.00	0.8018
	Metropolitan	27	75.00	60.19	24.98			
General health	Regional or remote	9	25.00	50.00	21.65	0.49	34.00	0.6292
	Metropolitan	27	75.00	45.74	23.03			

Table 2.19: SF36 by location summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 Scale	Group	Number (n=38)	Percent	Median	IQR	W	p-value
Role functioning/physical	Regional or remote	9	25.00	50.00	100.00	146.50	0.3374
	Metropolitan	27	75.00	0.00	75.00		
Role functioning/emotional	Regional or remote	9	25.00	100.00	33.33	156.00	0.1847
	Metropolitan	27	75.00	66.67	83.33		
Emotional well-being	Regional or remote	9	25.00	76.00	16.00	151.50	0.2782
	Metropolitan	27	75.00	76.00	20.00		
Social functioning	Regional or remote	9	25.00	62.50	12.50	127.00	0.8533
	Metropolitan	27	75.00	62.50	43.75		
Health change	Regional or remote	9	25.00	50.00	50.00	141.50	0.4476
	Metropolitan	27	75.00	25.00	25.00		

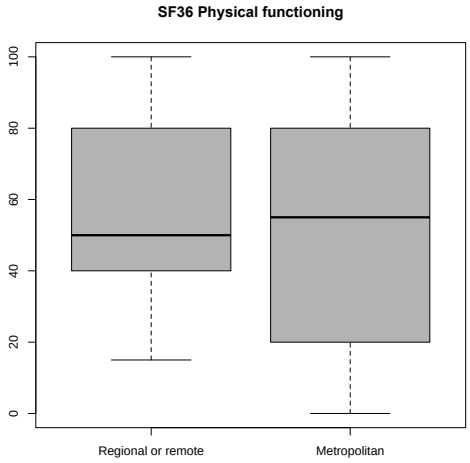


Figure 2.40: Boxplot of SF36 Physical functioning by location

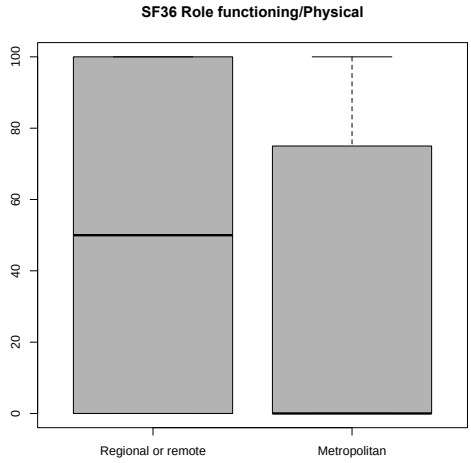


Figure 2.41: Boxplot of SF36 Role functioning/physical by location

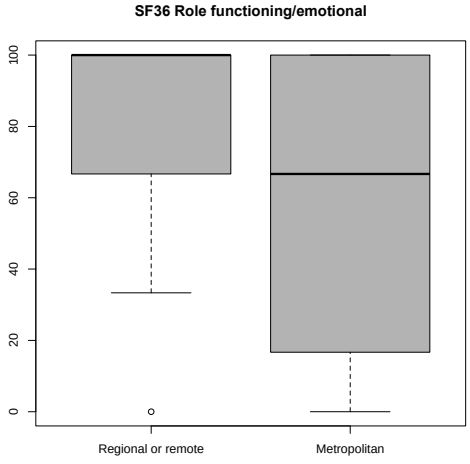


Figure 2.42: Boxplot of SF36 Role functioning/emotional by location

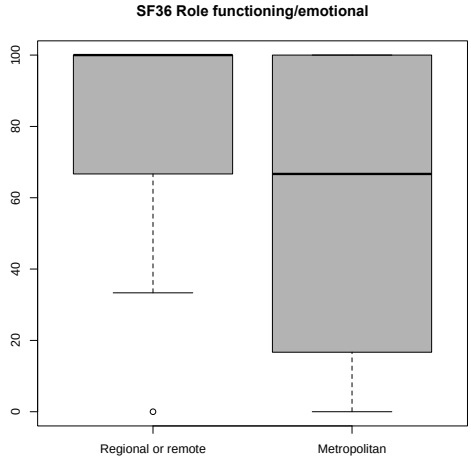


Figure 2.43: Boxplot of SF36 Energy/fatigue by location

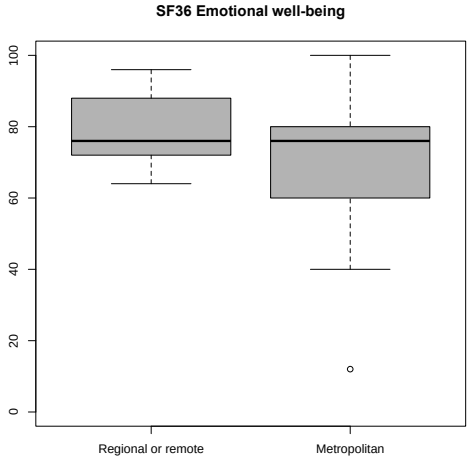


Figure 2.44: Boxplot of SF36 Emotional well-being by location

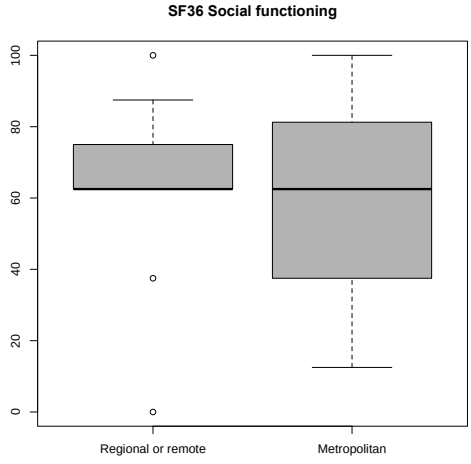


Figure 2.45: Boxplot of SF36 Social functioning by location

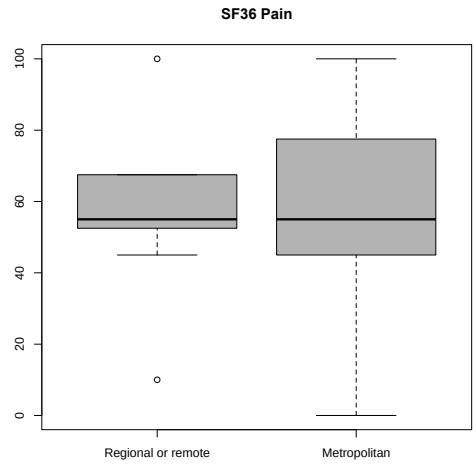


Figure 2.46: Boxplot of SF36 Pain by location

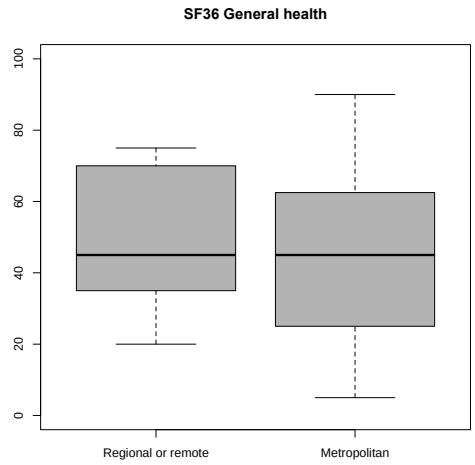


Figure 2.47: Boxplot of SF36 General health by location

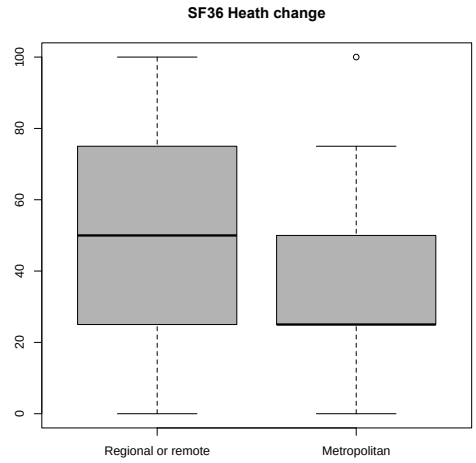


Figure 2.48: Boxplot of SF36 Health change by location

Comparisons of SF36 scales by SEIFA

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10, *High SEIFA* (n=25, 69.44%) compared to those with a mid to low SEIFA score of 1-6, *Mid to low SEIFA* (n=11, 30.56%).

Boxplots of each SF36 scale by **SEIFA** are displayed in Figures 2.49 to 2.57, summary statistics are displayed in Tables 2.20 to 2.21. A two-sample t-test was used when assumptions for normality and variance were met (Table 2.20), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.21).

No significant differences were observed between participants in the *High SEIFA* subgroup compared to those in the *Mid to low SEIFA* subgroup for any of the SF36 scales.

Table 2.20: SF36 by SEIFA summary statistics and two sample t-test

SF36 Scale	Group	Number (n=36)	Percent	Mean	SD	T	dF	p-value
Pain	Mid to low SEIFA	11	30.56	56.82	24.32	-0.45	34.00	0.6584
	Higher SEIFA	25	69.44	60.80	24.82			
General health	Mid to low SEIFA	11	30.56	45.91	19.21	-0.16	34.00	0.8765
	Higher SEIFA	25	69.44	47.20	24.11			

Table 2.21: SF36 by SEIFA summary statistics and Wilcoxon rank sum tests with continuity correction

SF36 Scale	Group	Number (n=36)	Percent	Median	IQR	W	p-value
Physical functioning	Mid to low SEIFA	11	30.56	45.00	25.00	133.50	0.9042
	Higher SEIFA	25	69.44	60.00	65.00		
Role functioning/physical	Mid to low SEIFA	11	30.56	25.00	62.50	132.00	0.8540
	Higher SEIFA	25	69.44	25.00	100.00		
Role functioning/emotional	Mid to low SEIFA	11	30.56	66.67	83.33	116.50	0.4522
	Higher SEIFA	25	69.44	100.00	66.67		
Energy/Fatigue*	Mid to low SEIFA	11	30.56	35.00	20.00	100.00	0.2015
	Higher SEIFA	25	69.44	50.00	25.00		
Emotional well-being	Mid to low SEIFA	11	30.56	72.00	12.00	108.00	0.3163
	Higher SEIFA	25	69.44	76.00	28.00		
Social functioning	Mid to low SEIFA	11	30.56	62.50	31.25	130.50	0.8212
	Higher SEIFA	25	69.44	62.50	50.00		
Health change	Mid to low SEIFA	11	30.56	50.00	25.00	162.50	0.3697
	Higher SEIFA	25	69.44	25.00	25.00		

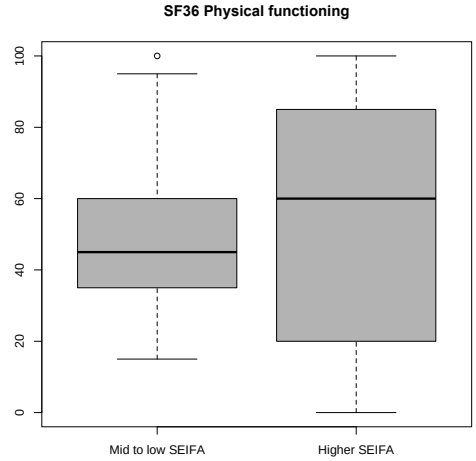


Figure 2.49: Boxplot of SF36 Physical functioning by SEIFA

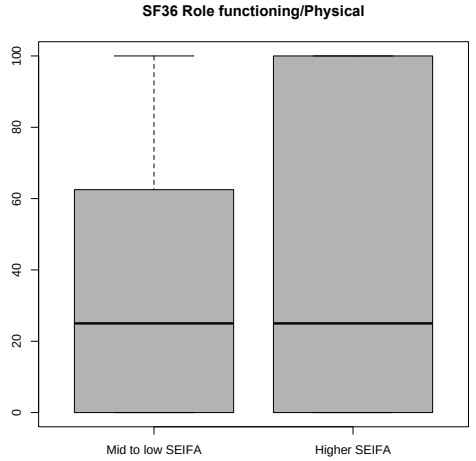


Figure 2.50: Boxplot of SF36 Role functioning/physical by SEIFA

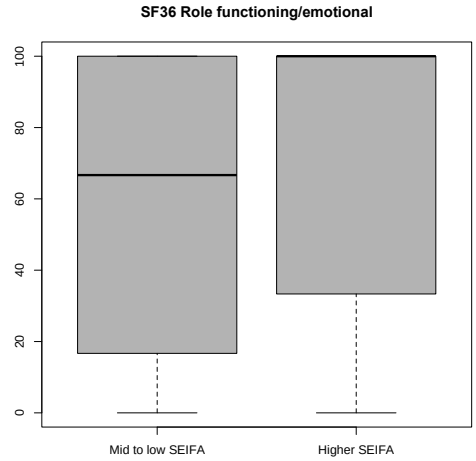


Figure 2.51: Boxplot of SF36 Role functioning/emotional by SEIFA

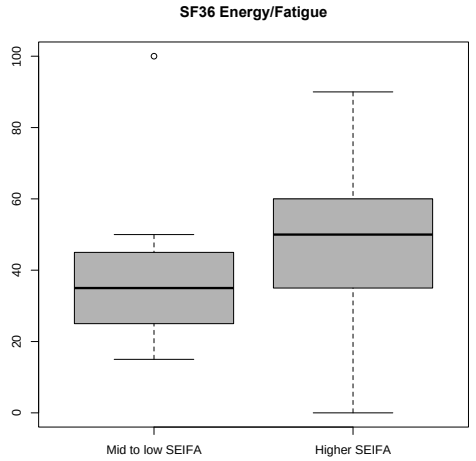


Figure 2.52: Boxplot of SF36 Energy/fatigue by SEIFA

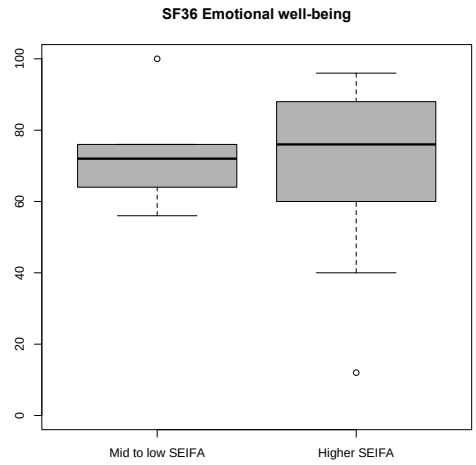


Figure 2.53: Boxplot of SF36 Emotional well-being by SEIFA

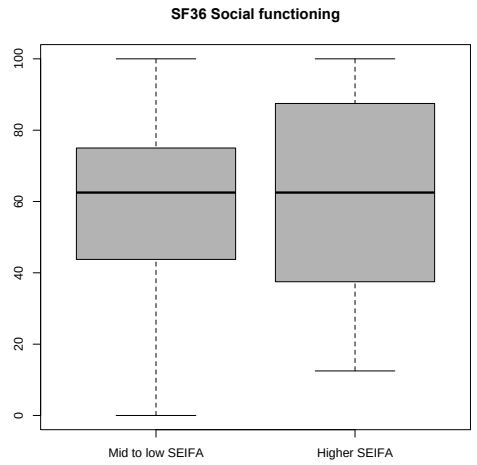


Figure 2.54: Boxplot of SF36 Social functioning by SEIFA

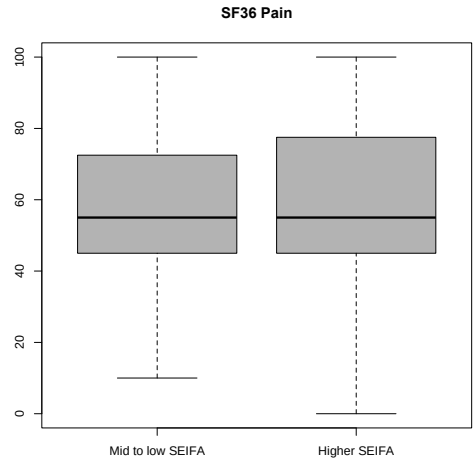


Figure 2.55: Boxplot of SF36 Pain by SEIFA

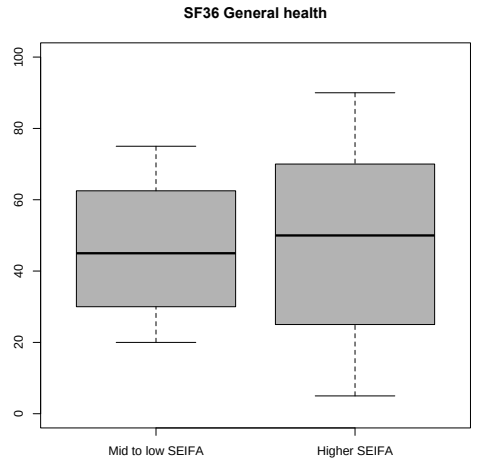


Figure 2.56: Boxplot of SF36 General health by SEIFA

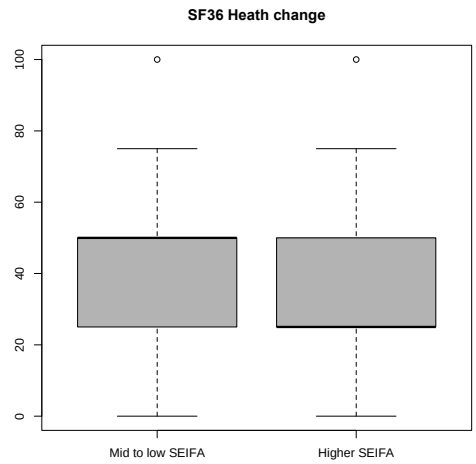


Figure 2.57: Boxplot of SF36 Health change by SEIFA

Section 3

Symptoms and diagnosis

Section 3 Summary: Symptoms and diagnosis

Symptoms

- Participants had between zero and 13 symptoms (median = 5.00, IQR = 3.00), most commonly three to four symptoms (n=6, 21.43%) (Table 3.1). The most common symptoms for all participants were fatigue (n=18, 64.29%), being short of breath (n=16, 57.14%), limb weakness (n=16, 57.14%), and light-headedness (n=16, 57.14%).

- The median quality of life was between 1.00 and 4.00, for all of the symptoms listed in the questionnaire, this is in the "Life was very distressing" to "Life was average" range. Median quality of life for the most common symptoms (fatigue, short of breath, light-headedness, and limb weakness) was between 3.00 and 4.00, in the life was a little distressing.

Symptoms leading to diagnosis

- In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was excessive weight loss (n=8, 22.22%). There were seven participants (19.44%) who described experiencing breathlessness and four participants (11.11%) who described having tiredness. A final four participants (11.11%) identified a specific physical sensation, such as numbness or tingling in their fingers or toes, which led to their diagnosis.

- When discussing symptoms leading to their diagnosis, participants described how soon after experiencing symptoms they sought medical attention. There were five participants (13.89%) that described having symptoms and not seeking medical attention initially but recognising the importance of those symptoms in hindsight. An additional three participants (8.33%) also mentioned having symptoms and not seeking medical attention initially, but they provided no reason for this.

- Overall, 18 participants (50.00%) described having symptoms and seeking medical attention relatively soon. There were eight participants (22.22%) that described having symptoms and not seeking medical attention initially, and a final five participants (13.89%) that described having no symptoms or not noticing them prior to diagnosis.

- There were nine participants (25.00%) that described a diagnostic pathway that required appointments with a general practitioner and two or more specialists. There were also nine participants (25.00%) who described receiving a diagnosis following referral from their general practitioner to a specialist. A final six participants (16.67%) described receiving diagnosis following a specialist ordering tests. They made no mention of a GP referral.

- When discussing symptoms, overall participants had either a strong recollection of symptoms (69.44%) or describes not experiencing any symptoms prior to diagnosis (11.11%).

Diagnostic tests

- Participants had between one and 11 diagnostic tests, most commonly five to six tests (n=11, 39.29%) (Median = 6.5, IQR = 3.25) (Table 3.5, Figure 3.5). The most common diagnostic tests were blood tests (n=23, 82.14%), electrocardiogram (n=18, 64.29%), and echocardiogram (n=16, 57.14%).

Time from symptoms to diagnosis

- Participants most commonly had more than a year between noticing symptoms and being diagnosed (n=11, 42.31%), followed by between 6 months and a year (n=7, 26.92%). There were five participants (19.23%)

that had noticed symptoms between one and six months before getting diagnosed, and three participants (11.54%) that had less than one month.

Time from diagnostic tests to diagnosis

- The majority of participants waited between 2 and 3 weeks (n=8, 28.57%) or more than 4 weeks (n=8, 28.57%).

Diagnosis provider and location

- The diagnosis was given most commonly by the haematologist (n=9, 32.14%), followed by a cardiologist (n=7, 25.00%). The diagnosis was most commonly given at a specialist clinic (n=28, 67.86%).

Understanding of disease at diagnosis

- Participants were asked in the structured interview how much they knew about their condition at diagnosis and the reason for their level of knowledge. There were 15 participants (41.67%) that gave no specific reason for their level of knowledge. There were eight participants (22.22%) who said they came to understand their condition more over time and through lived experience, and four participants (11.11%) described knowing very little about their condition at diagnosis, but that they were aware of family history with the condition.

- Overall, there were 27 participants (75.00%) that described knowing nothing or very little at diagnosis and these were the most common themes. There were three participants (8.33%) who noted that they knew good amount about the condition at diagnosis.

Emotional support at diagnosis

- Almost half of participants (including carers) had enough support (n=17, 47.22%), 6 participants (16.67%) had no support, and 13 participants (36.11%) had some support but it wasn't enough.

Information provided at diagnosis

- The majority of participants had enough information (n=20, 71.43%) at diagnosis. There were eight participants (28.57%) that had some information but not enough, and there were no participants that had no information at all at diagnosis.

Costs at diagnosis

- There were 12 participants (42.86%) who could recall the out of pocket expenses at diagnosis. There were eight participants who had no out of pocket expenses at diagnosis (28.57%), two that spent between $100 and $500 (7.14%), four who spent between $500 and $1000 (14.29%), and two who spent more than $1000 (7.14%) in out of pocket expenses

- In the follow-up question about the burden of costs at diagnosis, for 12 participants (60.00%) the cost was either slightly significant or not significant at all. For 5 participants (25.00%) the out of pocket expenses were somewhat significant, and for 3 participants (15.00%), the burden of out of pocket expenses were moderately significant.

Genetic tests and biomarkers

- The majority of participants had no conversation about biomarker/genomic/gene testing that might be relevant to treatment (n=17, 60.71%). There were three participants who brought up the topic with their doctor (10.71%), and eight whose doctor brought up the topic (28.57%).

- Over half of the participants (not including carers) have not had any testing but would like to (n=15, 53.57%). There were a total of 10 participants that had the test, either paying for it themselves (n=5, 17.86%), or not paying out of pocket (n=5, 17.86%). Three participants did not have the test and had no interest in having one (10.71%).

- The majority of participants were not sure if they had specific biomarkers (n=15, 53.57%), there were five that stated they had no biomarkers (17.86%), and eight that were able to name specific markers that they had.

Understanding of prognosis

- Participants were asked in the structured interview to describe what their current understanding of their prognosis was. There were 15 participants (41.67%) that described that they had a discussion about prognosis, and there were 14 participants (38.89%) did not mention having discussions about prognosis.

- Overall, 18 participants (50.00%) described having a clear understanding of their prognosis and 11 described having an unclear understanding (30.56%).

- There were two main themes that were equally reported, including participants describing their prognosis in relation to the specific medical interventions they need to manage their condition (n=9, 25.00%) and relating their prognosis to a specific timeframe that they are expected to live (n=9, 25.00%). There were eight participants (22.22%) that described their prognosis in relation to poor outcomes or as a terminal condition and five participants (13.89%) that understood their prognosis as positive and their condition as manageable.

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis. They could choose from a set lit of symptoms and could then specify other symptoms not listed.

Participants had between zero and 13 symptoms (Median = 5.00, IQR = 3.00), most commonly three to four symptoms (n=6, 21.43%) (Table 3.1). The most common symptoms for all participants were fatigue (n=18, 64.29%), being short of breath (n=17, 60.71%), limb weakness (n=16, 57.14%), and light-headedness (n=16, 57.14%). These symptoms were the most common regardless of diagnosis (Table 3.2).

Participants were asked a follow-up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from 1 to 7, where 1 is "Life was very distressing" and 7 is "Life was great" (Table 3.3, Figure 3.3). The median quality of life was between 1.00 and 4.00 for all of the symptoms listed in the questionnaire. This is in the "Life was very distressing" to "Life was average" range. Median quality of life for the most common symptoms (fatigue, short of breath, light-headedness, and limb weakness) was between 3.00 and 4.00, in the life was a little distressing to average range.

Table 3.1: Number of symptoms per participant

Number of symptoms per participant	All participants		ATTR-cardiac		All-cardiac		AL-amyloidosis	
	n=28	%	n=18	%	n=25	%	n=10	%
No symptoms	2	7.14	0	0.00	1	4.00	2	20.00
1 to 2	3	10.71	3	16.67	3	12.00	0	0.00
3 to 4	6	21.43	4	22.22	5	20.00	2	20.00
5 to 6	3	10.71	1	5.56	2	8.00	2	20.00
7 to 8	5	17.86	3	16.67	5	20.00	2	20.00
9 to 10	5	17.86	4	22.22	5	20.00	1	10.00
11 or more	4	14.29	3	16.67	4	16.00	1	10.00

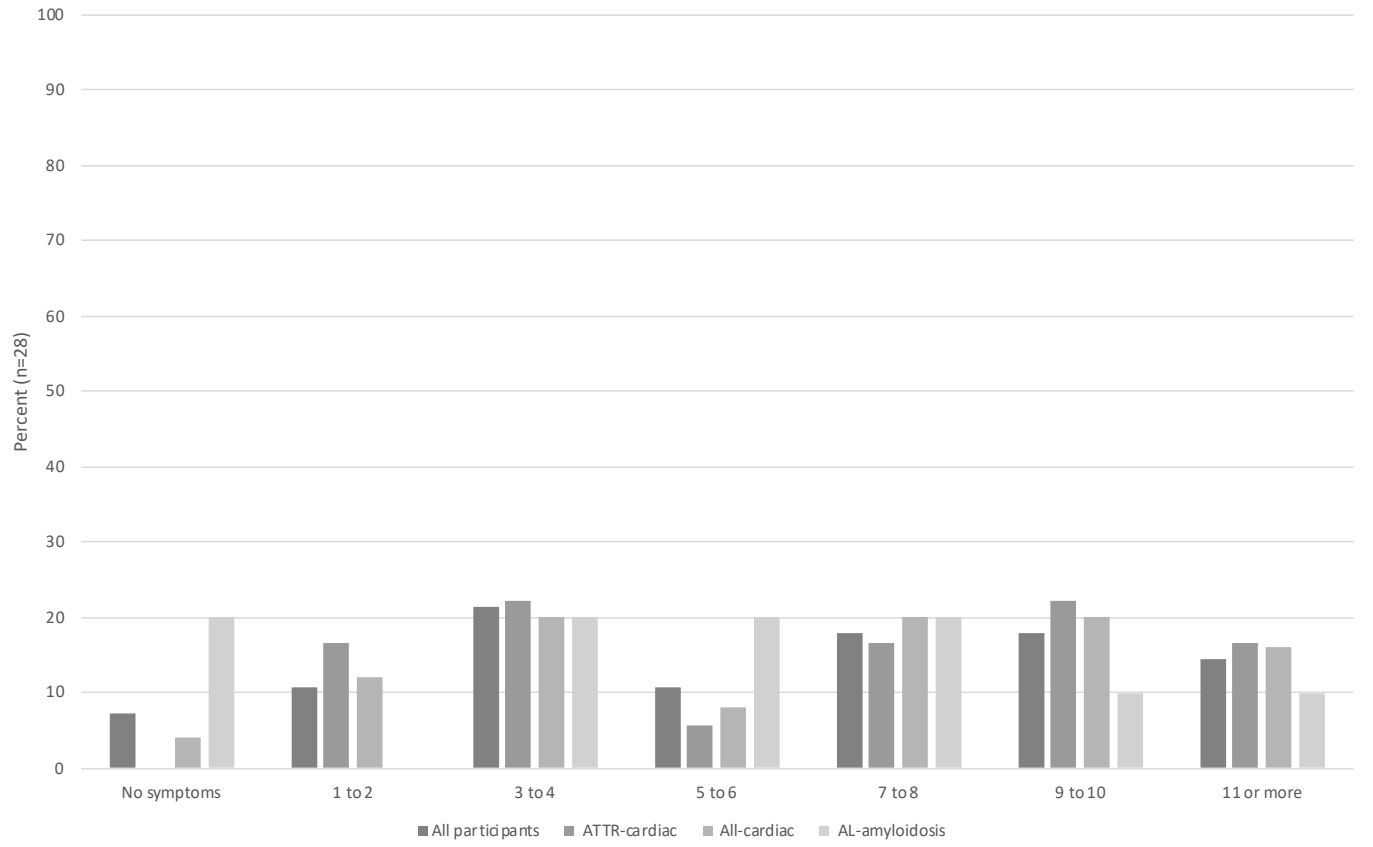
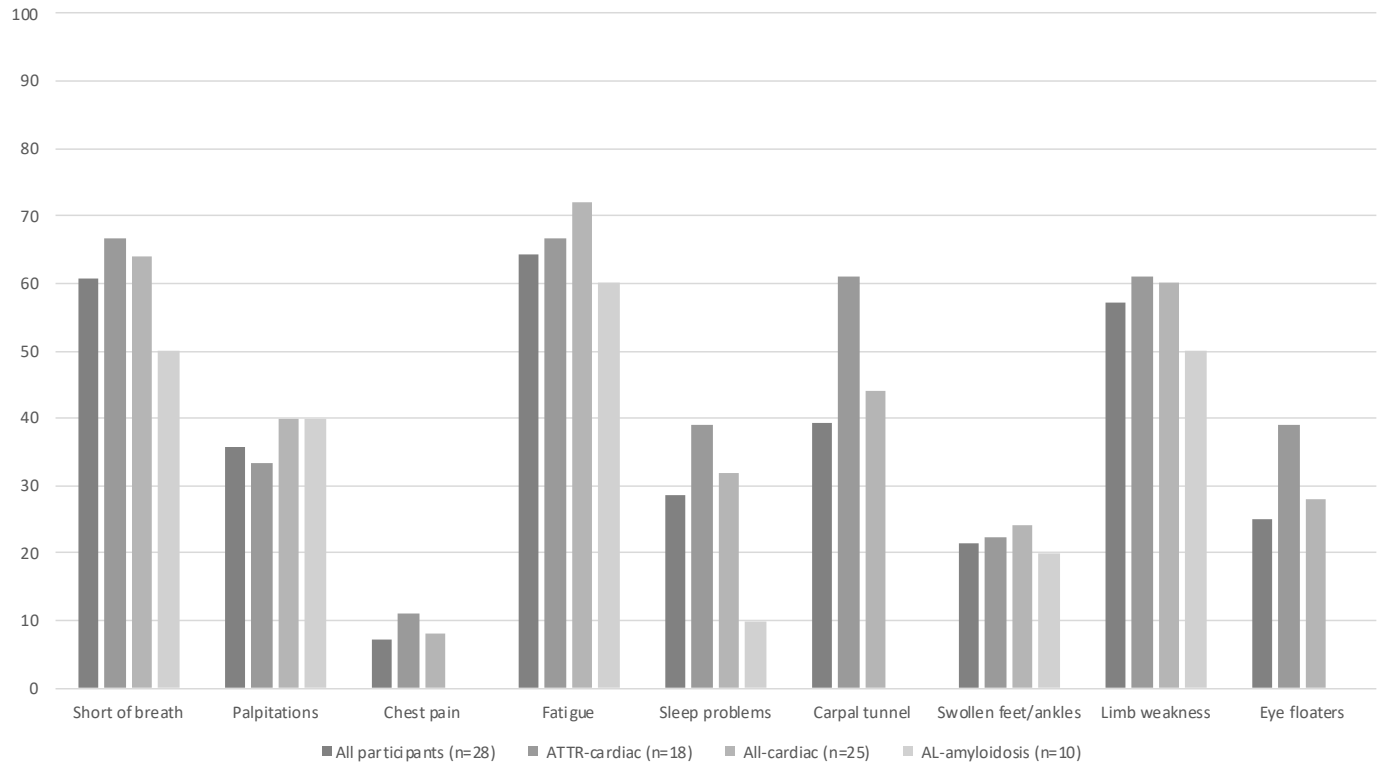


Figure 3.1: Number of symptoms per participant

Table 3.2: Symptoms

Symptom	All participants		ATTR-cardiac		All-cardiac		AL-amyloidosis	
	n=28	%	n=18	%	n=25	%	n=10	%
Short of breath	17	60.71	12	66.67	16	64.00	5	50.00
Palpitations	10	35.71	6	33.33	10	40.00	4	40.00
Chest pain	2	7.14	2	11.11	2	8.00	0	0.00
Fatigue	18	64.29	12	66.67	18	72.00	6	60.00
Sleep problems	8	28.57	7	38.89	8	32.00	1	10.00
Carpal tunnel	11	39.29	11	61.11	11	44.00	0	0.00
Swollen feet/ankles	6	21.43	4	22.22	6	24.00	2	20.00
Limb weakness	16	57.14	11	61.11	15	60.00	5	50.00
Eye floaters	7	25.00	7	38.89	7	28.00	0	0.00
Lightheaded	16	57.14	11	61.11	14	56.00	5	50.00
Decrease appetite	10	35.71	8	44.44	10	40.00	2	20.00
Bloating	7	25.00	6	33.33	7	28.00	1	10.00
Diarrhea/constipation	11	39.29	6	33.33	9	36.00	5	50.00
Nausea	2	7.14	2	11.11	2	8.00	0	0.00
Weight loss	13	46.43	8	44.44	12	48.00	5	50.00
Swollen tongue	3	10.71	1	5.56	3	12.00	2	20.00
Skin changes	5	17.86	0	0.00	5	20.00	5	50.00
Other	10	35.71	4	22.22	9	36.00	6	60.00



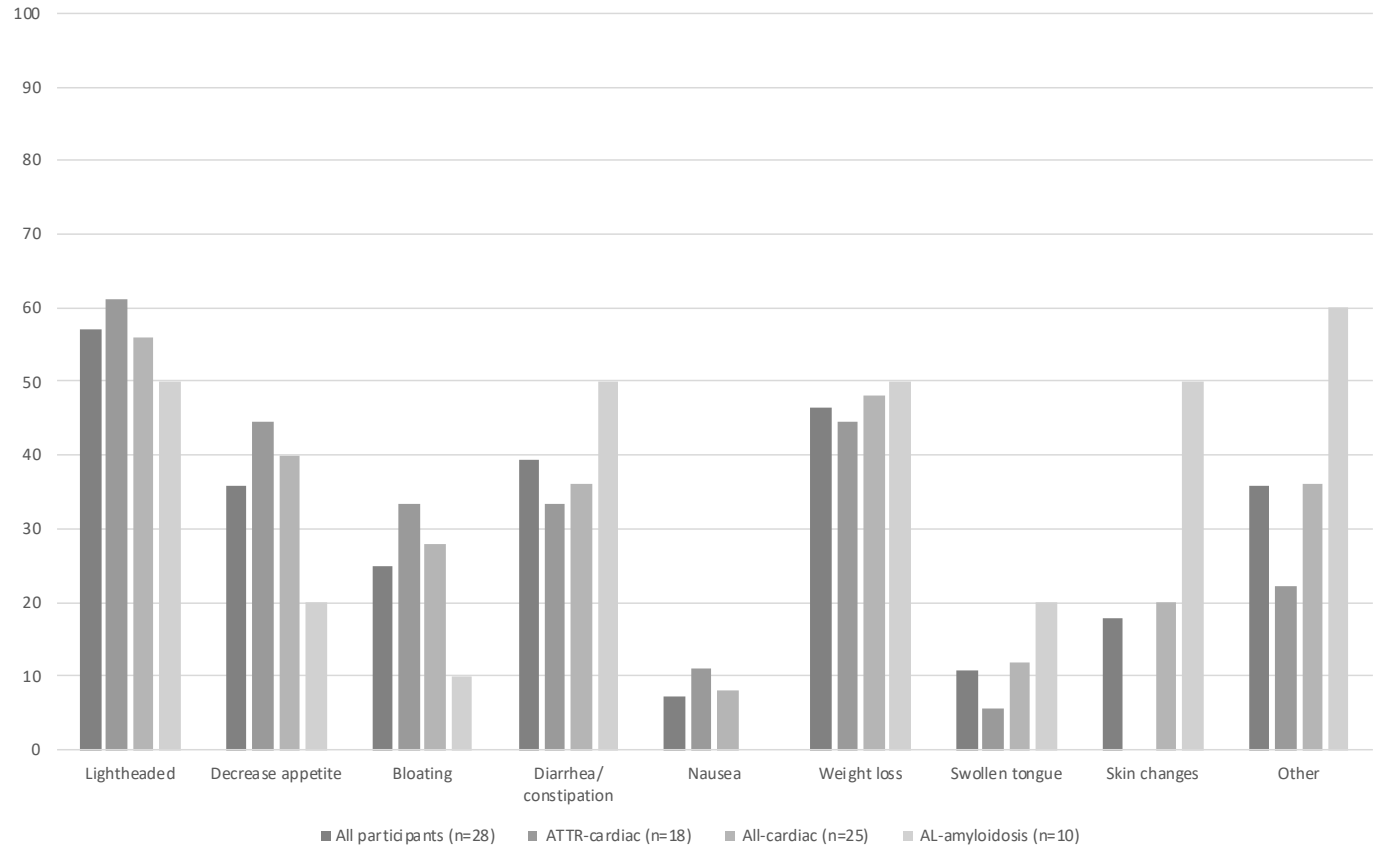


Figure 3.2: Symptoms

Table 3.3: Quality of life from symptoms

Symptom	Number (n=28)	Percent	Quality of life			
			Mean	SD	Median	IQR
Short of breath	17	60.71	4.00	1.70	4.00	2.00
Palpitations	10	35.71	3.63	1.51	3.00	2.25
Chest pain	2	7.14	1.00	0.00	1.00	0.00
Fatigue	18	64.29	3.33	1.33	3.00	1.75
Sleep problems	8	28.57	2.63	1.19	3.00	1.50
Carpal tunnel	11	39.29	3.82	1.47	4.00	2.00
Swollen feet/ankles	6	21.43	2.33	1.03	2.00	0.75
Limb weakness	16	57.14	3.25	1.44	3.00	3.00
Eye floaters	7	25.00	3.43	1.72	3.00	2.00
Lightheaded	16	57.14	3.70	1.46	4.00	2.00
Decrease appetite	10	35.71	2.90	1.10	3.00	0.75
Bloating	7	25.00	3.14	1.46	3.00	1.50
Diarrhea/constipation	11	39.29	3.45	1.69	3.00	2.50
Nausea	2	7.14	2.00	1.41	2.00	1.00
Weight loss	13	46.43	3.08	1.38	3.00	2.00
Swollen tongue	3	10.71	2.00	0.00	2.00	0.00
Skin changes	5	17.86	2.50	0.58	2.50	1.00

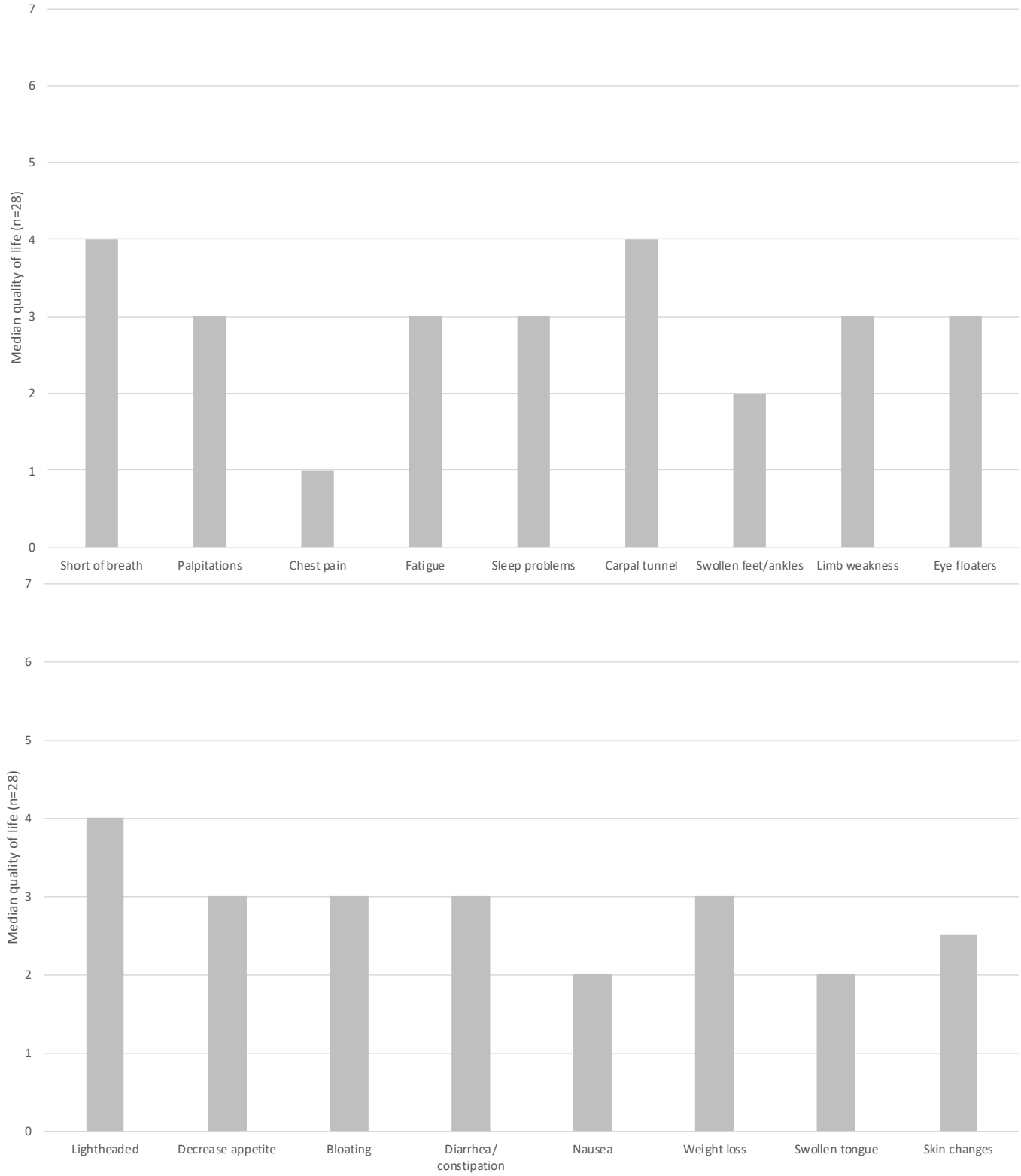


Figure 3.3: Quality of life from symptoms

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was excessive weight loss (n=8, 22.22%). There were seven participants (19.44%) who described experiencing breathlessness and four participants (11.11%) who described experiencing tiredness. A final four participants (11.11%) identified a specific physical sensation, such as numbness or tingling in their fingers or toes, which led to their diagnosis.

When discussing symptoms leading to their diagnosis, participants described how soon after experiencing symptoms they sought medical attention. There were five participants (13.89%) that described having symptoms and not seeking medical attention initially but recognising the importance of those symptoms in hindsight. An additional three participants (8.33%) also mentioned having symptoms and not seeking medical attention initially, but they provided no reason for this.

Overall, 18 participants (50.00%) described having symptoms and seeking medical attention relatively soon. There were eight participants (22.22%) that described having symptoms and not seeking medical attention initially, and a final five participants (13.89%) that described having no symptoms or not noticing them prior to diagnosis.

There were nine participants (25.00%) that described a diagnostic pathway that required appointments with a general practitioner and two or more specialists. There were also nine participants (25.00%) who described receiving a diagnosis following referral from their general practitioner to a specialist. A final six participants (16.67%) described receiving diagnosis following a specialist ordering tests. They made no mention of a GP referral.

When discussing their symptoms, twenty-five participants had a strong recollection of symptoms (69.44%) and four had not experienced any symptoms prior to diagnosis (11.11%).

In relation to subgroup variations, participants in the *Regional or remote* (11.11%) and *Mid to low SEIFA* (9.09%) subgroups experienced excessive weight loss less frequently than the general population (22.22%), while those in the *Female* subgroup described this more frequently (35.71%).

Participants in the *Aged 65 to 74* (31.58%) subgroup described breathlessness more frequently than the general population (19.44%), while those in the *University* (7.14%), and *Aged 75 or older* (0.00%) subgroups did not describe this at all.

No participants in the *AL amyloidosis*, *Aged 75 or older*, or *University* subgroups described a specific physical sensation such as numbness or tingling fingers as a symptom (0.00%). Whereas participants in the *Female* (21.43%), *Regional or remote* (22.22%), and *Mid to low SEIFA* (27.27%) subgroups described this more frequently than the general population (11.11%).

Participants in the general population (13.89%) described having symptoms and not seeking medical attention initially but recognising their importance in hindsight, while none of the participants in the *Regional or remote* (0.00%) and *Mid to low SEIFA* (0.00%) subgroups described this at all.

Participants in the *Regional or remote* subgroup also describe having symptoms and not seeking medical attention without describing their reasons more frequently (22.22%) than the general population (8.33%).

Participants in the *Carer* (25.00%), *Aged 55 to 64* (25.00%), and *Regional or remote* (33.33%) subgroups described having symptoms and seeking medical attention relatively soon less frequently than the general population (50.00%). Participant in the *AL amyloidosis* (70.00%), *Aged 75 or older* (75.00%), and *Trade or high school* (64.29%) subgroups describe this more frequently.

Participants in the *Mid to low SEIFA* subgroup describe having symptoms and not seeking medical attention initially less frequently (9.09%) than the general population (22.22%). Participants in the *AL amyloidosis* (10.00%) subgroup described this more frequently.

Finally, no participants in the *Aged 75 or older* (0.00%) or *Trade or high school* (0.00%) subgroups described experiencing no symptoms prior to diagnosis. Participants in the *Aged 55 to 64* (37.50%), *University* (28.57%) and *Regional or remote* (33.33%) subgroups described this more frequently than the general population (13.89%).

Symptoms leading to diagnosis: Excessive weight loss

Loss of weight, about 20 kilos and have regained about four kilos of that over the treatment time, et cetera. It's a net loss of 15 kilos to date. Participant 001AL

Then I started to have weight loss. Unexplained weight loss. I was eating but I was just-- I wasn't exercising any more than what I would normally. In fact, I'd cut back because I was feeling fatigued and I'd lost interest. Participant 001ATR

Then in 2008, in about eight or nine months I lost about 30, 35 kilos. After a series of blood tests, my GP looked at me one day and said, 'Oh, I think you better go and see a haematologist.'
Participant 002ALX

Symptoms leading to diagnosis: Breathlessness

The principal symptom was just shortness of breath and sort of a gripping thirst the whole way up for the first sort of ten, fifteen minutes. Very unusual. I consulted my GP here in LOCATION REGIONAL and he says, 'Oh, you might have diabetes or some other renal condition' and sent me for a bunch of tests, but anyway no diabetes. Participant 004AL

First time I started to notice something wasn't right was in August 2017, when I was getting out of breath. As a result of that, everyone thought I was having a heart attack, so they sent me to a cardiologist. Participant 004ATR

I first noticed it when I started to get a little bit out of breath. I am usually been fairly fit. I'm retired now. I'm 71 years old, then I retired. Before that, I was pretty fit. I noticed we went away on holidays about six months after I retired over to LOCATION. I noticed that I was getting a bit out of breath carrying luggage and stuff around. Where I shouldn't normally have been. Participant 008ATR

Symptoms leading to diagnosis: Tiredness

Yes. Well, he was feeling particularly tired and not a lot of energy. He wasn't able to do some of the things he'd always done very comfortably...Then we went on a family hike and our daughter was with us and she said afterwards that he really struggled walking up the mountain and that was not typical of NAME HUSBAND. We live on three acres of land, which is a sloped property and we garden intensively. On that note, I think she might have coerced NAME HUSBAND into seeking some further advice, but it was really breathlessness, not having stamina and tiredness. Participant 001CA

I was very fatigued. Kidney function was dropping fairly rapidly. I had no energy at all. I was having a lot of, well, daily slight nosebleeds, which I'd never had in my life. That was about it. It was mainly the fatigue and just getting up every morning and not wanting to do anything. Participant 017ATR

Symptoms leading to diagnosis: Specific physical sensation

I don't know how long ago now, maybe three years ago. Two, three years ago. I've got generalised osteoarthritis, so I go to a rheumatologist. I went back for a follow up appointment six months after first seeing her. I said to her, "Look, I've got this cotton wool between my toes. I just feel like I've got cotton wool- started off this fluffiness between my toes. Now I feel like I've got pebbles sitting on the soles of my feet sort of thing." Hadn't really thought about peripheral neuropathy. Participant 001ATR

The next symptom that he had was neuropathy, finding it very hard walking on his feet and also tiredness which probably would have been also from the heart, but very, very tired and very, very, very sore feet which we call the neuropathy through the legs. Participant 004CA

He did have the tingling in the middle finger. He immediately went to a doctor and I told him about 23andMe, and the doctor asked him, 'Do you wake up in the morning with your arms asleep?' He did for several nights, but he thought it was just aging. Participant 005CA

Seeking medical attention: Did not seek medical attention initially but realised importance of symptoms in hindsight

From 2016, it has just been one thing after another, one thing after another and I really just thought I'm not firing on all cylinders because of the stress in my life. But prior to that, about four years ago, I was having some oral surgery and the anaesthetist sent me off for a routine ECG. I did it, come back and I got a phone call from my GP saying to me, 'PARTICIPANT, we think you've had a heart attack.' My response was, 'When would I have had time to have had that?'. Participant 001ATR

Well, I didn't know they were symptoms of amyloidosis until I was diagnosed, so really, I haven't got the faintest idea when the symptoms started. I took early retirement in 2001 because I wasn't feeling 100%, but I wasn't prepared to commit for a five-year project. Then in 2008, in about eight or nine months I lost about 30, 35 kilos. Participant 002ALX

Yes, there were things that happened way back to 1999 that I now know was part of it. I had also had problems with my back and operations on my back, which I now know that's probably related to it. The first time that words were used that maybe a really astute cardiologist would've gone onto within 2009, I was told after a heart scan- - They came back and they said, "Look, everything's fine, but there is moderate thickening of the heart all." Participant 013ATR

Seeking medical attention: Experienced symptoms and did not seek medical attention initially (other)

Well, he was feeling particularly tired and not a lot of energy. He wasn't able to do some of the things he'd always done very comfortably. I kept saying, but you are aging, so maybe there's some of that in there too. Then we went on a family hike and our daughter was with us and she said afterwards that he really struggled walking up the mountain and that was not typical of NAME HUSBAND. We live on three acres of land, which is a sloped property and we garden intensively. On that note, I think she might have coerced NAME HUSBAND into seeking some further advice, but it was really breathlessness, not having stamina and tiredness. Participant 001CA

I first noticed it when I started to get a little bit out of breath. I am usually been fairly fit. I'm retired now. I'm 71 years old, then I retired. Before that, I was pretty fit. I noticed we went away on holidays about six months after I retired over to Canada. I noticed that I was getting a bit out of breath carrying luggage and stuff around. Where I shouldn't normally have been. Participant 008ATR

Well, my first I think was shortness of breath. My family noticed that my eyes had a twitch and the skin started to drop…Then I had a lot of trouble with shortness of breath. It sort of crept up on me within 6 to 12 months. Participant 009ATR

Seeking medical attention: Experience symptoms and sought medical attention relatively soon

The principal symptom was just shortness of breath and sort of a gripping thirst the whole way up for the first sort of ten, fifteen minutes. Very unusual. I consulted my GP here in LOCATION REGIONAL and he says, 'Oh, you might have diabetes or some other renal condition' and sent me for a bunch of tests, but anyway no diabetes. Nothing was obvious in the renal stuff, but he sent me to a physician who diagnosed a disease called-- It was a form of diabetes, but it was essentially a disease of the pituitary gland and prescribed some medications for that. Participant 004AL

First time I started to notice something wasn't right was in August 2017, when I was getting out of breath. As a result of that, everyone thought I was having a heart attack, so they sent me to a cardiologist. The cardiologist did a whole lot of tests and said 'No, you're not having a heart attack', and that's where that stopped. They never actually tested for amyloidosis. Participant 004ATR

It all just started to keep building up and I knew there was something wrong, but I couldn't get to where they would understand what I was saying. The GP kept fobbing me off and sending me to-- I went to a rheumatologist, and I went to an immunologist and they all virtually said it was just in my head and there was nothing wrong and things like that. I started to get bad pains through my feet. I was eventually sent to a neurologist and he picked up. Participant 005AL

Seeking medical attention: No experience or did not notice symptoms prior to diagnosis

I didn't notice any symptoms until after I was given the information that I had an imbalance in my light chains, which I found that information out in February about two months after the urologist phoned me. Participant 003AL

Yes. I noticed things actually after I had already had the diagnosis of the disease, already through my father had it. I remember that very, very clearly. He was convinced that his father had had it. I finally found somewhere I could actually get a type testing done. I went to the NAME CLINIC. Around about the same time I had carpal tunnel in both wrists. When I had the carpal tunnel clearance, they tested for the-- they did the analysis and they did it on the material they took away from my wrists about the same time as I got the information genetically though the NAME CLINIC. Participant 015ATR

Given the fact that we had this report from 23andMe-- my brother was diagnosed a week before this, and I lined up and went along to my GP, and he said, "Yes, it looks like you've got carpal tunnel syndrome." All of those things came together, virtually, in a week or two, together. Participant 016ATR

Table 3.4 Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes having excessive weight loss, which led to their diagnosis	8	22.22	3	16.67	5	20.00	3	30.00	2	25.00	3	13.64	5	35.71	1	11.11	7	25.93
Participant describes having breathlessness, which led to their diagnosis	7	19.44	3	16.67	5	20.00	2	20.00	2	25.00	4	18.18	3	21.43	2	22.22	5	18.52
Participant describes having tiredness, which led to their diagnosis	4	11.11	2	11.11	2	8.00	0	0.00	2	25.00	1	4.55	3	21.43	1	11.11	3	11.11
Participant describes having another specified physical sensation, which led to their diagnosis e.g. numbness or tingling	4	11.11	2	11.11	2	8.00	0	0.00	2	25.00	1	4.55	3	21.43	2	22.22	2	7.41

Symptoms leading to diagnosis	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes having excessive weight loss, which led to their diagnosis	8	22.22	2	25.00	4	21.05	2	25.00	3	21.43	3	21.43	1	9.09	7	28.00
Participant describes having breathlessness, which led to their diagnosis	7	19.44	1	12.50	6	31.58	0	0.00	4	28.57	1	7.14	2	18.18	5	20.00
Participant describes having tiredness, which led to their diagnosis	4	11.11	0	0.00	3	15.79	1	12.50	2	14.29	0	0.00	3	27.27	1	4.00
Participant describes having another specified physical sensation, which led to their diagnosis e.g. numbness or tingling	4	11.11	1	12.50	3	15.79	0	0.00	2	14.29	0	0.00	3	27.27	1	4.00

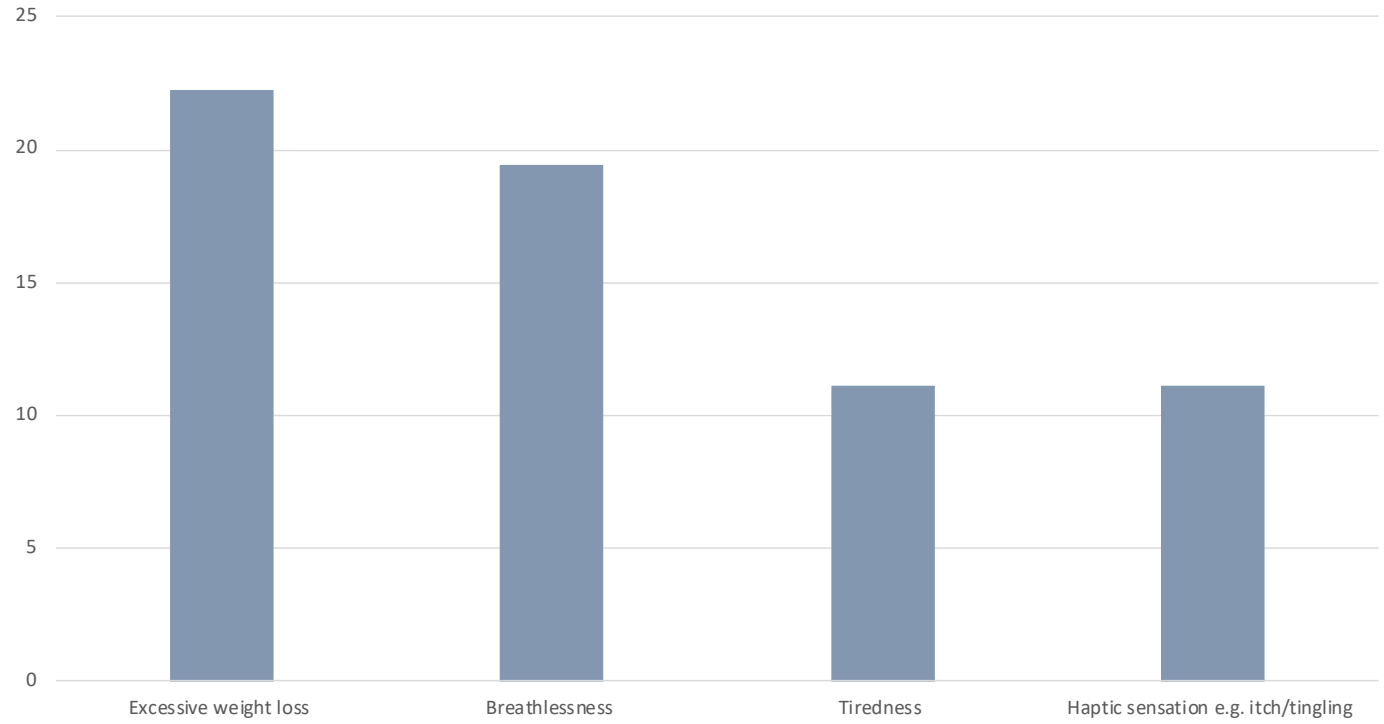


Figure 3.4: Symptoms leading to diagnosis

Table 3.5: Seeking medical attention

Seeking medical attention	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	5	13.89	3	16.67	3	12.00	1	10.00	1	12.50	3	13.64	2	14.29	0	0.00	5	18.52
Participant describes having symptoms and not seeking medical attention initially	3	8.33	2	11.11	2	8.00	0	0.00	1	12.50	2	9.09	1	7.14	2	22.22	1	3.70
Participant describes having symptoms and seeking medical attention relatively soon	18	50.00	9	50.00	14	56.00	7	70.00	2	25.00	11	50.00	7	50.00	3	33.33	15	55.56
Participant describes having symptoms and not seeking medical attention initially: Total	8	22.22	5	27.78	5	20.00	1	10.00	2	25.00	5	22.73	3	21.43	2	22.22	6	22.22
Participant describes having no symptoms or not noticing any symptoms before diagnosis	5	13.89	3	16.67	4	16.00	1	10.00	1	12.50	4	18.18	1	7.14	3	33.33	2	7.41

Seeking medical attention	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	5	13.89	1	12.50	2	10.53	2	25.00	2	14.29	2	14.29	0	0.00	5	20.00
Participant describes having symptoms and not seeking medical attention initially	3	8.33	0	0.00	3	15.79	0	0.00	2	14.29	0	0.00	1	9.09	2	8.00
Participant describes having symptoms and seeking medical attention relatively soon	18	50.00	2	25.00	10	52.63	6	75.00	9	64.29	7	50.00	6	54.55	12	48.00
Participant describes having symptoms and not seeking medical attention initially: Total	8	22.22	1	12.50	5	26.32	2	25.00	4	28.57	2	14.29	1	9.09	7	28.00
Participant describes having no symptoms or not noticing any symptoms before diagnosis	5	13.89	3	37.50	1	5.26	0	0.00	0	0.00	4	28.57	2	18.18	3	12.00

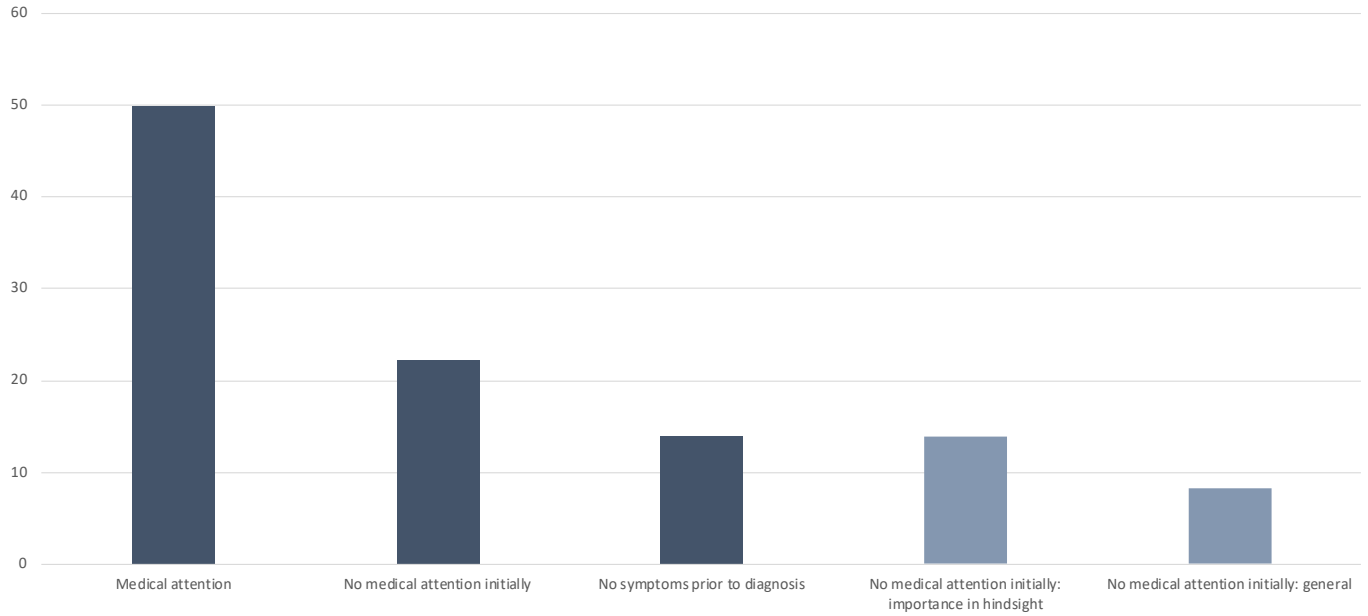


Figure 3.5: Seeking medical attention

Table 3.6: Description of diagnostic pathway

Path to diagnosis	All participants		ATTR-cardiac		All-cardiac		AL Amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=14	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes being referred directly to a specialist from their general practitioner but did not initially lead to their diagnosis: multiple specialists needed before diagnosis Total	9	25.00	4	22.22	8	32.00	5	50.00	0	0.00	9	40.91	0	0.00	3	33.33	6	22.22
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis Total	9	25.00	4	22.22	5	20.00	2	20.00	3	37.50	3	13.64	6	42.86	2	22.22	7	25.93
Participant describes being diagnosed through tests their specialist ordered	6	16.67	4	22.22	4	16.00	1	10.00	1	12.50	4	18.18	2	14.29	2	22.22	4	14.81

Path to diagnosis	All participants		55 to 64		65 to 74		75 and older		Trade or high school		University		Mid to low SEIFA		High SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes being referred directly to a specialist from their general practitioner but did not initially lead to their diagnosis: multiple specialists needed before diagnosis Total	9	25.00	0	0.00	6	31.58	2	25.00	3	21.43	6	42.86	2	18.18	7	28.00
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis Total	9	25.00	4	50.00	4	21.05	1	12.50	2	14.29	4	28.57	2	18.18	7	28.00
Participant describes being diagnosed through tests their specialist ordered	6	16.67	1	12.50	2	10.53	3	37.50	3	21.43	2	14.29	3	27.27	3	12.00

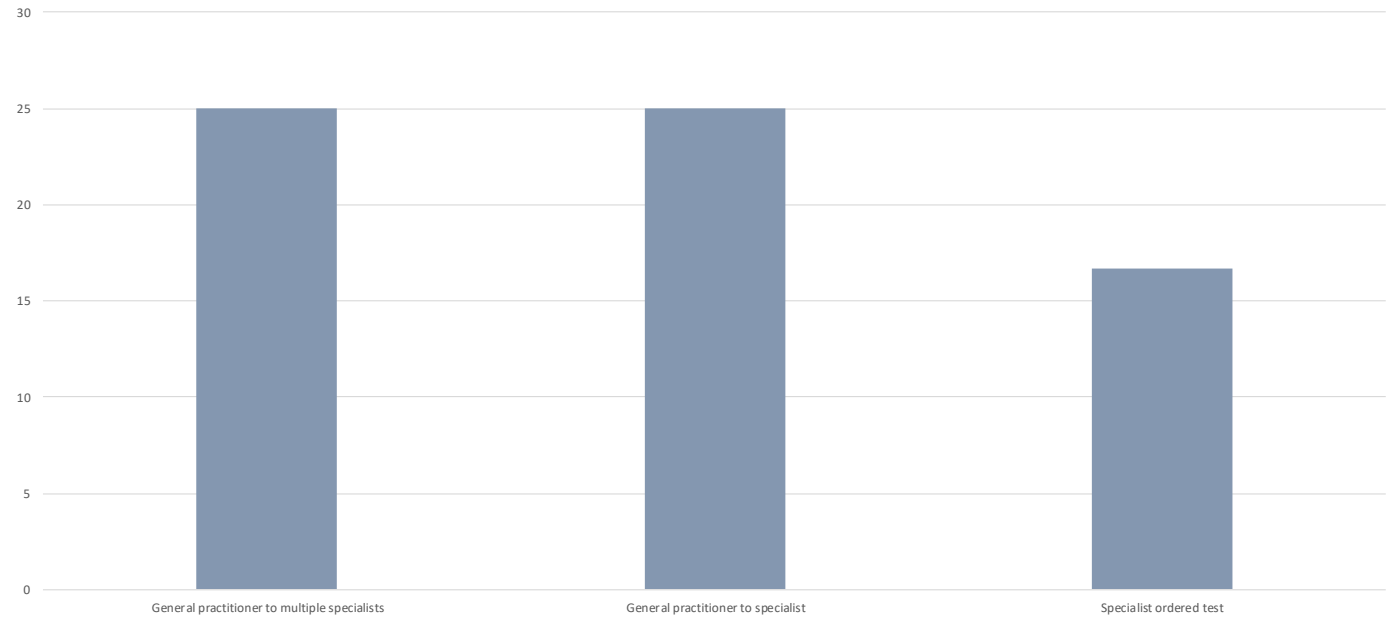


Figure 3.6: Description of diagnostic pathway

Table 3.7: Symptom recall

Symptom recall	All participants		ATTR-cardiac		All-cardiac		AL Amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=14	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	25	69.44	14	77.78	18	72.00	6	60.00	5	62.50	14	63.64	11	78.57	6	66.67	19	70.37
Participant describes not experience any symptoms that contributed to their diagnosis	4	11.11	3	16.67	4	16.00	1	10.00	0	0.00	4	18.18	0	0.00	2	22.22	2	7.41

Symptom recall	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	25	69.44	4	50.00	14	73.68	7	87.50	11	78.57	9	64.29	8	72.73	17	68.00
Participant describes not experience any symptoms that contributed to their diagnosis	4	11.11	2	25.00	1	5.26	0	0.00	0	0.00	4	28.57	1	9.09	3	12.00

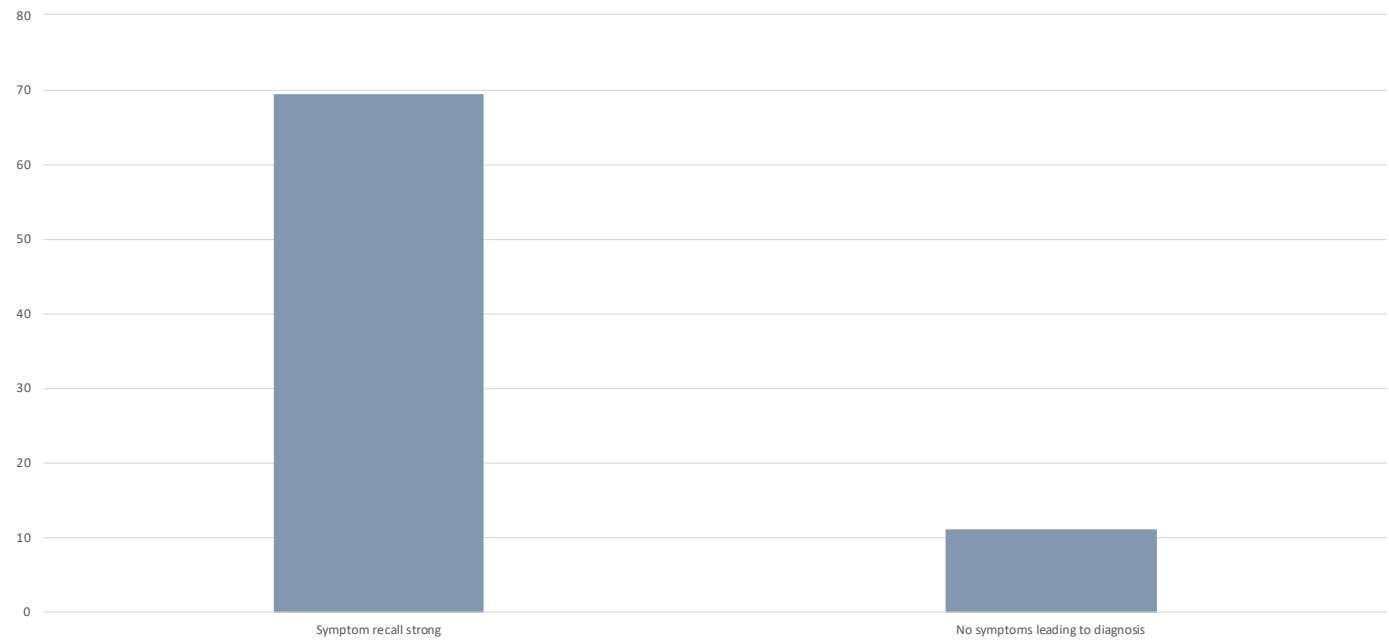


Figure 3.7: Symptom recall

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with amyloidosis. They could choose from a set list of diagnostic tests and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants had between one and 11 diagnostic tests, most commonly five to six tests (n=11, 39.29%) (Median = 6.5, IQR = 3.25) (Table 3.8, Figure 3.8). The most common diagnostic tests were blood tests (n=23, 82.14%), electrocardiogram (n=18, 64.29%), and echocardiogram (n=16, 57.14%) (Table 3.9, Figure 3.9).

Table 3.8: Number of diagnostic tests

Number of diagnostic tests per participant	All participants		ATTR-cardiac		All-cardiac		AL-amyloidosis	
	n=28	%	n=18	%	n=25	%	n=10	%
1 to 2	4	14.29	3	16.67	4	16.00	1	10.00
3 to 4	3	10.71	3	16.67	3	12.00	0	0.00
5 to 6	11	39.29	7	38.89	5	20.00	4	40.00
7 to 8	9	32.14	4	22.22	10	40.00	5	50.00
9 or more	1	3.57	1	5.56	3	12.00	0	0.00

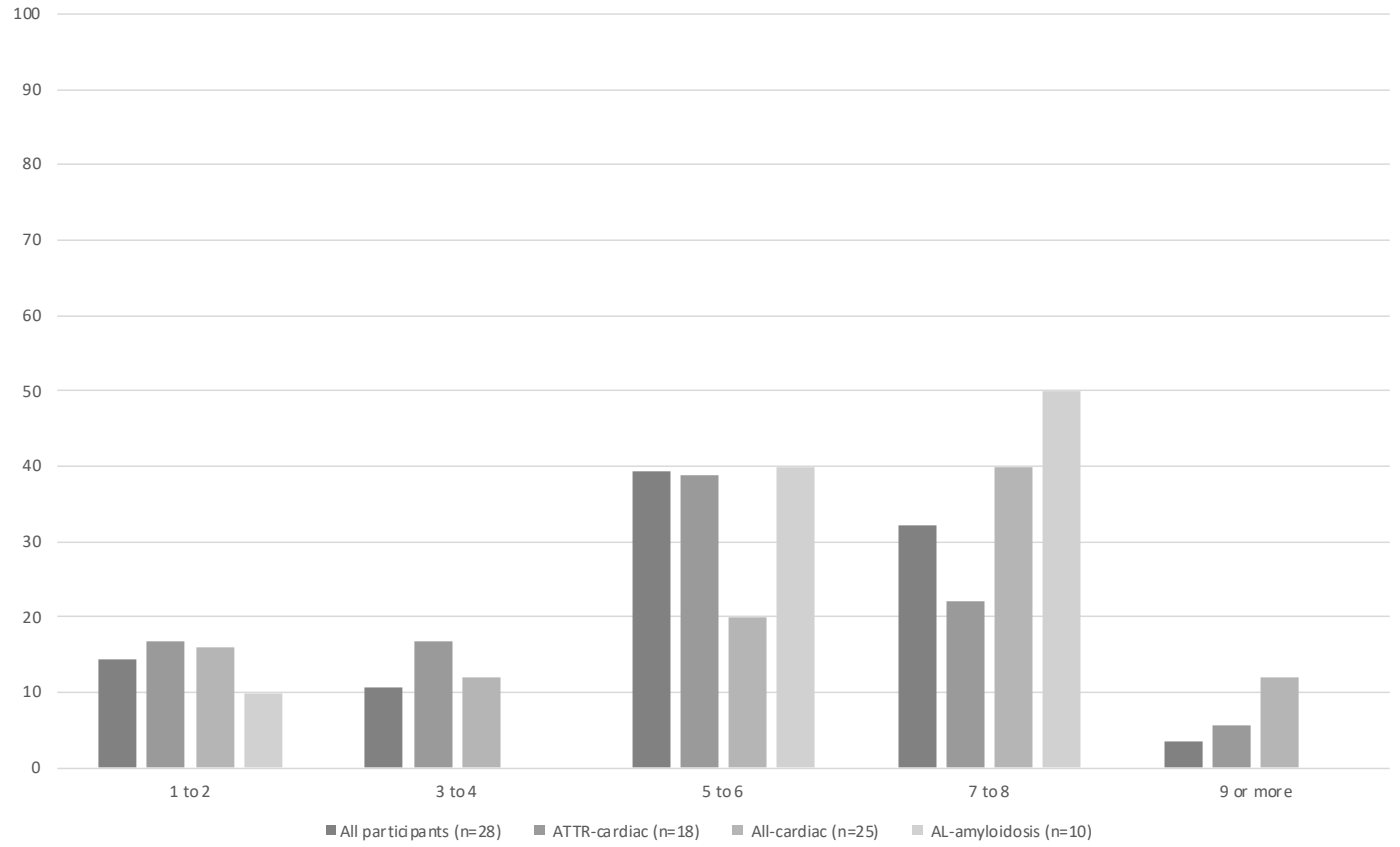
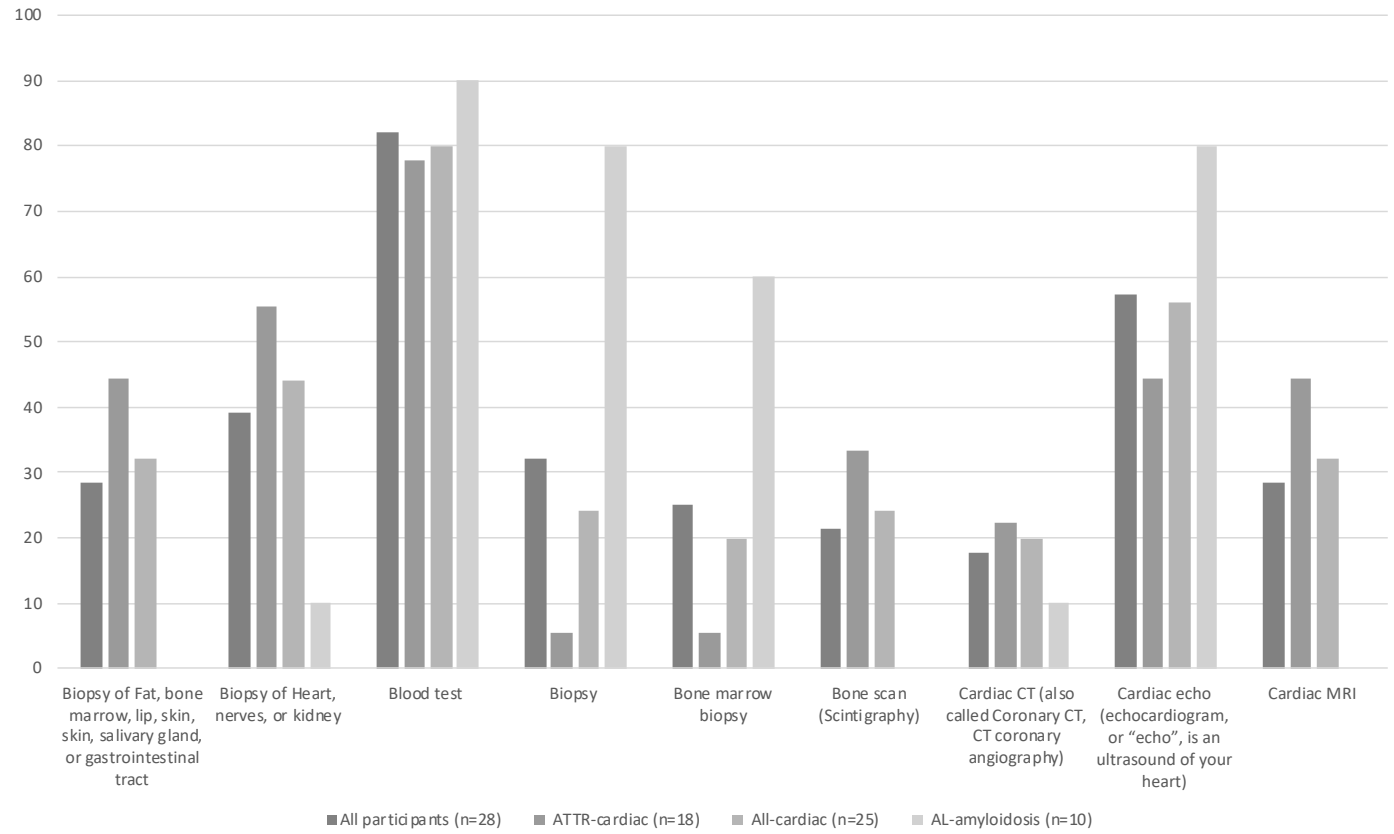


Figure 3.8: Number of diagnostic tests

Table 3.9: Diagnostic tests

Diagnostic test	All participants		ATTR-cardiac		All-cardiac		AL-amyloidosis	
	n=28	%	n=18	%	n=25	%	n=10	%
Biopsy of Fat, bone marrow, lip, skin, skin, salivary gland, or gastrointestinal tract	8	28.57	8	44.44	8	32.00	0	0.00
Biopsy of Heart, nerves, or kidney	11	39.29	10	55.56	11	44.00	1	10.00
Blood test	23	82.14	14	77.78	20	80.00	9	90.00
Biopsy	9	32.14	1	5.56	6	24.00	8	80.00
Bone marrow biopsy	7	25.00	1	5.56	5	20.00	6	60.00
Bone scan (Scintigraphy)	6	21.43	6	33.33	6	24.00	0	0.00
Cardiac CT	5	17.86	4	22.22	5	20.00	1	10.00
Cardiac echo	16	57.14	8	44.44	14	56.00	8	80.00
Cardiac MRI	8	28.57	8	44.44	8	32.00	0	0.00
Electrocardiogram (EKG)	18	64.29	12	66.67	16	64.00	6	60.00
Nuclear heart scan/Nuclear Stress Test/Radionuclide Scan	9	32.14	9	50.00	9	36.00	0	0.00
CT Scan	4	14.29	0	0.00	2	8.00	4	40.00
MRI	5	17.86	0	0.00	3	12.00	5	50.00
Physical exam	9	32.14	8	44.44	9	36.00	1	10.00
Urine test	15	53.57	7	38.89	12	48.00	8	80.00
Genetic sequencing	5	17.86	4	22.22	5	20.00	1	10.00
Medical history/ family medical history	9	32.14	7	38.89	9	36.00	2	20.00
Other	3	10.71	2	11.11	3	12.00	1	10.00



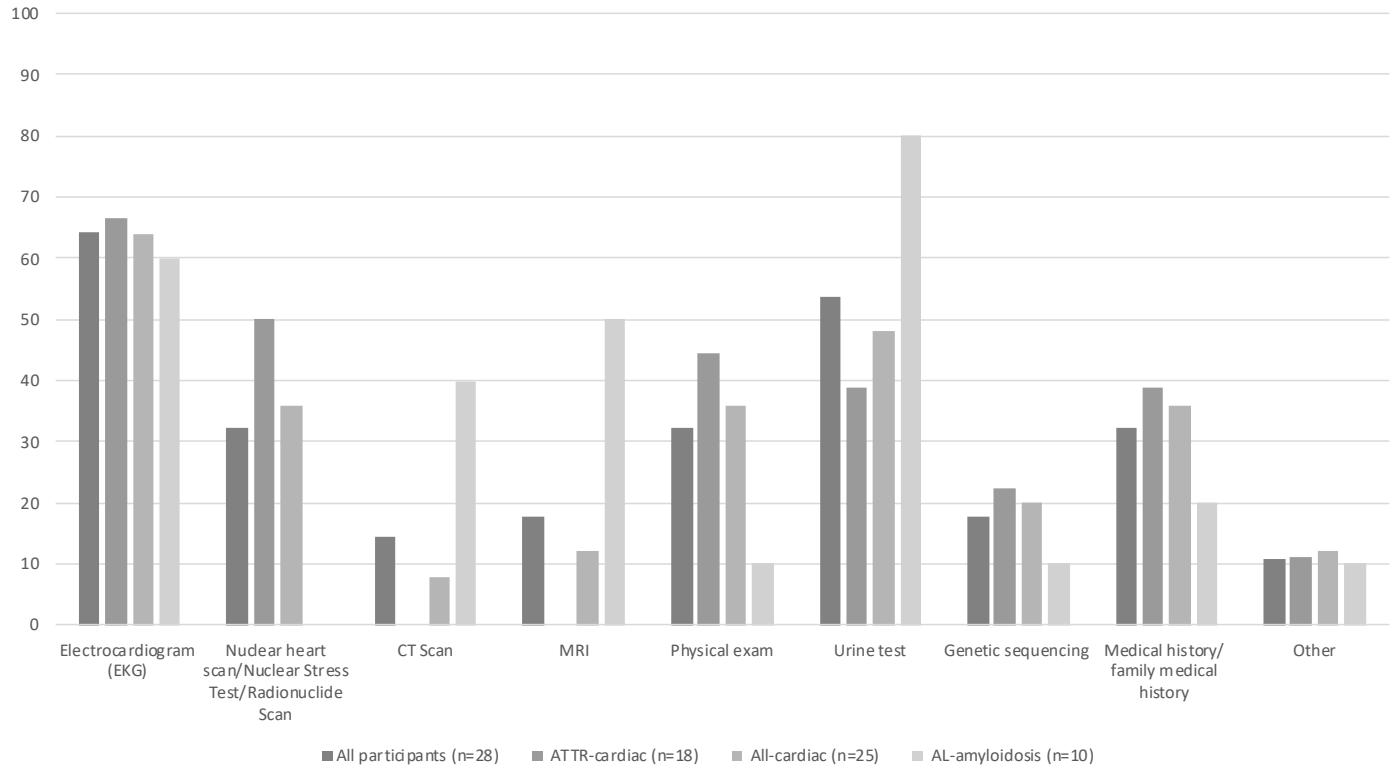


Figure 3.9: Diagnostic tests

Time from symptoms to diagnosis

Participants were asked in the online questionnaire to estimate the date when they first noticed symptoms and to estimate the date when they were diagnosed. Where both dates were given, an estimate of the length of time between noticing symptoms and getting a diagnosis was calculated.

There were 26 participants with enough data to estimate the length of time between noticing symptoms and receiving a diagnosis. Participants most commonly had more than a year between noticing symptoms and being diagnosed (n=11, 42.31%), followed by between 6 months and a year (n=7, 26.92%). There were five participants (19.23%) that had noticed symptoms between one and six months before getting diagnosed, and three participants (11.54%) that had less than one month.

Table 3.10: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Number (n=28)	Percent
Less than 1 month	3	11.54
1 month to 6 months	5	19.23
6 months to 1 year	7	26.92
More than 1 year	11	42.31

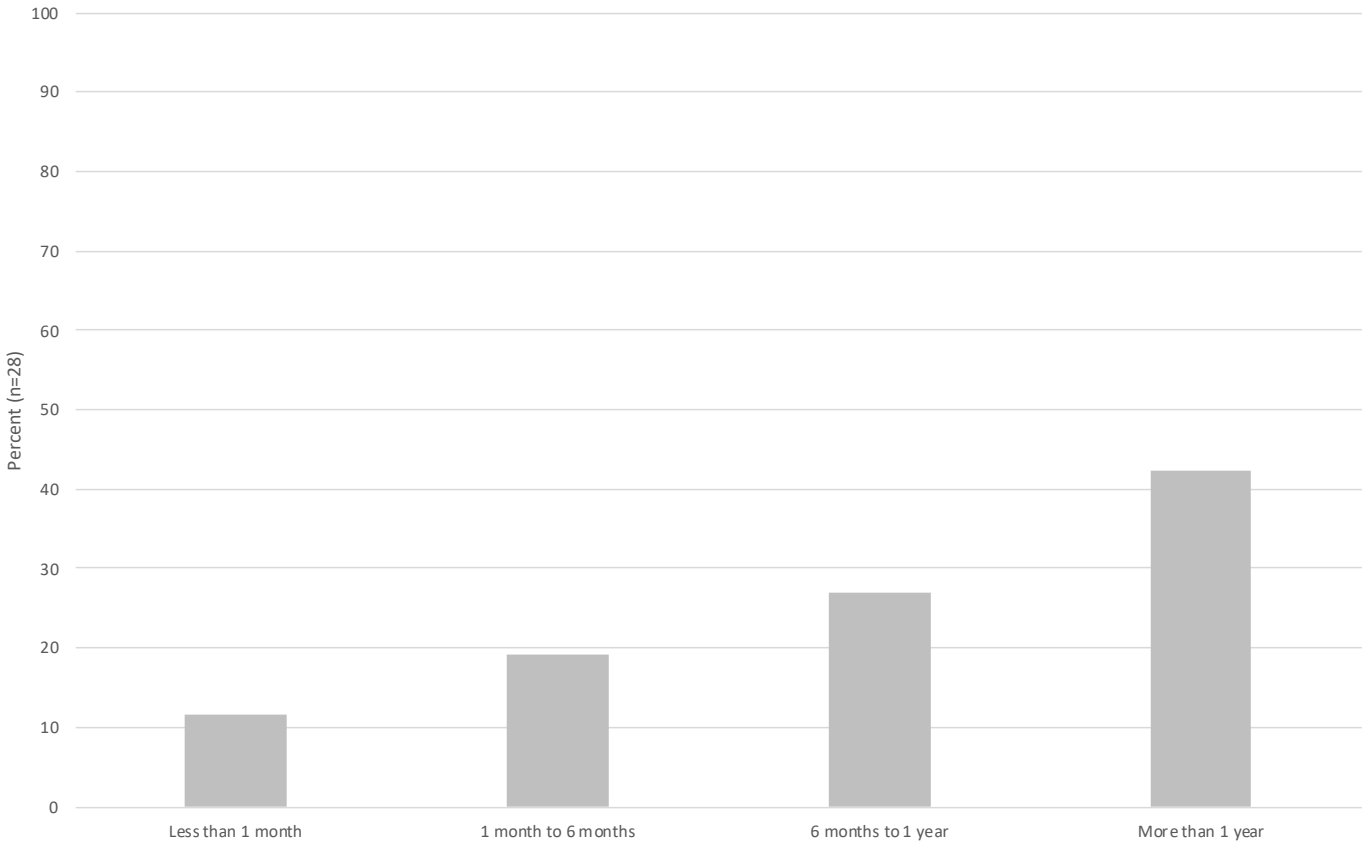


Figure 3.10: Time from symptoms to diagnosis

Time from diagnostic tests to diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

The majority of participants waited between two and three weeks (n=8, 28.57%) or more than four weeks (n=8, 28.57%) (Table 3.11, Figure 3.11).

Table 3.11: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=28	Percent
Diagnosed immediately at the consultation	2	7.14
Less than 1 week	4	14.29
Between 1 and 2 weeks	4	14.29
Between 2 and 3 weeks	8	28.57
4 weeks or more	8	28.57
Not sure	2	7.14

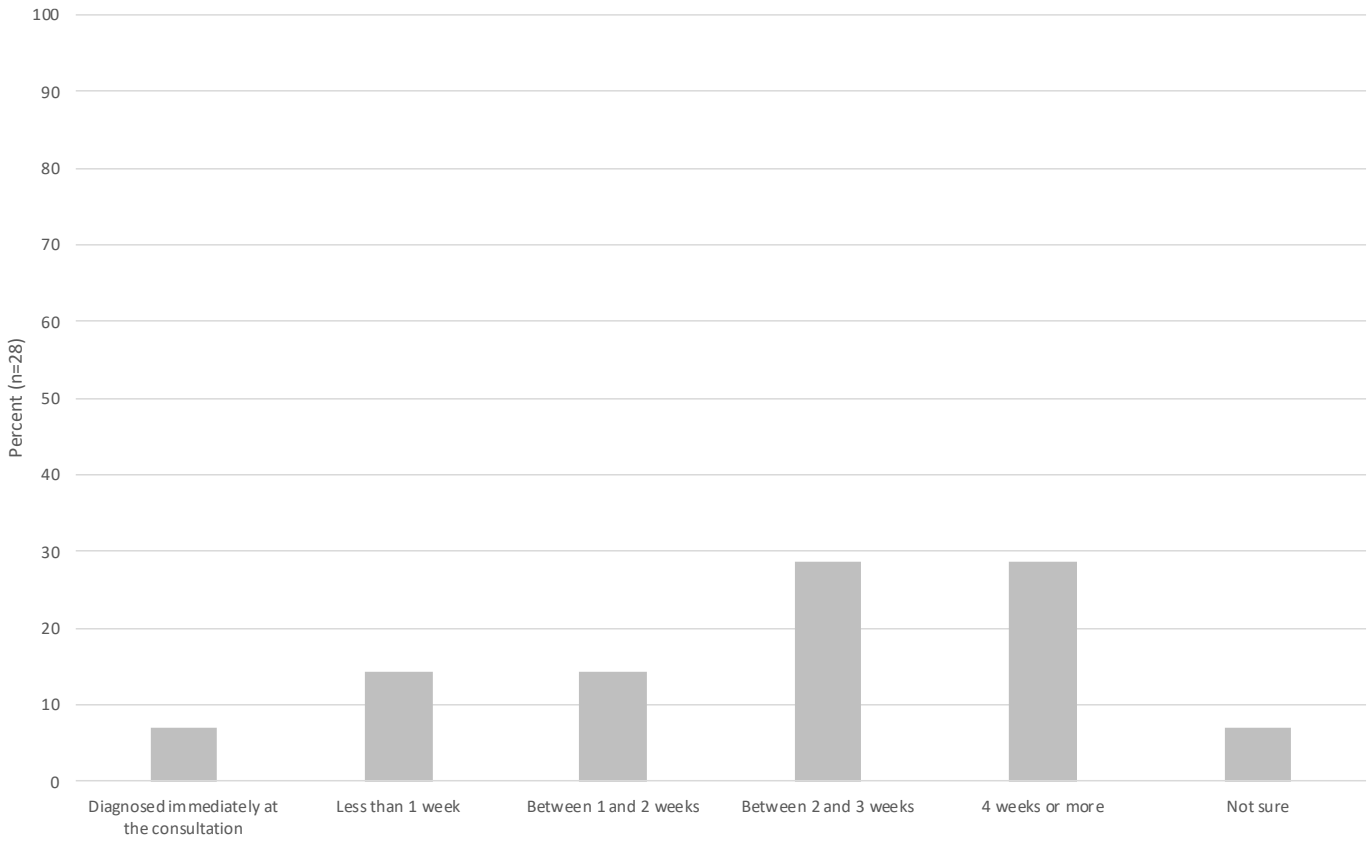


Figure 3.11: Time from diagnostic test to diagnosis

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

The diagnosis was given most commonly by the haematologist (n=9, 32.14%), followed by a cardiologist (n=7, 25.00%) (Table 3.12, Figure 3.12). The diagnosis was most commonly given at a specialist clinic (n=19, 67.86%). (Table 3.13, Figure 3.13).

Table 3.12: Diagnosis provider

Health professional gave diagnosis	Number (n=28)	Percent
Haematologist	9	32.14
Cardiologist	7	25.00
Neurologist	4	14.29
Nephrologist	3	10.71
Gastroenterologist	1	3.57
Other	4	14.29

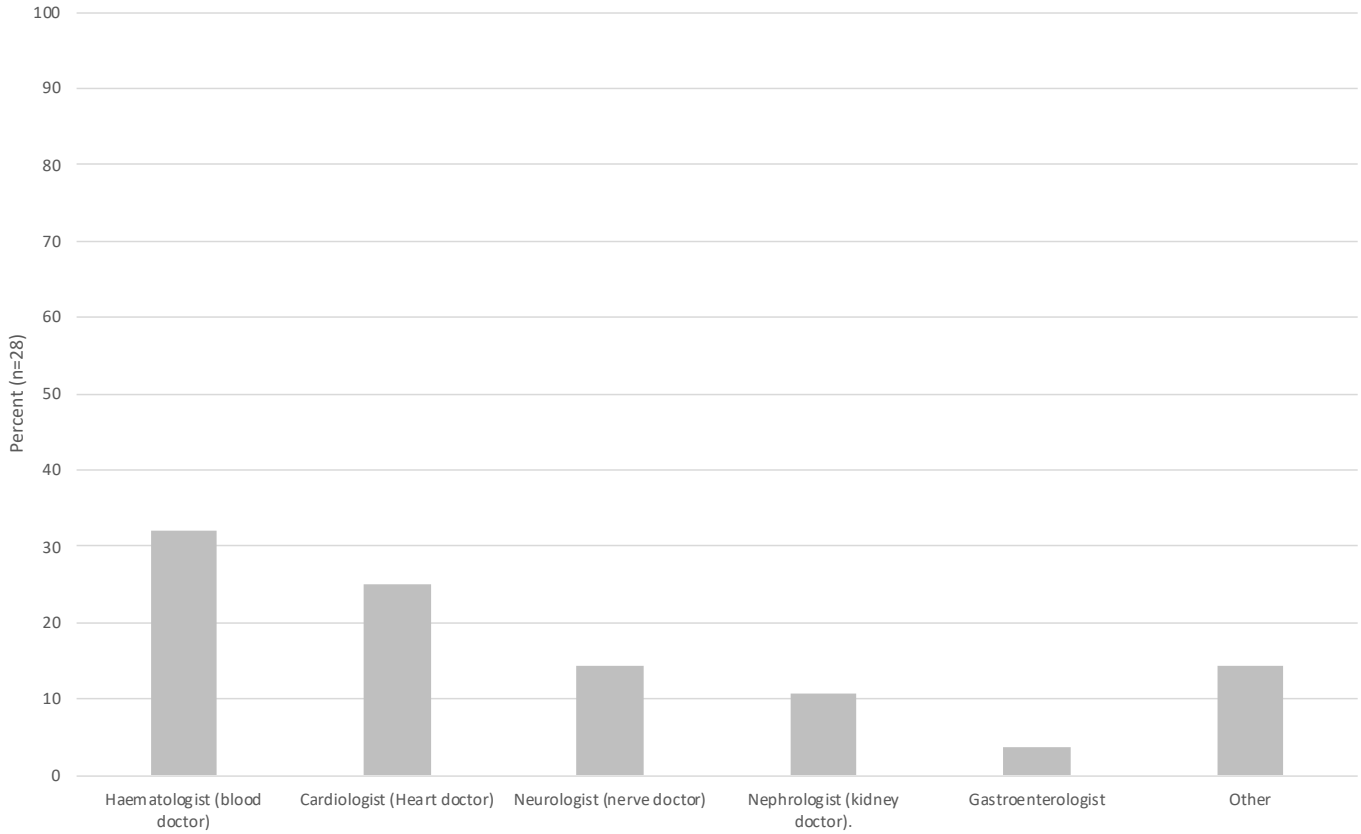


Figure 3.12: Diagnosis provider

Table 3.13: Diagnosis location

Location of diagnosis	Number (n=28)	Percent
Specialist clinic	19	67.86
Hospital	6	21.43
General practice (GP)	1	3.57
Home/phone call	2	7.14
Gastroenterologist	1	3.57
Other	4	14.29

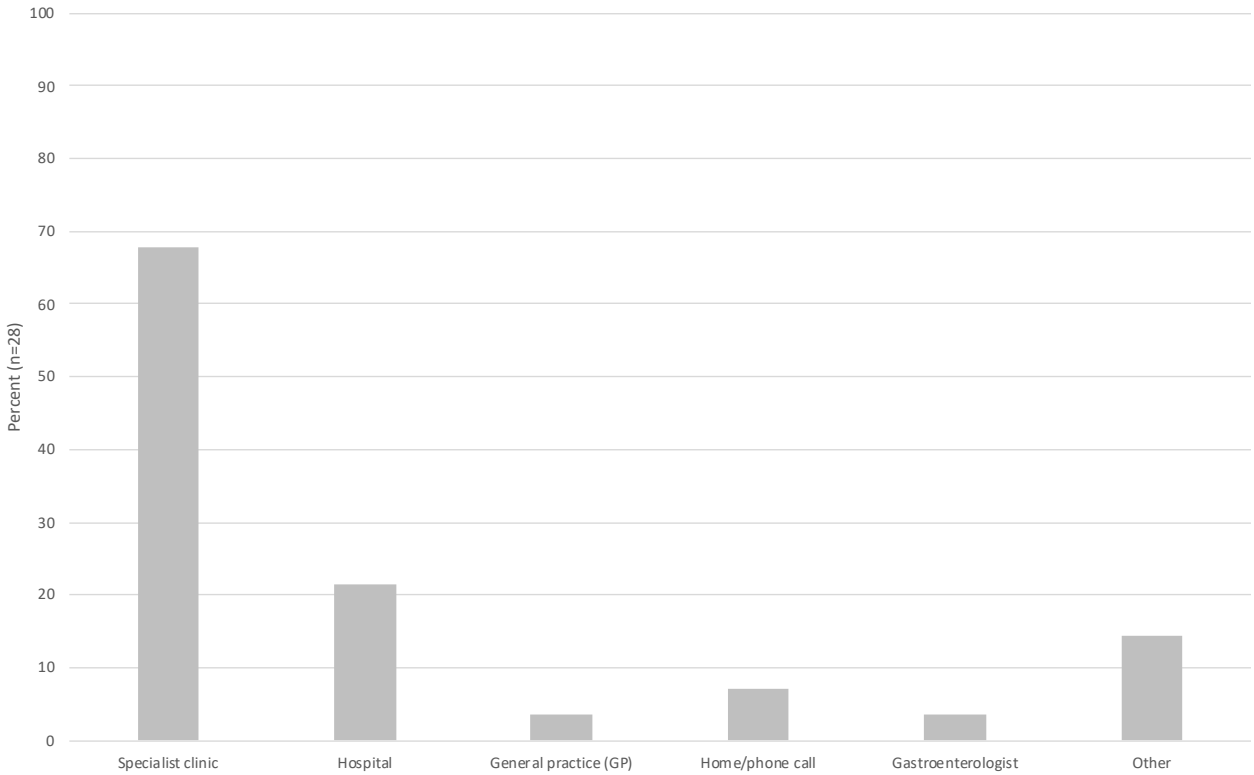


Figure 3.13: Diagnosis location

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis and the reason for their level of knowledge. There were 15 participants (41.67%) that gave no specific reason for their level of knowledge. There were eight participants (22.22%) who said they came to understand their condition more over time and through lived experience, and four participants (11.11%) described knowing very little about their condition at diagnosis, but that they were aware of family history with the condition.

Overall, there were 27 participants (75.00%) that described knowing nothing or very little at diagnosis and these were the most common themes. There were three participants (8.33%) that noted that they knew a good amount about the condition at diagnosis.

In relation to subgroup variations, participants in the *Carer* (25.00%), *Aged 55 to 64* (12.50%), *Female* (28.57%), and *Regional or remote* (11.11%) subgroups described no specific reason for their level of knowledge less frequently than the general population (41.67%), while those in the *Aged 65 to 74* (52.63%), *Trade or high school* (64.29%) and *Metropolitan* (51.85%) subgroup described this more frequently.

Participants in the *ATTR-cardiac* (11.11%), and the *Male* (9.09%) subgroups described knowing about their condition over time through lived experience, but not at diagnosis, less frequently than the general population (22.22%), while those in the *Carer* (37.50%), *Aged 75 or older* (37.50%), *Female* (42.86%), and *Regional or remote* (33.33%) subgroups described this more frequently.

No participants in the *AL amyloidosis* (0.00%), *Carer* (0.00%) and *Aged 75 or older* (0.00%) subgroups described having little knowledge but having a family history of the condition. Participants in the *ATTR-cardiac* (22.22%) and *Regional or remote* (22.22%) subgroups described this more frequently than the general population (11.11%).

Participants in the *ATTR-cardiac* (38.89%) *Aged 55 to 64* (37.50%), *Regional or remote* (44.44%), and *Mid to low SEIFA* (45.45%) subgroups described knowing nothing about the condition at diagnosis less frequently than the general population (55.56%). Participants in the *AL amyloidosis* (80.00%), and *Aged 75 or older* (75.00%) subgroups described this more frequently.

No participants in the *Al amyloidosis* (0.00%) or *Carer* (0.00%) subgroups described knowing very little about the condition at diagnosis. Participants in the *ATTR-cardiac* (38.89%) and *Trade or high school* (35.71%) subgroups described this more frequently than the general population (19.44%).

Participants in the *University* (21.43%) subgroups described knowing a good amount about the condition at diagnosis more frequently than the general population (8.33%).

No reason to level of knowledge

Zero. Nothing. I was aware of myeloma, but vaguely, but not AL. I'd not heard of it. It was just a brand-new word. Participant 004AL

I didn't know anything. Participant 005ATR

Nothing. Never heard of it. Participant 011ATR

Understanding over time through lived experience

Yes, has been very good. To be honest, I've just been bombarded with information overload in the last eight weeks, basically that's how long it's been since I've been diagnosed, really. Participant 001ATR

Nothing. But I very quickly learned quite a lot. My career back then, I've retired since, was a SCIENTIST. I had access to lots of journals and publications. I must admit, when I first started to look, it was rather frightening but the more that you look at it, the more you can see that there isn't an average or a normal or necessarily an expectation of outcomes. Everybody's very different. Participant 002AL

Absolutely nothing, in terms of I was soon referred to NAME HOSPITAL and NAME DOCTOR provided me with quite a lot of material. Initially, you're asking me immediately. I'm a retired vet, so I'm used to reviewing articles and taking all things, and so you immediately go and look up whatever you can. Participant 007ATR

Knew very little, but has family history of condition

Just what it had done to my mum, really. I saw my mum go through it basically her whole six or seven years before she passed away. Really that was the only-- very different to what happened to me. She had cysts and things, but the rapid weight loss she got necessarily before she got quite sick and then lost weight and also a bit of pain. I was really young, so I wasn't really interviewing her. I didn't really want to know; I was just a kid. Participant 006ATR

I had a little bit of an idea because my mom had this condition, and her brother. I had a little bit of an idea of what was going on once it sort of started to affect me. Participant 009ATR

Not a lot. Only that I knew my mother had it and she passed away about 20 years ago and the sign that she had it in her brain and apparently, she had it in sort of lots of different parts of the body and different organs and that was the same one. Participant 014ATR

Knew nothing prior to diagnosis

Nothing. Initially nothing. I just went on a steep learning curve. Participant 004AL

I had never heard of it and I thought we were quite well-read and quite knowledgeable people. I had never heard of amyloidosis, so that put me as an ex-school librarian and researcher that put me in the fast track of having to find out as much about this as I possibly could. Participant 001CA

Nothing at all. Nothing at all. NAME HUSBAND probably told you, I think he did tell you this, that the haematologists we saw at the beginning was very abrupt, very non-empathetic basically said, "Oh, yes, it's this. You better get your affairs in order and take off your bucket list," and that's it. We saw our future go from somewhere in the distance straight up in front of our faces, then we both came home and got onto the internet. Participant 002CA

Knew very little prior to diagnosis

Just what it had done to my mum, really. I saw my mum go through it basically her whole six or seven years before she passed away. Really that was the only-- very different to what happened to me. She had cysts and things, but the rapid weight loss she got necessarily before she got quite sick and then lost weight and also a bit of pain. I was really young, so I wasn't really interviewing her. I didn't really want to know; I was just a kid. Participant 006ATR

I had a little bit of an idea because my mum had this condition, and her brother. I had a little bit of an idea of what was going on once it sort of started to affect me. Participant 009ATR

Not a lot. Only that I knew my mother had it and she passed away about 20 years ago and the sign that she had it in her brain and apparently, she had it in sort of lots of different parts of the body and different organs and that was the same one. Participant 014ATR

Good knowledge of condition prior to diagnosis

By the time I got the final diagnosis, I knew a lot. I've done a lot of reading. When I was first told about it, I knew absolutely nothing. When the first hints came through, I knew absolutely nothing. It was easy enough to find because the Mayo Clinic has got wonderful stuff. The London Free Hospital has got lots of stuff online. Of course, we're getting a web page in Australia. I've told by now; it's going to do the same thing. Once you get onto that, there is a lot of information out there. Participant 013ATR

A fair bit because, again, I had seen it with my dad. I had seen exactly what happened with him. I watched him go downhill, and I've, over the years, read more and more about what there was on the web. In fact, for about the past four GPs as I have been somewhat moving around, I've been teaching them about amyloidosis to try and get somewhere with accessing et cetera. Participant 015ATR

Table 3.14 Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	15	41.67	8	44.44	11	44.00	5	50.00	2	25.00	11	50.00	4	28.57	1	11.11	14	51.85
Participant describes knowing about the condition over time through lived experience but not at diagnosis	8	22.22	2	11.11	4	16.00	3	30.00	3	37.50	2	9.09	6	42.86	3	33.33	5	18.52
Participant describes knowing very little about the condition at diagnosis but notes they have a family history of the condition	4	11.11	4	22.22	4	16.00	0	0.00	0	0.00	3	13.64	1	7.14	2	22.22	2	7.41
Participant describes knowing nothing about the condition at diagnosis	20	55.56	7	38.89	12	48.00	8	80.00	5	62.50	13	59.09	7	50.00	4	44.44	16	59.26
Participant describes knowing very little about the condition at diagnosis	7	19.44	7	38.89	7	28.00	0	0.00	0	0.00	3	13.64	4	28.57	2	22.22	5	18.52
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	3	8.33	2	11.11	3	12.00	1	10.00	0	0.00	3	13.64	0	0.00	1	11.11	2	7.41

Understanding of disease at diagnosis	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	15	41.67	1	12.50	10	52.63	4	50.00	9	64.29	4	28.57	4	36.36	11	44.00
Participant describes knowing about the condition over time through lived experience but not at diagnosis	8	22.22	2	25.00	3	15.79	3	37.50	2	14.29	3	21.43	2	18.18	6	24.00
Participant describes knowing very little about the condition at diagnosis but notes they have a family history of the condition	4	11.11	1	12.50	2	10.53	0	0.00	2	14.29	2	14.29	2	18.18	2	8.00
Participant describes knowing nothing about the condition at diagnosis	20	55.56	3	37.50	11	57.89	6	75.00	8	57.14	7	50.00	5	45.45	15	60.00
Participant describes knowing very little about the condition at diagnosis	7	19.44	1	12.50	4	21.05	1	12.50	5	35.71	2	14.29	3	27.27	4	16.00
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	3	8.33	1	12.50	1	5.26	1	12.50	0	0.00	3	21.43	0	0.00	3	12.00

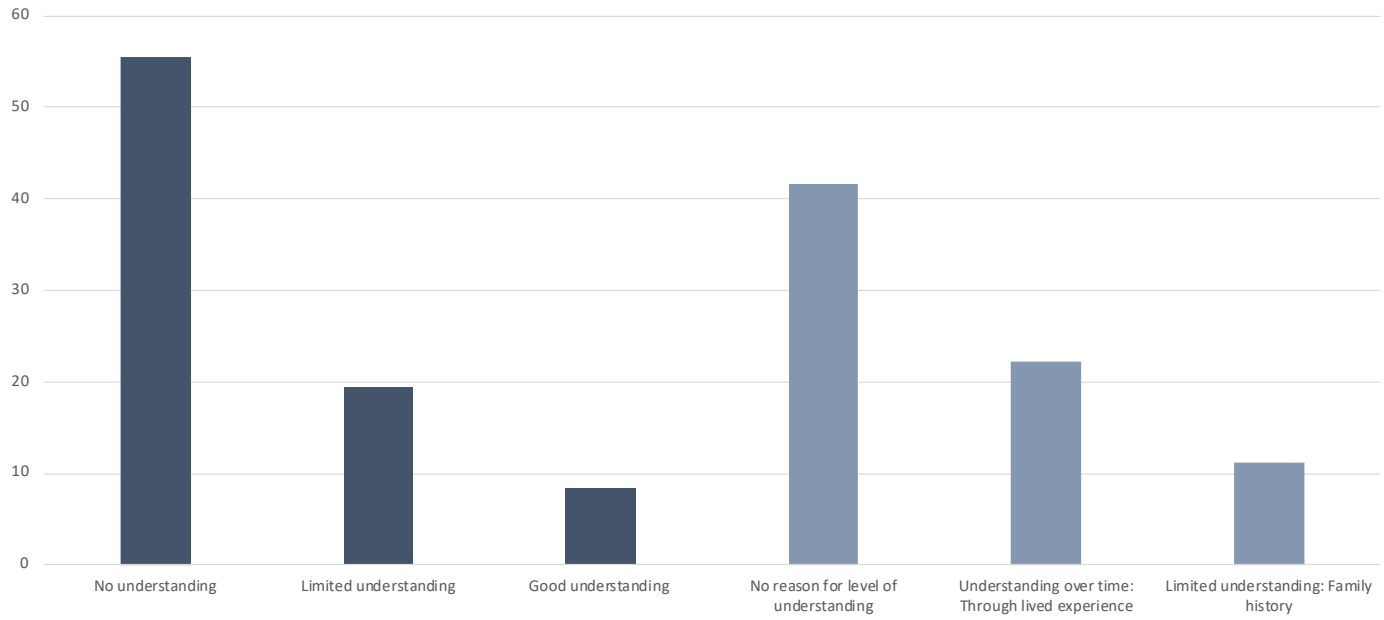


Figure 3.14 Understanding of disease at diagnosis

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

Almost half of participants (including carers) had enough support (n=17, 47.22%), six participants (16.67%) had no support, and 13 participants (36.11%) had some support but it wasn't enough (Table 3.15, Figure 3.15).

In relation to subgroup variations, participants in the *AL amyloidosis* (70.00%), *75 or older* (62.50%), and *Mid to low SEIFA* (63.63%) subgroups had enough support between testing and diagnosis compared to the general population (47.22%), and *Carers* (25.00%), and those in the *Regional or remote* (33.33%) subgroup had less support.

There were no participants in the *AL amyloidosis* subgroup who stated they had some support, but it wasn't enough, compared to the general population (16.67%).

In the study population, there were 36.11% participants who had no support between diagnostic tests and diagnosis, compared to *Carers* (62.50%), *Females* (50.00%), and those who lived in *Regional or remote* areas (55.56%) who had no support more often, and those in the *Aged 75 or older* (25.00%) subgroup who had no support less often.

Table 3.15: Emotional support at diagnosis

Support at diagnosis	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=7	%	n=9	%	n=27	%
I/we had enough support	17	47.22	8	44.44	13	52.00	7	70.00	2	25.00	11	50.00	6	42.86	3	33.33	14	51.85
I/we had some support but it wasn't enough	6	16.67	5	27.78	5	20.00	0	0.00	1	12.50	5	22.73	1	7.14	1	11.11	5	18.52
I/we had no support	13	36.11	5	27.78	7	28.00	3	30.00	5	62.50	6	27.27	7	50.00	5	55.56	8	29.63

Support at diagnosis	All participants		Aged 55 to 64		Aged 65 to 74		Aged 74 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
I/we had enough support	17	47.22	3	37.50	9	47.37	5	62.50	8	57.14	7	50.00	7	63.64	10	40.00
I/we had some support but it wasn't enough	6	16.67	2	25.00	3	15.79	1	12.50	2	14.29	3	21.43	1	9.09	5	20.00
I/we had no support	13	36.11	3	37.50	7	36.84	2	25.00	4	28.57	4	28.57	3	27.27	10	40.00

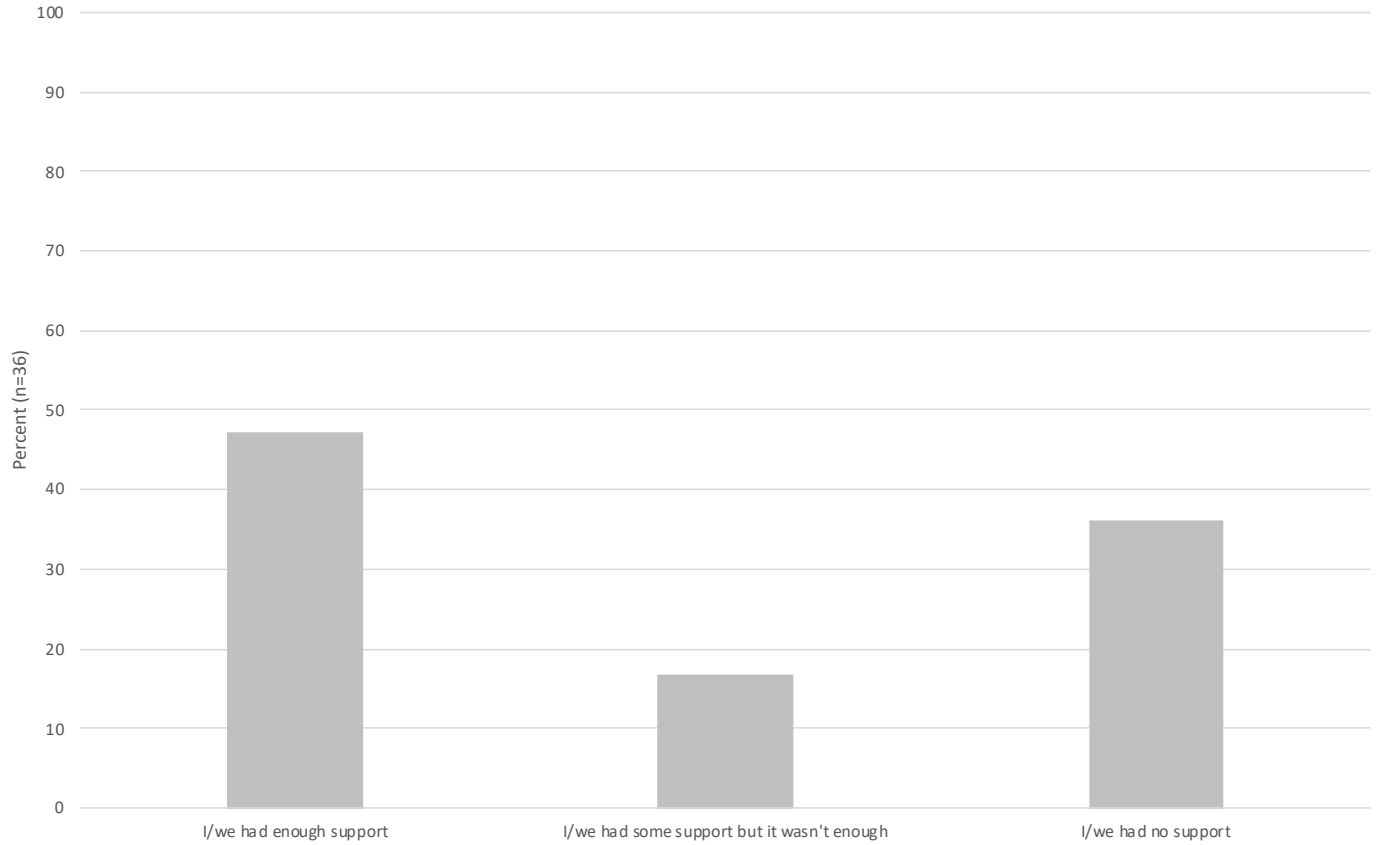


Figure 3.15: Emotional support at diagnosis

Information at diagnosis

Participants (excluding carers) were asked in the online questionnaire how much information they or their family received at diagnosis.

The majority of had enough information (n=20, 71.43%), eight participants (28.57%) had some information but not enough, and there were no participants that had no information (0.00%) (Table 3.16, Figure 3.16).

In relation to subgroup variations, the subgroups did not differ more or less than 10% of the general population.

Table 3.16: Information at diagnosis

Information at diagnosis	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=7	%	n=9	%	n=27	%
I/we had enough information	20	71.43	13	72.22	19	76.00	7	70.00	NA	NA	15	71.43	5	71.43	4	66.67	16	72.73
I/we had some information but it wasn't enough	8	28.57	5	27.78	6	24.00	3	30.00	NA	NA	6	28.57	2	28.57	2	33.33	6	27.27
I/we had no information	0	0.00	0	0.00	0	0.00	0	0.00	NA	NA	0	0.00	0	0.00	0	0.00	0	0.00

Information at diagnosis	All participants		Aged 55 to 64		Aged 65 to 74		Aged 74 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
I/we had enough information	20	71.43	4	66.67	10	76.92	5	62.50	9	64.29	11	78.57	5	62.50	15	75.00
I/we had some information but it wasn't enough	8	28.57	2	33.33	3	23.08	3	37.50	5	35.71	3	21.43	3	37.50	5	25.00
I/we had no information	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00

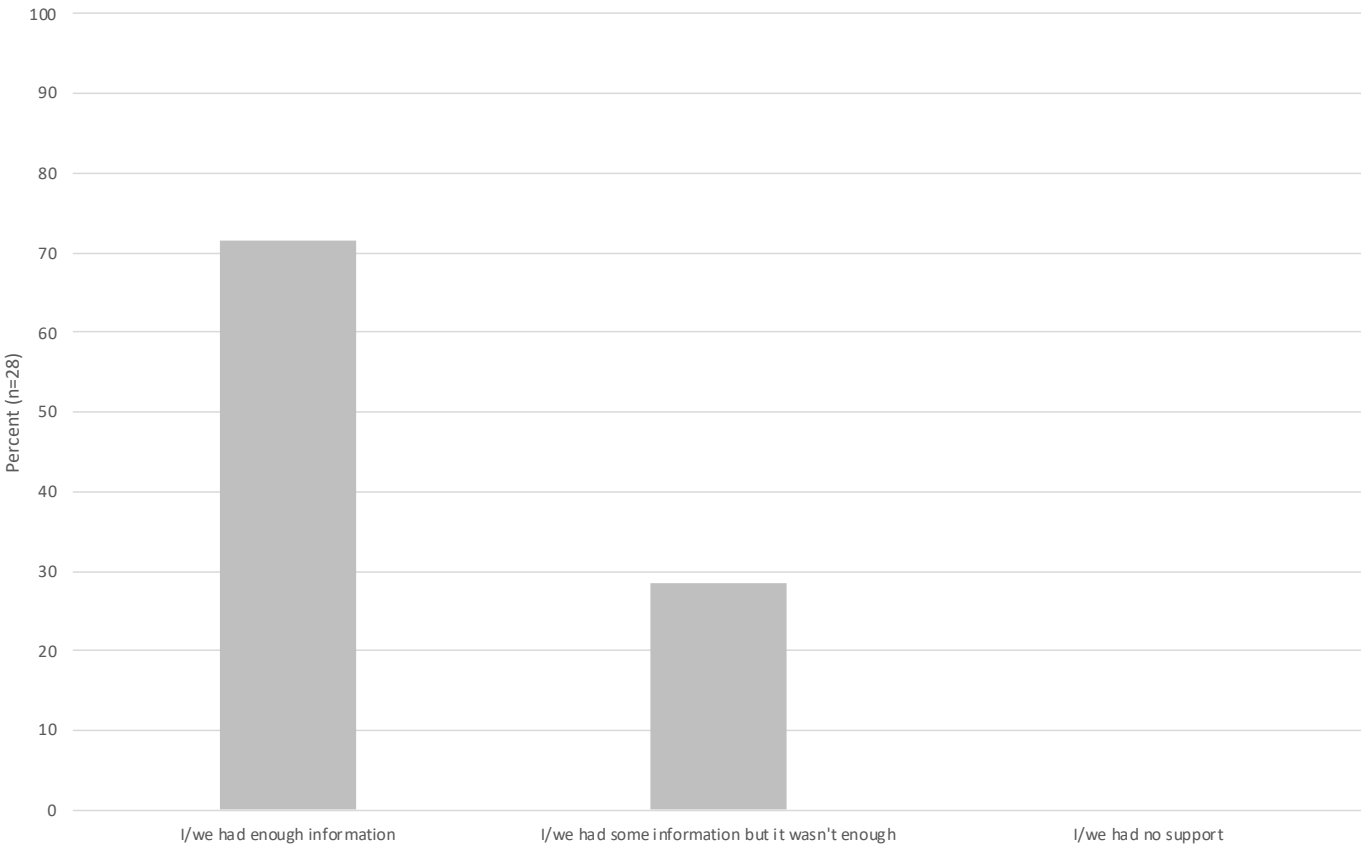


Figure 3.16: Information at diagnosis

Costs at diagnosis

Participants noted in the online questionnaire the amount of out of pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 12 participants (42.86%) who could recall the out of pocket expenses at diagnosis. There were eight participants who had no out of pocket expenses at diagnosis (28.57%), two that spent between $100 and $500 (7.14%), four who spent between $500 and $1000 (14.29%), and two who spent more than $1000 (7.14%) in out of pocket expenses (Table 3.17, Figure 3.17).

As a follow up question, participants were asked how much of a burden the out of pocket expenses at diagnosis were.

For 12 participants (60.00%) the cost was either slightly significant or not significant at all. For five participants (25.00%) the out of pocket expenses were somewhat significant, and for three participants (15.00%), the burden of out of pocket expenses were moderately significant (Table 3.18, Figure 3.18).

Table 3.17: Costs at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=28)	Percent
$0	8	28.57
$100 - $500	2	7.14
$500 to $1000	4	14.29
More than $1000	2	7.14
Unsure	12	42.86

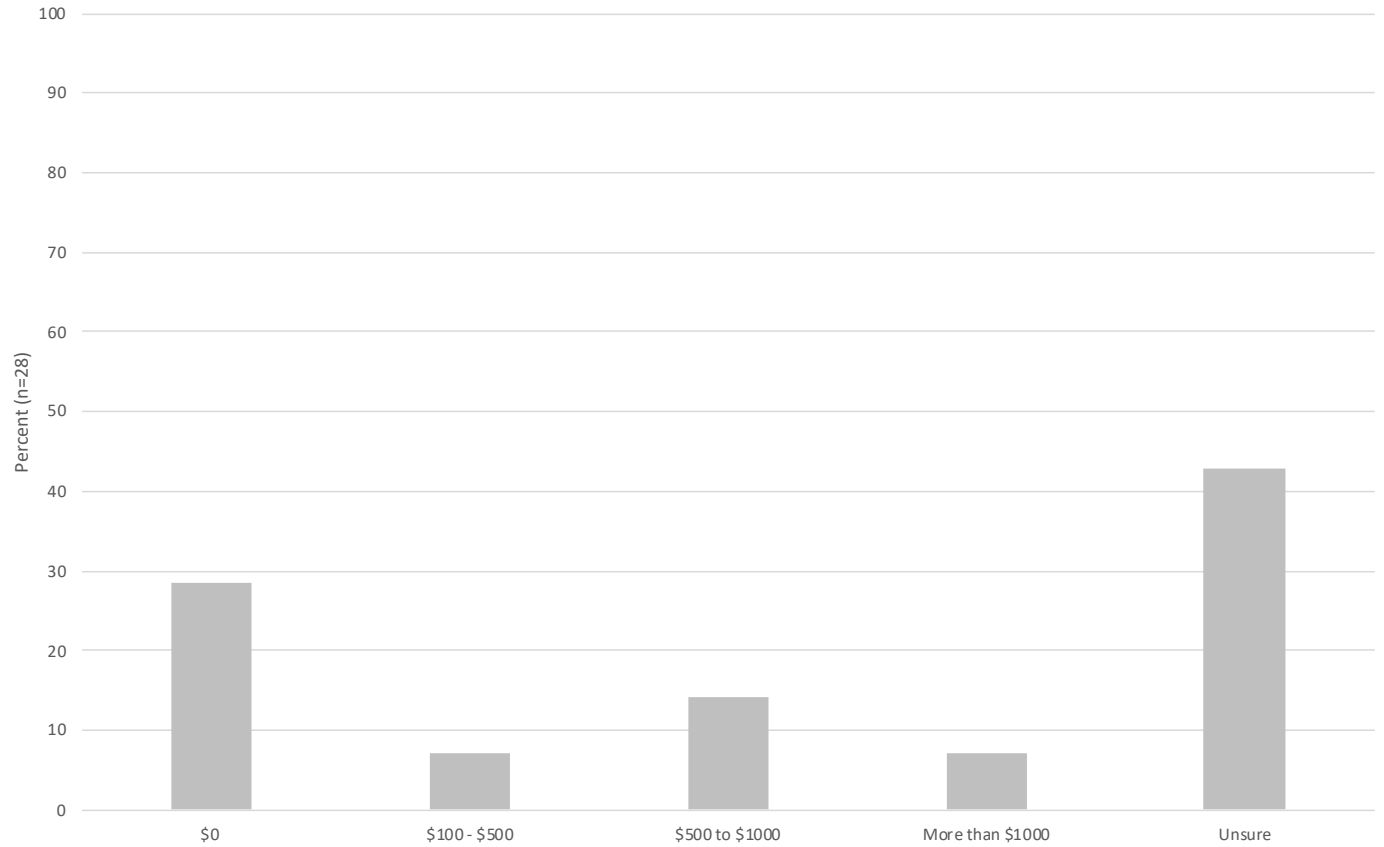


Figure 3.17: Costs at diagnosis

Table 3.18: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=20)	Percent
Not at all significant	7	35.00
Slightly significant	5	25.00
Somewhat significant	5	25.00
Moderately significant	3	15.00
Extremely significant	0	0.00

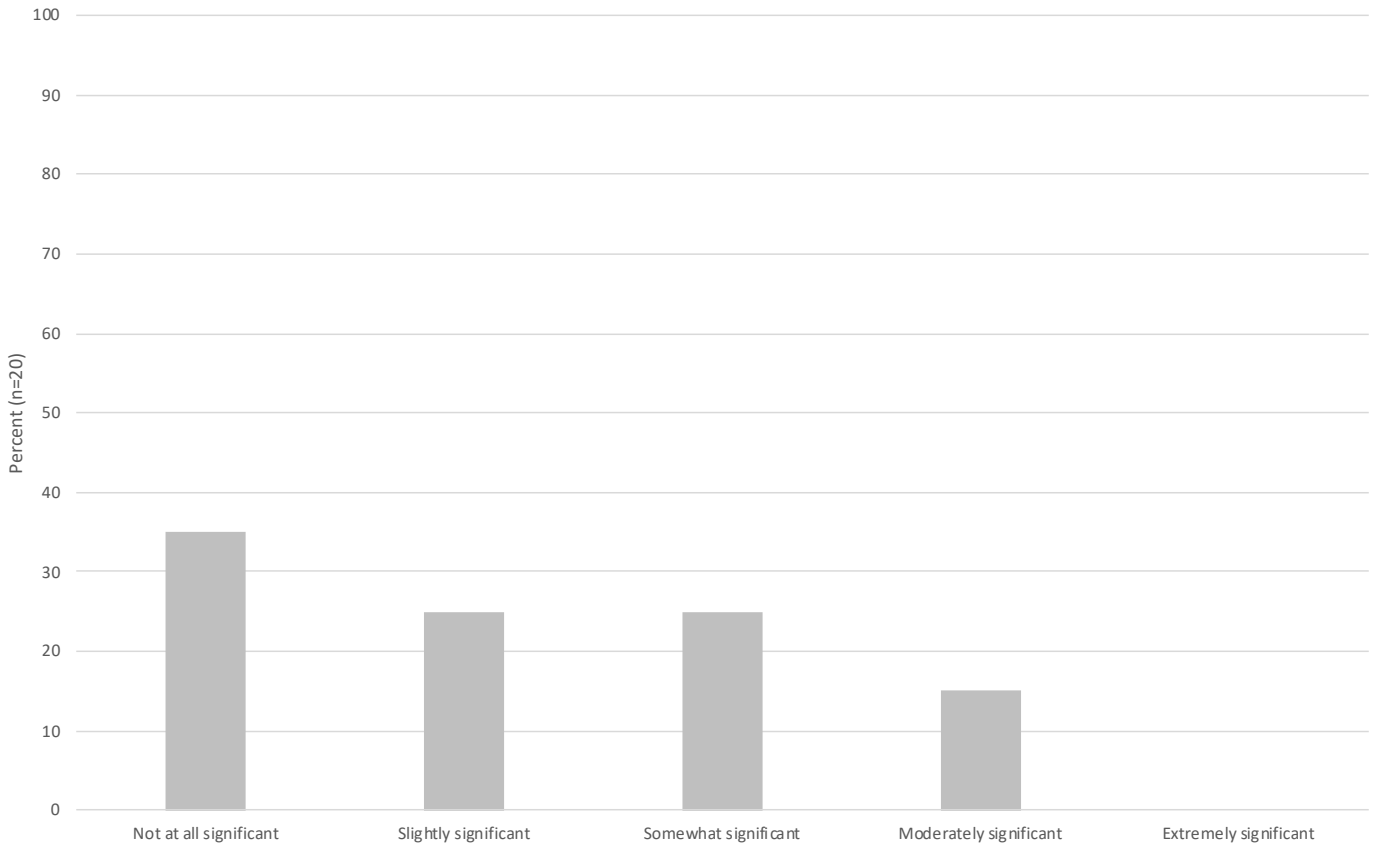


Figure 3.18: Burden of diagnostic costs

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

The majority of participants had no conversation about biomarker, genomic or gene testing that might be relevant to treatment (n=17, 60.71%). There were three participants who brought up the topic with their doctor (10.71%), and eight whose doctor brought up the topic (28.57%) (Table 3.19, Figure 3.19).

In relation to subgroup variations, participants in the Trade or high school (78.85%) subgroup did not have discussions about biomarkers, genomic and gene testing more frequently than in the general population (60.71%), while in the *Regional or remote* (50,00%), *Aged 55 to 64* (16.67%), and *University* (42.86%) subgroups did not have these discussions less often.

Table 3.19: Discussions about biomarkers

Discussions about biomarkers	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=28	%	n=18	%	n=25	%	n=10	%	n=8	%	n=21	%	n=7	%	n=6	%	n=22	%
I brought up the topic with my doctor for discussion	3	10.71	1	5.56	3	12.00	2	20.00	NA	NA	1	4.76	2	28.57	1	16.67	2	9.09
My doctor brought up the topic with me for discussion	8	28.57	7	38.89	8	32.00	1	10.00	NA	NA	7	33.33	1	14.29	2	33.33	6	27.27
No one has ever spoken to me about this type of test	17	60.71	10	55.56	14	56.00	7	70.00	NA	NA	13	61.90	4	57.14	3	50.00	14	63.64

Discussions about biomarkers	All participants		Aged 55 to 64		Aged 65 to 74		Aged 74 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=28	%	n=6	%	n=13	%	n=8	%	n=14	%	n=14	%	n=8	%	n=20	%
I brought up the topic with my doctor for discussion	3	10.71	2	33.33	1	7.69	1	12.50	0	0.00	3	21.43	3	37.50	3	15.00
My doctor brought up the topic with me for discussion	8	28.57	3	50.00	4	30.77	7	87.50	3	21.43	5	35.71	5	62.50	5	25.00
No one has ever spoken to me about this type of test	17	60.71	1	16.67	8	61.54	0	0.00	11	78.57	6	42.86	0	0.00	12	60.00

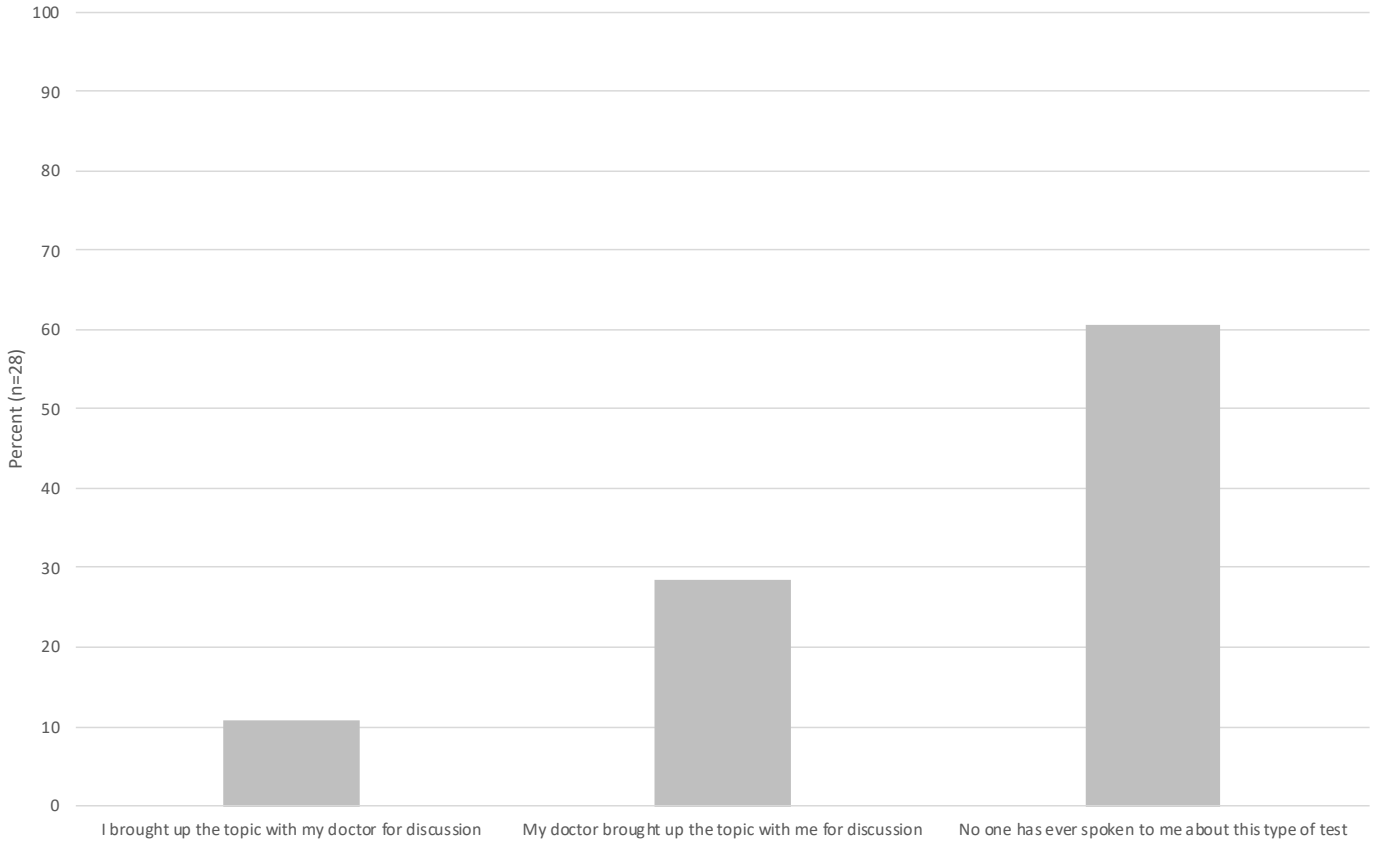


Figure 3.19: Discussions about biomarkers

Experience of genetic tests and biomarkers

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had with no out of pocket expenses, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

Over half of the participants (not including carers) have not had any testing but would like to (n=15, 53.57%). There were a total of 10 participants that had the test, either paying for it themselves (n=5, 17.86%), or not paying out of pocket (n=5, 17.86%). Three participants did not have the test and had no interest in having one (10.71%) (Table 3.20, Figure 3.20).

In relation to subgroup variations, participants in the *Regional or remote* (66.67%), *Aged 65 to 74* (69.23%), and *Trade or high school* (64.29%) subgroups more frequently responded that they did not have the test but would like to, compared to the general population (53.57%), and participants in the *Female* (28.57%), *Aged 55 to 64* (16.67%) and *University* (42.86%) subgroups wanted this less often.

Table 3.20: Experience of genetic tests and biomarkers

Experience of biomarker tests	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=28	%	n=18	%	n=25	%	n=10	%	n=8	%	n=21	%	n=7	%	n=7	%	n=22	%
I have had this test and did not have to pay out of pocket for it	5	17.86	4	22.22	5	20.00	1	10.00	NA	NA	4	19.05	1	14.29	1	16.67	4	18.18
I have had this type of test and paid for it myself	5	17.86	2	11.11	4	16.00	3	30.00	NA	NA	3	14.29	2	28.57	1	16.67	4	18.18
I have not had this test and am not interested in it	3	10.71	2	11.11	2	8.00	1	10.00	NA	NA	1	4.76	2	28.57	0	0.00	3	13.64
I have not had this test but would like to	15	53.57	10	55.56	14	56.00	5	50.00	NA	NA	13	61.90	2	28.57	4	66.67	11	50.00

Experience of biomarker tests	All participants		Aged 55 to 64		Aged 65 to 74		Aged 74 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=28	%	n=6	%	n=15	%	n=8	%	n=14	%	n=14	%	n=8	%	n=20	%
I have had this test and did not have to pay out of pocket for it	5	17.86	2	33.33	2	15.38	1	12.50	1	7.14	4	28.57	1	12.50	4	20.00
I have had this type of test and paid for it myself	5	17.86	3	50.00	2	15.38	0	0.00	1	7.14	4	28.57	1	12.50	4	20.00
I have not had this test and am not interested in it	3	10.71	0	0.00	0	0.00	3	37.50	3	21.43	0	0.00	1	12.50	2	10.00
I have not had this test but would like to	15	53.57	1	16.67	9	69.23	4	50.00	9	64.29	6	42.86	5	62.50	10	50.00

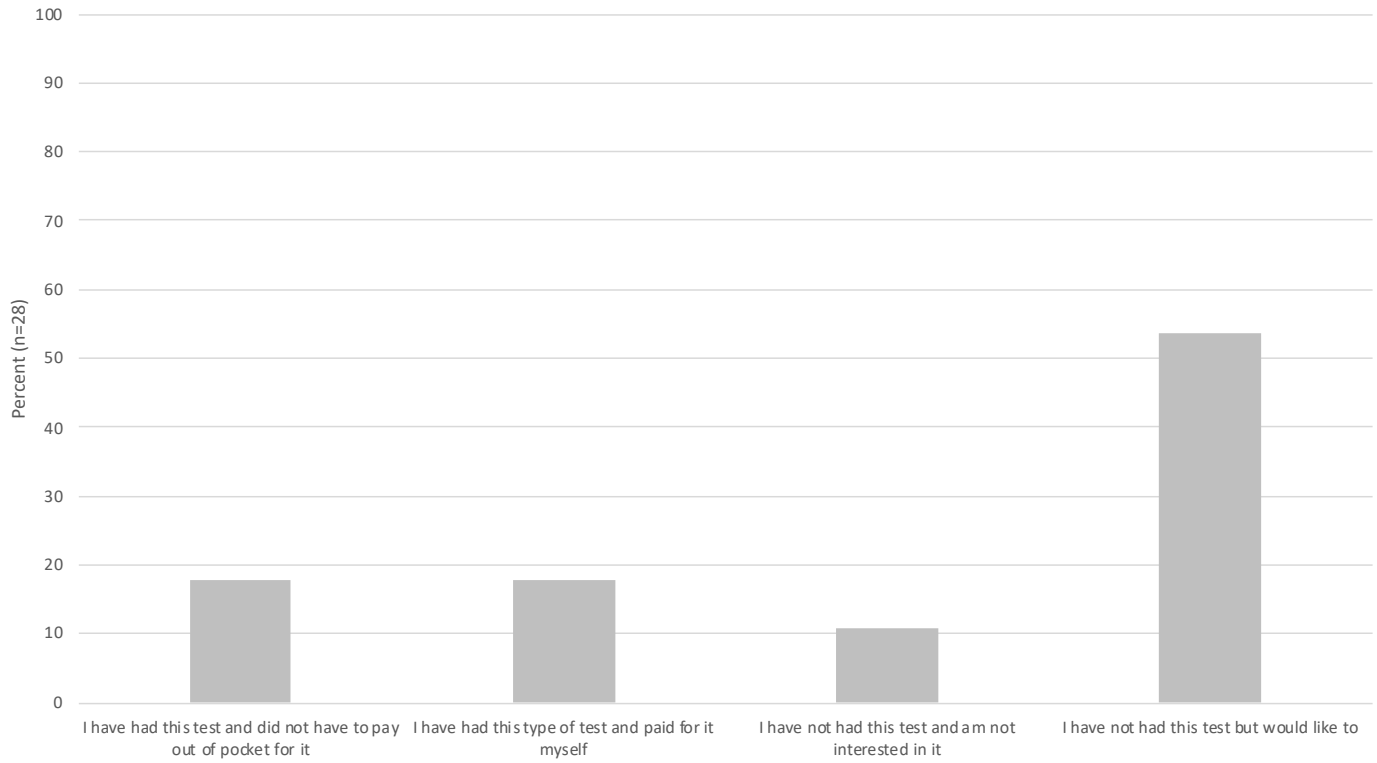


Figure 3.20: Experience of genetic tests and biomarkers

Specific biomarkers or genetic markers

For the final question about biomarkers, participants were asked about specific biomarkers that they had that are relevant to amyloidosis. Participants could choose biomarkers from a list, and specify other biomarkers not listed.

The majority of participants were not sure if they had specific biomarkers (n=15, 53.57%), there were five that stated they had no biomarkers (17.86%), and eight that were able to name specific markers that they had (Table 3.21, Figure 3.21).

Table 3.21: Specific biomarkers or genetic markers

Specific biomarkers	Number (n=18)	Percent
Not sure	15	53.57
I do not have any markers	5	17.86
Named marker	8	28.57

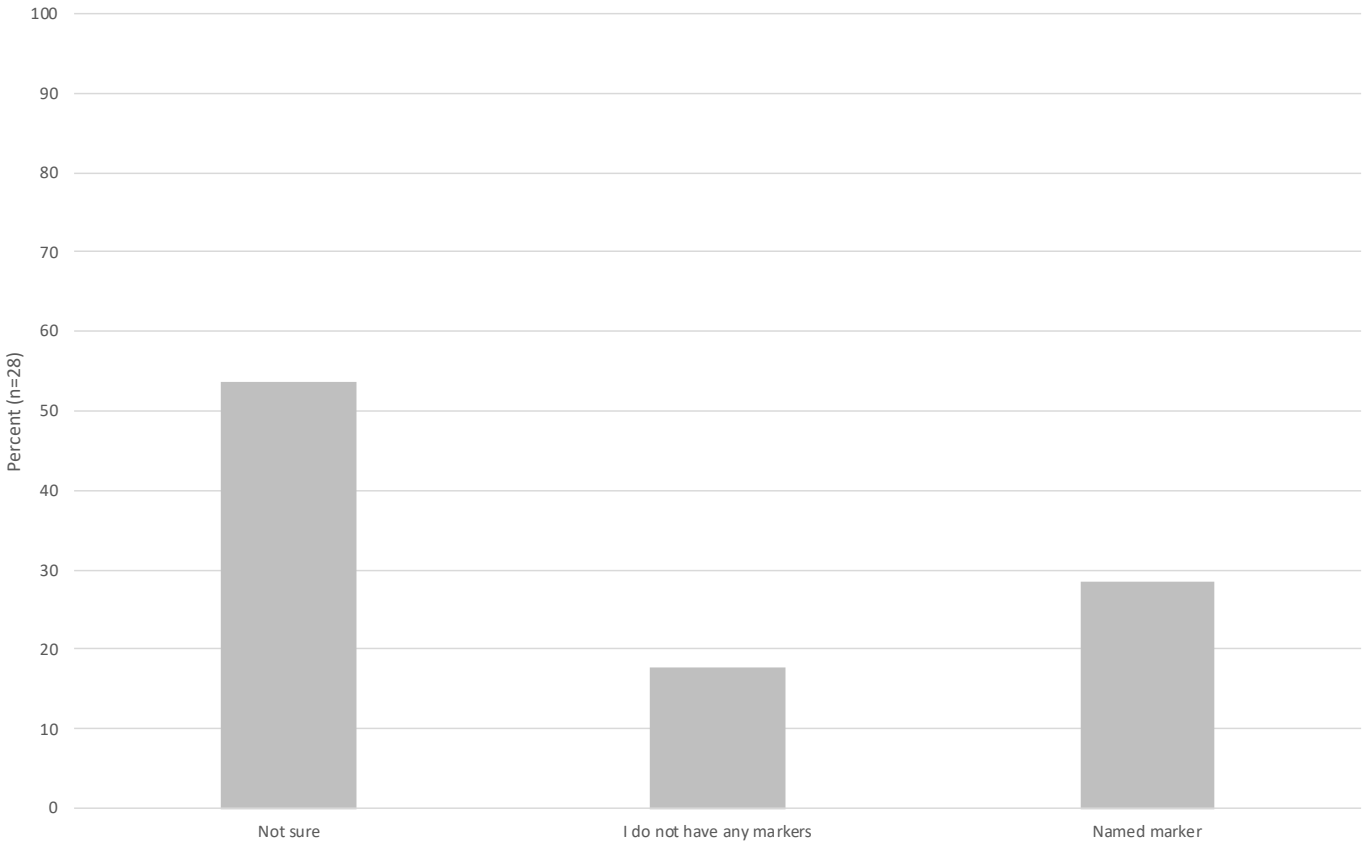


Figure 3.21: Specific biomarkers or genetic markers

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. There were 15 participants (41.67%) that described that they had a discussion about prognosis, and there were 14 participants (38.89%) did not mention having discussions about prognosis.

Overall, 18 participants (50.00%) described having a clear understanding of their prognosis and 11 described having an unclear understanding (30.56%).

There were two main themes that were equally reported, including participants describing their prognosis in relation to the specific medical interventions they need to manage their condition (n=9, 25.00%) and relating their prognosis to a specific timeframe that they are expected to live (n=9, 25.00%). There were eight participants (22.22%) that described their prognosis in relation to poor outcomes or as a terminal condition and five participants (13.89%) that understood their prognosis as positive and their condition as manageable.

In relation to subgroup variations, participants in the AL amyloidosis subgroup described having discussions about prognosis less frequently (30.00%) than the general population (41.67%), while those in *Regional or remote* (55.56%), and *Mid to low SEIFA* (54.55%) subgroups described this more frequently.

Participants in the *Carer* (25.00%), *Female* (21.43%), *Aged 55 to 64* (25.00%), and *Regional or remote* (27.27%) subgroups made no mention of discussions less often than the general population (38.89%), while participants in the *AL amyloidosis* (60.00%), and *Male* (50.00%) made no mention of discussions more often.

In relation to subgroup variations, participants in the *Carer* (25.00%), *Aged 75 or older* (37.50%) and *Female* (35.71%) subgroups described having a clear understanding of their prognosis overall less frequently than the general population (50.00%), whereas participants in the *ATTR-cardiac* (78.57%),

All cardiac (60.00%) and *Mid to low SEIFA* (63.64%) subgroups described this more frequently.

Participants in the *AL amyloidosis* (20.00%) and *Mid to low SEIFA* (18.18%) subgroups described having an unclear understanding of their prognosis less frequently than the general population (30.56%), whereas participants in the *ATTR-cardiac* (42.86%) and *Aged 75 or older* (62.50%) subgroups described this more frequently.

In relation to subgroup variations, participants in the *Mid to low SEIFA* subgroup described their prognosis in relation to medical interventions the need to manage their condition less frequently (9.09%) than the general population (25.00%), while those in the and *Aged 75 or older* (37.50%) subgroups described this more frequently.

Participants in the *Carer* (12.50%) and *Female* (7.14%) subgroups described their prognosis in relation to a specific timeframe that they are expected to live less frequently than the general population (25.00%), while those in the *Male* (36.36%), *Aged 75 or older* (37.50%), *University* (35.71%) and *Mid to low SEIFA* (36.36%) subgroups described this more frequently.

Participants in the AL amyloidosis (0.00%) and Higher SEIFA (8.00%) subgroups described their prognosis in relation to poor outcomes or as terminal less frequently than the general population (22.22%), while those in the ATTR-cardiac (33.33%), Aged 55 to 64 (37.50%), Regional or remote (44.44%) and Mid to low SEIFA (54.55%) described this more frequently.

No participants in the *Aged 75 or older* (0.00%) or *Mid to low SEIFA* (0.00%) subgroups described their prognosis as positive and their condition as manageable, compared to the general population (13.89%).

Participants in the *Carer* (25.00%), *Aged 75 or older* (37.50%) and *Female* (35.71%) subgroups described having a clear understanding of their prognosis overall less frequently than the general population (50.00%), whereas participants in the *ATTR-cardiac* (78.57%), *All cardiac* (60.00%) and *Mid to low SEIFA* (63.64%) subgroups described this more frequently.

Participants in the *AL amyloidosis* (20.00%) and *Mid to low SEIFA* (18.18%) subgroups described having an unclear understanding of their prognosis less frequently than the general population (30.56%), whereas participants in the *ATTR-cardiac* (42.86%) and *75 or older* (62.50%) subgroups described this more frequently.

Clear understanding of prognosis (Total)

The technician told me that, that was in 27th of July, '17. I said, 'I must have had very good medication, or my bone density must have been really good to start with, so there had been no effect on that.' Up until that last year until December when the light chain stated to go out of sync again. What then happened was that I've had monthly light chain tests and the full blood count, everything else is perfectly normal except for the light chains were out of balance, and it was decided that as the difference got to about 42 to 46 between the kappa and the lambdas, I decided that I should go on to ixazomib or Ninlaro, that's the same thing. They will start as soon as they can get the medication, the medication has been approved by the company, and it's must be on compassionate grounds because I won't have to pay for it. Participant 003AL

I think pretty good. I think it's pretty good, the treatment has got the light chain down to just a little bit above normal, the high range of normal. It's gone from being through the roof down to high range normal. All that means is that there's less stuff now sticking to different organs and my body failure. Participant 004ATR

They say that I am in haematological remission which means my light chains have stayed down and that's over a year since I finished my chemotherapy. Participant 012ATR

Unclear understanding of prognosis (Total)

No, I've no idea…I haven't really discussed it, I don't know. I guess if my congestive heart failure is managed then it may be reasonable. I was actually relieved that I didn't have AL, because that, to me, is pretty much like going down the path of multiple myeloma. Participant 001ATR

Now at this particular point in time, it's really hard because last time he saw NAME CLINICIAN, there was no proteins in the blood. It's been traced for a little while. We've managed to get it right down and keep it down. As far as his prognosis and how

it's all going to play out, I have no idea. Participant 003CA

No, not really. My local GP says, 'Look, just forget about it. I wouldn't worry about it.' I'm not having any treatment except the ophthalmologist checks me every probably six weeks to see how the eye is going. Participant 010ATR

What our understanding was, we were told then and there that it was terminal. That's what we were told…They did tell us at one stage that they thought that he had 12 to 18 months at that stage to live. As you can imagine we were rocketed. We didn't know what this was, we had no idea. Participant 004CA

I had to go to the docs or hospital to get into their book so that I could then use their pharmacy to get to doctors and all the medication. Literally, I was seeing him first thing Monday morning, 9:00 AM, first patient. I asked him, 'What is my outlook? How long have I got basically?' He said, 'Well, three years, that's it', which came as a bit of a shock. Participant 011ATR

From, again, the initial discussions with the team at the university clinic, from where we are now at my age, I've probably got about another 10 years. Of that 10 years, probably about six or seven of them will be useful. By useful I mean, I will actually be able to do things before I end up housebound or chair bound because I won't be able to do things. So, 10 years and so from now, seven years useful. Participant 015ATR

Prognosis related to poor outcomes or terminal condition

It's a fatal but slow disease. There could be more but I'm aware that there's 29 types of amyloidosis. I don't know if that's part of the hereditary AL or AA altogether, but the AL amyloidosis, and I think AA is a bit much quicker. For AL, if you're not diagnosed, get treatment, chemo and drugs within a year, your chances of living are very poor, and even if you do, your chances are very poor but this hATTR-V and N, N is the mutant type, it's much slower, but it's still fatal and there's still no cure. Participant 005CA

Yes. It's not very good. When you read about it. Well, when I went to say I had this stress test, the specialist said, 'Probably, there's no cure for it. You might only have a couple of months.' He wasn't very-- I was a bit disappointed with his attitude. That's the way some of them are. They're going to be straight to the point and let you know what's happening I supposed. Participant 014ATR

My treatment was in 2015. I'm five years down the track now. From my own perspective, I think that it won't flare up again, I guess, and that I'll have some heart failure or stroke. The last year, I had stents put in, and my heart efficiency was pretty low. It's only about 50% now. My kidneys are about 28%. They've been down to 18. I guess if it flares up again, it's going to be much harder next time to get through it. I don't think I'm going to die an old age, if that's what you mean. I think it's not going to be good. Participant 017ATR

Prognosis is positive: Condition manageable with treatment

It is. I feel it's great news at this point in time. My treatment has been carfilzomib plus dexamethasone. The holiday from that, because the vectors are stable, is good, but also because of side effects, I don't have to deal with them, is also very good. At the moment, life is good. Because my haemoglobin levels are up just inside the normal level at 120 or 125 or whatever it is, right on the lower threshold, life's a lot better. Participant 004AL

I think pretty good. I think it's pretty good, the treatment has got the light chain down to just a little bit above normal, the high range of normal. It's gone from being through the roof down to high range normal. All that means is that there's less stuff now sticking to different organs and my body failure. Participant 004ATR

My understanding is that you can get it under control and into the ordinary category of being prone to any one of the other conditions that affect the whole boat. Participant 006AL

Table 3.22: Understanding of prognosis: Discussion had

Understanding of prognosis: Discussion had	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant had discussion about prognosis	15	41.67	9	50.00	10	40.00	3	30.00	3	37.50	9	40.91	6	42.86	5	55.56	10	37.04
Participant made no mention of whether they discussed their prognosis	14	38.89	6	33.33	11	44.00	6	60.00	2	25.00	11	50.00	3	21.43	3	33.33	11	40.74
Other or unclear	5	13.89	1	5.56	2	8.00	1	10.00	3	37.50	2	9.09	3	21.43	1	11.11	4	14.81
Participant describes having no discussion about prognosis	2	5.56	2	11.11	2	8.00	0	0.00	0	0.00	0	0.00	2	14.29	0	0.00	2	7.41

Understanding of prognosis: Discussion had	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant had discussion about prognosis	15	41.67	4	50.00	7	36.84	4	50.00	6	42.86	6	42.86	6	54.55	9	36.00
Participant made no mention of whether they discussed their prognosis	14	38.89	2	25.00	8	42.11	3	37.50	5	35.71	7	50.00	3	27.27	11	44.00
Other or unclear	5	13.89	2	25.00	3	15.79	0	0.00	1	7.14	1	7.14	2	18.18	3	12.00
Participant describes having no discussion about prognosis	2	5.56	0	0.00	1	5.26	1	12.50	2	14.29	0	0.00	0	0.00	2	8.00

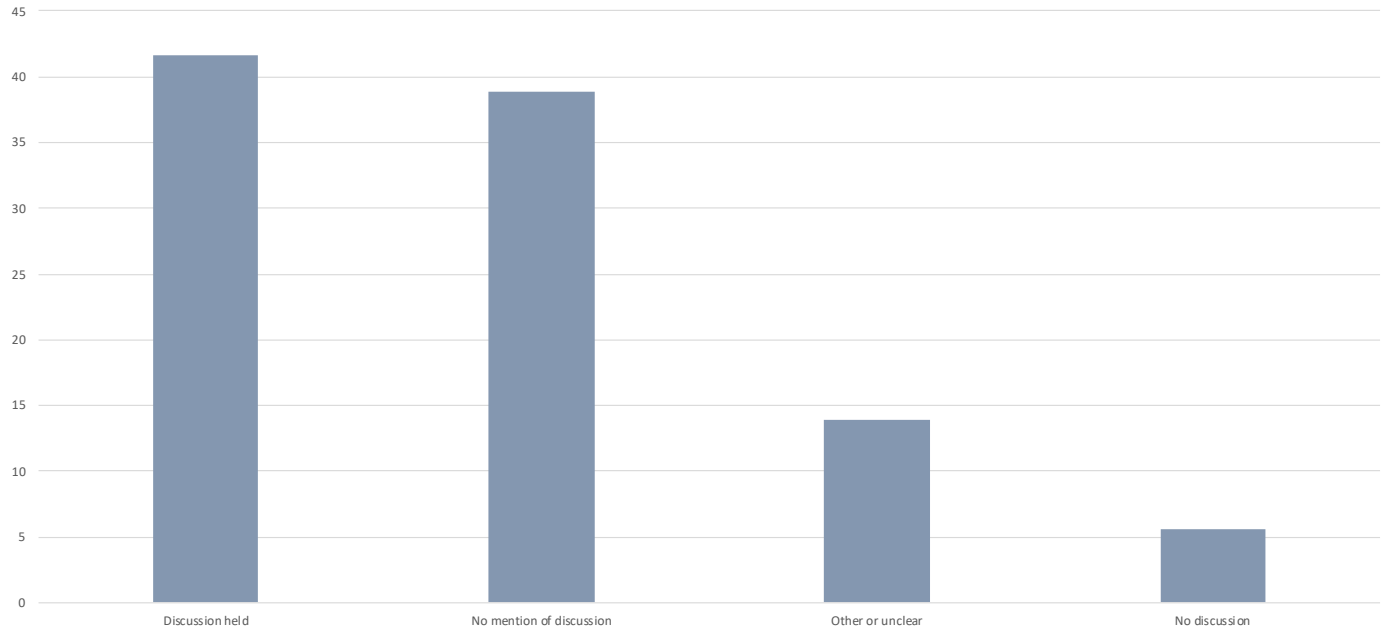


Figure 3.22: Understanding of prognosis: Discussion had

Table 2.23: Understanding of prognosis: Clear or unclear understanding

Understanding of prognosis: Clear or unclear understanding	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes having a discussion about prognosis and they have a clear understanding	9	25.00	5	27.78	6	24.00	2	20.00	2	25.00	4	18.18	5	35.71	3	33.33	5	20.00
Participant does not mention any discussion about their prognosis, but has a clear understanding	9	25.00	6	33.33	9	36.00	3	30.00	0	0.00	9	40.91	0	0.00	2	22.22	6	24.00
Participant describes having a discussion about prognosis but still has an unclear understanding and/or would like further discussions	6	16.67	4	22.22	4	16.00	1	10.00	1	12.50	5	22.73	1	7.14	2	22.22	4	16.00
Participant does not mention any discussion about their prognosis, and has an unclear understanding	3	8.33	0	0.00	1	4.00	1	10.00	2	25.00	1	4.55	2	14.29	1	11.11	3	12.00
Participant does not mention any discussion about their prognosis (general)	2	5.56	0	0.00	1	4.00	2	20.00	0	0.00	1	4.55	1	7.14	0	0.00	2	8.00
Participant describes having no discussion about prognosis and they do not have a clear understanding	2	5.56	2	11.11	2	8.00	0	0.00	0	0.00	0	0.00	2	14.29	0	0.00	2	8.00

Understanding of prognosis: Clear or unclear understanding	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes having a discussion about prognosis and they have a clear understanding	9	25.00	3	37.50	5	26.32	1	12.50	3	21.43	4	28.57	4	36.36	5	20.00
Participant does not mention any discussion about their prognosis, but has a clear understanding	9	25.00	1	12.50	5	26.32	2	25.00	5	35.71	4	28.57	3	27.27	6	24.00
Participant describes having a discussion about prognosis but still has an unclear understanding and/or would like further discussions	6	16.67	1	12.50	2	10.53	3	37.50	3	21.43	2	14.29	2	18.18	4	16.00
Participant does not mention any discussion about their prognosis, and has an unclear understanding	3	8.33	1	12.50	1	5.26	1	12.50	0	0.00	1	7.14	0	0.00	3	12.00
Participant does not mention any discussion about their prognosis (general)	2	5.56	0	0.00	2	10.53	0	0.00	0	0.00	2	14.29	0	0.00	2	8.00
Participant describes having no discussion about prognosis and they do not have a clear understanding	2	5.56	0	0.00	1	5.26	1	12.50	2	14.29	0	0.00	0	0.00	2	8.00

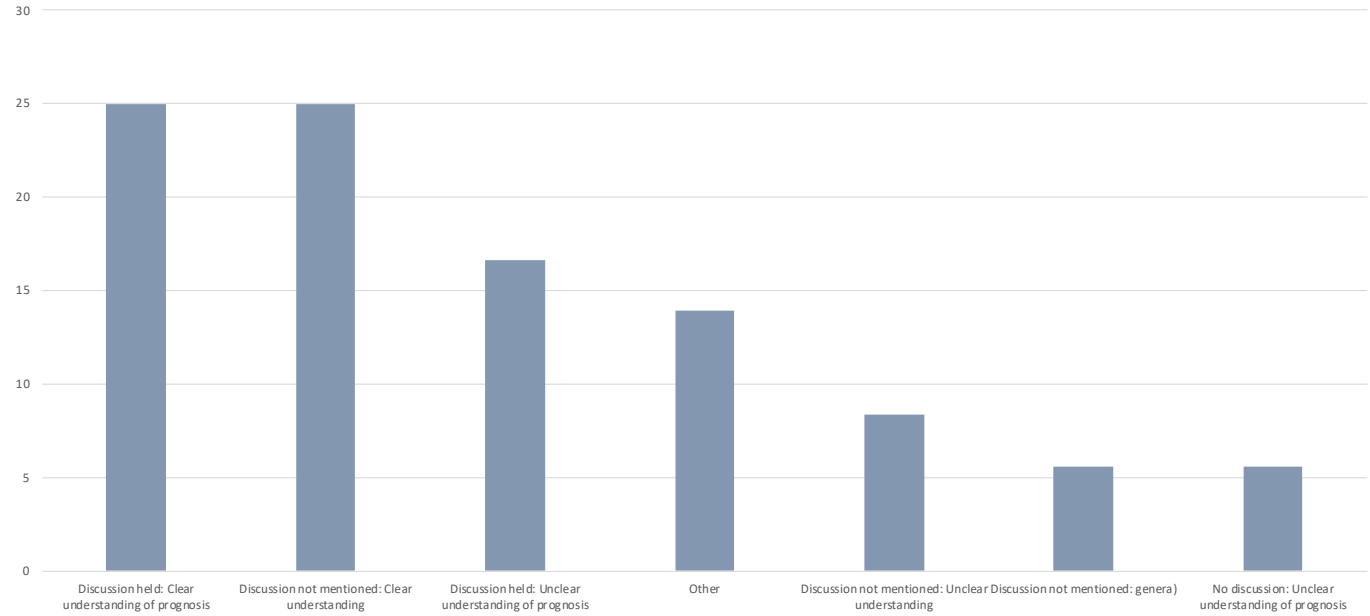


Figure 3.23: Understanding of prognosis: Clear or unclear understanding

Table 2.24: Understanding of prognosis: Specific

Understanding of prognosis: Specific	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes prognosis in relation to the specific medical interventions they need to manage their condition	9	25.00	5	27.78	7	28.00	2	20.00	2	25.00	6	27.27	3	21.43	2	22.22	7	25.93
Participant describes prognosis in relation to a specific timeframe that they are expected to live	9	25.00	6	33.33	8	32.00	2	20.00	1	12.50	8	36.36	1	7.14	2	22.22	7	25.93
Participant describes prognosis in relation to poor outcomes/terminal condition	8	22.22	6	33.33	6	24.00	0	0.00	2	25.00	6	27.27	2	14.29	4	44.44	4	14.81
Participant describes prognosis in relation to it being positive: Condition is manageable	5	13.89	2	11.11	4	16.00	2	20.00	1	12.50	3	13.64	2	14.29	2	22.22	3	11.11
Participant describes prognosis in relation to no evidence of disease or that they are in remission	3	8.33	1	5.56	2	8.00	2	20.00	0	0.00	1	4.55	2	14.29	0	0.00	3	11.11
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	3	8.33	2	11.11	2	8.00	1	10.00	0	0.00	1	4.55	2	14.29	1	11.11	2	7.41

Understanding of prognosis: Specific	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes prognosis in relation to the specific medical interventions they need to manage their condition	9	25.00	2	25.00	3	15.79	3	37.50	3	21.43	4	28.57	1	9.09	8	32.00
Participant describes prognosis in relation to a specific timeframe that they are expected to live	9	25.00	2	25.00	4	21.05	3	37.50	3	21.43	5	35.71	4	36.36	5	20.00
Participant describes prognosis in relation to poor outcomes/terminal condition	8	22.22	3	37.50	3	15.79	2	25.00	3	21.43	3	21.43	6	54.55	2	8.00
Participant describes prognosis in relation to it being positive: Condition is manageable	5	13.89	1	12.50	4	21.05	0	0.00	3	21.43	1	7.14	0	0.00	5	20.00
Participant describes prognosis in relation to no evidence of disease or that they are in remission	3	8.33	0	0.00	3	15.79	0	0.00	1	7.14	2	14.29	1	9.09	2	8.00
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	3	8.33	0	0.00	0	0.00	3	37.50	2	14.29	1	7.14	1	9.09	2	8.00

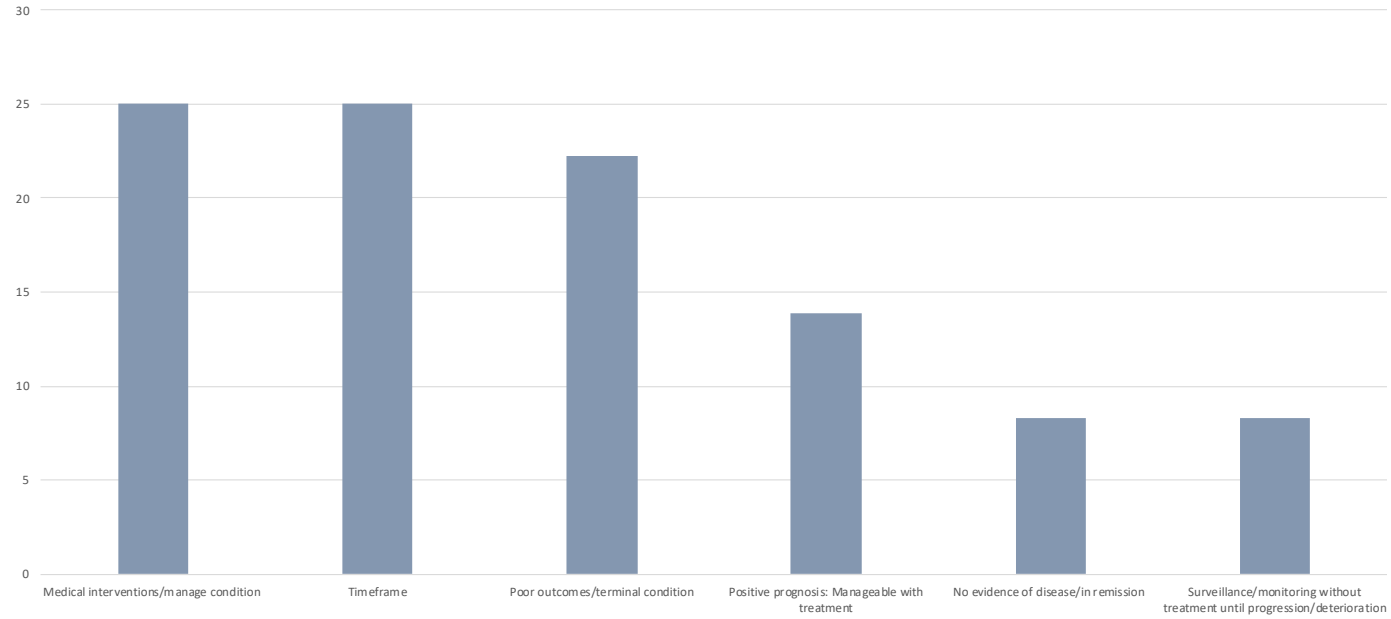


Figure 3.24: Understanding of prognosis: Specific

Section 4

Decision-making

Section 4 Summary: Decision-making

Discussions about treatment

- Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common response from participants was that it was difficult to remember/other response (n=14, 38.89%) which was closely followed by multiple treatment options were discussed which was described by 13 participants (36.11%). Six participants described discussing one treatment option (16.67%) and three participants described no treatment options being discussed (8.33%).

- Among participant who discussed multiple treatment options, five described participating in decision-making (13.89%), four described not participating in the decision-making process (11.11%) and four described being told what to do without discussion (11.11%). Three participants described being presented with no options because no therapies were available (8.33%). Out of those who were presented with one option three participants described being told what to do without discussion (8.33%) and two participants described some but very little discussion (5.56%).

- Some participants described discussions of specific treatments. Six participants described discussing the option of a stem cell transplant (16.67%), while four participants described discussing the option of a liver transplant (11.11%). Other participants described being presented with the option of chemotherapy (n=3, 8.33%), Green tea extract (n=3, 8.33%), Velcade or dexamethasone (n=3, 8.33%) and Bone marrow transplant (n=2, 5.56%).

Decision-making

- Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was quality of life as part of multiple aspects that they consider when making decisions about treatment and this was described by 13 participants (36.11%). This was followed by efficacy as part of multiple aspects they consider (n=9, 25.00%); side effects as part of multiple aspects they consider (n=9, 25.00%); the long term impact and side effects of treatment as part of multiple aspects they consider (n=7, 19.44%), taking the advice of their clinician as part of multiple aspects they consider (n=6, 16.67%), considering the potential impact on their family or dependents as part of multiple aspects they consider (n=5, 13.89%), survival benefit as part of multiple aspects they consider (n=5, 13.89%) and taking the advice of their clinician as the only aspect they consider (n=5, 13.89%).

Changes in decision-making

- Participants were asked if the way they made decisions had changed over time. There were 15 participants (41.67%) that felt the way they made decisions about treatment had not changed over time, and 12 participants (33.33%) that described decision-making changing. Nine participants (25.00%) were unsure/other or gave no response.

- Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed and/or assertive (n=7, 19.44%). Three participants described their decision-making changing over time as they are more aware of their health, responsibilities and/or limitations (8.33%) Other participants described changing over time as they are more accepting of their condition and choices available (n=1, 2.78%), they are more focused on how treatment impacts their family and dependents (n=1, 2.78%), they are more cautious and considered (n=1, 2.78%) and they are more focused on quality of life or the impact of side effects (n=1, 2.78%).

- Among participants who described no change in the way they make decisions the most common response was that this was because they had always been informed/assertive (n=7, 19.44%) followed by those who did not mention any reason (n=4, 11.11%). Other responses were that there had been no change because they always took the advice of clinicians (n=2, 5.56%) and because they have had no treatment options to choose from (n=1, 2.78%).

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common response from participants was that it was difficult to remember/other response (n=14, 38.89%) which was closely followed by multiple treatment options were discussed which was described by 13 participants (36.11%). Six participants described discussing one treatment option (16.67%) and three participants described no treatment options being discussed (8.33%).

Among participant who discussed multiple treatment options, five described participating in decision-making (13.89%), four described not participating in the decision-making process (11.11%) and four described being told what to do without discussion (11.11%). Three participants described being presented with no options because no therapies were available (8.33%). Out of those who were presented with one option three participants described being told what to do without discussion (8.33%) and two participants described some but very little discussion (5.56%).

Some participants described discussions of specific treatments. Six participants described discussing the option of a stem cell transplant (16.67%), while four participants described discussing the option of a liver transplant (11.11%). Other participants described being presented with the option of chemotherapy (n=3, 8.33%), Green tea extract (n=3, 8.33%), Velcade or dexamethasone (n=3, 8.33%) and Bone marrow transplant (n=2, 5.56%).

In relation to subgroup variations, participants in the subgroups *ATTR-cardiac* (22.22%), *All cardiac* (20.00%), *AL amyloidosis* (20.00%), *Male* (13.64%), *Aged 75 or older* (12.50%), *Trade or high school* (21.43%) and *University* (21.43%) described it being difficult to remember/other response less frequently than the general population (38.89%) while those in the subgroups *Carer* (100.00%), *Female* (78.57%) and *Aged 55 to 64* (62.50%) described this more frequently.

Participants in the subgroups *AL amyloidosis* (50.00%), *Male* (50.00%) and *Trade or high school* (50.00%) described discussing multiple options more frequently than the general population (36.11%) while those in the subgroups *Carer* (0.00%), *Female* (14.29%), *Aged 55 to 64* (25.00%) and *Mid to low SEIFA* (18.18%) described this less frequently.

Participants in the subgroups *AL amyloidosis* (30.00%), *Male* (27.27%) and *Mid to low SEIFA* (27.27%) described discussion one treatment option more frequently than the general population (16.67%) whereas no participants in *Female* (0.00%), and *Carer* (0.00%) described this.

Participants in the subgroup *Aged 75 or older* described no treatment option being presented more frequently (37.50%) than the general population (8.33%).

No participants in the *Carer* (0.00%), or *Female* (0.00%) subgroups described being presented with multiple treatment options and participating in the decision-making process compared to the general population (13.89%).

Participants in the *ATTR-cardiac* subgroup (22.22%), and *Trade or high school* subgroup (28.57%) described being presented with multiple treatment options but not participating in the decision-making process more frequently than the general population (11.11%) while those in the *AL amyloidosis* subgroup (0.00%), *University* (0.00%), *Regional or remote* (0.00%), and *Carer* subgroup (0.00%) did not describe this at all.

Participants in the *AL amyloidosis* (30.00%) subgroup described being presented with multiple options and told what to do without discussion more frequently than the general population (11.11%), while those in the *Carer* (0.00%), *Aged 55 to 64* (0.00%) and *Mid to low SEIFA* (0.00%) subgroups did not describe this at all.

Participants in the *Aged 75 or older* subgroup described being presented with no options/approach as no therapies are available more frequently (37.50%) than the general population (8.33%).

Participants in the *AL amyloidosis* (20.00%) and *Trade or high school* (21.43%) subgroups described being presented with on option/approach and being told what to do without discussion more frequently than the general population (8.33%).

Participants in the *AL amyloidosis* subgroup (20.00%) and *Aged 75 or older* (25.00%) described being presented with one option/approach and having some but very little discussion more frequently than the general population (5.56%).

Participants in the *AL amyloidosis* subgroup (30.00%), *Aged 75 or older* subgroup (37.50%) and *University* subgroup (28.57%) described being presented with the option of a stem cell transplant more frequently than the general population (16.67%), while those in the *Carer* (0.00%), and *Aged 55 to 64* (0.00%) did not describe this at all.

No participants in the *AL amyloidosis* (0.00%), *Aged 75 or older* (0.00%), *Female* (0.00%), and *Carer* (0.00%) subgroups described being presented with the option of a liver transplant, while those in the *ATTR-cardiac* subgroup (22.22%), *Regional or remote* (22.22%), *Aged 55 to 64* (25.00%), and *University* (21.43%) subgroups described this more frequently than the general population (11.11%).

Participants int the subgroups *AL amyloidosis* (20.00%) and *Aged 75 or older* (25.00%) described being presented with the option of chemotherapy more frequently than the general population (8.33%).

Participants in the subgroup *AL amyloidosis* described being presented with the option of Velcade or dexamethasone more frequently (30.00%) than the general population (8.33%).

Participants in the subgroup *AL amyloidosis* described being presented with the option of a bone marrow transplant more frequently (20.00%) than the general population (5.56%).

Multiple treatment options presented

Well, I was in his hands. He told me what he went through which was generally, oral chemo, et cetera. That was it. Then suddenly, well, that didn't work. On one particular visit, 'We got to do plan B,' and then he explained to me all about the stem cell transplants. ***Participant 001ALX***

He did suggest that a bone marrow transplant could probably fix the problem, but the pre-treatment would probably kill me. We decided not to go with that. Apart from that, he didn't really talk much about it. He put me on to oral chemo and dexamethasone on the grounds that my system at that stage was so bad that he didn't think I could've taken intravenous chemo. ***Participant 2ALX***

Well, they were essentially a two-track conversation. The first element was, 'we've got to get these rogue protein levels under control'. The recommended treatment for that or the first port of call sort of treatment was Velcade plus dexamethasone plus the cyclophosphamide. The overall objective was to contemplate a stem cell transplant once the levels had been reduced and had become stable on the assumption that all of the normal body functions would have recovered slightly as well. Remember my kidney function's a bit impaired and my heart function a bit impaired. Because I was fit and because I was otherwise very healthy, I'd no other condition and I was … it was still seen as I was a candidate for stem cell transplant albeit with an elevated risk, but not to the level that would preclude a bone marrow transplant—sorry, a stem cell transplant. Those were the two tracks of conversation. ***Participant 004AL***

One treatment option presented

I spoke to them about a liver transplant and then they took into account my age and my condition with the amyloid, how bad it was. I said it was no good doing one it was too far gone… They said to me then that there's no other treatments. All we can do is the best we can with what we've got and they were doing nothing at this stage for us. Participant 009ATR

Well, he said, 'There's really only experimental drugs.' So, I was still ongoing. He recommended that I go into Doctors now for one called, temyphibus I think it's called. Participant 011ATR

Well, the conversation went that it was very hard to treat, especially my type, and that the doctor said that we've got to start this trial. Velcade had been used for a long time, I think, before I started this trial. The trial was different. As far as I can make out, that it was always been given intravenously. I was probably one of the first to have it injected into the fatty part of the stomach. Participant 005AL

Multiple options presented: Participated in decision-making

When I was first diagnosed the first thing, they wanted to do was get me onto the transplant list for a liver transplant, that was through the neurologist and the cardiologist. Essentially that was the first thing then they found NAME SPECIALIST, who's more of a specialist in amyloidosis specifically, the haematologist. He immediately put me on to medical drugs, a combination of drugs to try to stabilize me which I'm still on today. Then he laid out basically every option there was for me, and he does with every patient. We talked through getting assessed for the liver transplant and making sure to make sure-when it's transplants you got to test people to make sure whether I'm going, what severity it was, how it progressed and those kinds of things. Then talked through all the different other options on the horizon or overseas in Italy just around a lot of others, I can't remember more off the top of my head. Participant 6ATR

Well, that sort of thing we spoke about was this trial that might be coming up with this new drug that has been. I think it is called Paprizine or something like that. Apparently, it's available in other countries already…Probably if I have enough money and well, I asked the doctor the other day and said, 'What's going on over in LOCATION, where this is the Bible over there?' and he said, 'Well, yes it is, but to get treatment over there you got to be a resident and you need to have a lot of money.' Well, that puts us out of the case. We're only normal sort of people. He did say that there was some other option, but we have to talk about it. NAME DOCTOR in LOCATION METROPOLITAN, she's my kidney specialist. Apparently, her pile of drugs that might help but they can make you bleed internally, and I'll have to go off some of my blood thinners that I'm on now. We're going to have a discussion about that and I'm going back up on the eighteenth of this coming month so probably now a bit more then. Participant 014ATR

When I was first diagnosed, we talked about the possibility of including a liver transplant because this was about three years ago now, and he said I would be a good candidate for it but we both agreed that it wasn't really viable at that stage even though that biologically is the wrong thing to do. It was also at that stage there was medications and regimes coming along, but there's nothing that had been fully released here in Australia, so it was pretty much wait and see and monitor, not only because I had got in there, because I knew my history, I had got in before hardly anything had had a chance to show. Participant 015ATR

Multiple options presented: Did not participate in decision-making

All we've discussed is I'm currently taking the green tea extract twice a day and was told that it's probably found that people—If they took it at the time that they often suffered the side effect of it. Which was insomnia, so they suggested I take even in the afternoon, morning and mid-afternoon. Which I do, on an empty stomach. Any other, other than, and also the possibility of getting on to these two drug trials coming up. They're kind of hoping that I might be able but there's a lot of people now. They're living in hope as well. To get onto the two drugs, one is Tafamidis, something like that, which I think stops the protein from attaching to the amyloid fibrils. The other one is Patisiran or something like that, which stops the liver from producing the amyloid or the protein. Any other treatments, it's not been discussed. I have no idea. I really, I don't know what I'm in for, to be honest. Participant 001ATR

They were going to try and get me onto the-- trial in Australia, which one of the drugs is? I think, one of the options for the trial is-- because it's cardio involvement I've had a recorder, I had to recorder implanted in my chest in LOCATION METROPOLITAN. When they investigated the recorder here on a Wednesday, that Friday, I was in having a defibrillator pacemaker fitted. Then, as a result of having that fitted, I had a fluid buildup, which, because of me being admitted to the hospital, it made me ineligible for the trial. Other than the trial or the current treatment I'm on, that's pretty much all they've discussed. Participant 004ATR

When I was first diagnosed, the oncologist, haematologist, he said that we would do stem cell, but he was going away. He'd booked something, and he couldn't stop it for two or three weeks. He said as soon as he got back, they'd start stem cell on me. That was probably one of the worst weeks of my life, because I did a lot of reading, and I was at that stage 70-years-old, not very well, very low kidney function. In my own research, it showed that I was in a very high bracket of people who don't get through stem cell treatment. When he came back and he was about to start it, he had a meeting with, I think, NAME SPECIALIST at NAME HOSPITAL, who, as you know, runs the amyloidosis stuff there, and they decided that stem cell was going to be too severe for me. They put me on dex and thalidomide. I did six months on that. Participant 017ATR

Multiple options presented: Told what to do without discussion

That was with the renal specialist. He really just was talking about cyclophosphamide. I don't recall it being in combination with any other drugs although now I know that it's traditionally given in combination with dexamethasone and thalidomide as one combination. He just talked about cyclophosphamide. Once I contacted the haematologist, he said that he would like to try the combination of cyclophosphamide, thalidomide, and dexamethasone, but really only to check that the cells in the bone marrow were responsive to that treatment. If they're responsive to that, then there would be responsive, hopefully, to stem cell transplants. He put me on that combination just for a couple of months just to check that they were affecting the free light chains, and they did, and then we just scheduled the stem cell transplant. There wasn't really an option to go on a clinical trial at that point. The trial that was going on then was for relapsed amyloidosis. I wasn't a candidate for the clinical trial that he was on. It was before Velcade came on the scene, I think. He just offered me what was probably the best option at the time. Participant 002AL

I was told about the Velcade treatment, and that it had been shown to work against reducing the imbalances of the kappa lambda chains, the light chains and I was told that what possible side effects there might be. Then we started basically, and I've got comments that I've written down after each treatment and right though this and then I took my blood pressure and everything else. I had very few side effects apart from, I think, the dexameth which gave me a few hassles about sleeping and things like that. I was given dexameth either by IV at the hospital, they ran out once and they gave me

tablets then as well. Then I took 20-milligram tablets, 5 of them the day after, say, on the treatment day and the day after I was given dexameth… Really, that was all we discussed. He said the results was good. I was just on a monitoring regime until just recently. Participant 003AL

Of course, you put your faith in your cardiologist or with the doctors, of course, and he just said, 'Well, look, you're going to have to start up straight away on this chemo.' I had no idea what was involved, so we started on the chemo and then about halfway through the chemo system, another cardiologist specialist came in and gave me a good talk because they were talking about giving me a stem cell transplant. There were grave concerns because my age put me right on the limit and they said, 'You may not even—Two things, you may not even survive the stem cell transplant, or it'll have no effect.' I think I was only about two weeks away from having that when they decided to put the hold on that because it just seemed a little bit too risky. Participant 013ATR

Specific treatment discussed: Stem cell transplant

Because I was fit and because I was otherwise very healthy, I'd no other condition and I was… it was still seen as I was a candidate for stem cell transplant albeit with an elevated risk, but not to the level that would preclude a bone marrow transplant—sorry, a stem cell transplant. Those were the two tracks of conversation. Participant 004AL

When I was first diagnosed, the oncologist, haematologist, he said that we would do stem cell, but he was going away. He'd booked something, and he couldn't stop it for two or three weeks. He said as soon as he got back, they'd start stem cell on me. That was probably one of the worst weeks of my life, because I did a lot of reading, and I was at that stage 70-years-old, not very well, very low kidney function. In my own research, it showed that I was in a very high bracket of people who don't get through stem cell treatment. Participant 017ATR

He put me on that combination just for a couple of months just to check that they were affecting the free light chains, and they did, and then we just scheduled the stem cell transplant. Participant 002AL

Specific treatment discussed: Liver transplant

I spoke to them about a liver transplant and then they took into account my age and my condition with the amyloid, how bad it was. I said it was no good doing one it was too far gone…They said to me then that there's no other treatments. All we can do is the best we can with what we've got and they were doing nothing at this stage for us. Participant 009ATR

Essentially it was medical treatment versus the liver transplant which he then at that point said, 'You don't need.' Based off my specific thing and generally what he was actually recommending in my case. Participant 006ATR

The second time, as I was put on that treatment, I was assessed for a liver and a heart transplant because this protein is produced by the liver. It produces trans-direction and it converts it into this amyloid. One treatment or intervention was to—And the heart, I should say, is the key organ. Participant 016ATR

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes it being difficult to remember/other response	14	38.89	4	22.22	5	20.00	2	20.00	8	100.00	3	13.64	11	78.57	3	33.33	11	40.74
Participant describes discussing multiple options	13	36.11	8	44.44	11	44.00	5	50.00	0	0.00	11	50.00	2	14.29	3	33.33	10	37.04
Participant describes discussing one treatment option	6	16.67	3	16.67	6	24.00	3	30.00	0	0.00	6	27.27	0	0.00	2	22.22	4	14.81
Participant describes no treatment options being discussed	3	8.33	3	16.67	3	12.00	0	0.00	0	0.00	2	9.09	1	7.14	1	11.11	2	7.41

Discussions about treatment	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes it being difficult to remember/other response	14	38.89	5	62.50	8	42.11	1	12.50	3	21.43	3	21.43	5	45.45	9	36.00
Participant describes discussing multiple options	13	36.11	2	25.00	7	36.84	3	37.50	7	50.00	6	42.86	2	18.18	11	44.00
Participant describes discussing one treatment option	6	16.67	1	12.50	4	21.05	1	12.50	3	21.43	3	21.43	3	27.27	3	12.00
Participant describes no treatment options being discussed	3	8.33	0	0.00	0	0.00	3	37.50	1	7.14	2	14.29	1	9.09	2	8.00

Table 4.2: Discussions about treatment, options discussed

Discussions about treatment: Options discussed	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes being presented with multiple options: Participated in the decision-making process	5	13.89	3	16.67	4	16.00	2	20.00	0	0.00	5	22.73	0	0.00	2	22.22	3	11.11
Participant describes being presented with multiple options: Did not participate in the decision-making process	4	11.11	4	22.22	4	16.00	0	0.00	0	0.00	3	13.64	1	7.14	0	0.00	4	14.81
Participant describes being presented with multiple options: They were told what to do without discussion	4	11.11	1	5.56	3	12.00	3	30.00	0	0.00	3	13.64	1	7.14	1	11.11	3	11.11
Participant describes being presented with no options/approach: No therapies are available	3	8.33	3	16.67	3	12.00	0	0.00	0	0.00	2	9.09	1	7.14	1	11.11	2	7.41
Participant describes being presented with one option/approach: They were told what to do without discussion	3	8.33	1	5.56	3	12.00	2	20.00	0	0.00	3	13.64	0	0.00	1	11.11	2	7.41
Participant describes being presented with one option/approach: Some but very little discussion	2	5.56	0	0.00	1	4.00	2	20.00	0	0.00	1	4.55	1	7.14	0	0.00	2	7.41

Discussions about treatment: Options discussed	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes being presented with multiple options: Participated in the decision-making process	5	13.89	1	12.50	2	10.53	1	12.50	2	14.29	3	21.43	1	9.09	4	16.00
Participant describes being presented with multiple options: Did not participate in the decision-making process	4	11.11	1	12.50	2	10.53	1	12.50	4	28.57	0	0.00	1	9.09	3	12.00
Participant describes being presented with multiple options: They were told what to do without discussion	4	11.11	0	0.00	3	15.79	1	12.50	1	7.14	3	21.43	0	0.00	4	16.00
Participant describes being presented with no options/approach: No therapies are available	3	8.33	0	0.00	0	0.00	3	37.50	1	7.14	2	14.29	1	9.09	2	8.00
Participant describes being presented with one option/approach: They were told what to do without discussion	3	8.33	0	0.00	3	15.79	0	0.00	3	21.43	0	0.00	2	18.18	1	4.00
Participant describes being presented with one option/approach: Some but very little discussion	2	5.56	0	0.00	0	0.00	2	25.00	1	7.14	1	7.14	0	0.00	2	8.00

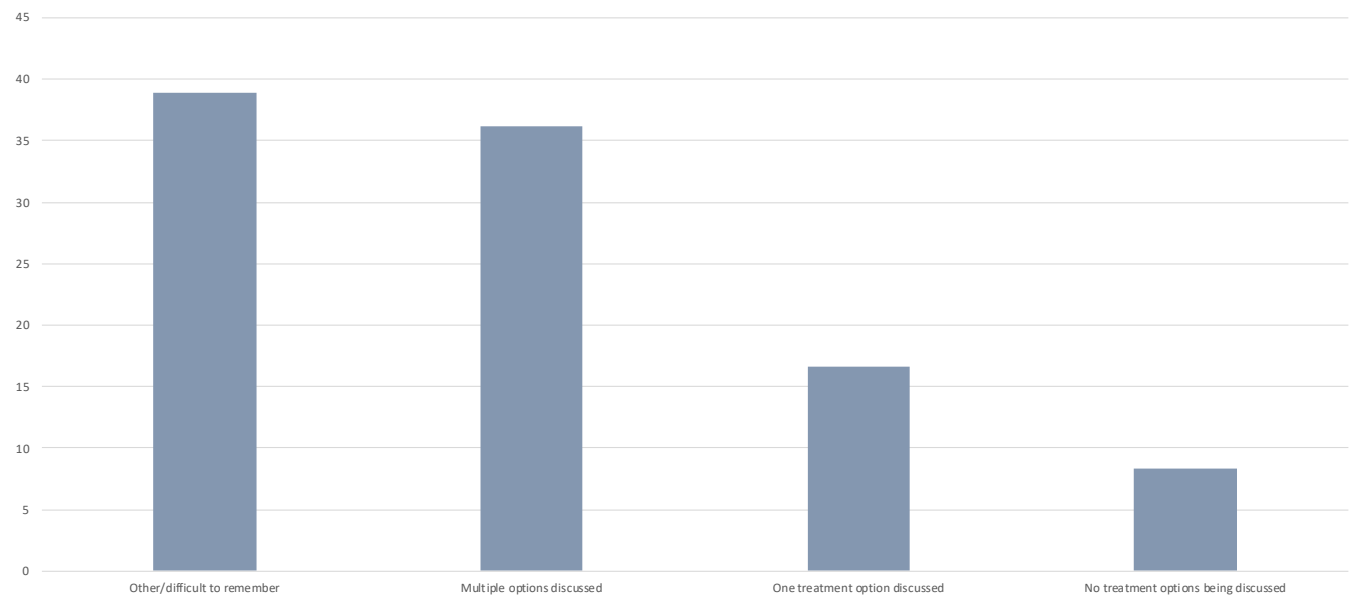


Figure 4.1: Discussions about treatment

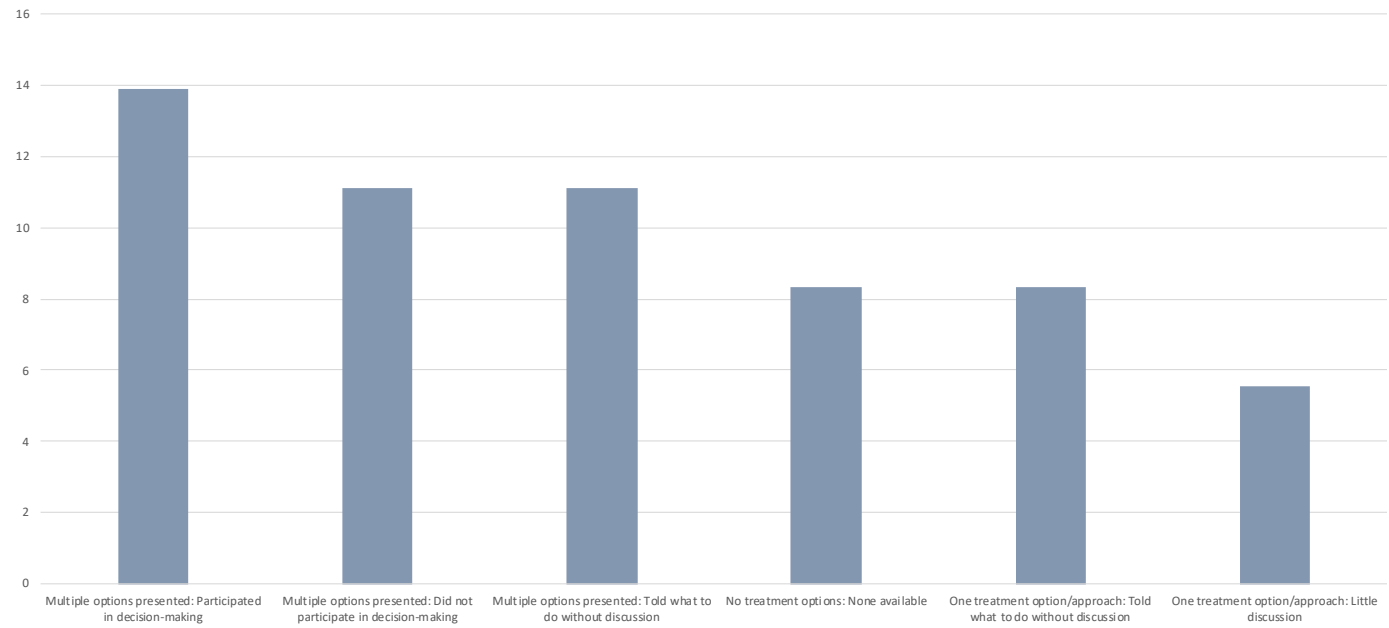


Figure 4.2: Discussions about treatment, options discussed

Table 4.3: Specific treatment discussed

Discussions about treatment: Options discussed	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes being presented with the option of stem cell transplant	6	16.67	3	16.67	5	20.00	3	30.00	0	0.00	5	22.73	1	7.14	1	11.11	5	18.52
Participant describes being presented with the option of liver transplant	4	11.11	4	22.22	4	16.00	0	0.00	0	0.00	4	18.18	0	0.00	2	22.22	2	7.41
Participant describes being presented with the option of chemotherapy	3	8.33	1	5.56	1	4.00	2	20.00	0	0.00	3	13.64	0	0.00	0	0.00	3	11.11
Participant describes being presented with the option of Green tea extract	3	8.33	3	16.67	3	12.00	0	0.00	0	0.00	2	9.09	1	7.14	1	11.11	2	7.41
Participant describes being presented with the option of Velcade or dexamethasone	3	8.33	0	0.00	2	8.00	3	30.00	0	0.00	3	13.64	0	0.00	1	11.11	2	7.41
Participant describes being presented with the option of Bone marrow transplant	2	5.56	0	0.00	1	4.00	2	20.00	0	0.00	2	9.09	0	0.00	1	11.11	1	3.70

Discussions about treatment: Options discussed	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes being presented with the option of stem cell transplant	6	16.67	0	0.00	3	15.79	3	37.50	2	14.29	4	28.57	1	9.09	5	20.00
Participant describes being presented with the option of liver transplant	4	11.11	2	25.00	1	5.26	0	0.00	1	7.14	3	21.43	2	18.18	2	8.00
Participant describes being presented with the option of chemotherapy	3	8.33	0	0.00	1	5.26	2	25.00	2	14.29	1	7.14	0	0.00	3	12.00
Participant describes being presented with the option of Green tea extract	3	8.33	1	12.50	1	5.26	1	12.50	1	7.14	2	14.29	1	9.09	2	8.00
Participant describes being presented with the option of Velcade or dexamethasone	3	8.33	0	0.00	2	10.53	1	12.50	2	14.29	1	7.14	1	9.09	2	8.00
Participant describes being presented with the option of Bone marrow transplant	2	5.56	0	0.00	1	5.26	1	12.50	1	7.14	1	7.14	0	0.00	2	8.00

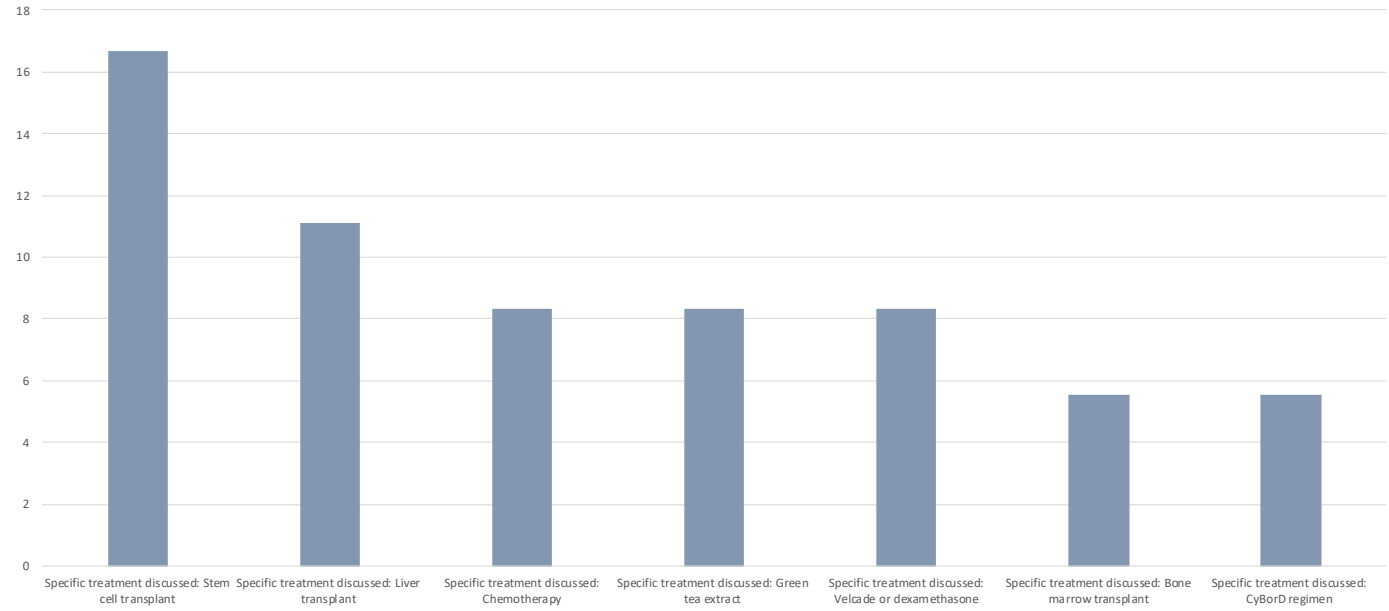


Figure 4.3: Specific treatment discussed

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported consideration was quality of life as part of multiple aspects that they consider when making decisions about treatment and this was described by 13 participants (36.11%). This was followed by efficacy as part of multiple aspects they consider (n=9, 25.00%); side effects as part of multiple aspects they consider (n=9, 25.00%); the long term impact and side effects of treatment as part of multiple aspects they consider (n=7, 19.44%), taking the advice of their clinician as part of multiple aspects they consider (n=6, 16.67%), considering the potential impact on their family or dependents as part of multiple aspects they consider (n=5, 13.89%), survival benefit as part of multiple aspects they consider (n=5, 13.89%) and taking the advice of their clinician as the only aspect they consider (n=5, 13.89%).

In relation to subgroup variations, participants in the *Regional or remote* (22.22%), and *Mid to low SEIFA* (18.18%) subgroups described taking quality of life as part of multiple aspects they consider less frequently than the general population (36.11%), while those in the *Aged 75 or older* (50.00%) subgroup described this more frequently.

Participants in the subgroups *AL amyloidosis* (50.00%), *Aged 75 or older* (50.00%), *Male* (40.91%), *University* (42.86%), and *Regional or remote* (44.44%) described taking efficacy taking efficacy into account as part of multiple aspects that they consider more frequently than the general population (25.00%) while those in subgroups *Carer* (0.00%), *Aged 55 to 64* (0.00%), and *Female* (0.00%) did not describe this at all.

Participants in the *Aged 75 or older* subgroup (12.50%) described taking side effects into account as part of multiple aspects they consider less frequently than the general population (25.00%).

Participants in the subgroups *Aged 75 or older* (37.50%) and *University* (35.71%) described taking the long-term impact and side effects of treatment into account as part of multiple aspects that they consider more frequently than the general population (19.44%), whereas those in the subgroups *Mid to low SEIFA* (9.09%), *Aged 65 to 74* (5.26%) and *Carer* (0.00%) described this less frequently.

Participants in the subgroups *AL amyloidosis* (40.00%) and *University* (28.57%) described taking the advice of their clinician into account as part of multiple aspects that they consider more frequently than the general population (16.67%) while those in the *Carer* subgroup did not describe this at all (0.00%).

Participants in the *Aged 75 or older* subgroup described taking into account the potential impact on their family or dependents more frequently (25.00%) than the general population (13.89%).

Participants in the subgroups *Aged 55 to 64* (25.00%) and *University* (28.57%) described taking the survival

benefit into account as part of multiple aspects they consider more frequently than the general population (13.89%) while those in the *Carer* (0.00%), *Aged 75 or older* (0.00%), *Regional or remote* (0.00%), and *Mid to low SEIFA* (0.00%) subgroups did not describe this at all.

Participants in the *Mid to low SEIFA* (27.27%) subgroup described taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment more frequently than the general population (13.89%), while participants in the *Aged 55 to 64* (0.00%) subgroup did not describe this at all.

Quality of life (as part of multiple considerations)

My decisions about treatment are pretty much based on the quality of life and the effect of the treatment. That's probably the same thing, isn't it? I mean, quality of life and the treatment and what the actual amyloidosis does. Participant 001AL

Quality of life, as we get further along in the journey, the quality of life balance I think is really important. A few times, he's been losing track now because we've just gone back on chemo again as of last Friday. Participant 002CA

I list the benefits and the risks and what the outcome. The outcome is to live longer. The outcome is to live with the quality of life and not be restricted to our bed or our medication and the ongoing care. Participant 002ATR

Efficacy (as part of multiple considerations)

Obviously, efficacy is the principal one. Does the damn thing work, and will it have long-term effects, will it result with the AL being under control or diminished to the point where it's not an issue? Those to me were the principal issues. Participant 004AL

The first thing is asking how realistic it is in terms of a way for me to get better. That's the first step that I go through with NAME and/or whoever the specialist who is discussing it. Then second stage is really about the risks involved. Participant 006ATR

The thing that I ask with them is what it's going to do for me, and is it going to help me, or what are the side effects? That's you're but outside that, no, we haven't been asked to look into much the treatments as yet. Participant 009ATR

Side effects (as part of multiple considerations)

An experienced doctor would be able to fill you in with what options there are, what side effects you will have, will affect the lifestyle, et cetera. I don't think that any of the other doctors really have that experience. An experienced doctor would have far better knowledge and far better to be able to impart that knowledge to the patient and outline what some of the effects would be. Participant 006AL

The secondary one was side effects. The tertiary one would have been effects on lifestyle, diet changes, exercise changes, the ability to live a normal life type of thing. Those would be the hierarchy for me. Participant 004AL

The thing that I ask with them is what it's going to do for me, and is it going to help me, or what are the side effects? That's you're but outside that, no, we haven't been asked to look into much the treatments as yet.
Participant 009ATR

Long term impact/side effects (as part of multiple considerations)

How it would affect me and how long it would be, the length of time. Participant 003ALX

As long as it doesn't affect my other organs, my kidney and my liver were the main things, I just keep taking that tablet. Participant 003ATR

I am looking for not a short-term gain, but I look to see what the benefits are, what the side effects could be, the timescales for them to actually be noticeable, and then long-term prognosis down the line, is that long-term, how we would go. Those are the sort of things I'm looking for. Participant 015ATR

Taking the advice of their clinician (as part of multiple considerations)

Anyway, recommendations by him. He's my haematologist, and I would think a haematologist should have a pretty good idea of the effects of a particular drug on your blood system. Participant 016ATR

Well, when you're making decisions about a treatment, you just do what your oncologist or haematologist recommends. There wasn't really much alternative for me. I couldn't do stem cell, and here, just thinking about my overall health hell coming out of it and the side effects of it, and that was about it, yes. Participant 017ATR

An experienced doctor would be able to fill you in with what options there are, what side effects you will have, will affect the lifestyle, et cetera. I don't think that any of the other doctors really have that experience. An experienced doctor would have far better knowledge and far better to be able to impart that knowledge to the patient and outline what some of the effects would be. Participant 006AL

Impact on family and dependents (as part of multiple considerations)

I would consider my family, my husband and I, we were to involve and see if I had to go away somewhere or could have the treatments here in LOCATION METROPOLITAN, usual concerns that me as a potential patient would have with relation to treatment. Participant 003ALX

I was keeping my peace, at least somewhat even a normal life. That became it's now like how actually, how my little life at this stage, and then, I guess costs and probably the family and friends. Participant 006ATR

Well, I make those decisions in conjunction with my wife. The things that we focus on are, if there's a treatment available, would we just rush in and say-- just anything to get another year of life-- and we're not inclined to that way. The way things are going it's restricting my wife's life, and it's restricting mine, not being able to go on bush walks and not being able to-- Well, I can't even go and pick up a carton of beer from the bottle shop without someone putting it in the car because of the symptoms. Participant 013ATR

Survival benefit (as part of multiple considerations)

The outcome is to live longer. The outcome is to live with the quality of life and not be restricted to our bed or our medication and the ongoing care. So, in question aligned to you to make the decision of how successful it is. If you take the liver transplant for example—what is the length of time that somebody needs afterwards, what are the complications of the liver transplant, what is that like, what medications are we on, what are the side effects of the medication, what is the ongoing care that is involved, would there be treatment after the transplant, and so forth. Participant 002ATR

The first thing is asking how realistic it is in terms of a way for me to get better. That's the first step that I go through with NAME and/or whoever the specialist who is discussing it. Then second stage is really about the risks involved. The other thing is because of my character which has been affected today to a certain extent. It's do I have to go off somewhere is there a chance I get nothing for six months, eight months, a year or whatever that I've then regressed and become much worse. Personally, for me, one of the biggest reasons I really wasn't particularly fond of the idea of a liver transplant, is that I could still go to work every day at this stage. I can still go and drink with my friends. I'm still quite young. Participant 006ATR

Yes, I mean if it got side effects, we deal with those and maybe change or then modify something about the length of the treatment. How long am I? How sick am I going to be? How long it's going to be? What's going to be the outcome? I'd be prepared to do it. Participant 001ATR

Advice of clinician (only consideration)

Look, we were lost. We went to see NAME CLINICIAN hoping that what he knew about amyloidosis, he would be able to give him some treatment. NAME CLINICIAN basically told us that the only thing that they give him was a drug called diflunisal, which we basically said, 'Yes, okay. We'll go on that.' Participant 004CA

Well, I just take what the doctors—I've got full trust in my doctors. I know I'm very, very lucky to be in LOCATION METROPOLITAN here because the NAME HOSPITAL and the Amyloid Centre and the NAME HOSPITAL is one of the top three in the world, they're in constant communication with the Mayo Clinic in America, and the London Amyloidosis Clinic updated on trials, working and failed. The head haematologist I had, he's one of the top guys. Well, he would be the top guy in Australia I would say, if not one of the top guys in the world. Like I said, I have complete faith or whatever they say or recommend. Participant 005AL

Well, mainly the recommendation of the haematologist, NAME SPECIALIST because you can go online and read about this and it's so complex.

You have to be guided by the professionals that you are being treated by. Participant 14ATR

Table 4.4: Considerations when making decisions

Considerations when making decisions about treatment	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	13	36.11	7	38.89	10	40.00	3	30.00	3	37.50	8	36.36	5	35.71	2	22.22	11	40.74
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	9	25.00	4	22.22	7	28.00	5	50.00	0	0.00	9	40.91	0	0.00	4	44.44	5	18.52
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	9	25.00	4	22.22	7	28.00	3	30.00	2	25.00	5	22.73	4	28.57	3	33.33	6	22.22
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	7	19.44	5	27.78	6	24.00	2	20.00	0	0.00	5	22.73	2	14.29	2	22.22	5	18.52
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	6	16.67	2	11.11	5	20.00	4	40.00	0	0.00	5	22.73	1	7.14	1	11.11	5	18.52
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	5	13.89	3	16.67	3	12.00	1	10.00	1	12.50	2	9.09	3	21.43	1	11.11	4	14.81
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	5	13.89	4	22.22	5	20.00	1	10.00	0	0.00	2	9.09	3	21.43	0	0.00	5	18.52
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	5	13.89	3	16.67	4	16.00	1	10.00	1	12.50	3	13.64	2	14.29	1	11.11	4	14.81

Considerations when making decisions about treatment	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	13	36.11	3	37.50	5	26.32	4	50.00	5	35.71	5	35.71	2	18.18	11	44.00
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	9	25.00	0	0.00	4	21.05	4	50.00	3	21.43	6	42.86	2	18.18	7	28.00
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	9	25.00	2	25.00	6	31.58	1	12.50	4	28.57	3	21.43	2	18.18	7	28.00
Participant describes taking the long term impact and side effects of treatment into account as part of multiple aspects that they consider when making decisions about treatment	7	19.44	2	25.00	1	5.26	3	37.50	2	14.29	5	35.71	1	9.09	6	24.00
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	6	16.67	1	12.50	3	15.79	2	25.00	2	14.29	4	28.57	2	18.18	4	16.00
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	5	13.89	1	12.50	1	5.26	2	25.00	2	14.29	2	14.29	1	9.09	4	16.00
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	5	13.89	2	25.00	2	10.53	0	0.00	1	7.14	4	28.57	0	0.00	5	20.00
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	5	13.89	0	0.00	4	21.05	1	12.50	3	21.43	1	7.14	3	27.27	2	8.00

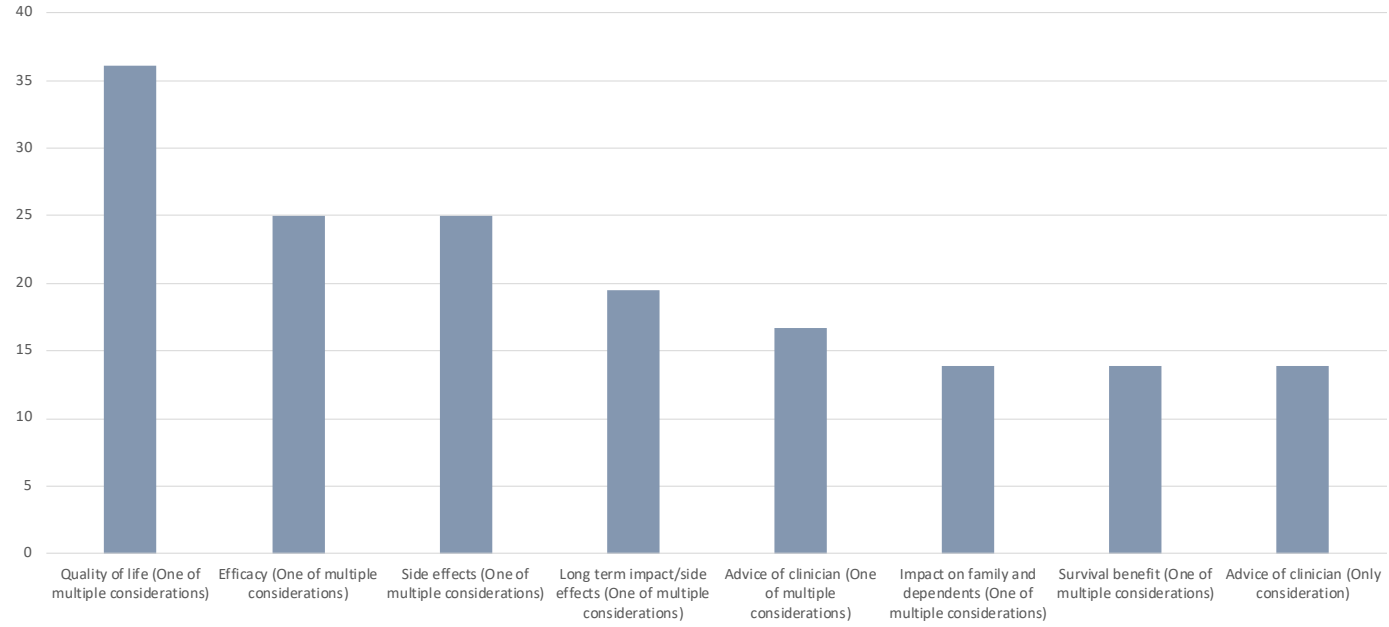


Figure 4.4 Considerations when making decisions

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 15 participants (41.67%) that felt the way they made decisions about treatment had not changed over time, and 12 participants (33.33%) that described decision-making changing. Nine participants (25.00%) were unsure/other or gave no response.

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed and/or assertive (n=7, 19.44%). Three participants described their decision-making changing over time as they are more aware of their health, responsibilities and/or limitations (8.33%) Other participants described changing over time as they are more accepting of their condition and choices available (n=1, 2.78%), they are more focused on how treatment impacts their family and dependents (n=1, 2.78%), they are more cautious and considered (n=1, 2.78%) and they are more focused on quality of life or the impact of side effects (n=1, 2.78%).

Among participants who described no change in the way they make decisions the most common response was that this was because they had always been informed/assertive (n=7, 19.44%) followed by those who did not mention any reason (n=4, 11.11%). Other responses were that there had been no change because they always took the advice of clinicians (n=2, 5.56%) and because they have had no treatment options to choose from (n=1, 2.78%).

In relation to subgroup variations, participants in the subgroups *AL amyloidosis* (60.00%), *Regional or remote* (55.56%), and *Aged 75 or older* (62.50%) described no change in decisions-making over time more frequently than the general population (41.67%) while those in the subgroups *Carer* (25.00%) and *Aged 55 to 64* (25.00%) described this less frequently.

Participants in the *Aged 55 to 64* subgroup (50.00%) described decision-making changing over time more frequently than the general population (33.33%), while those in the subgroups *Female* (21.43%) and *Mid to low SEIFA* (18.18%) described this less frequently.

Participants in the subgroups *Carer* (50.00%), *Female* (35.71%), and *Mid to low SEIFA* (36.36%) were unsure/other or gave no response more frequently than the general population (25.00%), while those in the subgroups *AL amyloidosis* (10.00%), *Aged 75 or older* (12.50%), and *University* (14.29%) described this less frequently.

Participants in the *Carer* (0.00%), *Female* (7.14%), and the *Trade or high school* (7.14%) subgroups described decision-making changing over time as they are more informed and/or assertive less frequently than the general population (19.44%), while those in the subgroup *University* (42.86%) described this more frequently.

Participants in the *University* (35.7%), *Regional or remote* (44.44%), and *AL Amyloidosis* (30.00%) subgroups described no change in decision-making

as they have always been informed and/or assertive more frequently than the general population (19.44%), while those in the *Trade or high school* subgroup (0.00%) did not describe this at all.

No participants in the subgroups *Carer* (0.00%), *Female* (0.00%) and *Aged 55 to 64* (0.00%) described no change in decision-making and did not mention any reason, whereas those in the subgroups *Aged 75 or older* (25.00%) and *Trade or high school* (21.43%) described this more frequently than the general population (11.11%).

Participants in the *AL amyloidosis* subgroup described no change in decision-making over time as they have always taken the advice of clinicians more frequently (20.00%) than the general population (5.56%).

No change (total)

I think I probably make decisions in the same kind of way because I've always wanted to be informed, I guess. I like to make informed choices and weigh things up. I like to understand what the treatments are doing and how they work, but that's probably just assigned to me really. Participant 002AL

As much as the same way as I've always done. Amyloidosis isn't the first health scare I had. Participant 002ALX

Oh, pretty well the same. NAME HUSBAND has always been a very independent person, was late marrying, late becoming a father. I think one of the biggest impacts of this disease was all of a sudden, he had no control. I don't know whether he would say that. I don't think he would say that, but he'd always been in control of his life. Participant 002CA

Change (total)

No, the decision-making, I think, is helped by knowledge about the disease, understanding about it, talking to other people, talking to various specialists about it. I feel reasonably informed and I think that makes the decisions a lot easier. Participant 001AL

As time has gone on, he has definitely let down his guard and discusses it much more, but in saying this, I did have to say to him that this condition that he has is impacting on the whole family and we are all part of this. I did have to throw that comment out a few times which may have encouraged him to look at things a bit differently. Participant 001CA

I think it's changed. I think for a long time, I've made a lot of decisions, thinking about NAME HUSBAND and what he'd want and all that sort of thing, but often he wasn't in a situation to make a decision. I've ended up being the decision-maker and the driver in a lot of ways, and I guess that's where the carer side of me kicks in and doing the very best I can, for all concerned that at the end of the day I'm making a decision. That's probably one of the biggest changes as a carer that has changed our relationship. Participant 003CA

Changed over time: more informed/assertive

No, the decision-making, I think, is helped by knowledge about the disease, understanding about it, talking to other people, talking to various specialists about it. I feel reasonably informed and I think that makes the decisions a lot easier. Participant 001AL

My decision has changed because I've learned and understood much more things that I didn't know before. Participant 005ATR

No, because I think in the beginning when you're first told you've got it, I'm going to do whatever it takes, this is what we're going to do. We're going to—You think you're invincible and then the reality of everything sets in a bit. Anything now I would research into. I wouldn't make that statement. 'Oh, yes, I'm going to go and, have everything and it will be terrific,' because you realise that's not the case. I guess you do look at it a bit thoroughly is a good way to put it. Participant 012ATR

No change over time: has always been informed/assertive

Oh, pretty well the same. NAME HUSBAND has always been a very independent person, was late marrying, late becoming a father. I think one of the biggest impacts of this disease was all of a sudden, he had no control. I don't know whether he would say that. I don't think he would say that, but he'd always been in control of his life. Participant 002CA

No, I'm pretty consistent and the way I make decisions point at my background IN PROFESSION... I try not to let emotions and other things get in the way too much. A very objective sort of a person, and always seeking outcome, not one to delay or defer decision-making. Participant 004AL

I think I probably make decisions in the same kind of way because I've always wanted to be informed, I guess. I like to make informed choices and weigh things up. I like to understand what the treatments are doing and how they work, but that's probably just assigned to me really. Participant 002AL

No change over time: no reason described or noted

As much as the same way as I've always done. Amyloidosis isn't the first health scare I had. Participant 002ALX

I'll probably do the same way. Participant 014ATR

In the same way, I think, yes. Participant 017ATR

Table 4.5: Decision-making over time

Decision-making over time	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
No change over time	15	41.67	7	38.89	11	44.00	6	60.00	2	25.00	9	40.91	6	42.86	5	55.56	10	37.04
Changed over time	12	33.33	7	38.89	9	36.00	3	30.00	2	25.00	9	40.91	3	21.43	2	22.22	10	37.04
Other/unsure/no response	9	25.00	4	22.22	5	20.00	1	10.00	4	50.00	4	18.18	5	35.71	2	22.22	7	25.93

Decision-making over time	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
No change over time	15	41.67	2	25.00	8	42.11	5	62.50	7	50.00	6	42.86	5	45.45	10	40.00
Changed over time	12	33.33	4	50.00	5	26.32	2	25.00	4	28.57	6	42.86	2	18.18	10	40.00
Other/unsure/no response	9	25.00	2	25.00	6	31.58	1	12.50	3	21.43	2	14.29	4	36.36	5	20.00

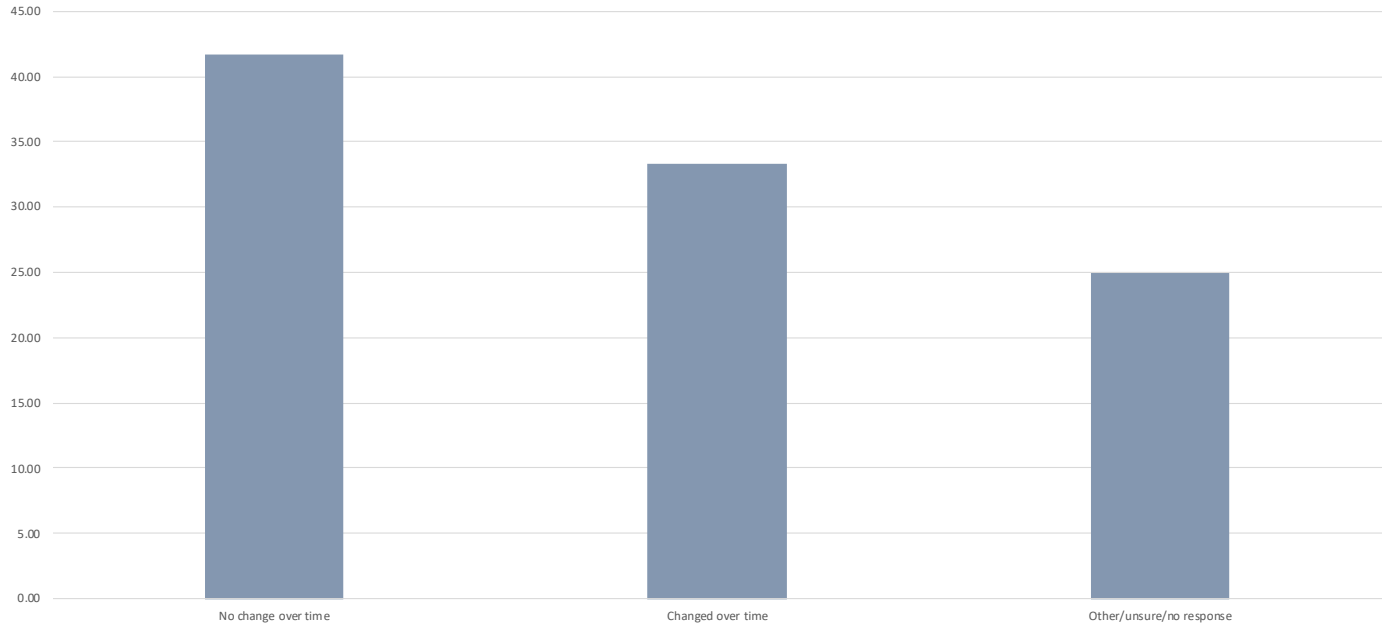


Figure 4.5: Decision-making over time

Table 4.6: Decision-making over time, rationale for change

Decision-making over time: Rationale for change	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes decision-making changing over time as they are more informed and/or more assertive	7	19.44	5	27.78	6	24.00	2	20.00	0	0.00	6	27.27	1	7.14	1	11.11	6	22.22
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	8.33	2	11.11	2	8.00	0	0.00	1	12.50	1	4.55	2	14.29	1	11.11	2	7.41
Participant describes decision-making changing over time as they are more accepting of their condition and choices available (however not by choice)	1	2.78	1	5.56	1	4.00	0	0.00	0	0.00	1	4.55	0	0.00	0	0.00	1	3.70
Participant describes decision-making changing over time as they are more focused on how treatment impacts their family and dependents	1	2.78	0	0.00	0	0.00	0	0.00	1	12.50	0	0.00	1	7.14	1	11.11	0	0.00
Participant describes decision-making changing over time as they are more cautious and considered	1	2.78	1	5.56	1	4.00	0	0.00	0	0.00	1	4.55	0	0.00	0	0.00	1	3.70
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	1	2.78	0	0.00	1	4.00	1	10.00	0	0.00	1	4.55	0	0.00	0	0.00	1	3.70

Decision-making over time: Rationale for change	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes decision-making changing over time as they are more informed and/or more assertive	7	19.44	2	25.00	3	15.79	1	12.50	1	7.14	6	42.86	2	18.18	5	20.00
Participant describes decision-making changing over time as they are more aware of their health, responsibilities and/or limitations	3	8.33	0	0.00	2	10.53	0	0.00	1	7.14	1	7.14	1	9.09	2	8.00
Participant describes decision-making changing over time as they are more accepting of their condition and choices available (however not by choice)	1	2.78	1	12.50	0	0.00	0	0.00	1	7.14	0	0.00	0	0.00	1	4.00
Participant describes decision-making changing over time as they are more focused on how treatment impacts their family and dependents	1	2.78	0	0.00	1	5.26	0	0.00	0	0.00	0	0.00	0	0.00	1	4.00
Participant describes decision-making changing over time as they are more cautious and considered	1	2.78	0	0.00	0	0.00	1	12.50	1	7.14	0	0.00	0	0.00	1	4.00
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	1	2.78	0	0.00	1	5.26	0	0.00	1	7.14	0	0.00	0	0.00	1	4.00

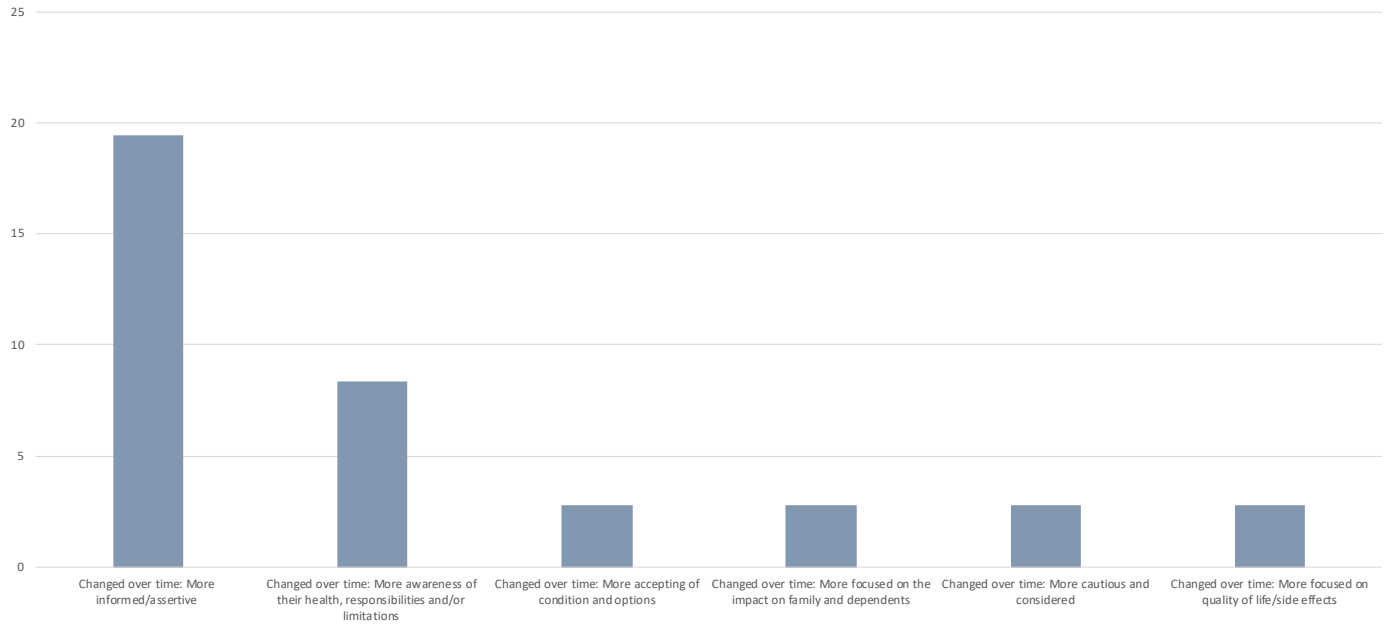


Figure 4.6: Decision-making over time, rationale for change

Table 4.7: Decision-making over time, rationale for no change

Decision-making over time: Rationale for no change	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes no change in decision-making over time as they have always been informed/assertive	7	19.44	2	11.11	5	20.00	3	30.00	2	25.00	3	13.64	4	28.57	4	44.44	3	11.11
Participant describes no change in decision-making but does not mention any reason	4	11.11	3	16.67	3	12.00	1	10.00	0	0.00	4	18.18	0	0.00	1	11.11	3	11.11
Participant describes no change in decision-making over time as they have always taken advice of clinicians	2	5.56	0	0.00	1	4.00	2	20.00	0	0.00	1	4.55	1	7.14	0	0.00	2	7.41
Participant describes no change in decision-making over time as they have not had treatment options to choose from	1	2.78	1	5.56	1	4.00	0	0.00	0	0.00	1	4.55	0	0.00	0	0.00	1	3.70

Decision-making over time: Rationale for no change	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes no change in decision-making over time as they have always been informed/assertive	7	19.44	2	25.00	4	21.05	1	12.50	0	0.00	5	35.71	2	18.18	5	20.00
Participant describes no change in decision-making but does not mention any reason	4	11.11	0	0.00	2	10.53	2	25.00	3	21.43	1	7.14	2	18.18	2	8.00
Participant describes no change in decision-making over time as they have always taken advice of clinicians	2	5.56	0	0.00	1	5.26	1	12.50	2	14.29	0	0.00	1	9.09	1	4.00
Participant describes no change in decision-making over time as they have not had treatment options to choose from	1	2.78	0	0.00	1	5.26	0	0.00	1	7.14	0	0.00	0	0.00	1	4.00

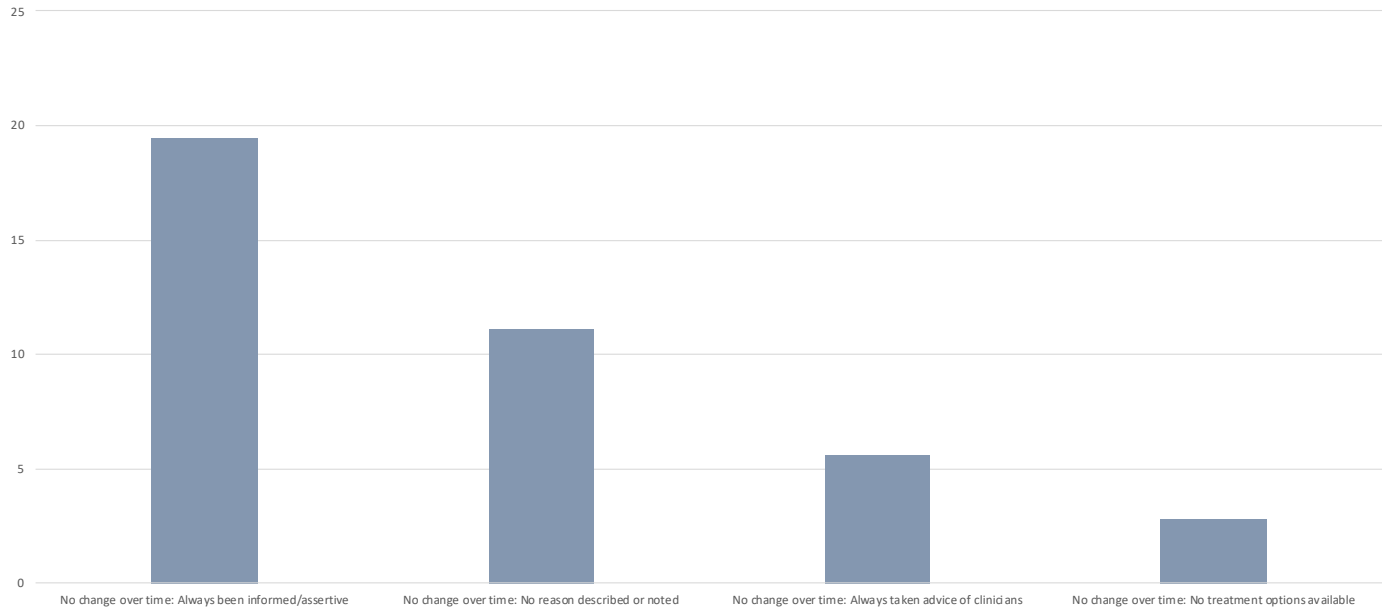


Figure 4.7: Decision-making over time, rationale for no change

Section 5

Treatment

Section 5 Summary: Treatment

Main provider of treatment

- The haematologist was the main provider of amyloidosis treatment for the majority of participants (n=19, 67.86%).

Access to healthcare professionals

- All participants had access to a general practitioner (n=28, 100.00%) and the majority had access to a cardiologist (n=26, 92.86%), and haematologist (n=24, 85.71%) for the treatment of their amyloidosis.

Respect shown

- The majority of participants indicated that they had been treated with respect throughout their experience (n=31, 86.11%), five participants (13.89%) participants felt they had been treated with respect with the exception of one or two occasions, there were no participants who felt they weren't treated with respect.

Healthcare system

- The majority of participants had private healthcare insurance (n=23, 82.14%), five participants (17.86%) asked if they want to be treated as a public or private patient. The majority of participants had not been asked if they had private health insurance (n=15, 53.57%). Throughout their treatment, equal numbers of participants were treated as a public patient (n=11, 39.29%), or private patient (n=11, 39.29%), and most commonly in the public hospital system (n=13, 46.43%) (Table 5.4).

Affordability of healthcare

- The majority of participants never cancelled their appointments due to cost (n=23, 82.14.00%), while four (14.29%) participants rarely had to cancel appointments. Almost all participants (n=27, 96.43%) never had any trouble paying for prescriptions.

Cost of amyloidosis

- Almost all participants never or rarely found it difficult to pay for basic necessities such as housing food and electricity (n=25, 89.29%). There were two participants (7.14%) had to pay for additional carers for themselves or their family. Participants spent between $0 and $1400 per month on amyloidosis. The amount spent was extremely significant or moderately significant burden for 4 participants (14.29%), five found it somewhat significant (17.86%), and 19 participants found costs slightly or not at all significant (67.86%).

Changes to employment status

- Half of the participants (n=18, 50.00%) of this PEEK study were retired at the time of the amyloidosis diagnosis. There were six participant (16.67%) that quit their job, and four (11.11%) reduced their work hours.

- There were 25 (89.29%) participants with a main partner or carer, 13 partners or main carers (46.43%) did not have a job or were retired at the time of diagnosis, seven (25.00%) had no change in employment status, and three (10.71%) quit their job.

Reduced income due to amyloidosis

- A third of participants (32.14%) had a reduced family income due to amyloidosis. Participants noted a drop in monthly income of between $100 to over $5,000 per month. For 18 of these participants (54.54%), the burden of this reduced income was extremely or moderately significant.

Treatment

- The most common drugs taken for *ATTR-cardiac* subgroup were loop-acting diuretics (n=8, 44.44%), followed by doxycycline (n=7, 38.89%), and Diffusional (n=5, 27.78%).

- The most common treatment for *AL-amyloidosis* subgroup was Melphalan and Dexamethasone (50.00%).

Surgery

- There were five participants that had surgery, four participants had a single surgery for amyloidosis, and one patient had four or more surgeries. The types of surgeries that participants had include pacemaker related surgeries, liver transplant, defibrillator fitting, and carpal tunnel surgery.

Lifestyle changes

- Nearly half of the participants made no lifestyle changes (n=13, 46.43%). The most common lifestyle changes were exercise (n=12, 42.86%), and diet (n=9, 32.14%).

Complementary therapies

- There were 24 participants (85.71%) that used some form of complementary therapies to manage their amyloidosis. The most common complementary therapies used were exercise (n=18, 64.29%) and dietary supplements (n=13, 46.43%), and for ATTR-cardiac participant, half weighed themselves daily (n=9, 50.00%).

Clinical trials

- There was a total of 26 participants (92.86%) that had discussions about clinical trials, either by bringing up the topic themselves (n=5, 17.86%) or their doctor bringing up the topic (n=21, 75.00%).

- There was a single participant (3.57%) who had taken part in a clinical trial, and 22 (78.57%) who would like to take part in a clinical trial if there was a suitable one.

Description of mild side effects

- In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common description of ‘mild side effects’ was in relation to a specific symptom as an example (n=19, 52.78%). The most common specific side effects given as an example was fatigue and/or tiredness (n=7, 19.44%) followed by diarrhoea (n=4, 11.11%). Another description of ‘mild side effects’ was those that can be self-managed and do not interfere with daily life (n=15, 41.67%).

Description of severe side effects

- In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of ‘severe side effects’ given was a specific side effect given as an example (n=17, 47.22%). The most common specific side effect given was pain (n=6, 16.67%), followed by neuropathy/sensory disturbance (n=4, 11.11%) and nausea or vomiting (n=4, 11.11%). Other descriptions

of ‘severe side effects’ included those that impact everyday life/ability to conduct activities of daily living (n=12, 33.33%). Four participants described coping with all side effects (11.11%).

Adherence to treatment

- Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common theme described was adhering as per the advice of their specialist or as long as its prescribed (n=16, 44.44%). Participants also reported not giving up on any treatment (n=6, 16.67%) and adhering to treatment for a specific amount of time (n=5, 13.89%).

What needs to change to feel like treatment is effective

- Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 11 participants (30.56%) was needing to experience evidence of stable disease or no disease progression. This was followed by needing to experience an improvement in general wellbeing (n=9, 25.00%).

Information needed to be confident in new treatments

- Participants were asked to describe what information would be needed to be confident in a new treatment. The most common response from17 participants (47.22%) was needing the advice of their clinician followed by 14 participants (38.89%) was needing to know about side effects to feel confident about trying a new treatment. There were 11 participants (30.56%) that reported needing scientific evidence and this was followed by needing to conduct their own research (n=9, 25.00%); needing to know about efficacy (n=9, 25.00%) and needing to know the overall benefits (n=8, 22.22%).

Support needed for treatment at home

- Participants were asked to describe what support they would need if they were having treatment at home. The two most common responses were participants not needing support (n=8, 22.22%) and needing support from their friends or family (n=8, 22.22%). There were seven participants that reported needing regular check-ups with a GP or nurse (19.44%) and this was followed by needing someone to call if they have a question or issue (n=4, 11.11%). Four participants described needing training and education on how to administer treatment.

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of amyloidosis.

The haematologist was the main provider of amyloidosis treatment for the majority of participants (n=19, 67.86%) (Table 5.1, Figure 5.1).

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=28)	Percent
Cardiologist (Heart doctor)	3	10.71
Haematologist (blood doctor)	19	67.86
Amyloidosis clinic/specialist team in clinic	4	14.29
Immunologist	1	3.57
Ophthalmologist	1	3.57

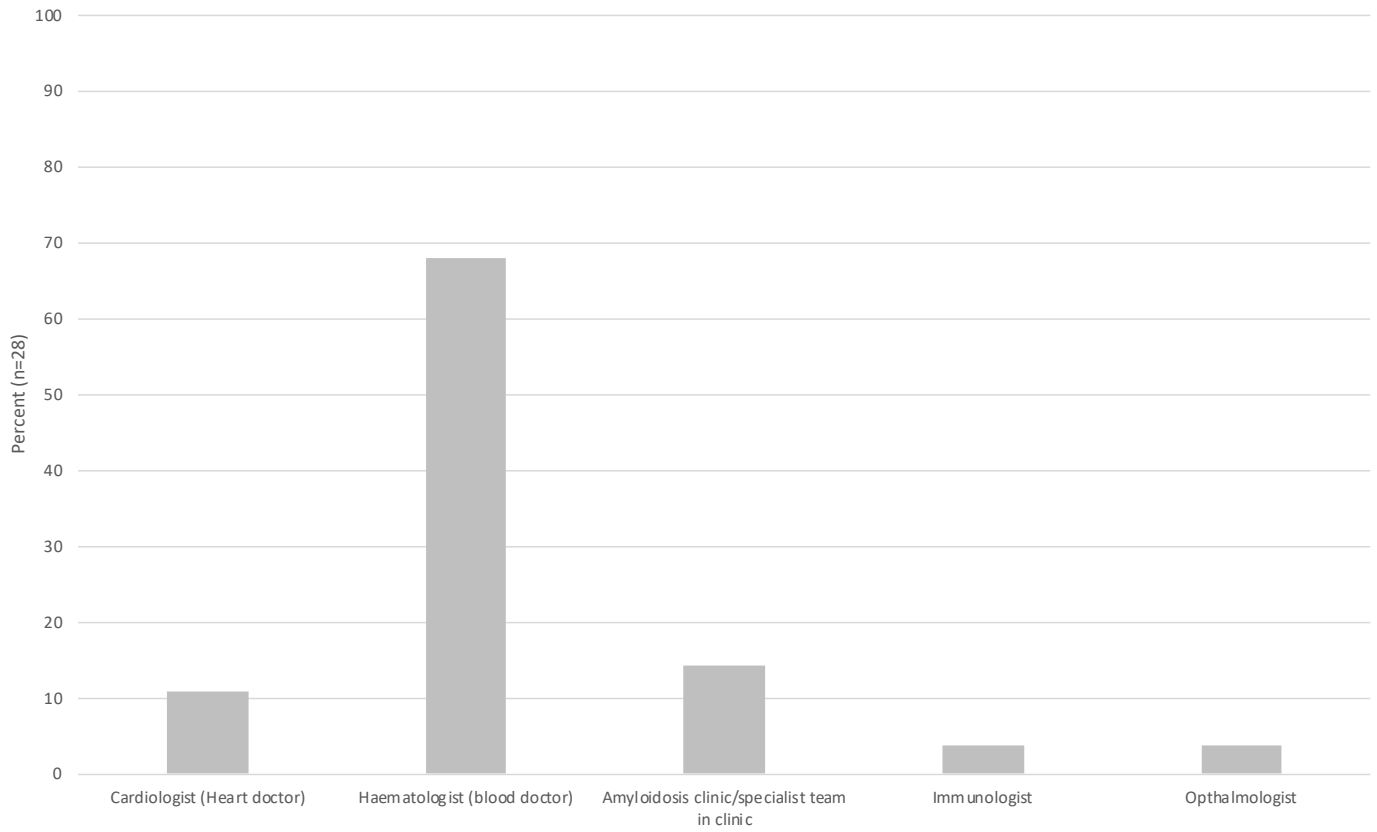


Figure 5.1: Main provider of treatment

Access to healthcare professionals

In the online questionnaire, participants shared the healthcare professionals they had access to for the treatment and management of amyloidosis.

All participants had access to a general practitioner (n=28, 100.00%) and the majority had access to a cardiologist (n=26, 92.86%), and haematologist (n=24, 85.71%) (Table 5.2, Figure 5.2).

Table 5.2: Access to healthcare professionals

Healthcare professional	Number (n=28)	Percent
General Practitioner	28	100.00
Cardiologist (Heart doctor)	26	92.86
Haematologist (blood doctor)	24	85.71
Pharmacist	14	50.00
Gastroenterologist	12	42.86
Neurologist (nerve doctor)	10	35.71
Nephrologist (kidney doctor)	8	28.57
Dietician/nutritionist	7	25.00
Chiropractor	6	21.43
Exercise physiologist	5	17.86
Physiotherapist	5	17.86
Psychologist	3	10.71
Specialist nurse or Care coordination nurse	3	10.71
Occupational therapist	2	7.14
Osteopath	2	7.14
Social worker	2	7.14
Complementary therapist	2	7.14
Counsellor	1	3.57
Genetic Counselor	1	3.57
Immunologists	1	3.57
Ophthalmologist	1	3.57
Podiatrist	1	3.57
Urologist	1	3.57
Weight loss specialist	1	3.57

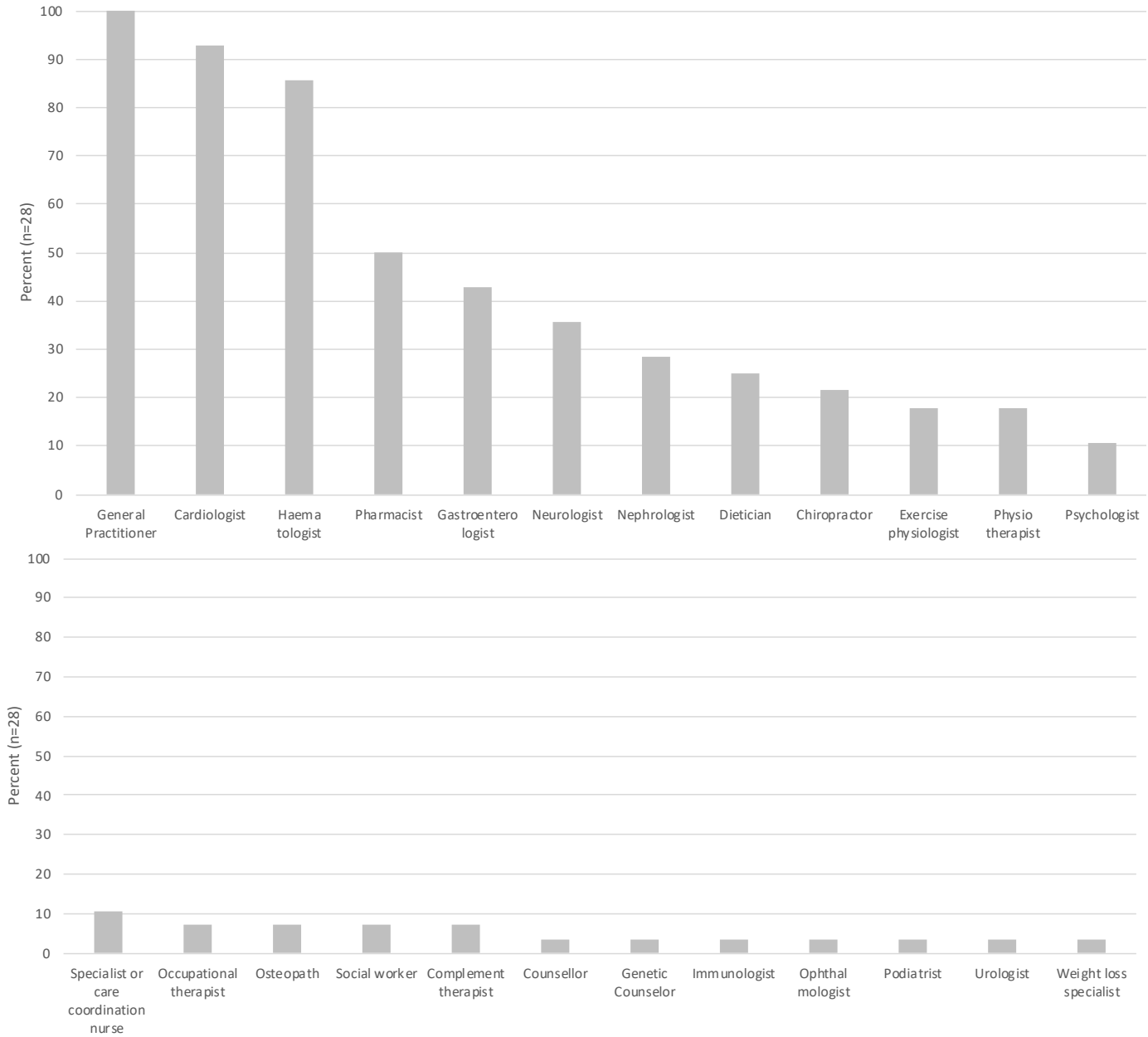


Figure 5.2: Access to healthcare professionals

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire.

The majority of participants indicated that they had been treated with respect throughout their experience (n=31, 86.11%), five participants (13.89%) felt they had been treated with respect with the exception of one or two occasions, there were no participants who felt they weren't treated with respect (Table 5.3, Figure 5.3).

Table 5.3: Respect shown

Respect shown	Number (n=28)	Percent
Yes	31	86.11
Yes, with the exception of one or two occasions	5	13.89
No	0	0.00

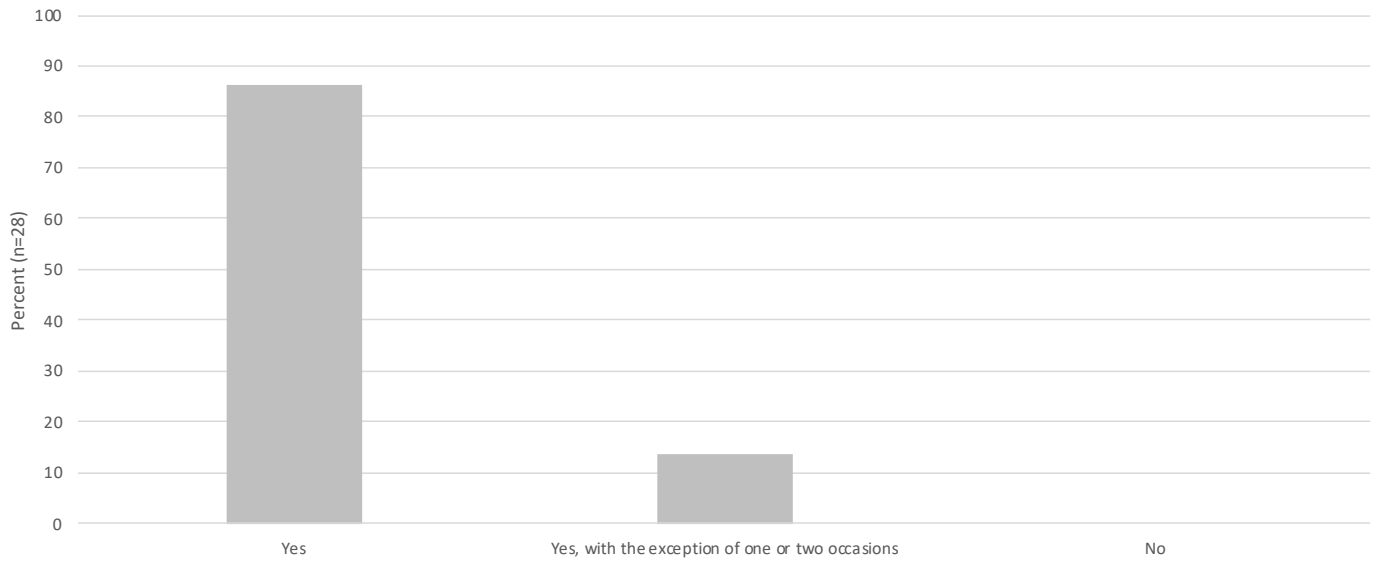


Figure 5.3: Respect shown

Healthcare system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private healthcare insurance (n=23, 82.14%), five participants (17.86%) asked if they want to be treated as a public or private patient. The majority of participants had not been asked if they had private health insurance (n=15, 53.57%).

Throughout their treatment, equal numbers of participants were treated as a public patient (n=11, 39.29%), or private patient (n=11, 39.29%), and most commonly in the public hospital system (n=13, 46.43%) (Table 5.4).

Table 5.4: Healthcare system

Health services and insurance	Response	Number (n=28)	Percent
Private health insurance	No	5	17.86
	Yes	23	82.14
Asked whether you want to be treated as a public or private patient	No	23	82.14
	Yes	5	17.86
Asked whether you had private health insurance	No	15	53.57
	Yes	13	46.43
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	4	14.29
	I'm not sure	2	7.14
	Private patient	11	39.29
	Public patient	11	39.29
Which hospital system have you primarily been treated in	Both public and private	9	32.14
	Private	6	21.43
	Public	13	46.43

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire. The first question was about having to delay or cancer healthcare appointments because they were unable to afford them.

The majority of participants never canceled their appointments due to cost (n=23, 82.14.00%), while four (14.29%) participants rarely had to cancel appointments (Table 5.5, Figure 5.4).

Table 5.5: Healthcare appointments

Delay or cancel healthcare appointments due to affordability	Number (n=28)	Percent
Never	23	82.14
Rarely	4	14.29
Sometimes	1	3.57
Often	0	0.00
Very often	0	0.00

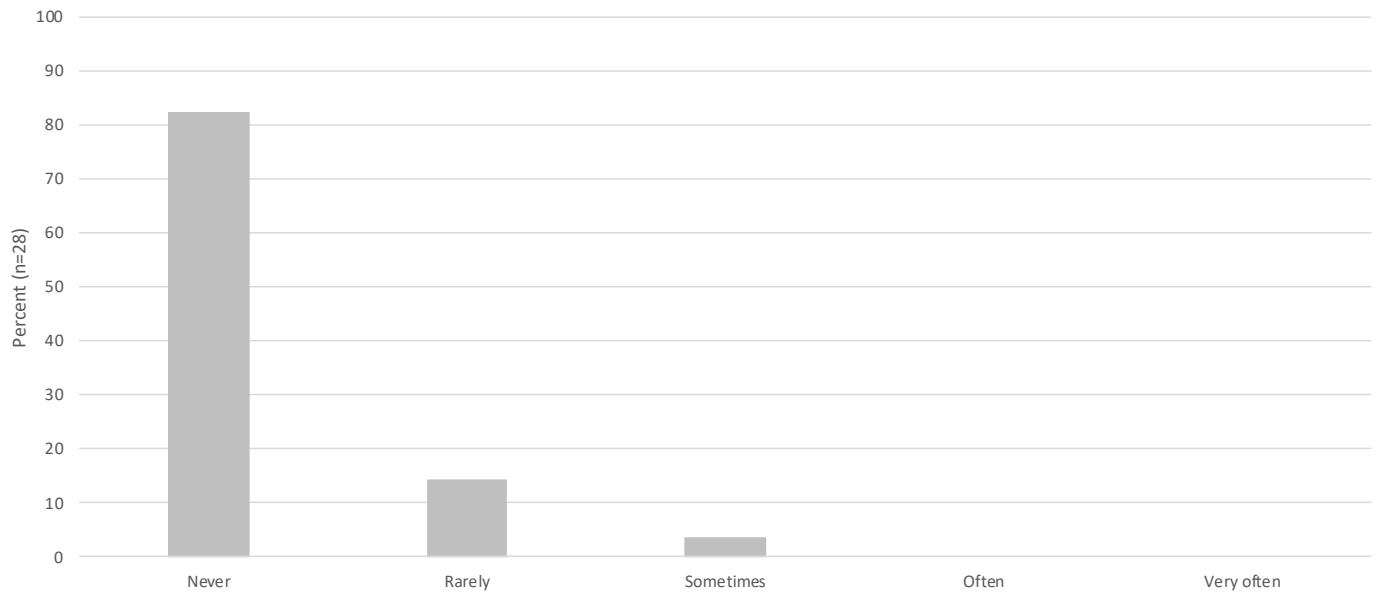


Figure 5.4: Healthcare appointments

Filling prescriptions

Participants were then asked if they were unable to fill prescriptions for essential medicines due to cost.

Almost all participants (n=27, 96.43%) never had any trouble paying for prescriptions (Table 5.6, Figure 5.5).

Table 5.6: Filling prescriptions

Did not fill prescriptions due to cost	Number (n=28)	Percent
Never	27	96.43
Rarely	0	0.00
Sometimes	1	3.57
Often	0	0.00
Very often	0	0.00

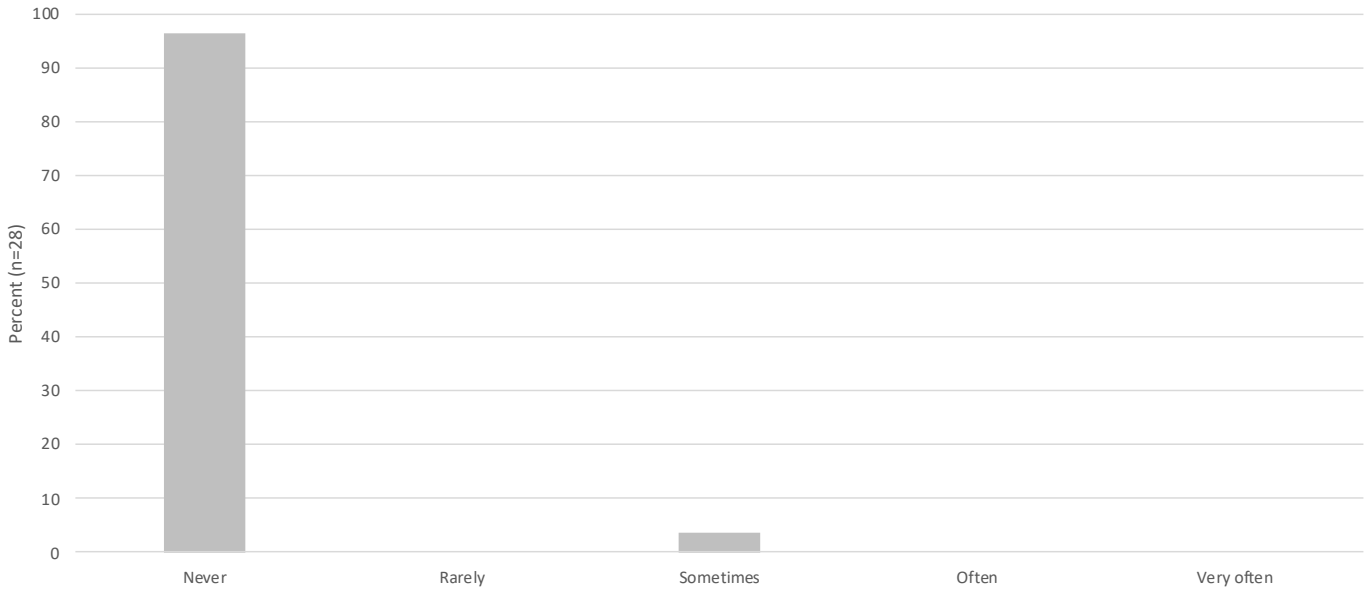


Figure 5.5: Filling prescriptions

Paying for basic essentials

Participants were asked as a result of their diagnosis with amyloidosis, if it made it difficult to pay for basic necessities such as housing, food and electricity.

Almost all participants never or rarely found it difficult to pay for basic necessities such as housing food and electricity (n=25, 89.29%) (Table 5.7, Figure 5.6).

Table 5.7: Paying for basic essentials

Difficult to pay for basic essentials	Number (n=28)	Percent
Never	23	82.14
Rarely	2	7.14
Sometimes	2	7.14
Often	0	0.00
Very often	1	0.00

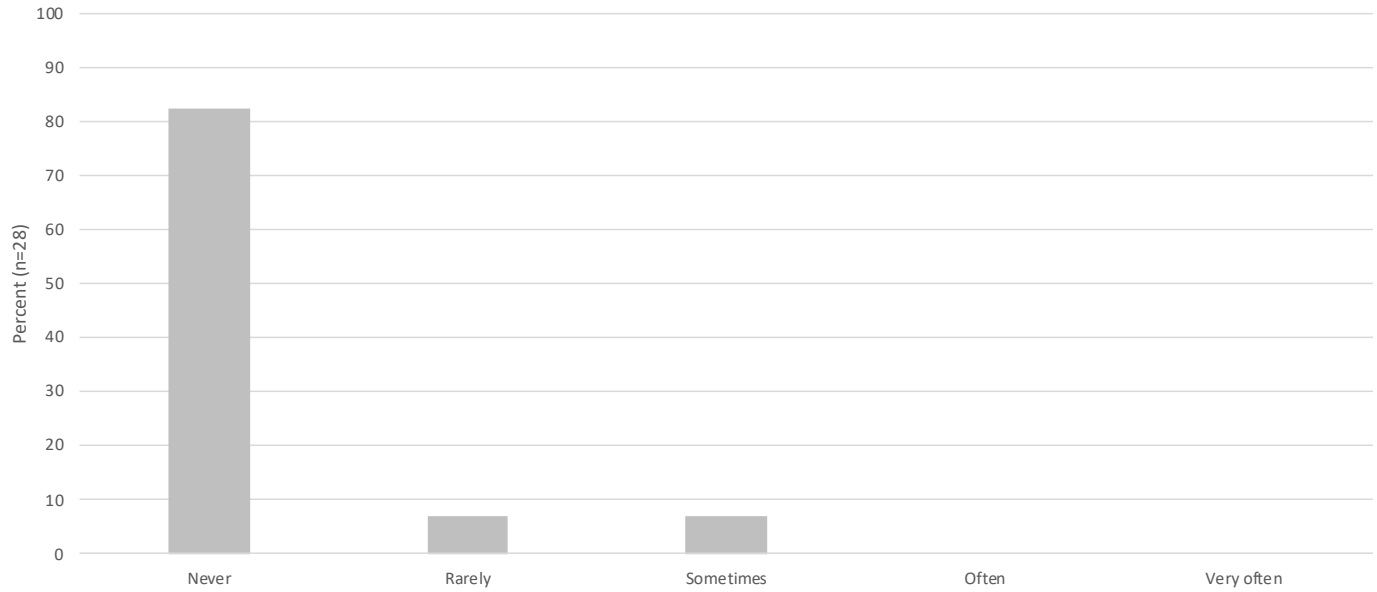


Figure 5.6: Paying for basic essentials

Pay for additional carers

Participants were then asked if as a result of their diagnosis with amyloidosis, if they had to pay for additional carers for themselves or their family.

There were two participants (7.14%) who had to pay for additional carers for themselves or their family (Table 5.8, Figure 5.7).

Table 5.8: Pay for additional carers

Pay for additional carers for self or family	Number (n=28)	Percent
No	26	92.86
Yes	2	7.14

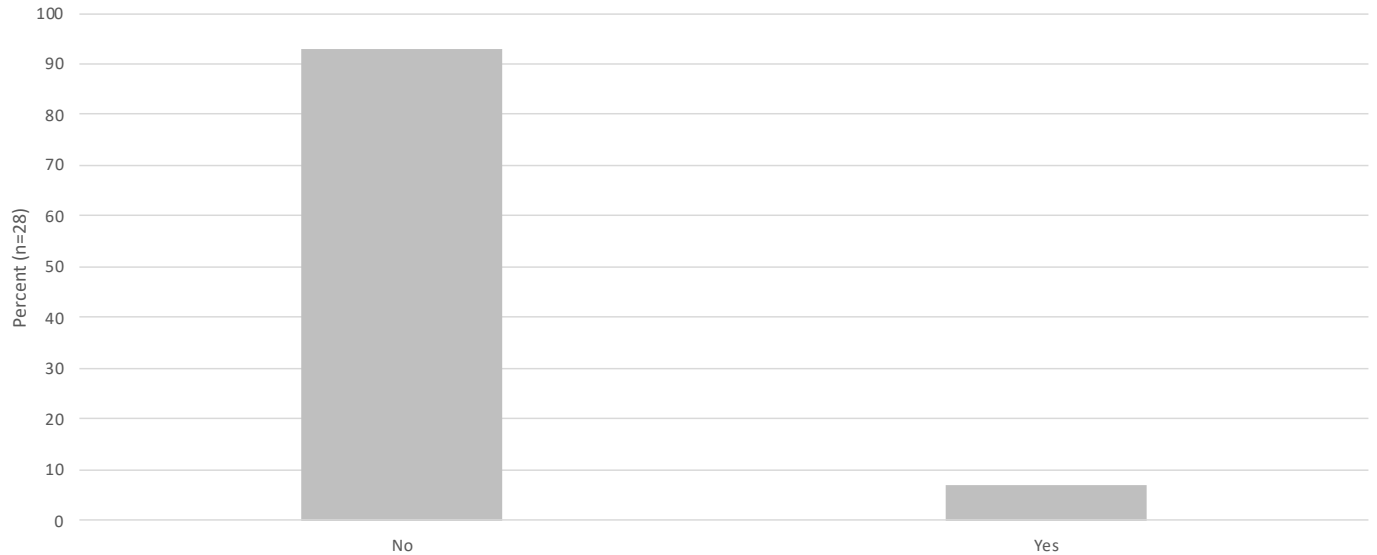


Figure 5.7: Pay for additional carers

Cost of amyloidosis

In the online questionnaire, participants estimated the amount they spend per month due to amyloidosis, including doctors' fees, transport, carers, health insurance gaps and complementary therapies.

Where the response was given in a dollar amount, it is listed in the table below. Overall, participants described spending between $0 and $1400 per month on amyloidosis (Table 5.9, Figure 5.8).

Table 5.9: Cost of amyloidosis

Estimated monthly out of pocket expenses	Number (n=36)	Percent
$0	4	11.11
$1 to $50	6	16.67
$51 to $100	5	13.89
$101 to $200	3	8.33
$201 to $300	2	5.56
$301 to $400	6	16.67
$401 to $500	3	8.33
$500 or more	4	11.11
Not sure	3	8.33

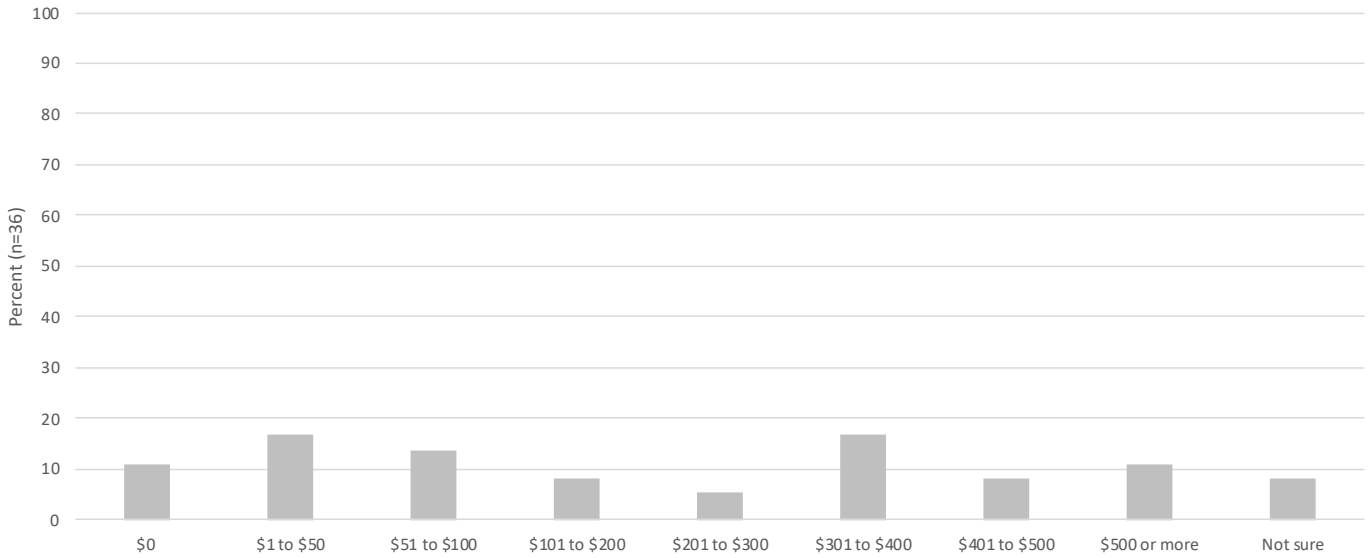


Figure 5.8: Cost of amyloidosis

Burden of cost

As a follow up question, for participants who had monthly expenses due to amyloidosis were asked if the amount spent was a burden.

The amount spent was extremely significant or moderately significant burden for 4 participants (14.29%), five found it somewhat significant (17.86%), and 19 participants found costs slightly or not at all significant (67.86%) (Table 5.10, Figure 9).

Table 5.10: Burden of cost

Burden of out of pocket expenses	Number (n=28)	Percent
Extremely significant	2	7.14
Moderately significant	2	7.14
Somewhat significant	5	17.86
Slightly significant	7	25.00
Not at all significant	12	42.86

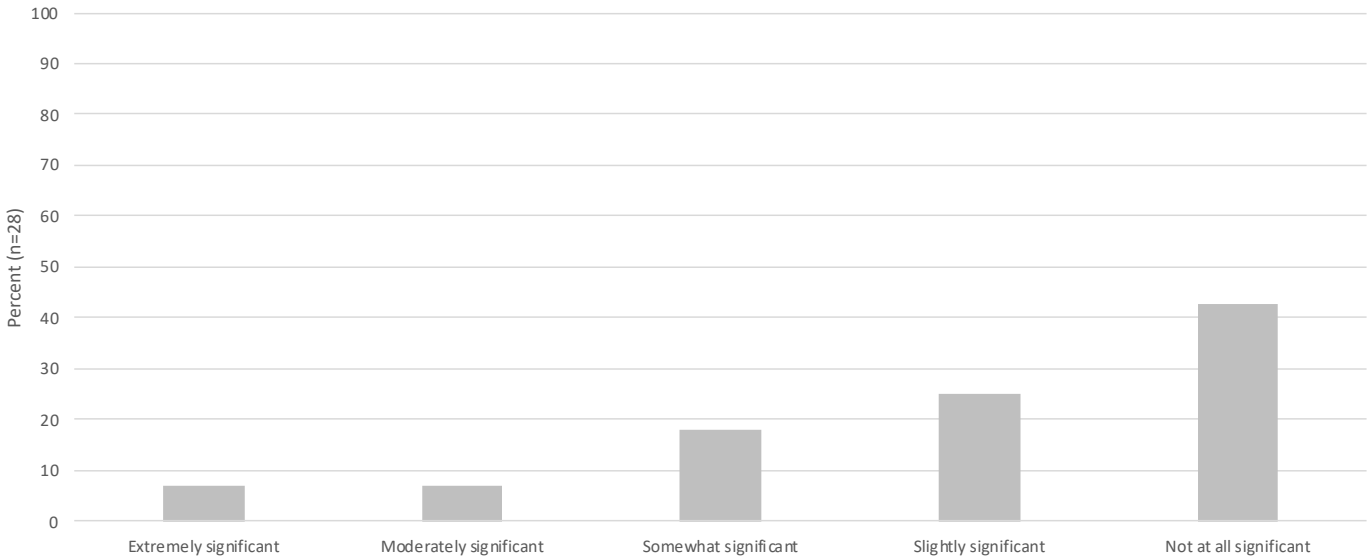


Figure 5.9: Burden of cost

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment.

Half of the participants (n=18, 50.00%) of this PEEK study were retired at the time of the amyloidosis diagnosis. There were six participant (16.67%) that quit their job, and four (11.11%) reduced their work hours (Table 5.11, Figure 5.10).

Table 5.11: Changes to employment status

Changes in work status due to condition	Number (n=36)	Percent
My work status has not changed	8	22.22
I was retired or did not have a job	18	50.00
I have had to quit my job	6	16.67
I have reduced the number of hours that I work	4	11.11
I have taken leave from work without pay	1	2.78
I have taken leave from work with pay	2	5.56
I have accessed my Superannuation early due to my condition	1	2.78

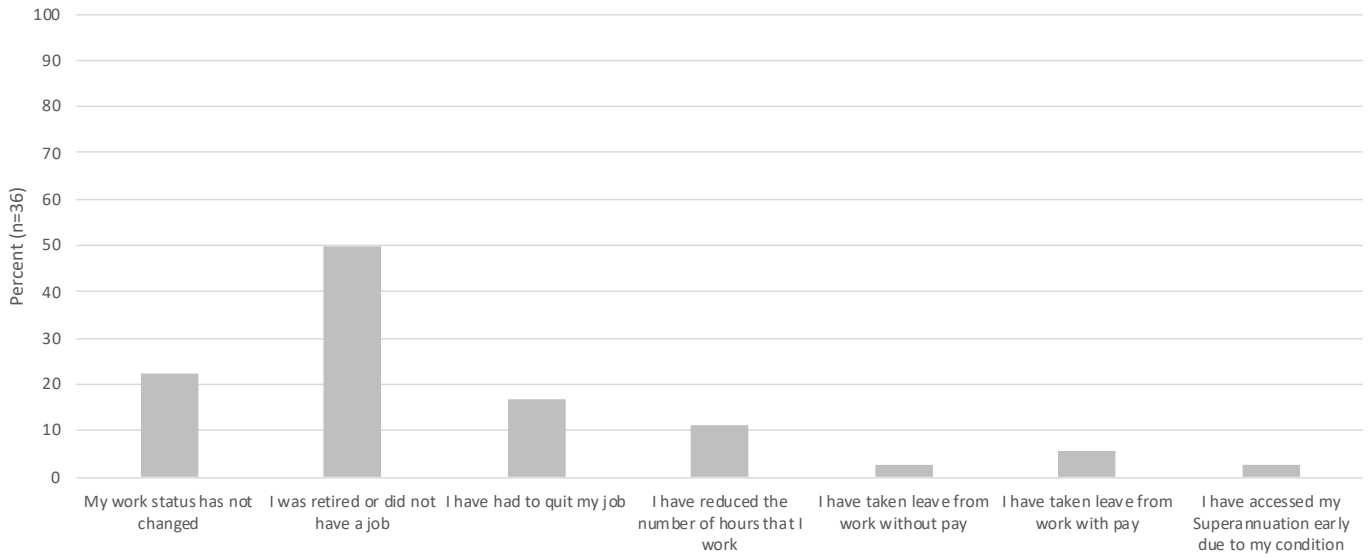


Figure 5.10: Changes to employment status

Changes to partner/main carer employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their carer or partner due to amyloidosis. Participants were able to choose multiple changes to employment.

There were 25 (89.29%) participants with a main partner or carer, 13 partners or main carers (46.43%) did not have a job or were retired at the time of diagnosis, seven (25.00%) had no change in employment status, and three (10.71%) quit their job (Table 5.12, Figure 5.11).

Table 5.12: Changes to partner/main carer employment status

Changes to partner/main carer work	Number (n=28)	Percent
I do not have a partner/main carer	3	10.71
My partner/main carer was retired or did not have a job when I was diagnosed	13	46.43
The employment status of my partner/main carer status has not changed since I was diagnosed	7	25.00
My partner/main carer had to quit their job	3	10.71
My partner/main carer reduced the number of hours that they work	2	7.14
My partner/main carer took leave from work with pay	1	3.57

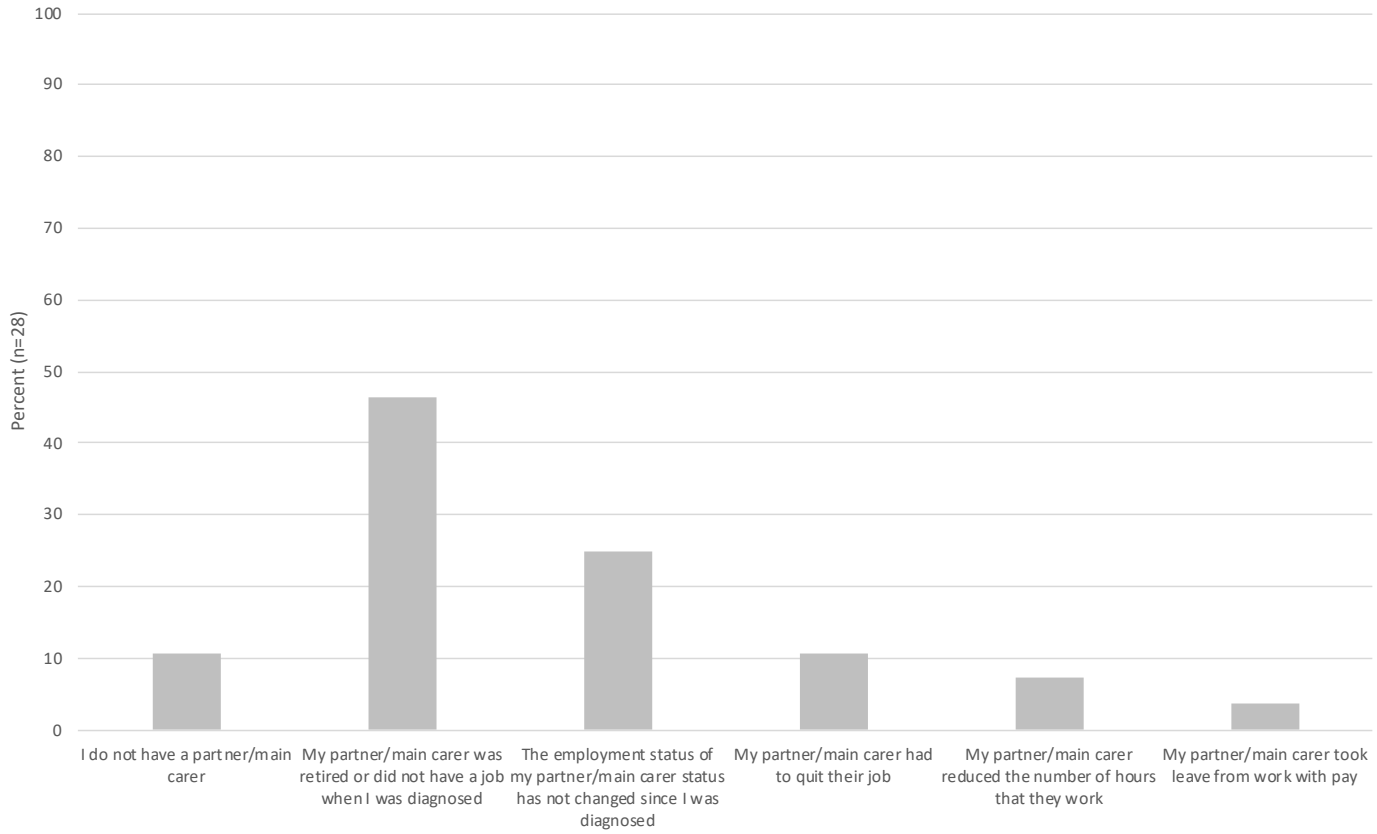


Figure 5.11: Changes to partner/main carer employment status

Reduced income due to amyloidosis

Participants were then asked if they had a reduced family or household income due to amyloidosis.

A third of participants (32.14%) had a reduced family income due to amyloidosis.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to amyloidosis. Where a dollar amount was given, it is listed in the table below.

Participants noted a drop in monthly income of between $100 to over $5,000 per month (Table 5.13, Figure 5.12).

Table 5.13: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=13)	Percent
$1 to $100	1	7.69
$1000 to $2000	3	23.08
$2001 to $5000	4	30.77
More than $5001	3	23.08
Not sure	2	15.38

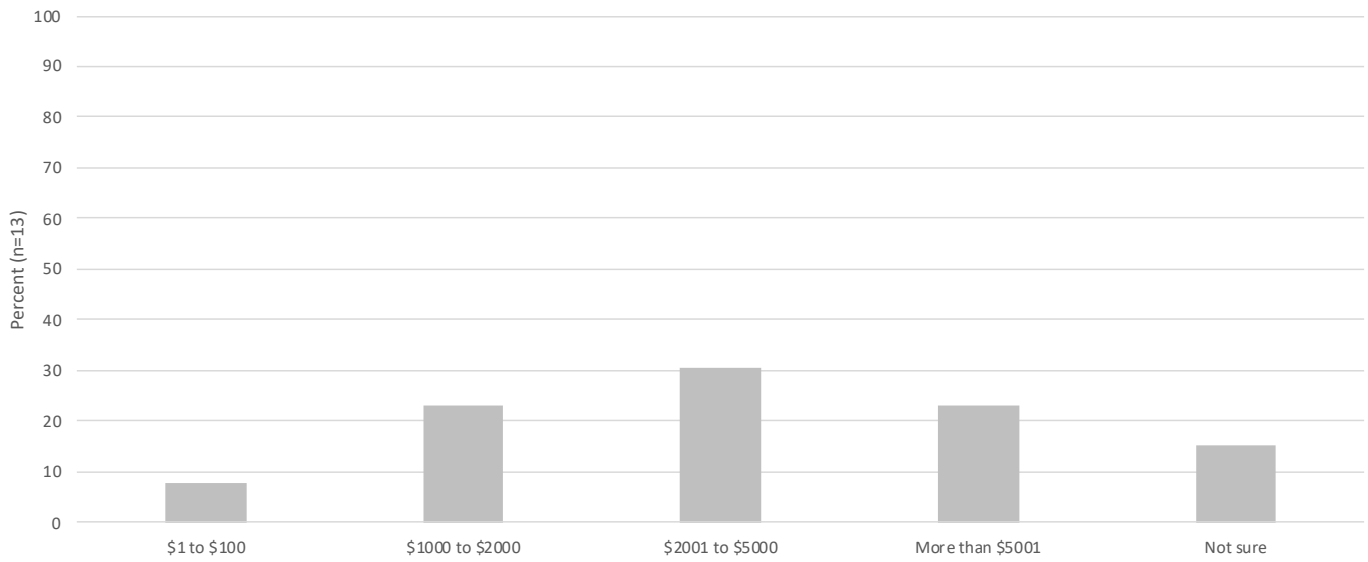


Figure 5.12: Estimated monthly loss of income

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden.

For five of these participants (55.55%), the burden of this reduced income was extremely or moderately significant (Table 5.14, Figure 5.13).

Table 5.14: Burden of reduced income

Burden of reduced income	Number (n=9)	Percent
Extremely significant	3	33.33
Moderately significant	2	22.22
Somewhat significant	1	11.11
Slightly significant	3	33.33
Not at all significant	0	0.00

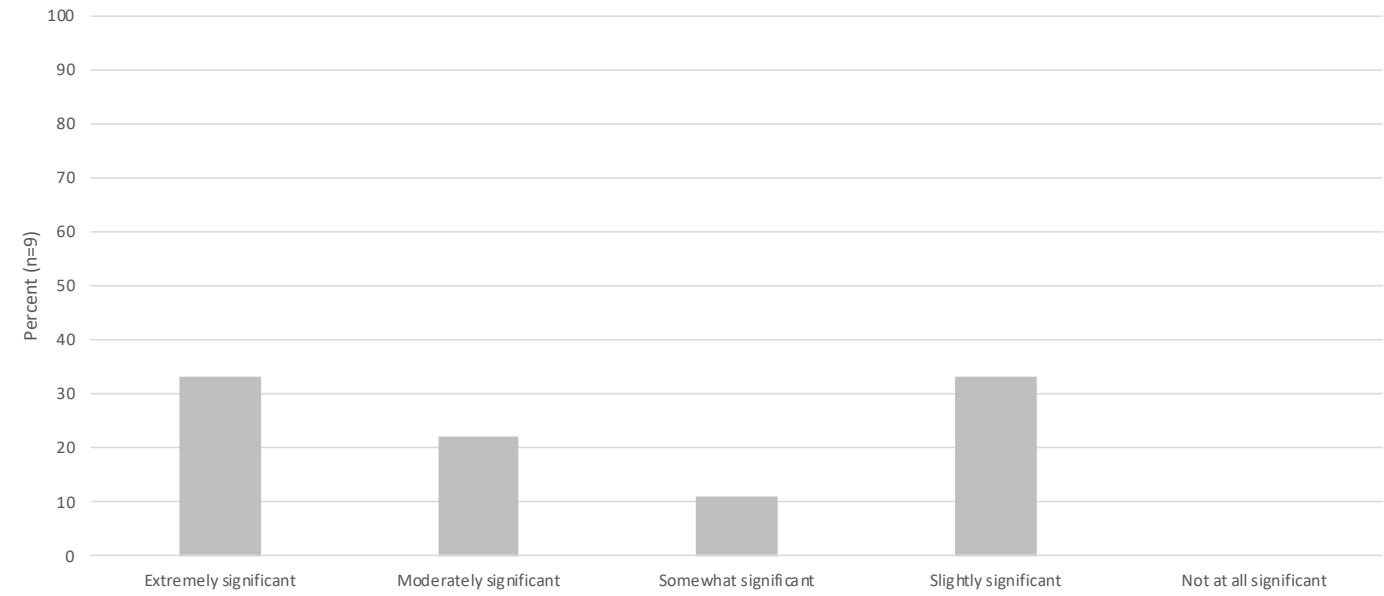


Figure 5.13: Burden of reduced income

Treatment – ATTR

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. A summary of the treatments is given in Table 5.15.

As a follow-up question (within the questionnaire), participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great').

Another follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective).

The most common treatment for ATTR-cardiac was Loop-acting diuretics (n=8, 44.44%), with most participants still taking this treatment. The median quality of life was 3.5, in the life was a little distressing to average range, and the median effectiveness was 4, in the effective range. The next most common treatment was doxycycline (n=7, 38.89%). Most participants were still taking this treatment, the median quality of life was 3, in the life was a little distressing range, and the median effectiveness was 4, in the effective range.

Table 5.15: Summary of treatments for ATTR-cardiac

Treatment summary	Tafamidis	Patisiran	Diflunisal	Doxycycline	Loop-acting diuretics	Potassium-sparing diuretics
Number (n=18)	n=2	n=1	n=5	n=7	n=8	n=5
Percent	11.11	5.56	27.78	38.89	44.44	27.78
Treatment status	Stopped early (1) Treatment ongoing (1)	Treatment ongoing (1)	Treatment ongoing (4) Completed as planned (1)	Treatment ongoing (5) Completed as planned (1) Not specified (1)	Treatment ongoing (6) Completed as planned (1) Not Started yet (1)	Treatment ongoing (4) Completed as planned (1)
Median quality of life	3 Life was a little distressing	3 Life was a little distressing	4 Life was average	3 Life was a little distressing	3.5 Life was a little distressing - average	2.5 Life was distressing - a little distressing
Median effectiveness	2 Somewhat effective	4 Effective	3 Moderately effective	4 Effective	4 Effective	4 Effective
No side effects	2	1	4	1	3	0
Gas/bloating	0	0	1	0	0	0
Loss of appetite or taste sensation	0	0	0	4	0	0
Difficulty or pain when swallowing	0	0	0	2	0	0
Diarrhoea	0	0	0	1	0	0
Oral	0	0	0	1	0	0
Sore mouth or tongue	0	0	0	1	0	0
Tooth discolouration, changes in tooth enamel	0	0	0	1	0	0
Hives	0	0	0	1	0	0
Fatigue	0	0	0	1	1	1
Nail changes	0	0	0	1	0	0
Sensitivity to the sun	0	0	0	3	0	0
Nausea and vomiting	0	0	0	1	0	0
Feeling faint or dizzy, especially on standing up	0	0	0	0	4	2
Thirst	0	0	0	0	3	2
Rash	0	0	0	0	1	0
Diarrhoea	0	0	0	0	1	0
Low blood potassium	0	0	0	0	1	1
Headache	0	0	0	0	1	1
Increased cholesterol	0	0	0	0	1	1

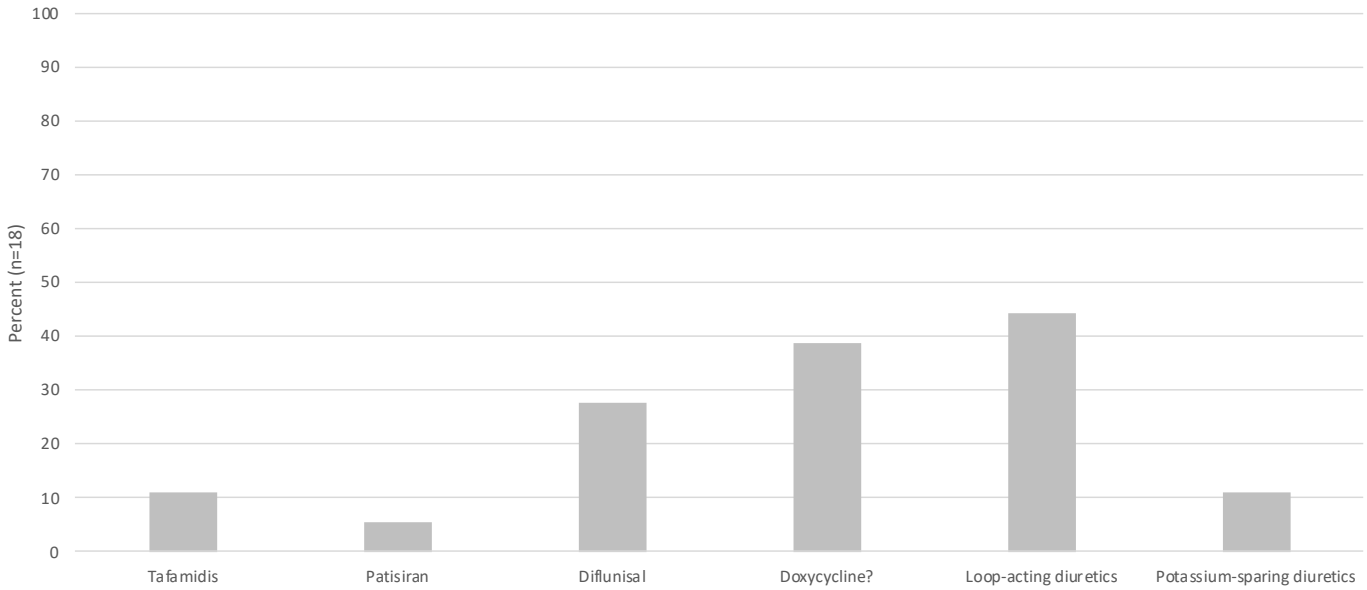


Figure 5.14: Summary of treatments for ATTR-cardiac

Treatment – AL amyloidosis

In the online questionnaire, participants answered a series of questions about their treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. A summary of the treatments is given in Table 5.16.

As a follow-up question (within the questionnaire), participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great').

Another follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective).

The most common treatment for AL amyloidosis was Melphalan and Dexamethasone (n=5, 50.00%), the median quality of life was 2 in the life was distressing range, and the median effectiveness was 4, in the effective range. Bortezomib, Cyclophosphamide, Dexamethasone was taken by 5 participants with AL amyloidosis (50.00%). The median quality of life was 3 in the life was a little distressing range, and the median effectiveness was 3, in the moderately effective range.

Table 5.16: Summary of treatments AL amyloidosis

Treatment summary	Melphalan and Dexamethasone	Cyclophosphamide, Thalidomide and Dexamethasone	Lenalidomide and Dexamethasone	Melphalan, Bortezomib, and Dexamethasone	Pomalidomide and Dexamethasone	Bortezomib, Cyclophosphamide, Dexamethasone	Dexamethasone and Rituximab	Autologous stem cell
Number (n=10)	5	4	3	1	1	5	1	2
Percent	50.00	40.00	30.00	10.00	10.00	50.00	10.00	20.00
Treatment status	Ongoing (2) Stopped early (1) Completed as planned (2)	Ongoing (1) Stopped early (2) Completed as planned (1)	Ongoing (1) Stopped early (2)	Completed as planned (1)	Ongoing (1)	Ongoing (2) Stopped early (1) Completed as planned (2)	Stopped early (1)	Completed as planned (2)
Median quality of life	2 Life was distressing	3 Life was a little distressing	2 Life was distressing	2 Life was distressing	5 Life was good	3 Life was a little distressing	2 Life was distressing	2.5 Life was distressing to a little distressing
Median effectiveness	4 Effective	2.5 Somewhat to moderately effective	2 Somewhat effective	3 moderately effective	4 Effective	3 moderately effective	2 Somewhat effective	5 Very effective
No side effects	0	0	0	0	0	0	0	0
Infection risk/neutropenia	4	1	3	0	1	3	1	1
Fatigue	4	3	3	1	0	5	1	2
Joint or muscle pain	3	1	2	1	0	2	0	0
Low platelets	1	1	1	1	0	1	0	0
Hair loss,	2	1	1	1	0	2	0	1
Anaemia	2	1	2	1	0	2	0	0
Mood swings	3	3	2	1	0	2	1	0
Swelling in your hands and feet	1	2	1	0	0	1	0	0
Trouble sleeping	3	1	1	1	0	2	1	0
Constipation	2	1	3	0	1	4	1	0
Numbness or tingling in fingers and toes	3	1	1	1	0	2	0	0
Dizziness or light-headed	4	2	2	1	0	3	0	0
Skin rash	1	1	2	1	0	2	0	0
Changes in taste and smell	3	1	2	1	0	0	0	0
Fever or chills	2	0	1	1	0	1	0	0
Nausea or vomiting	2	1	1	1	0	0	0	1
Headache	2	1	1	1	0	1	0	0
Diarrhoea	1	0	0	1	0	0	0	0
Heartburn	1	0	1	0	0	1	0	0
Loss of appetite	0	0	0	0	0	0	0	2

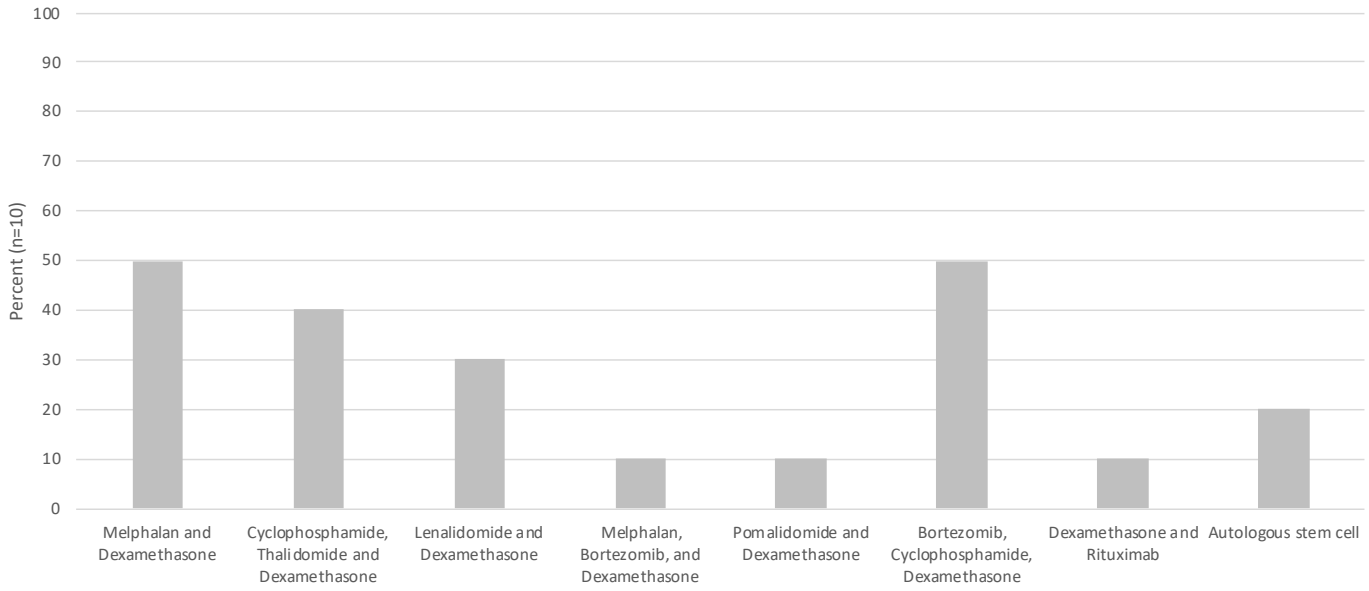


Figure 5.15: Summary of treatments AL amyloidosis

Surgery

In the online questionnaire, participants noted which surgeries they had for the treatment of amyloidosis, excluding biopsies.

There were five participants that had surgery, four participants had a single surgery for amyloidosis, and one patient had four or more surgeries. The types of surgeries that participants had include pacemaker related surgeries, liver transplant, defibrillator fitting, and carpal tunnel surgery (Table 5.17).

Table 5.17: Summary of surgeries

Surgery overview	Detail	Number
Number had surgery	-	5
Number of surgeries per participant	1 surgery	4
	4 or more	1
Type of surgery	Liver transplant	1
	Pacemaker	2
	Defibrillator fitted	1
	Carpal tunnel surgery	1

Lifestyle changes since diagnosis

Participants selected from a list the lifestyle changes they had made since being diagnosed with amyloidosis.

As a follow-up question (within the questionnaire), participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great').

Another follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective).

Nearly half of the participants made no lifestyle changes (n=13, 46.43%). The most common lifestyle changes were exercise (n=12, 42.86%), and diet (n=9, 32.14%) (Table 5.18, Figure 5.16).

Table 5.18: Lifestyle changes

Lifestyle changes	Number (n=28)	Percent
No lifestyle changes	13	46.43
Exercise	12	42.86
Diet	9	32.14
Reduced Alcohol	1	3.57
Quit smoking	1	3.57

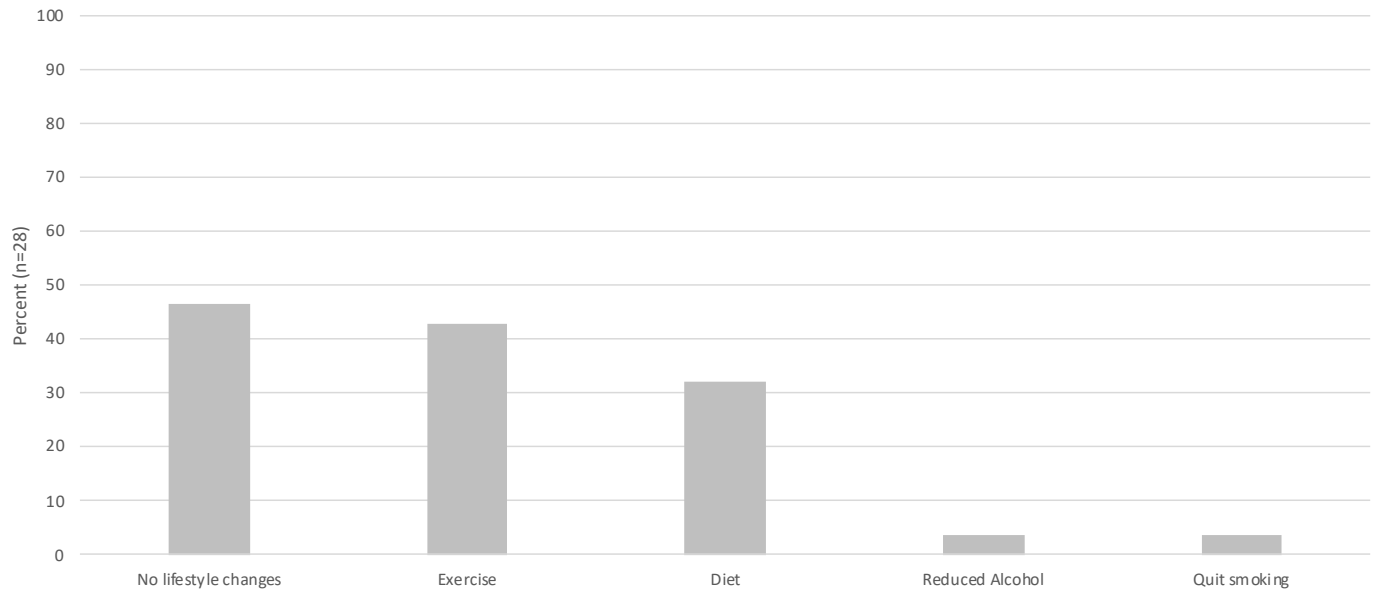


Figure 5.16: Lifestyle changes

Complementary therapies

In the online questionnaire, participants noted the complementary therapies that they used. In particular, they noted their experience of relaxation techniques, massage therapy, acupuncture, dietary supplements, homeopathy, and naturopathy.

As a follow-up question (within the questionnaire), participants were asked to rate their quality of life on a scale of 1 to 7, while using each specific treatment (with 1 being 'Life was very distressing and 7 being 'Life was great').

Another follow-up question was asked in relation to how effective the participant felt the treatment was on a scale of 1 to 5 (with 1 being ineffective and 5 being very effective).

There were 24 participants (85.71%) that used some form of complementary therapies to manage their amyloidosis.

The most common complementary therapies used were exercise (n=18, 64.29%) and dietary supplements (n=13, 46.43%), and for ATTR-cardiac participant, half weighed themselves daily (n=9, 50.00%) (Table 5.19).

The median quality of life for the most common complementary therapies are as follows: the median for exercise was 4.5, in the life was average to good range, the median quality of life for supplements was 3, in the life was a little distressing range, and the median quality of life for daily weighing was 4, in the life was average range.

The median effectiveness for exercise, and daily weighing was 3, in the moderately effective range. The median effectiveness for supplements was 2, in the somewhat effective range.

Table 5.19: Complementary therapies summary

Complementary therapies	Massage therapy	Acupuncture	Exercise	Supplements	Mindfulness or relaxation	Homeopathy	Naturopathy	Diet (fluid intake steady/limited salt intake (ATTR only n=18)	Daily weigh (ATTR only n=18)
Number (n=28)	6	2	18	13	7	1	1	8	9
Percent	21.43	7.14	64.29	46.43	25.00	3.57	3.57	44.44	50.00
Median quality of life	3.5 Life was a little distressing to average	4.5 Life was average to good	4.5 Life was average to good	3 Life was a little distressing	4 Life was average	4 Life was average	5 Life was good	3.5 Life was a little distressing to average	4 Life was average
Median effectiveness	4 Effective	3.5 Moderately effective to effective	3 Moderately effective	2 Somewhat effective	3 Moderately effective	2 Somewhat effective	2 Somewhat effective	3 Moderately effective	3 Moderately effecti

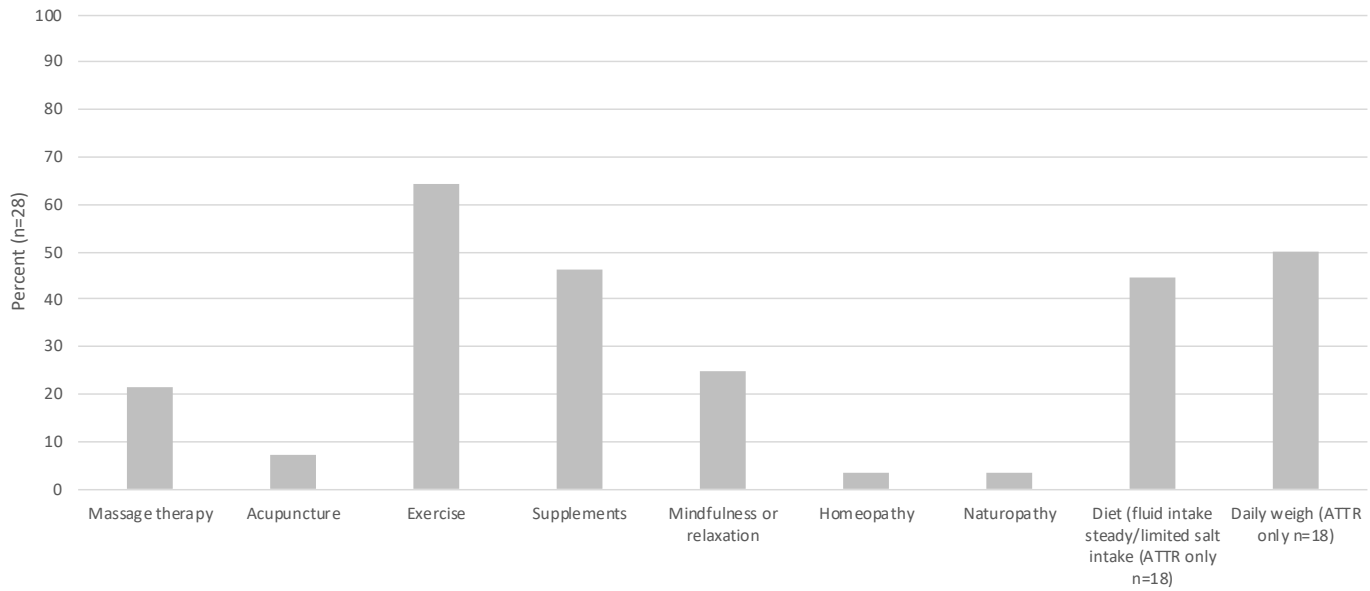


Figure 5.17: Complementary therapies

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion.

There was a total of 26 participants (92.86%) that had discussions about clinical trials, either by bringing up the topic themselves (n=5, 17.86%) or their doctor bringing up the topic (n=21, 75.00%) (Table 5.20, Figure 5.18).

Table 5.20: Discussions about clinical trials

Clinical trial discussions	Number (n=28)	Percent
I brought up the topic of clinical trials with my doctor for discussion	5	17.86
My doctor brought up the topic of clinical trials for discussion	21	75.00
No one has ever spoken to me about clinical trials	2	7.14

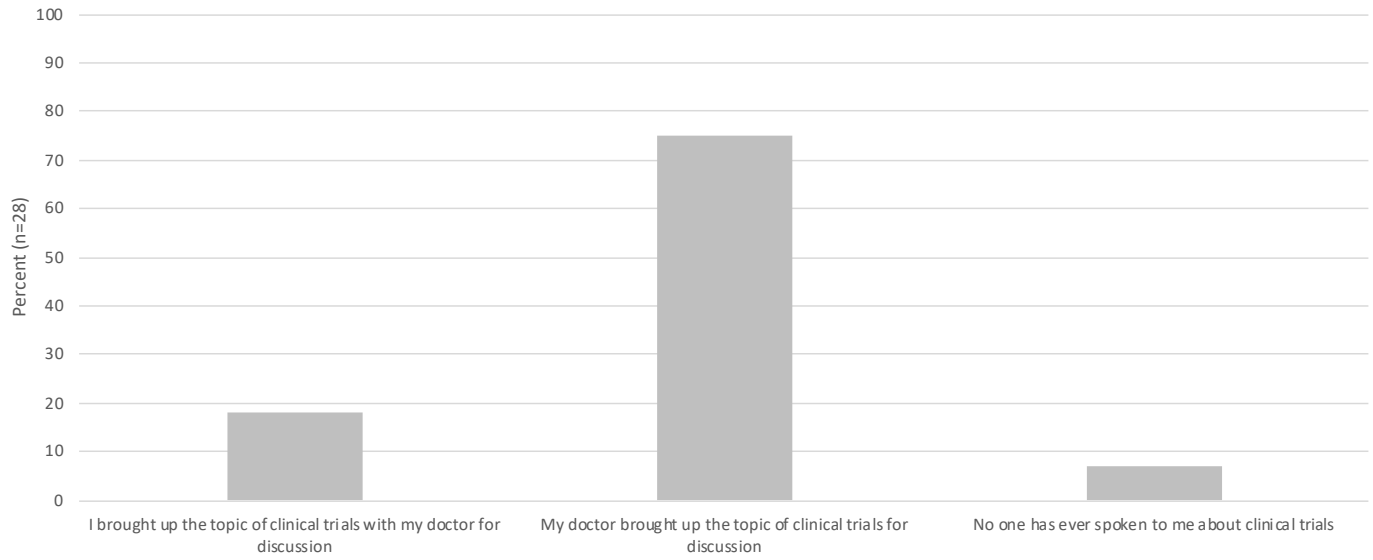


Figure 5.18: Discussions about clinical trials

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part.

There was a single participant (3.57%) who had taken part in a clinical trial, and 22 (78.57%) who would like to take part in a clinical trial if there was a suitable one (Table 5.21, Figure 5.19).

Table 5.21: Clinical trial participation

Clinical trial participation	Number (n=28)	Percent
I have not participated in a clinical trial and do not want to	5	17.86
I have not participated in a clinical trial but would like to if there is one for me	22	78.57
I have participated in a clinical trial	1	3.57

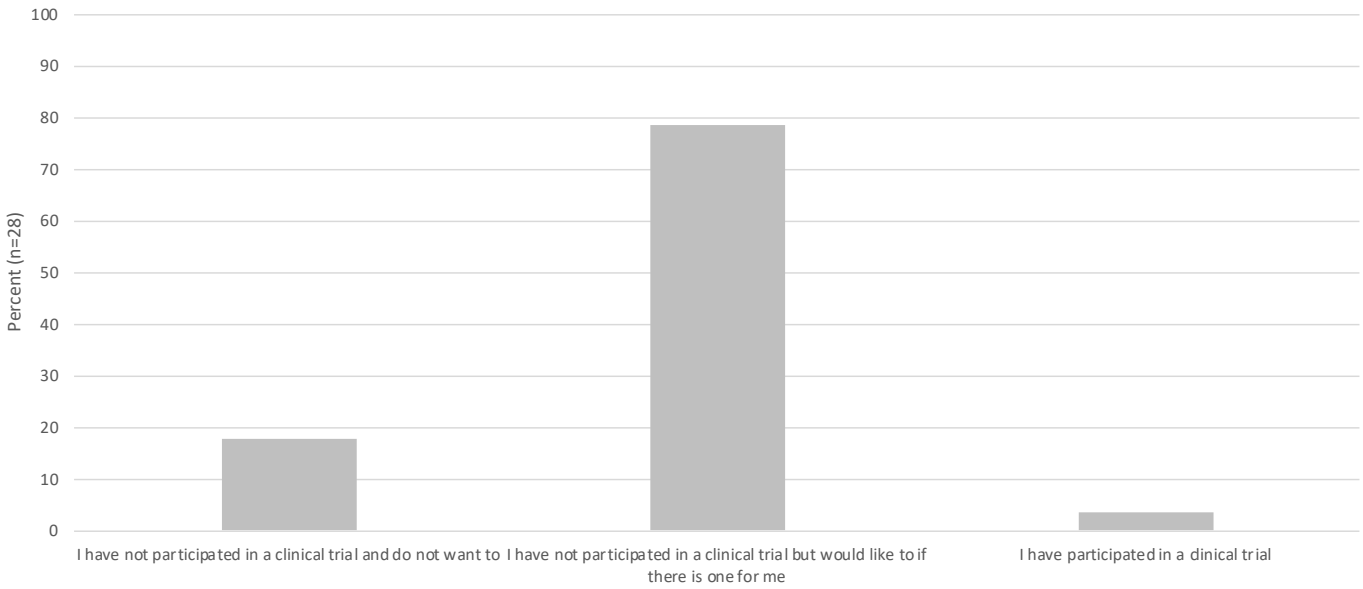


Figure 5.19: Clinical trial participation

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common description of mild side effects was in relation to a specific symptom as an example (n=19, 52.78%). The most common specific side effects given as an example was fatigue and/or tiredness (n=7, 19.44%) followed by diarrhoea (n=4, 11.11%). Another description of mild side effects was those that can be self-managed and do not interfere with daily life (n=15, 41.67%).

The general population (19.44%) described mild side effects as fatigue and/or tiredness, while participants in *Regional or remote* subgroup did not describe this at all (0.00%).

Participants in the subgroups *Aged 75 or older* (25.00%) and *Female* (21.43%) described mild side effects as diarrhoea more frequently than the general population (11.11%), while those in subgroups *Aged 55 to 64* (0.00%), *Regional or remote* (0.00%), and *Mid to low SEIFA* (0.00%) did not describe this at all.

Overall participants in the subgroups *Aged 75 or older* (87.50%) and *Trade or high school* (64.29%) described a specific side as an example more frequently than the general population (52.78%), while participants in the *Carer* (37.50%), and *Aged 55 to 64* (25.00%) subgroups described this less frequently.

Participants in the subgroups *AL amyloidosis* (60.00%), *Aged 55 to 64* (62.50%), *University* (64.29%) and *Higher SEIFA* (52.00%) described mild side effects as those that can be self-managed and do not interfere with daily life more frequently than the general population (41.67%) while those in the subgroups *Trade or high school* (28.57%), *Mid to low SEIFA* (18.18%), *Aged 65 to 74* (26.32%), and *Carer* (25.00%) described this less frequently.

Example provided to describe mild side effects

Mild side effects is probably tiredness because as soon as you lie down, as a mild side effect immediately, you feel better and I think with that, it has a bit to do with the blood pressure which then goes up and then I might sleep for half an hour or an hour or something and you get up and it's okay. I'd say in the mild effects, I'd say there's fatigue, a little bit of tiredness. Participant 001AL

A headache maybe, a bit of nausea, maybe a bit of constipation, just something that you wouldn't normally have in everyday living basically whereas for severe ones would be like absolutely ill, really, really ill. Participant 001ATR

It's a bit like the dizziness from one of those drugs as I've-- Combined with the heart, you know you just can't leap up out of the chair. There's no way in the world that you're going to go walking up a mountain or those sort of things. Participant 003ATR

Self-managed/Do not interfere with life

Mild, is just so that I can continue on with your life, but yes, it's an inconvenience, so I guess it's mild. Participant 001ALX

I think everything that I had I would probably term mild because I could cope with them. I didn't feel I needed any additional medication to prevent sickness or diarrhoea or things like that. They were all manageable. I think mild side effects to me are manageable and hopefully, they're relatively short term. Participant 002AL

It's inconvenient, but I'm able and understand how to control it. Participant 001AL

Fatigue/tiredness

Just means that by mid-afternoon I have tendency to curl up in a ball on the couch and go to sleep. Yes. Participant 004ATR

For me, for example, a mild side effect is I can walk up a flight of stairs but when I get to the top, I'll just literally stop for two or three seconds and then carry on doing what I'm doing. Participant 015ATR
Well, as you described, things that I can cope with, day-to-day living, limitations on what I can do, tiredness. Participant 006AL

Diarrhoea

Can I also probably put in there, in the mild, I had constant diarrhoea and constant gas problems. That's been virtually constant forever since the diagnosis. Again, sometimes the bowel movement becomes urgent, which can be very inconvenient, of course, if you're doing things. I control this with Imodium. Participant 001AL

I don't know the answer really to that because for NAME HUSBAND, one of the side effects of just about every drug he is on is diarrhoea, and the diarrhoea is part of his disease right from the very beginning. Participant 002CA

My bowels as I said, over the last few months, have been quite loose, and a doctor has been giving me- a specialist has been giving me some tablets for that. Participant 010ATR

Table 5.22: Description of mild side effects

Description of mild side effects	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes mild side effects giving the specific example of fatigue/tiredness	7	19.44	3	16.67	5	20.00	2	20.00	2	25.00	4	18.18	3	21.43	0	0.00	7	25.93
Participant describes mild side effects giving the specific example of diarrhoea	4	11.11	1	5.56	3	12.00	2	20.00	1	12.50	1	4.55	3	21.43	0	0.00	4	14.81
Participant provides a specific side effect as an example	19	52.78	10	55.56	15	60.00	6	60.00	3	37.50	13	59.09	6	42.86	4	44.44	15	55.56
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	15	41.67	7	38.89	11	44.00	6	60.00	2	25.00	9	40.91	6	42.86	4	44.44	11	40.74

Description of mild side effects	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes mild side effects giving the specific example of fatigue/tiredness	7	19.44	2	25.00	4	21.05	1	12.50	3	21.43	2	14.29	2	18.18	5	20.00
Participant describes mild side effects giving the specific example of diarrhoea	4	11.11	0	0.00	2	10.53	2	25.00	1	7.14	2	14.29	0	0.00	4	16.00
Participant provides a specific side effect as an example	19	52.78	2	25.00	10	52.63	7	87.50	9	64.29	7	50.00	5	45.45	14	56.00
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	15	41.67	5	62.50	5	26.32	4	50.00	4	28.57	9	64.29	2	18.18	13	52.00

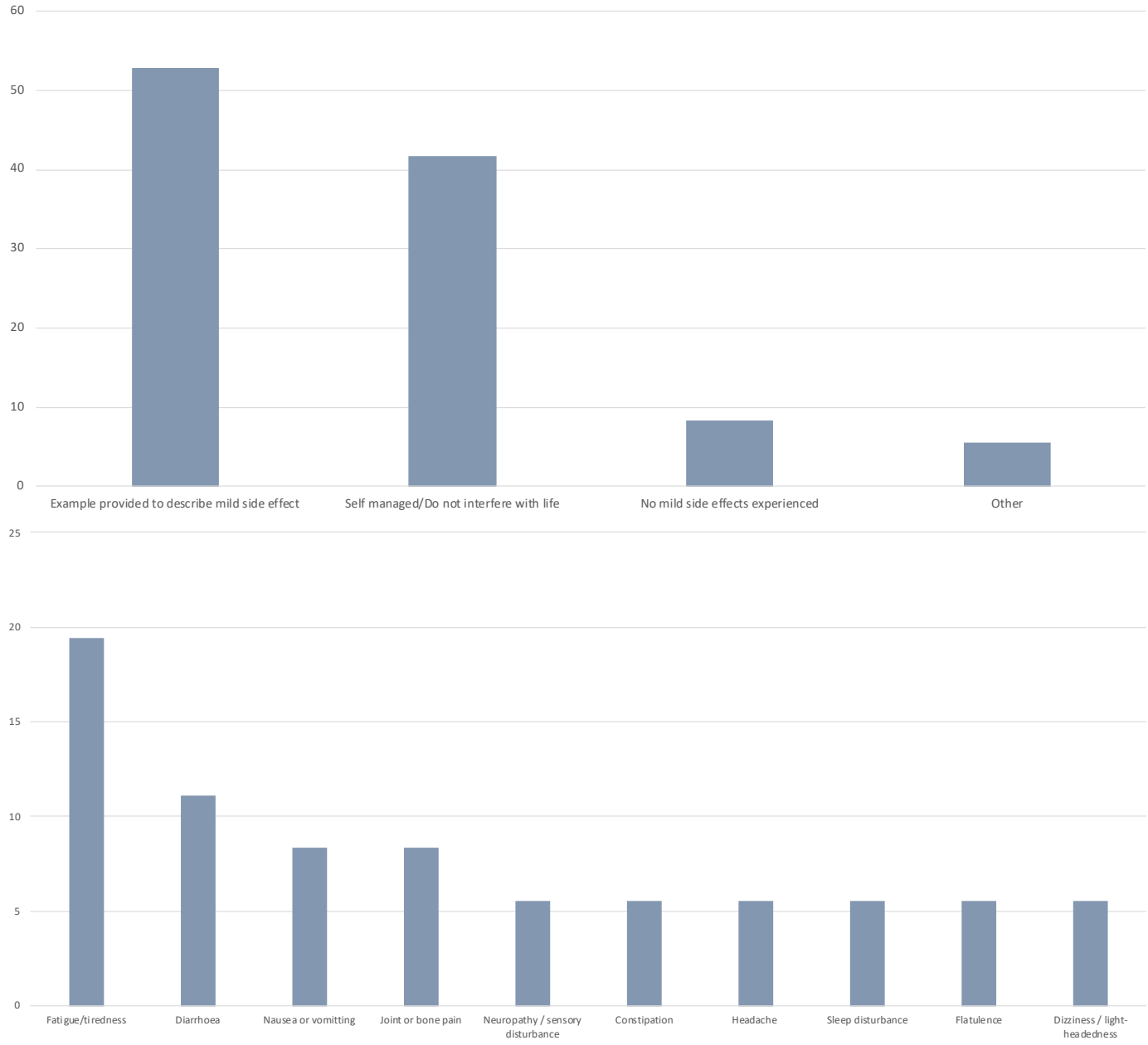


Figure 5.20: Description of mild side effects

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects given was a specific side effect given as an example (n=17, 47.22%). The most common specific side effect given was pain (n=6, 16.67%), followed by neuropathy/sensory disturbance (n=4, 11.11%) and nausea or vomiting (n=4, 11.11%). Other descriptions of severe side effects included those that impact everyday life/ability to conduct activities of daily living (n=12, 33.33%). Four participants described coping with all side effects (11.11%).

In relation to subgroup variations, participants in the ATTR-cardiac (5.56%) subgroup described severe side effects as pain less frequently than the general population (16.67%), while those in the subgroups *AL amyloidosis* (50.00%) and *University* (28.57%) described this more frequently. Participants in the *Carer* (0.00%) subgroup did not describe this at all.

Participants in the *Regional or remote* (22.22%) and *University* (21.43%) subgroups described severe side effects as neuropathy more frequently than the general population (11.11%), while those in the *Carer* (0.00%), and *Female* (0.00%) subgroups did not describe this at all.

Participants in the *Regional or remote* subgroup described severe side effects as nausea or vomiting more frequently (22.22%) than the general population (11.11%).

Overall, participants in the subgroups *AL amyloidosis* (60.00%), *Aged 55 to 64* (62.50%), and *Regional or remote* (66.67%) described severe side effects as a specific side effect more frequently than the general population (47.22%) while those in the subgroup *Aged 75 or older* (25.00%) describe this less often.

Participants in the subgroups *Aged 55 to 64* (50.00%), *Regional or remote* (44.44%), and *Mid to low SEIFA* (45.45%) described severe side effects as those that impact everyday life/ability to conduct activities of daily living more frequently than the general population (33.33%) while those in the *Aged 75 or older* subgroup (12.50%) described this less frequently.

Participants in the *Aged 75 or older* (37.50%), and *Trade or high school* (28.57%) subgroups described coping with all side effects more frequently than the general population (11.11%), while those in the *Carer* (0.00%), *Aged 55 to 64* (0.00%), *University* (0.00%), and *Regional or remote* (0.00%) subgroups did not describe this at all.

Example provided to described severe side effect

I have-- What do you call it? The skin--Paraesthesia and that's on the chest. Again, that ranges from mild to sometimes quite severe in the sense that it's like jabs. It feels like jabs in the chest, but I've had that virtually all the time. It's like an itchy and stabbing skin thing. Participant 001AL

For instance, we have Dex. He was on, I mentioned, dexamethasone. At one stage, I was ready to divorce him because it actually changed his personality. Participant 003CA

When they get to a joint like a knee, mainly my knees, where the arteries and veins narrow, they dam up, and I got the most tremendous pain in my knees, hospitalized, couldn't move, couldn't stand up, couldn't do anything. That was severe pain. Participant 005AL

Impact everyday life/conduct daily living

Well, as you mentioned there, I couldn't continue with my normal life. It put me out of work and possibly admitted to hospital. Participant 001ALX

Severe where it gets a problem or something that becomes much bigger, and it becomes a roadblock. If he's too sick to be doing something. If it interferes with the day to day running of your life a lot, then to me that's more severe. Participant 003CA

The severe side effects where it definitely compromises your life to some degree. That would be painful, or it compromised a particular bodily function, so pain plus loss of function. Haemorrhoids definitely ended up in that category, difficult sitting, difficult making bowel movement, et cetera. The discomfort was definitely in the severe or significant. The neuropathy, at times, got like that, not often but from time to time. Participant 004AL

Coped with all side effects/Had to

Well, I could cope with them, it was just that anybody around me couldn't cope with me, that's the dexamethasone. Participant 002ALX

Like if I had it in my heart or something like that, that would be very disturbing, but I guess I would cope with it because I'm the sort of person who thinks, if you've got that you just cope with it. If they told me there's no treatment, well, I guess I'd accept it and just think that's the way it is.
. Participant 017ATR

Well, I coped with them all. I thought one of the severe side effects was weight loss. I guess I lost about 20 kilos. Yes, I don't think I had any real severe side effects. Participant 017

Pain

That might mean seeking help whether it's for like the mental health side of things or relief for sickness or diarrhoea or pain. Participant 002AL

Side effects like very bad pain in your body, various places. Participant 003AL

The severe side effects where it definitely compromises your life to some degree. That would be painful or it compromised a particular bodily function, so pain plus loss of function. Participant 004AL

Neuropathy/Sensory disturbance

The skin-- Paresthesia and that's on the chest. Again, that ranges from mild to sometimes quite severe in the sense that it's like jabs. Participant 001AL

The neuropathy, at times, got like that, not often but from time to time. Participant 004AL

That's like the stage where I am now with different things, with the neuropathy, my shortness of breath. My eyes, I've got problems with my eyes. My feet, my hands, I've got the carpal tunnel in my hands really bad. In my feet, I've got no feeling in my hands or my feet. In my mouth, the left side of my face. I've got no taste, no smell. It's all gone. Participant 009ATR

Nausea or vomiting

I think that when once he started chemotherapy, severe [clears throat] side effects were nausea and not being able to eat. In fact, not totally not able to eat but I had to choose pretty carefully about what I prepared for food. Participant 001CA

You have an ability to cope with things and if I felt that I was not able to cope with the side effects, then I would probably label it as a severe side effect. That might mean seeking help whether it's for like the mental health side of things or relief for sickness or diarrhoea or pain. Participant 002AL

Again, nausea, aches, pains, not being able to see straight, that sort of stuff, yes. Stuff that would-- for instance, under the mild side effects I start working-- I'm back at work three days a week part time so I can deal with that. Severe side effects I wouldn't be doing all that, so yes. Participant 004ATR

Table 5.23: Description of severe side effects

Description of severe side effects	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes severe side effects giving the specific example of pain	6	16.67	1	5.56	6	24.00	5	50.00	0	0.00	5	22.73	1	7.14	2	22.22	4	14.81
Participant describes severe side effects giving the specific example of neuropathy/sensory disturbance e.g. tingling or numbness	4	11.11	2	11.11	4	16.00	2	20.00	0	0.00	4	18.18	0	0.00	2	22.22	2	7.41
Participant describes severe side effects giving the specific example of nausea or vomiting	4	11.11	2	11.11	3	12.00	1	10.00	1	12.50	2	9.09	2	14.29	2	22.22	2	7.41
Participant provides a specific side effect as an example	17	47.22	8	44.44	14	56.00	6	60.00	3	37.50	11	50.00	6	42.86	6	66.67	11	40.74
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	12	33.33	7	38.89	9	36.00	3	30.00	2	25.00	8	36.36	4	28.57	4	44.44	8	29.63
Participant describes coping with all side effects (because you have to or it's all that they've known)	4	11.11	2	11.11	3	12.00	2	20.00	0	0.00	3	13.64	1	7.14	0	0.00	4	14.81

Description of severe side effects	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes severe side effects giving the specific example of pain	6	16.67	1	12.50	4	21.05	1	12.50	2	14.29	4	28.57	1	9.09	5	20.00
Participant describes severe side effects giving the specific example of neuropathy/sensory disturbance e.g. tingling or numbness	4	11.11	1	12.50	2	10.53	1	12.50	1	7.14	3	21.43	1	9.09	3	12.00
Participant describes severe side effects giving the specific example of nausea or vomiting	4	11.11	1	12.50	2	10.53	1	12.50	1	7.14	2	14.29	1	9.09	3	12.00
Participant provides a specific side effect as an example	17	47.22	5	62.50	10	52.63	2	25.00	6	42.86	8	57.14	5	45.45	12	48.00
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	12	33.33	4	50.00	7	36.84	1	12.50	6	42.86	4	28.57	5	45.45	7	28.00
Participant describes coping with all side effects (because you have to or it's all that they've known)	4	11.11	0	0.00	1	5.26	3	37.50	4	28.57	0	0.00	1	9.09	3	12.00

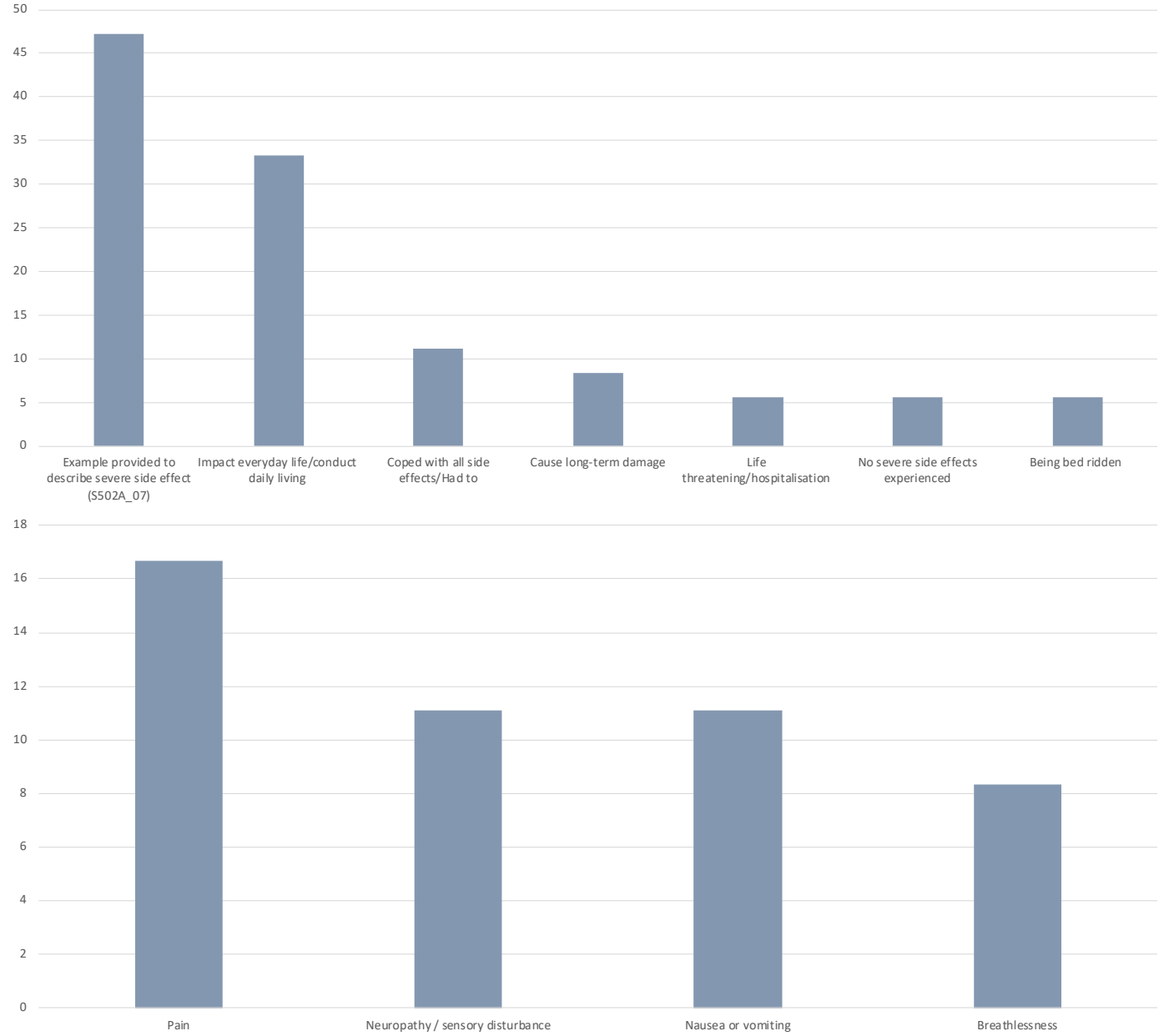


Figure 5.21: Description of severe side effects

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common theme described was adhering as per the advice of their specialist or as long as its prescribed (n=16, 44.44%). Participants also reported not giving up on any treatment (n=6, 16.67%) and adhering to treatment for a specific amount of time (n=5, 13.89%).

In relation to subgroup variations, participants in the subgroups *ATTR-cardiac* (61.11%), *All cardiac* (56.00%), *Aged 75 or older* (75.00%) and *Trade or high school* (64.29%) described adhering to treatment as per the advice of their specialist or for as long as prescribed more frequently than the general population (44.44%), while those in the *Regional or remote* (22.22%) subgroup described this less frequently. No participants in the *Carer* (0.00%) subgroup described this at all.

Participants in the *AL amyloidosis* (30.00%), and *Trade or high school* (35.71%) subgroups described not giving up on any treatment more frequently than the general population (16.67%), while those in the *Carer* (0.00%), and *Aged 55 to 64* (0.00%) subgroups did not describe this at all.

There were no participants in the *Carer* subgroup that described adhering to treatment for a specific amount of time (0.00%), compared to the general population (13.89%).

Advice of specialist/as prescribed

Again, it's on the advice of a haematologist who said, 'It will take a little while. We need to see this for at least four weeks, six weeks, and then have a look and whatever it is.' I'm guided by the time advised, but I've always been happy to continue even though you don't feel all that flash, on the basis that it has been advised to at least to go a couple of months to see what it's like. Participant 001AL

I'm again guided by the physician. In my particular case, I'd go in and explain the side effects, we try something different, I go in again. Eventually, he decided this was enough, we can't go any further. We're going to try something else. Participant 001ALX

Well, I would stick with it basically and discuss it with-- I wouldn't make the decision by myself I would discuss it with my practitioners. No, I'm not a self-prescriber or self-treater. I work with the people who have greater knowledge and skills than I do. Participant 001ATR

Has not given up on any treatment

I've never been in that situation, so I really don't know. I can't answer that one. I've never stopped a medication other than on doctor's advice. Up until 20 years ago, I'd probably never in my life had very much medication. Participant 002ALX

I don't give up. I keep going until I'm told and take it. Participant 005AL

I've only had experience with the Velcade and I stayed with the whole course, 16 weeks. Even after six weeks, the blood markers on the light chains indicated that it was working and so that made perfect sense to continue using it right to the end. I dare say that I would do exactly the same with a new treatment that we're going to start whenever the medication arrives. Participant 003AL

Specific amount of time

Two to four weeks is what I would do. If it's severe, then it's less than two weeks. If it's tolerable between mild and severe, I'll only give it two weeks and see how it takes, because some medications do take longer. Some medications would take more than a month until it will take effect. If I read the material that says what happened, and the case studies out there are patients or people who are taking their medications and their input into consideration of how long I should stay on it. Participant 002ATR

With the green tea, I only stuck with it for one week regardless of whether it would've been beneficial in my life. I guess that's the only one I can go on at present because, like the Difluzole when they put me on that, we did a blood test within the first month to make sure that it didn't have some side effects against my kidney or it was giving me some side effect that was more noticeable like more drowsiness or more dizziness or something like that. I guess you're probably going to rely a lot on the person who's prescribing it. That you have a bit of a follow-up. Let's say one month would be about the maximum you want to stay on it before you did some checks to see if it was affecting you. Participant 003ATR

It was a couple of months for both Velcade and Revlimid. I'm no physician nor a doctor or MD specialist, but if you've been taking it for 8 to 10 weeks and nothing's happening, you've got to say, 'That's long enough.' That was the benchmark that NAME CLINICIAN and I agreed with, 8 to 10 weeks.

You may say as a specialist you may know more quickly than that, but as a non-specialist then I wouldn't know, but I being-- if you aren't seeing any reaction after 10 weeks, you have to say, 'Something's not right.' Participant 004AL

Table 5.24: Adherence to treatment

Adherence to treatment	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	16	44.44	11	61.11	14	56.00	5	50.00	0	0.00	10	45.45	6	42.86	2	22.22	14	51.85
Participant describes not giving up on any treatment	6	16.67	3	16.67	5	20.00	3	30.00	0	0.00	5	22.73	1	7.14	2	22.22	4	14.81
Participant describes adhering to treatment for a specific amount of time: Total	5	13.89	4	22.22	5	20.00	1	10.00	0	0.00	3	13.64	2	14.29	1	11.11	4	14.81

Adherence to treatment	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	16	44.44	3	37.50	7	36.84	6	75.00	9	64.29	7	50.00	5	45.45	11	44.00
Participant describes not giving up on any treatment	6	16.67	0	0.00	4	21.05	2	25.00	5	35.71	1	7.14	2	18.18	4	16.00
Participant describes adhering to treatment for a specific amount of time: Total	5	13.89	1	12.50	2	10.53	1	12.50	2	14.29	3	21.43	1	9.09	4	16.00

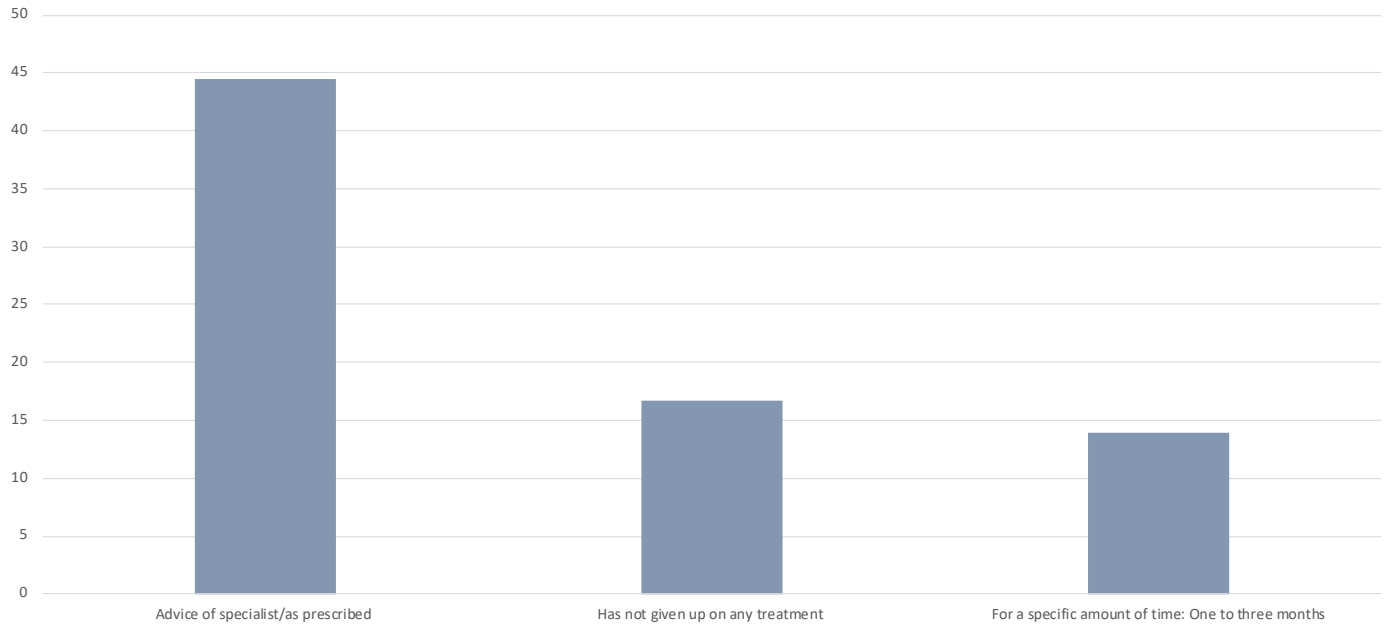


Figure 5.22: Adherence to treatment

What needs to change to feel like treatment is effective

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 11 participants (30.56%) was needing to experience evidence of stable disease or no disease progression. This was followed by needing to experience an improvement in general wellbeing (n=9, 25.00%).

In relation to subgroup variations, participants in the *ATTR-cardiac* (16.67%), and *Mid to low SEIFA* (9.09%) subgroups described needing to experience evidence of stable disease or no disease progression less frequently than the general population (30.56%), while those in the subgroups *Regional or remote* (44.44%), and *AL amyloidosis* (60.00%) described this more frequently.

Participants in the subgroups *AL amyloidosis* (50.00%), *Aged 75 or older* (37.50%), and *Mid to low SEIFA* (36.36%) described needing to experience an improvement in general wellbeing more frequently than the general population (25.00%), while those in the subgroups *Aged 55 to 64* (12.50%), and *Carer* (12.50%) described this less frequently.

Evidence of stable/no disease progression

You feel better. Some of these questions I hear them often, but they're very difficult to answer because we're guided by what our doctors tell us and we don't have any knowledge ourselves to be able to decide if yes, yes, oh, this is good or bad. We're guided by what the doctor tells us. Participant 001ALX

It has to actually alter the condition for which it's being prescribed, which in the case of the amyloid and test too, you have to see an improvement in the various blood tests in that and in general health, and things like antibiotics, you think the problem has to go away or it hasn't been successful. To me, so long as the anticipated improvement is achieved or close to, then I consider the treatment has been successful. Participant 002ALX

Well, I'll keep going with it because I think the-- If the echocardiogram and the blood test show that this condition stabilized. The other alternative I would consider is if they established a new drug which would not just keep it stabilized but remove the traces of amyloids that are on my heart. Participant 011ATR

Improvement in general wellbeing (quality of life)

Gauging that is how much can you walk? Walking up. We have three stories at home, so two sets of stairs. How much can I do outside? Things like that. It's general activity level and lethargy, so it's physical, the way you feel and just general well-being. That's how I gauge it. That's what I look for always. Can I keep doing or do at least what I'm doing or more? It does also affect moods. It affects mood. If you're feeling unwell all the time and you're a bit frustrated and things like that, yes, it affects the mood too. Participant 001AL

Certainly, the physical feeling of betterment, which would lead to an overall mental feeling of wellness whatever the treatment would be that I might be on. Participant 003ALX

Just being able to do a bit more. With the Pomalidomide, when I'm on it, I'm not as anxious to get out. You know what I mean? I go to the shops and when someone says, 'Do you want to go for a walk,' and I'll say no, but I just procrastinate a lot. I'll say, 'We'll go here, and we'll do that', but when it really comes to the crunch, I'm more likely to say, 'Unless it's important to both of us or our grandchildren or something--', I'll just say, 'Oh no. I'll just let it go.' Participant 005AL

Table 5.25: What needs to change to feel like treatment is effective

What needs to change to feel treatment is effective	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participants reported needing to experience evidence of stable disease/no disease progression	11	30.56	3	16.67	6	24.00	6	60.00	2	25.00	7	31.82	4	28.57	4	44.44	7	25.93
Participants reported needing to experience an improvement in general wellbeing (quality of life)	9	25.00	3	16.67	6	24.00	5	50.00	1	12.50	6	27.27	3	21.43	2	22.22	7	25.93

What needs to change to feel treatment is effective	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participants reported needing to experience evidence of stable disease/no disease progression	11	30.56	2	25.00	6	31.58	3	37.50	4	28.57	5	35.71	1	9.09	10	40.00
Participants reported needing to experience an improvement in general wellbeing (quality of life)	9	25.00	1	12.50	5	26.32	3	37.50	4	28.57	4	28.57	4	36.36	5	20.00

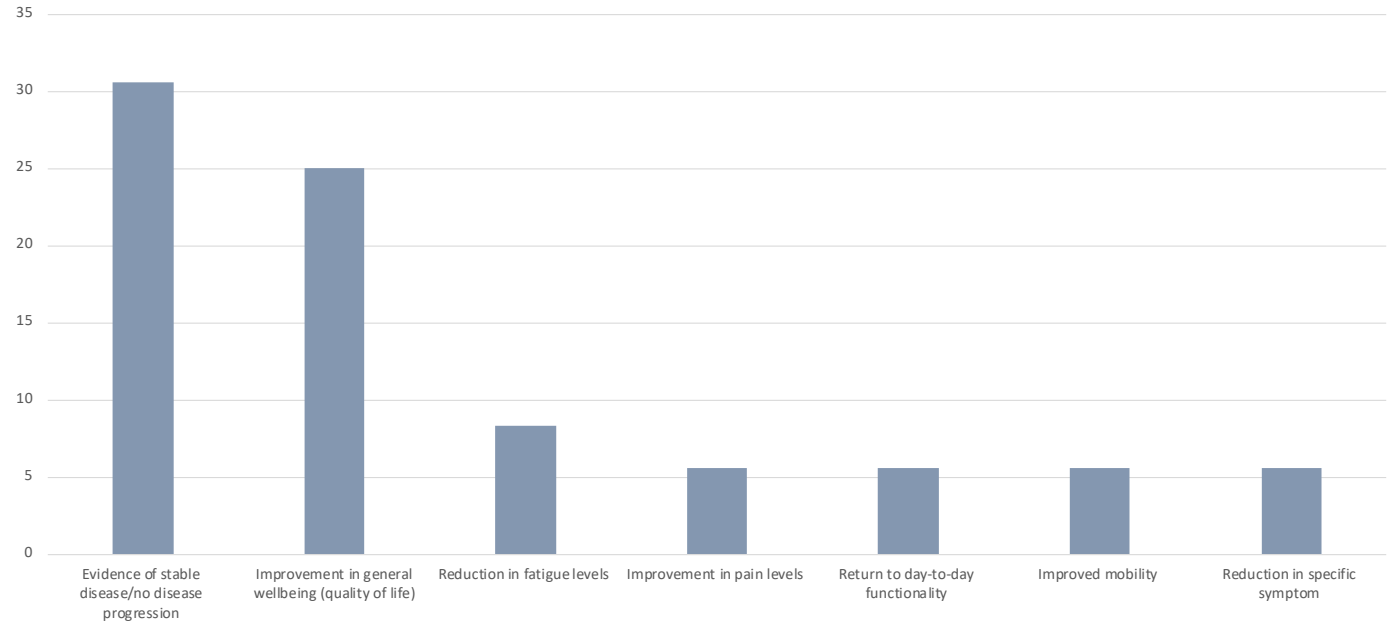


Figure 5.23: What needs to change to feel like treatment is effective

Information needed to be confident in a new treatment

Participants were asked to describe what information would be needed to be confident in a new treatment. The most common response, from 17 participants (47.22%), was needing the advice of their clinician followed by 14 participants (38.89%) needing to know about side effects to feel confident about trying a new treatment. There were 11 participants (30.56%) that reported needing scientific evidence, followed by those who described needing to conduct their own research (n=9, 25.00%); needing to know about efficacy (n=9, 25.00%) and needing to know the overall benefits (n=8, 22.22%).

In relation to subgroup variations, participants in the *Aged 55 to 64* (37.50%) subgroup described needing the advice of their clinician more frequently than the general population (47.22%), while those in *Mid to low SEIFA* (36.36%), *Regional or remote* (22.22%), and *Carer* (37.50%) subgroups described this less frequently.

Participants in the subgroups *University* (50.00%), *Aged 55 to 64* (62.50%) and *75 or older* (50.00%) described needing scientific evidence more frequently than the general population (30.56%), while those in the subgroups *Aged 65 to 74* (26.32%), *Trade or high school* (28.57%) and *Mid to low SEIFA* (27.27%) described this less frequently.

Participants in the *Carer* (12.50%) subgroup described needing to know about efficacy less frequently than the general population (25.00%), while those in the *Aged 75 and older* (9.09%) subgroup described this less frequently.

Participants in the *Carer* (37.50%), *Male* (36.36%), *Trade or high school* (50.00%), and *Mid to low SEIFA* (36.36%) subgroups needing to know about side effects to feel confident about trying a new treatment more frequently than the general population (38.89%), while those in the *University* (14.29%), *Female* (7.14%) subgroups described this less frequently. No participants described this in the *Aged 55 to 64* (0.00%) subgroup.

Participants in the *Regional or remote* (50.00%) subgroup described needing to conduct their own research more frequently than the general population (25.00%), while those in the *Trade or high school* (14.29%), and *Mid to low SEIFA* (9.90%) described this less often.

Participants in the subgroups *Aged 55 to 64* (37.50%), *Female* (35.71%) described needing to know the overall benefits more frequently than the general population (22.22%) while those in the *Regional or remote* (11.11%), *Mid to low SEIFA* (9.09%) subgroups described this less frequently. No participants *Aged 75 or older* (0.00%) described this at all.

Advice of clinician

Just as guided. I have a haematologist now. The haematologist I see, the registrar I see, I have confidence in both of them. What would make me? If somebody told me, 'Look, there's a trial or a new drug or something like that. This, and this, and this is the situation, et cetera,' I'd be totally guided by what they say because I'm really not in a position to make a decision, but I'm happy to try anything, I suppose. Participant 001AL

Well, I would just go by what the specialists tell me. I would take notice of what they say and their recommendations and I would go with it. Participant 010ATR

I need to know that my doctors think it'd be good. I've got to have complete faith in the amyloid clinic as a PA. I've been on two trials for them. They both worked. If they said to me, 'PARTICIPANT, we're going to take you off the Pomalidomide and we're going to try this for you.' No hesitation. Participant 005AL

Side effects

Well, I'd certainly need to know the side effects. I'd certainly need to know because if it came up it was a drug that was going to be trialled and they were trialling it. They started off doing the trial and then one person died, so they took that straight off the thing, so they're the sort of things you need to know. You need to know the possible side effects, the possible number of people that maybe because this is all quite legal stuff anyway, there's only so many they can have in the trials, et cetera. Participant 003ATR

The second set of tests, as I mentioned before, would be the side effects. Some medications have some very benign side effects or very mild. If they were harrowing, then I could put up with them for some time but not forever. Participant 004AL

For instance, if a treatment came available that would dissolve the stuff that's sitting around my heart at the moment, the thing I'd want to know is what is the toxicity of the treatment. Is the treatment likely be do me more damage in another way? Is it going to kill my liver as well as my kidneys stuff like that. We need to get the side effects of the treatment or how they got to trying it out. Participant 004ATR

Scientific evidence e.g. clinical trial results

Personally, I would probably like to have a look at the science and look at some evidence from clinical trials that might have been done, whether they're phase one or phase two trials just to see what the potential benefits of the treatment might be. Me being me, I would probably want to understand a bit about the science. Participant 002AL

I would read a hell of a lot about it. I would sit in NAME CLINICIAN's office and pick his brains until we came to an accord. I would want to know the scientific detail of the treatment. I'd also in my condition want to know why I was being put back on treatment. Participant 002ALX

I guess I'd want to know what the results of the clinical trials were and then normal information that you get about drugs, like what are the chances that it could work for me, what possible side effects could occur, those sorts of things. Participant 011ATR

Own research

Personally, I would look it up. I'm very good with computers so I would seek out as much information as I could. I'd rely on my doctor because clinical trials often have a baseline about what other people have experienced. I would consider my options, and if there was real hope for a better outcome, then I'd most likely go ahead with a clinical trial. I'd most likely go ahead. Participant 006AL

I would do some research myself. I'd also need to know that it wasn't going to adversely impact your quality of life. Again, whether or not I would go back to it would depend on how much good versus bad it was going to do. I'd also have to know that I can afford it, which is an interesting one with these kind of things. Participant 006ATR

I'd have to do some research on it. Talk to different people about the- doctors and my family just to make sure it was something that we- that it's the right direction for us. Participant 009ATR

Efficacy

I think you'd have to be certain of if the treatment that you're on is actually doing what it's designed to do, lowering the light chain levels in your blood and the plasma levels, then you would have to choose a new treatment if it had the same effectiveness but with lesser side effects. Participant 002CA

The likelihood of efficacy. It has a high probability, it's not a low probability for a person with my particular series of issues. That would be the first thing. It's got to have a reasonable chance or that's better than 50:50 chance of being effective and preferably having a long-term effectiveness. Participant 004AL

I'd like to know that there has been something done, or something tested that said whatever that or in RACS or whatever that we've determined that yes it does dissolve the amyloid from around the heart. Participant 004ATR

Benefits of treatment

For me, what would be the advantages of changing the treatment. If wasn't going to be better than what I'm already on and I would discuss it with as I said with a professional that I am dealing with, I wouldn't make the decision. If they advise me that this is a better option than what I was on and explain to me that all and why then, yes, I'd give it a try. Participant 001ATR

I think you'd have to be certain of if the treatment that you're on is actually doing what it's designed to do, lowering the light chain levels in your blood and the plasma levels, then you would have to choose a new treatment if it had the same effectiveness but with lesser side effects. Participant 002CA

I think the benefits and then the side effects. If the side effects outweigh the benefits so that he's not got a good quality of life that would be quite high up there. I think, and where it is on the trial, if it's the first trial and we don't know then what damage is possible. Participant 005CA

Table 5.26: Information needed to be confident in a new treatment

Information needed to be confident in new treatment	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes needing the advice of their clinician	17	47.22	9	50.00	12	48.00	5	50.00	3	37.50	10	45.45	7	50.00	2	22.22	15	55.56
Participant describes needing to know about side effects to feel confident about trying a new treatment	14	38.89	7	38.89	9	36.00	4	40.00	2	25.00	9	40.91	5	35.71	4	44.44	10	37.04
Participant describes needing scientific evidence to feel confident about trying a new treatment	11	30.56	6	33.33	8	32.00	3	30.00	1	12.50	7	31.82	4	28.57	3	33.33	8	29.63
Participant describes needing to conduct their own research to feel confident about trying a new treatment	9	25.00	6	33.33	8	32.00	3	30.00	3	37.50	8	36.36	1	7.14	3	33.33	6	22.22
Participant describes needing to know about efficacy to feel confident about trying a new treatment	9	25.00	4	22.22	6	24.00	2	20.00	2	25.00	6	27.27	3	21.43	4	44.44	5	18.52
Participant describes needing to know the overall benefits to feel confident about trying a new treatment (e.g. versus their current treatment)	8	22.22	3	16.67	5	20.00	3	30.00	2	25.00	3	13.64	5	35.71	1	11.11	7	25.93

Information needed to be confident in new treatment	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes needing the advice of their clinician	17	47.22	3	37.50	9	47.37	4	50.00	7	50.00	7	50.00	4	36.36	13	52.00
Participant describes needing to know about side effects to feel confident about trying a new treatment	14	38.89	5	62.50	5	26.32	4	50.00	4	28.57	7	50.00	3	27.27	11	44.00
Participant describes needing scientific evidence to feel confident about trying a new treatment	11	30.56	3	37.50	4	21.05	4	50.00	4	28.57	5	35.71	3	27.27	8	32.00
Participant describes needing to conduct their own research to feel confident about trying a new treatment	9	25.00	0	0.00	6	31.58	2	25.00	7	50.00	2	14.29	4	36.36	5	20.00
Participant describes needing to know about efficacy to feel confident about trying a new treatment	9	25.00	2	25.00	5	26.32	2	25.00	2	14.29	4	28.57	1	9.09	8	32.00
Participant describes needing to know the overall benefits to feel confident about trying a new treatment (e.g. versus their current treatment)	8	22.22	3	37.50	5	26.32	0	0.00	2	14.29	4	28.57	1	9.09	7	28.00

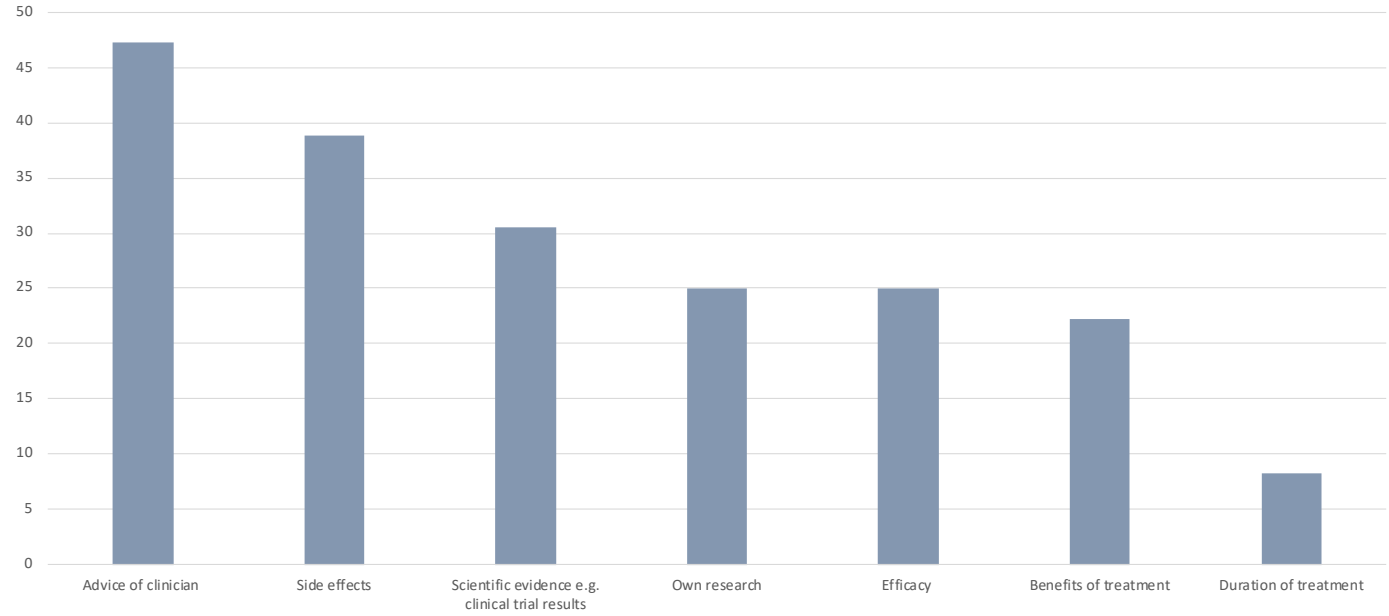


Figure 5.24: Information needed to be confident in a new treatment

Support needed for treatment at home

Participants were asked to describe what support they would need if they were having treatment at home. The two most common responses were participants not needing support (n=8, 22.22%) and needing support from their friends or family (n=8, 22.22%). There were seven participants that reported needing regular check-ups with a GP or nurse (19.44%). This was followed by needing someone to call if they have a question or issue (n=4, 11.11%). Four participants (11.11%) described needing training and education on how to administer treatment.

In relation to subgroup variations, no participants in the *Aged 75 or older* subgroup described not needing support (0.00%), compared to the general population (22.22%).

Participants in the *Mid to low SEIFA* (9.09%) subgroup described needing support from their friends or family less frequently than the general population (22.22%), while those in the subgroups *Trade or high school* (35.71%), *Aged 75 or older* (37.50%), and *AL amyloidosis* (40.00%) described this more frequently. Participants in the *Carer* (0.00%), and *Aged 55 to 64* (0.00%) did not describe this at all.

Participants in the *Mid to low SEIFA* subgroup described needing regular check-ups with a GP or nurse more frequently (36.36%) than the general population (19.44%).

Participants in *Female* subgroup described needing to have someone to call if they have a question or issue more frequently (21.43%) than the general population (11.11%) while no one in the *Regional or remote* subgroup described this (0.00%).

No participants in the *AL amyloidosis* subgroup (0.00%) described needing training and education whereas those in the subgroups *Aged 75 or older* (25.00%) and *Regional or remote* (22.22%) described this more frequently than the general population (11.11%).

Not needing support

Oh, none at all. I'm the one that manages all that so, I don't think-- I keep detailed lists every time the drug regime changes. I make notes every time we see a doctor and I feel quite comfortable doing that. Participant 002CA

It will be the same as the inpatient treatment. I would be having basically in the start weekly blood tests which would include the light chain test. We have a collection point within 2 kilometres of where I live, so that's no problem. I've never been told that I couldn't drive when I went on that treatment and I did ask, and I said, 'No, it's not a problem,' although when I was having it in the first lot my wife used to drop me off at the hospital and sometimes stay there, and then she'd drive me home. If this is at home, there's not even that problem because you don't have to drive on the day that you take them. Really, I don't think I need any additional support at this time. Participant 003AL

I've been taking it home now for around what, three years? I don't need any support. Participant 005AL

Support from family/friends

I don't think I'd need a lot of support. I've got my husband here in terms of someone else in the house, so I'm not alone. My doctors always said, if I have any worries, I can just contact him, call him, email him. I think with that support, and there's obviously support through the NAME CLINIC as well, of course, there is a little support group. I wouldn't feel uncomfortable having a treatment at home that involved a pill or a tablet kind of thing. I don't think I would need much additional support at all. Participant 002AL

I've got the all the support here, I think, I could need with my wife and family here. They're very good with me. Participant 009ATR

I would probably- one of my daughters. I've got three daughters. One of them would be here at the time when I need them, I'm sure. That's about all I need, I think, just for the reassurance, but as I said, I'm not a panicky person. Participant 010ATR

Checked regularly by GP/Nurse

Regular contact by the prescribing doctor or nurse. Participant 001ALX

I went to a new heart guy and he gave me access to a heart nurse. I could ring her anytime if I was worried about my blood pressure or something like that to say just, 'What do you think I should do,' because a couple of times I did need to go to hospital and things. That was terrific because you can't get onto the doctors usually, but you had access to her. She would come to the home and she did some blood tests here and she'd give me different things here. That was great and maybe it was just getting confident with them coming in that they can do the same job. Whereas with the chemo, I didn't feel comfortable with that, so I never had that at home. I always went to the hospital. Participant 012ATR

Yes, and somebody to check-in regularly and that sort of thing, which we have now in amyloidosis. Participant 017ATR

Someone to call (out of hours, 24/7 support)

Someone I can ring up the phone and say, 'NAME, I love NAME HUSBAND but I'm ready to knock his block off.' She'll say, 'Well, what's going on?' and we'd sort it all out. That sort of support is absolutely critical. Participant 003CA

I don't think I'd need a lot of support. I've got my husband here in terms of someone else in the house, so I'm not alone. My doctors always said, if I have any worries, I can just contact him, call him, email him. I think with that support, and there's obviously support through the NAME CLINIC as well, of course, there is a little support group. I wouldn't feel uncomfortable having a treatment at home that involved a pill or a tablet kind of thing. I don't think I would need much additional support at all. Participant 002AL

Well, if you just got to take, I'd want to have a 24-hour contact with somebody, if things weren't going well. Participant 017ATR

Training and education on how to administer treatment

Well, only the fact that you've got to be careful on how many you take I suppose. Some of the treatments I had to deal with at home after like with injecting stuff, you can either get a nurse to come and help you do that, or you'd have to just learn to do it yourself. Participant 003ATR

Well, it's the background from the doctor which I'm going to take with me at home will be there as an information to assist me in that respect, and secondly, and it is for certain people around the home the children, my wife, a friend, people just like that. I need to have their support. Even if is only one person, one person is enough. Participant 005ATR

The only thing I would need is some reference material that I could read up. I would like some data that I could read. Participant 007ATR

Table 5.27: Support needed for treatment at home

Treatment preference – support needed	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes not needing support	8	22.22	4	22.22	7	28.00	3	30.00	1	12.50	6	27.27	2	14.29	2	22.22	6	22.22
Participant describes needing support from their friends or family	8	22.22	4	22.22	6	24.00	4	40.00	0	0.00	5	22.73	3	21.43	2	22.22	6	22.22
Participant describes needing regular check ups with a GP or nurse to feel comfortable: Total (e.g. Various locations)	7	19.44	3	16.67	4	16.00	2	20.00	2	25.00	4	18.18	3	21.43	2	22.22	5	18.52
Participant describes that they would need to have someone to call if they have a question or issue (out of hours, 24/7 support)	4	11.11	2	11.11	3	12.00	1	10.00	1	12.50	1	4.55	3	21.43	0	0.00	4	14.81
Participant describes needing training and education on how to administer treatment	4	11.11	3	16.67	3	12.00	0	0.00	1	12.50	3	13.64	1	7.14	2	22.22	2	7.41

Treatment preference – support needed	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes not needing support	8	22.22	2	25.00	6	31.58	0	0.00	4	28.57	3	21.43	2	18.18	6	24.00
Participant describes needing support from their friends or family	8	22.22	0	0.00	5	26.32	3	37.50	5	35.71	3	21.43	1	9.09	7	28.00
Participant describes needing regular check ups with a GP or nurse to feel comfortable: Total (e.g. Various locations)	7	19.44	2	25.00	4	21.05	1	12.50	2	14.29	3	21.43	4	36.36	3	12.00
Participant describes that they would need to have someone to call if they have a question or issue (out of hours, 24/7 support)	4	11.11	1	12.50	2	10.53	1	12.50	2	14.29	1	7.14	2	18.18	2	8.00
Participant describes needing training and education on how to administer treatment	4	11.11	1	12.50	1	5.26	2	25.00	1	7.14	2	14.29	2	18.18	2	8.00

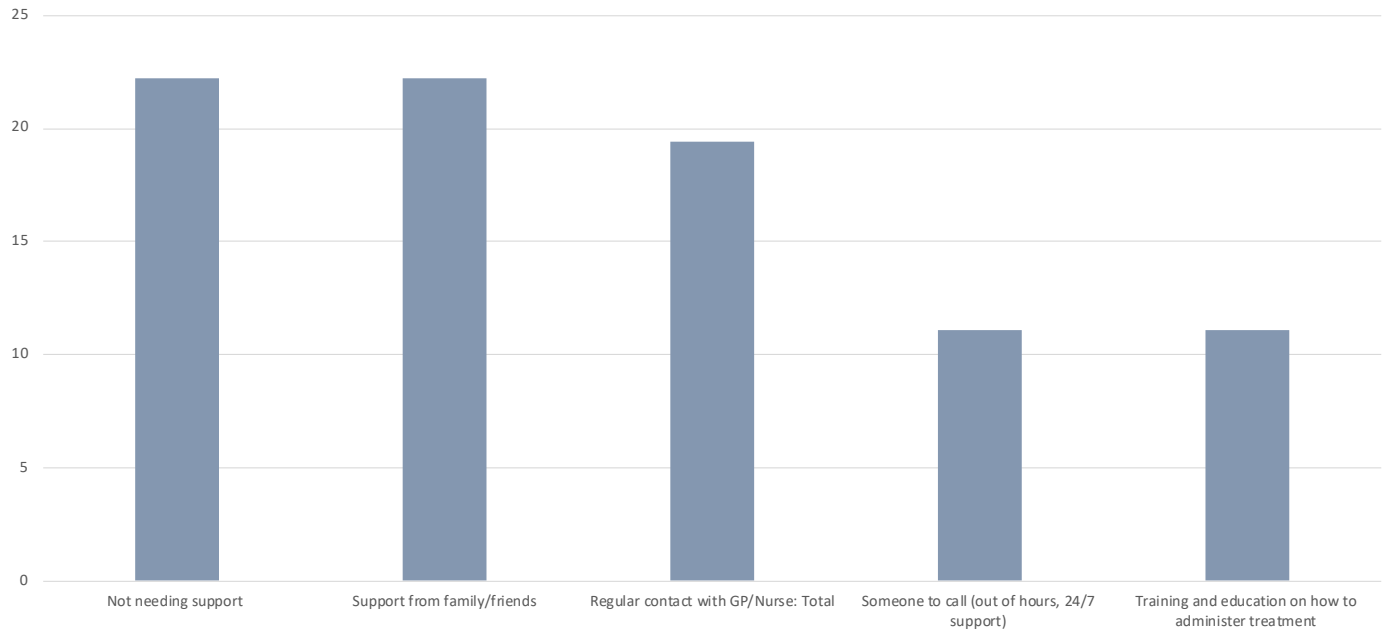


Figure 5.25: Support needed for treatment at home

Section 6

Information and communication

Section 6 Summary: Information and communication

Access to information

- In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 20 participants (55.56%) was through the internet in general. This was followed by books, pamphlets and newsletters (n=15, 41.67%) and information from specific health charities (n=12, 33.33%). There were eight participants (22.22%) that described accessing information through their treating clinician and seven participants (19.44%) that described accessing information through Facebook and/or social media. Other types of information accessed included other patients' experiences (n=4, 11.11%) and primarily through journals or research articles (n=4, 11.11%).

Information that has been helpful

- In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 12 participants (33.33%) was information from reliable source, and this was followed by talking to their doctor or specialists (n=7, 19.44%). There were six participants (16.67%) that described health charities as being helpful and six (16.67%) that described information that's easy to understand as being helpful. Other types of information described as being helpful included information about what to expect (n=5, 13.89%), information specific to their condition (n=5, 13.89%) and other people's experiences (n=4, 11.11%).

Information that has not been helpful

- In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response by 18 participants (50.00%) was that no information was not helpful, and this was followed by GP and specialists as being not helpful (n=5, 13.89%).

Information preferences

- Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone app. Overall, the most common theme was talking to someone (n=10, 27.78%). There were seven participants (19.44%) that described a preference for talking to someone plus online information. There were also seven participants (19.44%) that described online information as their main preference.

- There were 12 participants (33.33%) whose rationale for their preference was simply a personal preference or gave no strong rationale for their preference. Among those who gave a rationale for their preference, seven (19.44%) described it as due to being able to digest information at their own pace and six (16.67%) described it as due to being able to, or having time to, ask questions.

Timing of information

- Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was from the beginning/diagnosis (n=12, 33.33%) and this was followed by participants describing being receptive to information a specific amount of time after (n=7, 19.44%). There were six participants (16.67%) that described being receptive to information after the shock of diagnosis.

Partners in health

- The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score.

- The **"Partners in health: knowledge"** scale measures the participants knowledge of their health condition, treatments, their participation in decision-making and taking action when they get symptoms. Participants in this study had excellent knowledge about their condition and treatments.

- The **"Partners in health: coping"** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). Participants in this study had very good ability to manage the effects of their health condition on emotional well-being, social life and healthy behaviours.

- The **"Partners in health: treatment"** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. Participants in this study had an excellent ability to adhere to treatments and communicate with healthcare professionals.

- The **"Partners in health: recognition and management of symptoms"** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. Participants in this study had excellent recognition and management of symptoms.

Information given by health professionals

- Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=27, 75.00%), disease management (n=26, 72.22%), and disease cause (n=22, 61.11%) were most frequently given to participants by healthcare professionals, and information about psychological/social support (n=8, 22.22%), and complementary therapies (n=4, 11.11%) were given least often.

Information searched independently

- Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. Information about disease management (58.33%) disease cause (55.56%), and treatment options (55.56%) were most often searched for independently by participants. Psychological/social support (27.78%), and hereditary considerations (30.56%) were least searched for.

Information gaps

- The largest gaps in information, where information was neither given to patients nor searched for independently were for psychological/social support (n=21, 58.33%), hereditary considerations genes or genomic biomarker information (n=21, 58.33%), and complementary therapies (n=20, 55.56%). Participants were given most information either from healthcare professionals or independently for disease management (n=16, 44.44%), and treatment options (n=15, 41.67%). The topic that was most searched for independently following no information from health professionals was complementary therapies (n=12, 33.33%).

Most accessed information

- Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. Across all participants, information from the hospital or clinic where treated was most accessed, followed by information from non-profit or charities or patient organisations.

My Health Record

- My Health Record is an online summary of key health information, an initiative of the Australian Government. Eleven participants (39.29%) had accessed "My Health Record". There were 15 (53.57%) who had not, two participants did not know what it is (7.14%), and four participants (4.00%) were not sure. Of those that had accessed "My Health Record", five participants (45.45%) found it good or acceptable, six participants (54.54%) found it poor, or very poor.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 20 participants (55.56%) was through the internet in general, and this was followed by books, pamphlets and newsletters (n=15, 41.67%) and information from specific health charities (n=12, 33.33%). There were eight participants (22.22%) that described accessing information through their treating clinician and seven participants (19.44%) that described accessing information through Facebook and/or social media. Other types of information accessed included other patients experience (n=4, 11.11%) and primarily through journals or research articles (n=4, 11.11%).

In relation to subgroup variations, participants in the subgroups *Carer* (37.50%), *Aged 55 to 64* (25.00%), *Regional or remote* (44.44%), and *Mid to low SEIFA* (45.45%) described accessing information through the internet in general less frequently than the general population (55.56%), while those in the subgroups *Higher SEIFA* (60.00%), and *Aged 75 or older* (87.50%) described this more frequently.

Participants in the subgroup *AL amyloidosis* (60.00%) described receiving information from books, pamphlets and newsletters more frequently than the general population (41.67%), while those in the subgroups *Aged 55 to 64* (25.00%), and *Mid to low SEIFA* (27.27%) described this less frequently.

Participants in the subgroups *AL amyloidosis* (50.00%), and *Regional or remote* (44.44%) described accessing information through specific health charities more frequently than the general population (33.33%), while those in *ATTR-cardiac* (22.22%) and *Aged 55 to 64* (12.50%) subgroup described this less frequently.

Participants in the subgroups *Aged 55 to 64* (37.50%) and *Trade or high school* (35.71%) described accessing information through their treating physician more frequently than the general population (22.22%), while those in the subgroups *University* (7.14%) and *AL amyloidosis* (10.00%) described this less frequently.

Participants in the *Mid to low SEIFA* (9.09%) subgroup described accessed information through Facebook and/or social media less frequently than the general population (19.44%), whereas those in the *ATTR-cardiac* subgroup (33.33%) described this more frequently. Participants in the *Carer* (0.00%), *Aged 75 or older* (0.00%), and *Regional or remote* (0.00%) subgroups did not describe this at all.

Participants in the subgroups *AL amyloidosis* (30.00%), and *Aged 75 or older* (25.00%) described primarily accessing information through other patients' experiences, this is more frequently than the general population (11.11%). Participants in the *Mid to low SEIFA* (0.00%), *Aged 55 to 64* (0.00%) and *Carer* (0.00%) subgroups did not describe this at all.

Participants in the *Carer* (25.00%), *Female* (21.23%), and *Regional or remote* (22.22%) subgroups described accessing information primarily through journals and research articles more frequently than the general population (11.11%), while those in the subgroups *Trade or high school* (0.00%) and *Aged Aged 75 or older* (0.00%) do not describe this.

Internet (including health charities)

What type of information? I'm sorry, again, I don't know what you mean by type. I've read everything. I've looked up and read everything. I've got literature, internet. I've got stuff from the Amyloidosis association that I read a lot. I have, I think, read as much as I possibly can without getting too confused. Participant 001AL

Mainly going online. One thing, I find it a bit depressing to go online and read about stuff. Then also some of the case history that are written up by patients, some of the most recent new amyloidosis website in Australia, they are quite confronting some of the-- that I've mentioned before, some of the trials and tribulations that people have been through. Participant 011ATR

Just what's on the websites, and there's quite a bit of it there. I think there's quite a bit of information available there and talking to the people at the clinics I go to, and also, the woman that helps, NAME, who works with the Amyloidosis Society. They have been fantastic. Participant 017ATR

Books, pamphlets and newsletters

We got a pamphlet from the NAME hospital that gave us information on all the basics of the familial one and then we researched it online. There's a lot of stuff on the internet that when you drill right

down into it. You can pick up on the particular amyloid that I have. Participant 009ATR

Well, I've got a good little booklet. I think it's as much information as I need except, as I just said I don't think they're saying anything about the eye. I haven't heard much about that at all. No, I haven't really read anything about it. Participant 010ATR

Well, from the amyloid clinic in LOCATION METROPOLITAN, they give us some free data or information and read through a lot of literature. That was very good. Participant 014ATR

Specific health charity

We were very, very, very lucky. We were put in contact through Leukaemia Foundation, we literally spoke to a wonderful lady who helped us out not only via net but more or less with hypertension because we didn't know where to go but put us on to a lady who knew everything about amyloidosis. She was magnificent. The amount of brochures she gave me- literally sent out brochures. Basically, she met with us personally and not only one or two times but whenever we needed her. Participant 004CA

Yes, we're with the Australian Amyloidosis Association. We're members of that. In LOCATION here, they've brought their own group. We all get together and support each other, talk to each other, talk about our problem. Participant 009ATR

I did go into things like the Kidney Foundation, the Australian-- There's an Australian amyloidosis group too, but I don't really look at them now because, after two years, we're starting to feel comfortable with where things are at the moment. Participant 001CA

Facebook and/or social media

There are amyloid support groups both Australian based and international on different social media sites, I've got even a pamphlet for amyloid by the hospital in LOCATION METROPOLITAN where I was first diagnosed, I was given when I started-- yes that's pretty-- my doctors pretty much it. Participant 004ATR

There's a couple of decent YouTube videos that go through a couple of things as well. Aside from that, information used around- I've had a few different things, a couple of articles and things, but not much at all to be honest. Participant 006ATR

They have their Facebook groups and things, but I don't find them a good-- you get quite a lot of negativity and I understand that, but I don't bounce as well off that. I prefer to just go into facts and what is affecting me. That might sound selfish, but I think sometimes you have to protect yourself a bit, what you see and hear and not hear the negative stuff. Participant 012ATR

Treating clinician

I do go with NAME HUSBAND to the Amyloidosis Centre at the NAME HOSPITAL. That's usually with NAME CLINICIAN and two other cardiac specialists and a renal specialist. The cardiac and the renal specialist tend to be different each time you'd go. NAME CLINICIAN is the head of that centre and so he's the one that liaises, pulls everything together I suppose. Participant 001CA

I have read books on it, I've talked to doctors about it, I've researched on the Internet, I have been to seminars with the specialists in LOCATION METROPOLITAN. I've talked to a lot of people with it, I've talked with people who deal with it, I've talked to people who are active carers for it. Yes, I collect a lot of information on things like that. I like to know. Participant 002ALX

Yes. Apart from discussing it with the clinical team, and they gave me as much information as I wanted, I then went and confirmed through various websites to find out what is out there that way. I've also used a couple of Facebook groups to gain information that way as well, that's specific to the amyloid. Wide range of sources, and I use each one with a grain of salt until I get the information confirmed in other places. Participant 015ATR

Other patients' experiences

I talk to other patients and we have morning teas, and when we were not locked down with COVID, we used to have those three or four times a year. Participant 003AL

There's a lot of very informative information gleaned from the discussions from other patients. People are affected much worse than I am with their amyloidosis. The brochures that I've been given too, a guide to patients and families from the

Leukaemia Foundation, Amyloidosis, that's been very helpful. Participant 003ALX

I have read books on it, I've talked to doctors about it, I've researched on the Internet, I have been to seminars with the specialists in LOCATION METROPOLITAN. I've talked to a lot of people with it, I've talked with people who deal with it, I've talked to people who are active carers for it. Yes, I collect a lot of information on things like that. I like to know. Participant 002ALX

Journals (research articles)

I can't tell you now, but our daughter, actually, I think she saved the documents. It was out of medical paraphernalia, whatever medical libraries. She printed that and gave us a, I don't know, a 30-page document of very technical information, but there were pieces of it I was able to absorb and some of it, I had to get explained to me, but I think it was a collection of information. Then as time went on, I think I did too have an understanding of what the disease was and where it could go. Participant 001CA

It's the NAME CLINIC booklets. There's also the scientific journals that I was able to access at the time, there's websites in LOCATION and LOCATION. Participant 002AL

Apart from NAME DOCTOR giving us that information in 2014, and if she comes anything else, she sends it out, the medical camp have sent nothing. What we do is we do that ourselves. I go through London free cases; free Mayo clinic or PA have a few research cases. Free of cost, I don't pay for anything. Participant 005CA

Table 6.1: Access to information

Information accessed	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes accessing information through the internet in general	20	55.56	10	55.56	14	56.00	7	70.00	3	37.50	13	59.09	7	50.00	4	44.44	16	59.26
Participant describes receiving information from books, pamphlets and newsletters	15	41.67	6	33.33	9	36.00	6	60.00	3	37.50	9	40.91	6	42.86	4	44.44	11	40.74
Participant describes receiving information from a specific health charity	12	33.33	4	22.22	8	32.00	5	50.00	3	37.50	6	27.27	6	42.86	4	44.44	8	29.63
Participant describes primarily accessing information through treating clinician	8	22.22	5	27.78	5	20.00	1	10.00	2	25.00	4	18.18	4	28.57	2	22.22	6	22.22
Participant describes accessing information primarily through Facebook and/or social media	7	19.44	6	33.33	6	24.00	1	10.00	0	0.00	5	22.73	2	14.29	0	0.00	7	25.93
Participant describes primarily accessing information through other patient's experience	4	11.11	1	5.56	2	8.00	3	30.00	0	0.00	3	13.64	1	7.14	1	11.11	3	11.11
Participant describes accessing information primarily through journals (research articles)	4	11.11	1	5.56	2	8.00	1	10.00	2	25.00	1	4.55	3	21.43	2	22.22	2	7.41

Information accessed	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes accessing information through the internet in general	20	55.56	2	25.00	11	57.89	7	87.50	9	64.29	8	57.14	5	45.45	15	60.00
Participant describes receiving information from books, pamphlets and newsletters	15	41.67	2	25.00	8	42.11	4	50.00	7	50.00	5	35.71	3	27.27	12	48.00
Participant describes receiving information from a specific health charity	12	33.33	1	12.50	8	42.11	2	25.00	5	35.71	4	28.57	4	36.36	8	32.00
Participant describes primarily accessing information through treating clinician	8	22.22	3	37.50	3	15.79	2	25.00	5	35.71	1	7.14	3	27.27	5	20.00
Participant describes accessing information primarily through Facebook and/or social media	7	19.44	2	25.00	4	21.05	0	0.00	4	28.57	3	21.43	1	9.09	6	24.00
Participant describes primarily accessing information through other patient's experience	4	11.11	0	0.00	2	10.53	2	25.00	2	14.29	2	14.29	0	0.00	4	16.00
Participant describes accessing information primarily through journals (research articles)	4	11.11	1	12.50	2	10.53	0	0.00	0	0.00	2	14.29	1	9.09	3	12.00

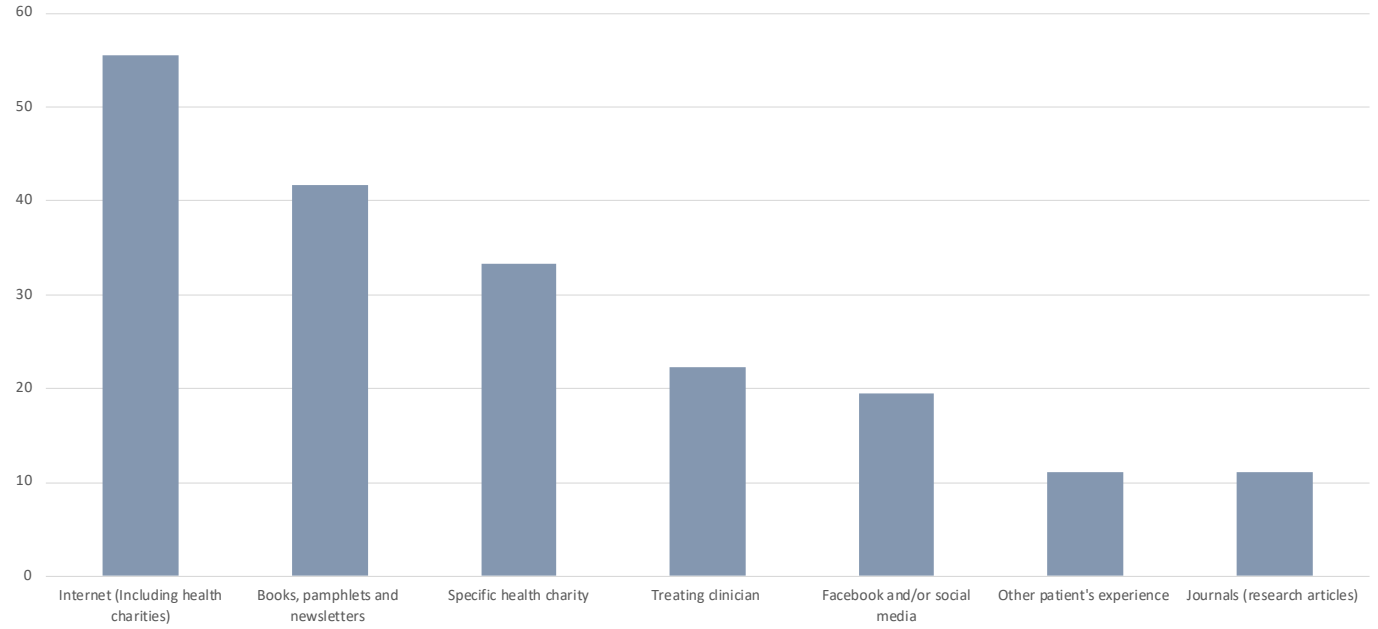


Figure 6.1: Access to information

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 12 participants (33.33%) was information from reliable source, and this was followed by talking to their doctor or specialists (n=7, 19.44%). There were six participants (16.67%) that described health charities as being helpful and six (16.67%) that described information that is easy to understand as being helpful. Other types of information described as being helpful included information about what to expect (n=5, 13.89%), information specific to their condition (n=5, 13.89%) and other people's experiences (n=4, 11.11%).

In relation to subgroup variations, participants in the *Aged 55 to 64* (50.00%), *Female* (50.00%), *Regional or remote* (44.44%), and *Mid to low SEIFA* (45.45%) subgroups described information from reliable sources as more frequently than the general population (33.33%), while those in the subgroups *AL Amyloidosis* (20.00%), *Aged 65 to 74* (21.05%), and *Male* (22.73%) described this less frequently.

Participants in the *AL amyloidosis* subgroup described talking to their doctor or specialist as helpful more frequently (50.00%) than the general population (19.44%), while those in the *Female* (7.14%) subgroup described this less frequently. Participants in the *Carer* (0.00%), and *Aged 55 to 64* (0.00%) subgroups did not describe this at all.

Participants in the subgroups *Trade or high school* (28.57%), *Regional or remote* (33.33%), and *Mid to low SEIFA* (27.27%) described health charities as helpful more frequently than the general population (16.67%).

Participants in the *University* (28.57%) subgroup described information that's easy to understand as helpful more frequently than the general population (16.67%), while those in the *Trade or high school* subgroup (0.00%), and *Mid to low SEIFA* (0.00%) did not describe this.

Participants in the *Regional or remote* subgroup described information about what to expect as helpful more frequently (33.33%) than the general population (13.89%), while those in the *Aged 55 to 64* (0.00%) subgroup did not describe this at all.

No participants in the *Regional or remote* subgroup (0.00%) described information specific to their condition (and sub-types) as helpful.

Participants in the *Regional or remote* subgroup (22.22%) described other people's experiences as helpful more frequently than the general population (11.11%), while those in the *Aged 75 or older* (0.00%), and *Carer* (0.00%) did not describe this at all.

Published information from reliable sources

The little booklet, 'Amyloidosis: A guide for patients and families', put out by the Leukaemia Foundation, I guess because they're more financially able to do these things, extremely informative, how is it treated. In my case, it says at this time there are no specific treatments that can directly clear amyloid deposits from tissues in the body, but for people like me with it in my skin, just see a skin specialist and they should do what they say. I've had a melanoma in the past, so I see a skin specialist once a year. That's very good information, this little booklet, full of information for me which I find very helpful and which I dip into every now and again just to refresh things in my mind. Participant 003ALX

Preferably the booklet about amyloid. Something that was written can be easily understood. I found that very helpful. Participant 003CA

What information's been most helpful? Probably the papers we've researched ourselves. Participant 005CA

Talking to a doctor or specialist

Probably talking to the professor in LOCATION METROPOLITAN and to NAME in LOCATION METROPOLITAN and talking to the scientific people. I'm interested in the science of the disease. Participant 002ALX

The doctors, you have to ask questions. You have to ask questions yourself. Doctors, they have a screen and they'll say, 'Oh, your numbers are good.' That's all they'll say unless you ask a specific question. When I had swollen feet, and then I knew my albumin count, and every time I went in there, I asked him, 'What's my albumin count?' They would tell me, so I knew when I was improving, or I wasn't improving. Everything, I ask a lot of questions. That's what I tell people, 'Look, you've got to ask questions. You've got to say--' There's three things, if you've got swollen feet, you've got to know what you albumin count is, and that's all related on blood pressure and different medical things, but if your albumin is increasing, that means your blood pressure's increasing, and you're getting some benefit from the treatment. The doctors really don't tell you. I mean they've only got a limited amount of time there too. Participant 005AL

I think doctor's input and me asking hopefully relevant questions. Anything else that may come to mind I'll make a note and bring that up in the next doctor's review. If, in fact, the doctor doesn't know, I'll speak to somebody else that may do or may know. I mentioned NAME DOCTOR before. He's been brought in and been able to answer my questions, so I think that that should answer your questions. Participant 006AL

Easy to understand information (layman's terms)

I like the way that a lot of information is being put into layman's terms because I think that helps a lot of patients that don't have a scientific background, and it should be easy to understand the most part of it. Participant 003AL

Preferably the booklet about amyloid. Something that was written can be easily understood. I found that very helpful. Participant 003CA

Information is being able to explain to me just gradually, gradually, otherwise because information sometimes isn't understood, at least for myself all at once. It's something like a study, it's something that gradually, gradually becomes clear in my mind just discovering something gradually, gradually, gradually. Participant 005ATR

Health charities

The little booklet, 'Amyloidosis: A guide for patients and families', put out by the Leukaemia Foundation, I guess because they're more financially able to do these things, extremely informative, how is it treated. Participant 003ALX

The information that has been the most helpful. I'm sorry, I should have mentioned The Leukaemia Foundation, even though it's an orphan disease and they adopted it. NAME, a health staff has given us ongoing support, but she had more knowledge of AL and AA. I got a bit mixed up in the beginning, but regardless of that she said, 'We can't tell you what to do but we can give volunteer financial person. Aside from that-- Can I have that question again. Participant 005CA

I've got a couple of newsletters that come out, one from the Leukaemia Foundation and another one from NAME HOPSITAL, in the amyloid clinic. I would take those, been pretty close to true and correct. I would sort of, read them whenever they come out, maybe once a month. Participant 008ATR

Condition-specific (including sub-types)

I did the other day specifically look at this one I've got, the hereditary one. More so that with symptoms and the family history and all the rest of it. But other than that no. I just generalize the information. Participant 001ATR

I really found the scientific papers useful for my purpose, but I think also the NAME CLINIC booklets and there's one I'm not sure that it's out of LOCATION METROPOLITAN in LOCATION. 'Understanding Amyloidosis'. They were really good because they laid out in layman's terms, but it is pretty comprehensively at the same time about the different amyloidosis and how we know what was happening. I think for even someone who can understand the science, it's good to have it laid out more simply. It's like the skeleton of the disease and the information and then you can add things to that from the science if you want to. Participant 002AL

Probably the brochures that we actually received that literally went into the amyloidosis, which explains all different types of amyloidosis, which literally shows us what our amyloidosis was. We didn't realise at that stage that we thought that all amyloidosis was treated normally, but it's not, and that's why they basically have to work out which amyloidosis you have because one treatment or one type may kill the other type. We literally believed everything from the brochures and most of those brochures came to us through leukaemia that helps us on amyloidosis. Participant 004CA

Hearing what to expect (e.g. from disease, side effects, treatment)

The description of the condition and the side effects mostly and how you might go about managing some of those. Just the description of the disease, the background, and the side effects. That's largely where the clinics or the network meetings have gone as well. They tend to offer a three-span schedule. One is new drugs or new treatments that have come about. Then, a general discussion on managing your life or lifestyle issues. What's the third one? Often a specialist like the stem cell transplant process or similar. They're doing very good. I'm quite impressed. Participant 004AL

We've had a workshop each year and I think the information there, it's been good overview information. I've not had carpal tunnel syndrome. I understand 50% of people with amyloidosis can have that. I've not really had any problems with nerves. It's useful to know that that can occur. Participant 011ATR

Gee, that's difficult. In terms of understanding the disease, the initial videos and things that I saw from the mail and from-- There's a video by the act of Michael York. It's just amazingly simple, but it puts it all in perspective. Generally, for the people before we talk anymore about it, have a look at the video… It tells you what things are happening there and it's not a medical slick. It's a cartoon type of thing, the people with hammers on the production line smashing amyloid stuff, and others, and that thing. It brings the message home. Yes. Participant 013ATR

Other people's experiences

I think what the AAN and NAME is going a fair way to improving the information that gets out to patients. Also, a number of patient groups that talk quite really with the clinic at NAME HOSPITAL and I've been invited to some of the meetings with NAME and a number of the specialists that are associated with that. Participant 003AL

Other than that, I don't really know anyone. I've spoken with a couple of people on my phone that have had the same problem. I've obviously got a cousin, my first cousin, up in LOCATION, that's got the same problem. Participant 008ATR

It's interesting hearing from other patients' journeys but in a positive way, if that makes sense. As I said, at NAME HOSPITAL they give you as much, as I guess, they think you can handle and things with follow-ups and things like that. Participant 012ATR

Table 6.2: Information that was helpful

Information that has been helpful	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes information from reliable sources as helpful	12	33.33	7	38.89	8	32.00	2	20.00	3	37.50	5	22.73	7	50.00	4	44.44	8	29.63
Participant describes talking to their doctor or specialist as helpful	7	19.44	2	11.11	6	24.00	5	50.00	0	0.00	6	27.27	1	7.14	1	11.11	6	22.22
Participant describes health charities information as helpful	6	16.67	3	16.67	4	16.00	2	20.00	1	12.50	3	13.64	3	21.43	3	33.33	3	11.11
Participant describes information that's easy to understand (layman's terms)	6	16.67	2	11.11	4	16.00	2	20.00	2	25.00	3	13.64	3	21.43	1	11.11	5	18.52
Participant describes information about what to expect as helpful (Disease progression)	5	13.89	3	16.67	4	16.00	1	10.00	1	12.50	4	18.18	1	7.14	3	33.33	2	7.41
Participant describes information specific to their condition (and sub-types) as helpful	5	13.89	2	11.11	3	12.00	2	20.00	1	12.50	1	4.55	4	28.57	0	0.00	5	18.52
Participant describes other people's experiences as helpful (Peer-to-peer)	4	11.11	3	16.67	4	16.00	1	10.00	0	0.00	3	13.64	1	7.14	2	22.22	2	7.41

Information that has been helpful	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes information from reliable sources as helpful	12	33.33	4	50.00	4	21.05	3	37.50	4	28.57	5	35.71	5	45.45	7	28.00
Participant describes talking to their doctor or specialist as helpful	7	19.44	0	0.00	4	21.05	2	25.00	4	28.57	3	21.43	2	18.18	5	20.00
Participant describes health charities information as helpful	6	16.67	1	12.50	4	21.05	1	12.50	4	28.57	1	7.14	3	27.27	3	12.00
Participant describes information that's easy to understand (layman's terms)	6	16.67	1	12.50	4	21.05	1	12.50	0	0.00	4	28.57	0	0.00	6	24.00
Participant describes information about what to expect as helpful (Disease progression)	5	13.89	0	0.00	4	21.05	1	12.50	1	7.14	3	21.43	1	9.09	4	16.00
Participant describes information specific to their condition (and sub-types) as helpful	5	13.89	1	12.50	3	15.79	1	12.50	2	14.29	2	14.29	1	9.09	4	16.00
Participant describes other people's experiences as helpful (Peer-to-peer)	4	11.11	1	12.50	3	15.79	0	0.00	2	14.29	2	14.29	2	18.18	2	8.00

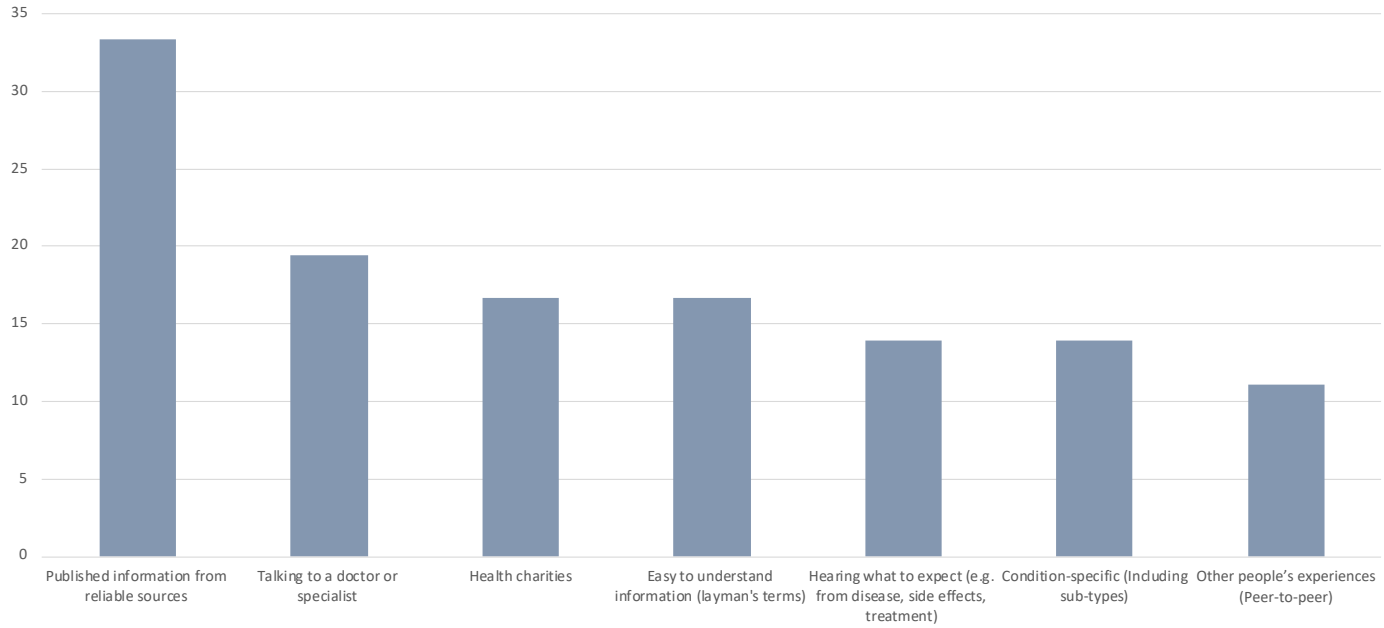


Figure 6.2: Information that was helpful

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response by 18 participants (n=18, 50.00%) was that no information was not helpful and this was followed by GP and specialists as being not helpful (n=5, 13.89%).

In relation to subgroup variations, participants in the subgroups *Carer* (37.50%), *Aged 55 to 64* (25.00%) and *University* (28.57%) described no information as not helpful less frequently than the general population (50.00%), while those in the subgroups *Aged 75 or older* (62.50%), *Trade or high school* (78.57%), *Regional or remote* (66.67%), and *Mid to low SEIFA* (63.64%) described this more frequently.

Participants in the *AL amyloidosis* (30.00%), *Aged 55 to 64* (25.00%), *Aged 75 or older* (25.00%), and *University* (28.57%) subgroups described their GP and specialist as not helpful more frequently than the general population (13.89%), while those in the *Carer* subgroup (0.00%) and *Female* subgroup (0.00%) did not describe this at all.

No information not helpful

No. I'm trying to think. No, I haven't had any ideas myself. Participant 001ALX

No, not really. I can't say that I have. Participant 001ATR

That has not been helpful? No, I think most of the stuff that I read because, again, I'm only reading stuff and things like the Boston Uni hospital and stuff like that. I don't bother reading-- well, again it's not too much individual stuff because everybody is so different. I don't try to down the track of reading other people's experiences as such. Participant 003ATR

GP/specialist

Yes, a couple of GPs in time that told me there is no such thing. Federal government bureaucrats that want to know if I was pregnant when I was taking thalidomide. I had to explain to him the difficulties of me actually conceiving. I was being very sarcastic, I thought it was a stupid bloody question. Participant 002ALX

I sought help from my GP initially and then I sought help from a specialist recognised by him. Then I raised the issue with my oncologist specialist some months late. Clearly, the condition was getting worse and the blood analyses show that. I had a bunch of tests in early 2017, had one in mid-2017 with my usual CML check-up. Then one in November, a six-monthly check-up for CML again and then another one when the GP ran the numbers again. Yet, there was no explanation for the condition. The signs were there clearly with the scan of the heart showing a slight thickening and my inability to manage urine and the compromised kidney functions. It's clearly there and yet it really took something like 15 months to get it. Why was that the case? Participant 004AL

The thing that has been the least helpful, you were probably going to ask me this question a little bit down the line anyway, is the lack of knowledge at GP level. Participant 015ATR

Table 6.3: Information that was not helpful

Information that has not been helpful	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes no information being not helpful	18	50.00	10	55.56	13	52.00	5	50.00	3	37.50	12	54.55	6	42.86	6	66.67	12	44.44
Participant describes the GP/specialist as being not helpful	5	13.89	2	11.11	4	16.00	3	30.00	0	0.00	5	22.73	0	0.00	2	22.22	3	11.11

Information that has not been helpful	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes no information being not helpful	18	50.00	2	25.00	10	52.63	5	62.50	11	78.57	4	28.57	7	63.64	11	44.00
Participant describes the GP/specialist as being not helpful	5	13.89	2	25.00	1	5.26	2	25.00	1	7.14	4	28.57	1	9.09	4	16.00

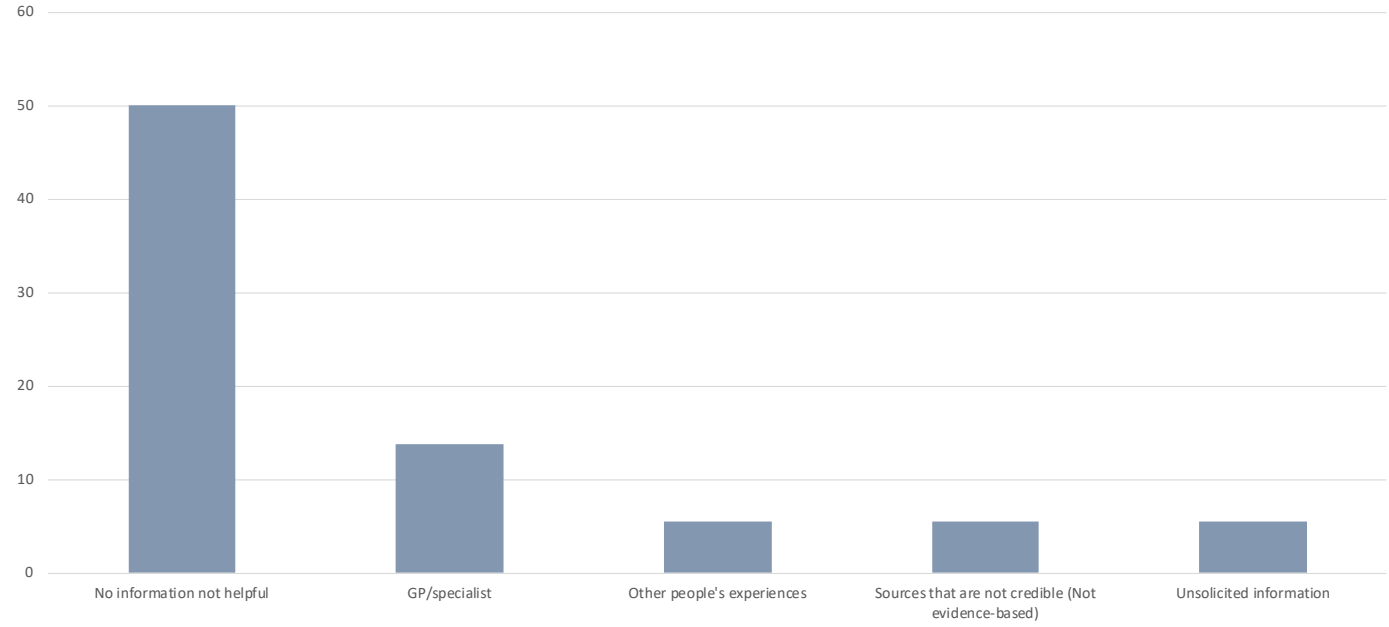


Figure 6.3: Information that was not helpful

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone app. Overall, the most common theme was talking to someone (n=10, 27.78%). There were seven participants (19.44%) that described a preference for talking to someone plus online information. There were also seven participants (19.44%) that described online information as their main preference.

There were 12 participants (33.33%) whose rationale for their preference was simply a personal preference or gave no strong rationale for their preference. Among those who gave a rationale for their preference, seven (19.44%) described it as due to being able to digest information at their own pace and six (16.67%) described it as due to being able to, or having time to, ask questions.

In relation to subgroup variations, participants in the *University* subgroup (14.29%), and *Regional or remote* subgroup (11.11%) described talking to someone as their main preference less frequently than the general population (27.78%), while those in the *Trade or high school* subgroup described this more frequently (42.86%).

Participants in the general population (19.44%) described talking to someone plus online information as their main preference, while those in the *Aged 75 or older* (0.00%) subgroup did not describe this at all.

Participants in the *Aged 75 or older* subgroup described online information as their main preferences more frequently (37.50%) than the general population (19.44%), while those in the *Female* (7.14%), and *Mid to low SEIFA* (9.09%) subgroups described this less frequently. Participants *Aged 55 to 64* (0.00%) did not describe this at all.

Participants in the *AL amyloidosis* (50.00%), *Male* (45.45%), and *Trade or high school* (50.00%) subgroups described their rationale for their preference as simply a person preference or had no strong rationale more frequently than the general population (33.33%), while those in the subgroups *Regional or remote* (11.11%), *Female* (14.29%), and *Carer* (12.50%) described this less frequently.

Participants in the subgroup *Regional or remote* (33.33%) described their rationale for their preference as due to being able to digest information at their own pace more frequently than the general population (19.44%).

Participants in the *Female* (35.71%) subgroup described their rationale for their preference as due to being able to/have time to ask questions more frequently than the general population (16.67%), while those in the *Male* (4.55%) subgroup described this less frequently. Participants in the *Regional or remote* (0.00%) did not describe this at all.

Talking to someone

Face-to-face. It's just the way that I've always dealt with that sort of-- In the scientific world, the work I do, over my years, I much prefer face-to-face and I can see from the person whether they-- I guess I get the feel as to whether they're legit or whether I'm beating the wind. I must admit, I don't trust a lot of the stuff on the internet. I usually always second guess it. Participant 002ALX

If I were to arrange them, I would say talking with someone first and phone app probably second and the journal and the net. Talking with someone, you can ask questions that are more specific to you rather than figuring out if it applies to you, or if it doesn't apply to you. Talking to someone and say, 'This drug would, or this treatment would, be just fixing this.' Then I can say, 'That's great for them, but what about this?' Then they can answer that. I think that's handy whether it's via phone call or video conferencing or even a chat, online chat. It's so much better than trying to cycle through loads and loads of information. Participant 002ATR

First thing I prefer face-to-face, I think that's just my generation, preferring face-to-face but I'm not-- I'm cynical of website information. When I first got diagnosed, I went online and the first thing you read is, 'You're not going to live 12 months.' You go, 'Yes, right.' Then you go and talk to your haematologist and he says, 'No, I'll be buying you a birthday card when you turn 89.' You get the two extremes. Participant 004ATR

Talking to someone plus online

Probably initially I like online stuff just because I can absorb it at my own time and when I might feel like it, as opposed to generally I don't want to talk about it, to be honest. As much as you can forget about it sometimes, so I go with that. But if it's important, I'd prefer to talk to someone in person. Initial stage something online that I can read through your phone or computer or whatever. When it gets into actually asking, I'd like to be able to ask questions and you're replying, and talk to someone in real life, as opposed to on the phone. That's really important. Participant 006ATR

I quite like the online ones, the network started a couple and they've been really good, interesting to hear the different peoples' journey and things of how they all got to where they are and that's been quite interesting. I like listening to the doctors but the ones that are able to explain it in a non-medical word way. Some of them are fantastic at what they do, but they can't share it in a palatable or easy way that everyone can understand, it gets too technical. I've always done seminars and things of nutrition I suppose, and I'm used to all that and I enjoy all that, I enjoy good speakers. I have to be able to feel I can relate to the person I'm talking to. That they are interested, I guess is the other thing, that they're interested because just going through the numbers and doing the motions. Yes, I enjoy that. Participant 012ATR

Initially, I liked the web. My initial research is web-based where I'll go pick up a heck of a lot of information and get things straight in my mind. Then I like to have it confirmed or refuted by talking to somebody about it. The two things, when working like that, allow me to get things straight in my mind about what it is and where we're going. Those are the two things I prefer. Participant 015ATR

Online

I suppose online would be the first place of choice because that's where we all go now for information and it's accessible at your own time. Participant 002CA

I don't have an app, but I certainly just go online and type in amyloidosis, and a whole lot of things comes up from the USA and on specific AL amyloidosis that always comes up. This ATTR medication, that came up last year. One of the other patients that I know quite well, one of his relatives in the UK sent him that information, which I was then able to access and read through. It's just like doing any other scientific research, you need to find information on new things, and I just follow that principle. Participant 003AL

I prefer online. I think that's the nature of the beast in a way. I prefer to access it in my own time and be able to digest it at my own pace and to explore further when necessary. If I don't get the answers, I'm happy to ask the question of someone in the discussion, but I like to cover all the bases as it were at my own tempo, when it's convenient, when I'm in the right mood, or when it's necessary. Participant 004AL

No strong reason for preference

Well, my generation does go to the computer, et cetera, and I know how to use the computer. I know how to look up the information, et cetera, et cetera, but I'm not what I would call a technical person. My reading of anything, and that means leisure reading or whatever it is, is much preferred in the written form and also in the discussion forum. When I talk to people in a discussion forum, I talk to people and see what happens, whether it's other patients with amyloidosis or at the clinic at NAME HOSPITAL, which I go to, or to the various professions. I find that is the most effective and preferred form of communication. Participant 001AL

All three of them, I have a preference. Talking to doctors, it would be my preferred option. I read about it somewhere, 'If it's affecting you, go then ask the doctor, 'I read this, what do you think about that?''. That's the approach I'm taking. Participant 001ALX

First thing I prefer face-to-face, I think that's just my generation, preferring face-to-face but I'm not-- I'm cynical of website information. When I first got diagnosed, I went online and the first thing you read is, 'You're not going to live 12 months.' You go, 'Yes, right.' Then you go and talk to your haematologist and he says, 'No, I'll be buying you a birthday card when you turn 89.' You get the two extremes. Participant 004ATR

Being able to digest information at their own pace

I'm a great reader, so I like getting booklet-type literature where I can read it and absorb it at my time and reread it again. Conversation phoning is also good because you can do the toing and froing ideas, discussions, thoughts that come up, you can pose a question to the person at the other end of the line, so to speak, so all of those, WhatsApp or probably booklets I probably prefer than phoning up for clarification or whatever. Participant 003ALX

I prefer online. I think that's the nature of the beast in a way. I prefer to access it in my own time and be able to digest it at my own pace and to explore further when necessary. If I don't get the answers, I'm happy to ask the question of someone in the discussion, but I like to cover all the bases as it were at my own tempo, when it's convenient, when I'm in the right mood, or when it's necessary. Participant 004AL

I now and then search online for a good article, something that I can process, to read, to learn, especially when I got them to me, I lot to choose. Just I can find my time and educating myself and understanding better. Yes, I do that. I go online, I don't talk with anybody else, I don't know anybody who is experiencing the same diseases that I have, so I haven't done that. The only thing I'm doing is to talking family, to talk with my doctor, to educate myself to read articles, to go online searching something that I can trust to really find the truth about what I don't know. I think when I find, and one can go. I even tried with some information like that, and sometimes it must read more than once to be understood properly and I go back to them and then I ask and explain. This is what I'm doing. Participant 005ATR

Being able to have time to ask questions

I think sometimes you have specific questions to yourself where it's good to talk to someone who's got the knowledge. I personally like a combination of sources of information. Participant 002AL

Talking with someone, you can ask questions that are more specific to you rather than figuring out if it applies to you, or if it doesn't apply to you. Talking to someone and say, 'This drug would, or this treatment would, be just fixing this.' Then I can say, 'That's great for them, but what about this?' Then they can answer that. I think that's handy whether it's via phone call or video conferencing or even a chat, online chat. It's so much better than trying to cycle through loads and loads of information. She probably knows much more, because people try so self-diagnose their-- A lot of hearsay and inconclusive treatment options. Participant 002ATR

Talking to someone that knew about, my preference was talking to someone. I think if you talk to someone that knows about the disease and can answer your questions and I think if it's someone that basically you can actually get has what the human touch rather than reading about something. Participant 004CA

Table 6.4: Information preferences

Information preferences	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Talking to someone as main preference	10	27.78	5	27.78	6	24.00	3	30.00	2	25.00	6	27.27	4	28.57	1	11.11	9	33.33
Talking to someone plus online information as main preference	7	19.44	5	27.78	6	24.00	1	10.00	1	12.50	5	22.73	2	14.29	2	22.22	5	18.52
Online information as main preference	7	19.44	4	22.22	6	24.00	2	20.00	1	12.50	6	27.27	1	7.14	2	22.22	5	18.52

Information preferences	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Talking to someone as main preference	10	27.78	3	37.50	5	26.32	2	25.00	6	42.86	2	14.29	3	27.27	7	28.00
Talking to someone plus online information as main preference	7	19.44	1	12.50	5	26.32	0	0.00	3	21.43	3	21.43	2	18.18	5	20.00
Online information as main preference	7	19.44	0	0.00	4	21.05	3	37.50	2	14.29	4	28.57	1	9.09	6	24.00

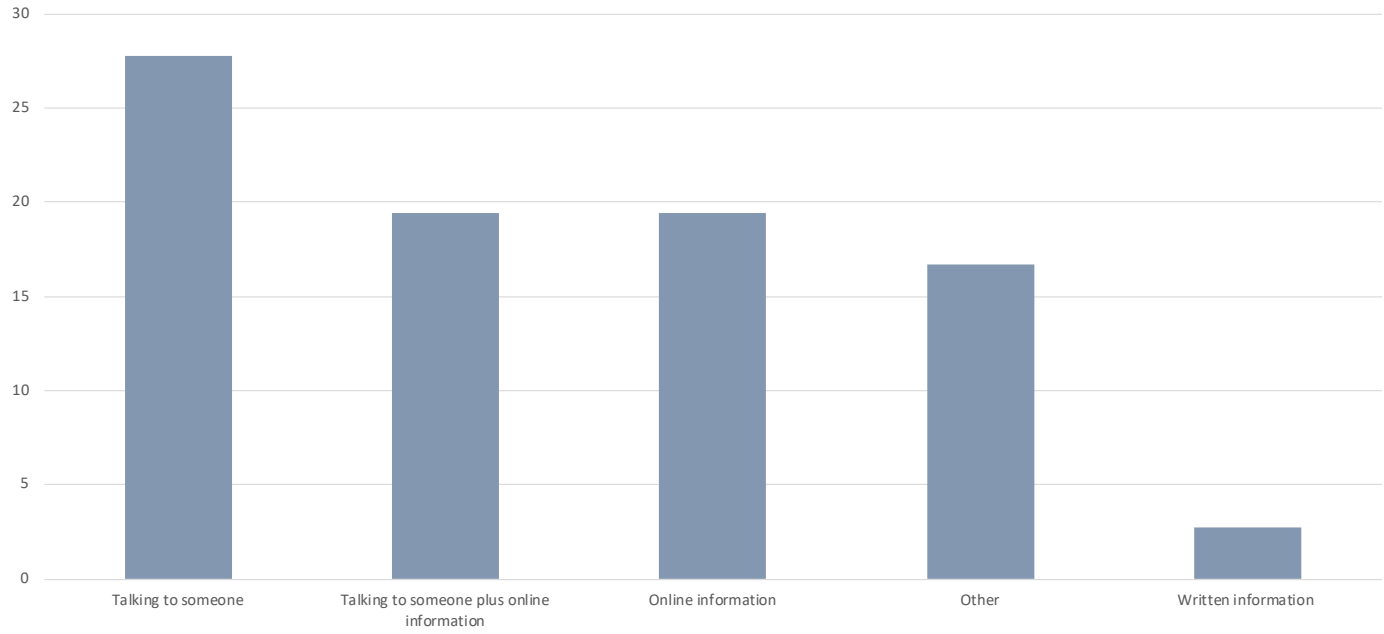


Figure 6.4: Information preferences

Table 6.5: Reasons for preference

Rationale for preferences	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Rationale for preference is simply a personal preference/no strong rationale	12	33.33	6	33.33	10	40.00	5	50.00	1	12.50	10	45.45	2	14.29	1	11.11	11	40.74
Rationale for preference is due to being able to digest information at their own pace	7	19.44	4	22.22	5	20.00	2	20.00	1	12.50	5	22.73	2	14.29	3	33.33	4	14.81
Rationale for preference is due to being able to/have time to ask questions	6	16.67	3	16.67	4	16.00	2	20.00	1	12.50	1	4.55	5	35.71	0	0.00	6	22.22

Rationale for preferences	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Rationale for preference is simply a personal preference/no strong rationale	12	33.33	2	25.00	7	36.84	3	37.50	7	50.00	4	28.57	3	27.27	9	36.00
Rationale for preference is due to being able to digest information at their own pace	7	19.44	2	25.00	3	15.79	1	12.50	2	14.29	4	28.57	2	18.18	5	20.00
Rationale for preference is due to being able to/have time to ask questions	6	16.67	1	12.50	2	10.53	2	25.00	2	14.29	3	21.43	1	9.09	5	20.00

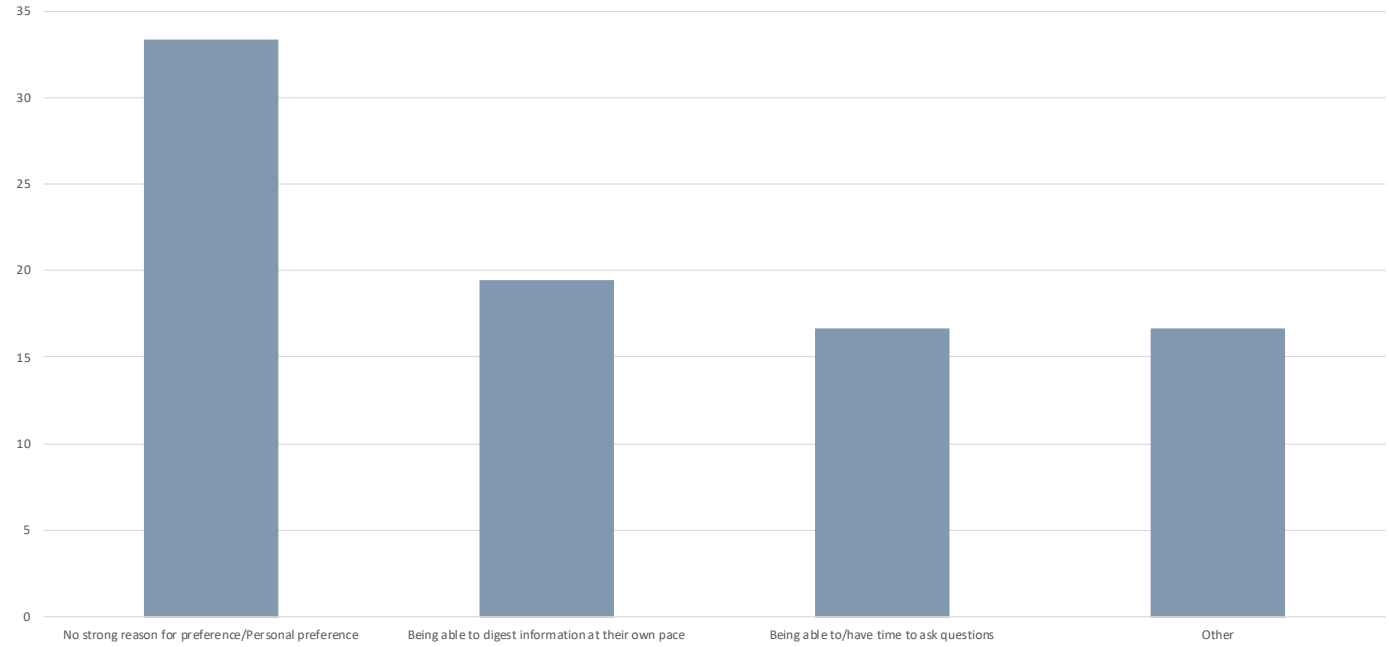


Figure 6.5: Reasons for preference

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was from the beginning or at diagnosis (n=12, 33.33%). This was followed by participants describing being receptive to information a specific amount of time after (n=7, 19.44%). There were six participants (16.67%) that described being receptive to information after the shock of diagnosis.

In relation to subgroup variations, participants in the *AL amyloidosis* (20.00%) subgroup described being receptive to diagnosis from the beginning or at diagnosis less frequently than the general population (33.33%), while those in the subgroups *ATTR-cardiac* (44.44%), and *University* (50.00%) described this more frequently. Participants in the *Aged 75 or older* (50.00%) subgroup did not describe this at all.

Participants in the *Trade or high school* (28.57%) subgroup being receptive to information after the shock of diagnosis more frequently than the general population (16.67%), while those in the *University* (0.00%) subgroup did not describe this at all.

From the beginning (diagnosis)

Well, at initial diagnosis, of course, I was more receptive to information, because I had never heard of amyloidosis, and I knew nothing about it. Initially, I was all out getting in every bit of information that I could. Participant 001AL

When was I most receptive? Probably, on initial diagnosis really. Because of it being new beforehand, but it hadn't been formalised, I had done a little bit of reading and-- But as I said, there was absolutely no point in talking to a medical person, because like I was in NAME HOSPITAL one day with a MEDICAL PROFESSIONAL who knows me really well, and we were just chatting. I said something about, 'Geez, how have you been and blah, blah, blah? Well, you know what? I've just been diagnosed with amyloid.' She went, 'Oh my God, I haven't heard of that word since I was in TRAINING.' Participant 001ATR

I think initially, I was. I was a bit traumatised, obviously, it was a very emotional time because we thought the prognosis was not good. However, at that stage, I just wanted to seek as much information as I possibly could. I really understood exactly what it was and that we weren't being at all misled that the prognosis wasn't good. Then saying that his specialist never ever said, I give people 6 months, 12 months or 18 months because they're not going to do that anyway. Everybody responds to these treatments differently, but I think at the very beginning I wanted an easily accessible, and easy to understand, and easy to interpret information that was not too directed at the medical clinic, but more maybe directed towards the layperson understanding the intricacies of the disease. Participant 001CA

After a specific amount of time

Probably two or three months, I think before I really started to sort it out. Participant 010ATR

This time I really understood it better. I really started taking and trying to prepare my own sets of questions and the like. I suspect if I look back through my notes, I'll see that I sent notes to NAME CLINICIAN and to NAME CLINICIAN and they're basically asking a whole bunch of questions because I'd done the research, I'd understood as much as the layman does or the partial scientist does, the issues around AL and the side effects and the management of it, and with melanoma to ask to the informed questions I guess. It was probably, I think, 8, 10, 12 weeks before I really got on top of it, understood it, and ask a sensible series of questions. Participant 004AL

Not at the beginning, because at the beginning it was just an absolute shock. I think probably after that six weeks, when it finally more or less pivots that this is happening to us and because we waited for such a long time for a diagnosis. Participant 004CA

After the shock of diagnosis

Well, it was overwhelming at the beginning because it was, as I said, the future comes out and hits you in the face, and then as you get used to the idea and you start on treatment. I don't know. Maybe for somebody who's new into the whole journey, giving them a little bit of time to get used to the idea of the diagnosis and that there are treatments available, so people have calmed down a bit maybe, or accepted maybe a bit more, and then you're more receptive, maybe, to more information. Participant 002CA

Probably after I've seen-- I was very anxious before I saw NAME DOCTOR. Between the diagnosis and seeing him, I had no idea having been told that I had nodular amyloidosis. Before I had any brochures or booklets or anything like that, that was a very anxious time. After I'd seen NAME DOCTOR, he gave me all the information, he spoke with my husband and I very clearly and concisely in an unhurried manner, and I went actually with a little dot point list of questions. He allayed any fears that I had, expanded my knowledge greatly, of course, of what it was, and after that while I came home and then digested all of that information, I was more receptive into absorbing the information and coming to terms with it and settling down in myself what it was, what I'm faced with, how to deal with it, and that made me comfortable. Participant 003ALX

Probably reasonably soon after getting the diagnosis, once he got the hit of the diagnosis. For me, it's, 'Okay, right. What can I do? What is this all about? I need to know about this. I need to know what to look for.' Probably reasonably quickly, I would have thought after getting the diagnosis, the next visit back to the doctor would have been the best time to have a session on, 'Okay, so here's some information and work it from there.' Participant 003CA

Table 6.6: Timing of information

Timing of information	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes being receptive from the beginning (diagnosis)	12	33.33	8	44.44	10	40.00	2	20.00	2	25.00	7	31.82	5	35.71	3	33.33	9	33.33
Participant describes a specific amount of time after diagnosis	7	19.44	4	22.22	6	24.00	2	20.00	1	12.50	4	18.18	3	21.43	2	22.22	5	18.52
Participant describes being receptive to information after the shock of diagnosis	6	16.67	3	16.67	3	12.00	1	10.00	2	25.00	3	13.64	3	21.43	2	22.22	4	14.81

Timing of information	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes being receptive from the beginning (diagnosis)	12	33.33	3	37.50	4	21.05	4	50.00	3	21.43	7	50.00	3	27.27	9	36.00
Participant describes a specific amount of time after diagnosis	7	19.44	1	12.50	4	21.05	2	25.00	4	28.57	2	14.29	3	27.27	4	16.00
Participant describes being receptive to information after the shock of diagnosis	6	16.67	2	25.00	3	15.79	1	12.50	4	28.57	0	0.00	2	18.18	4	16.00

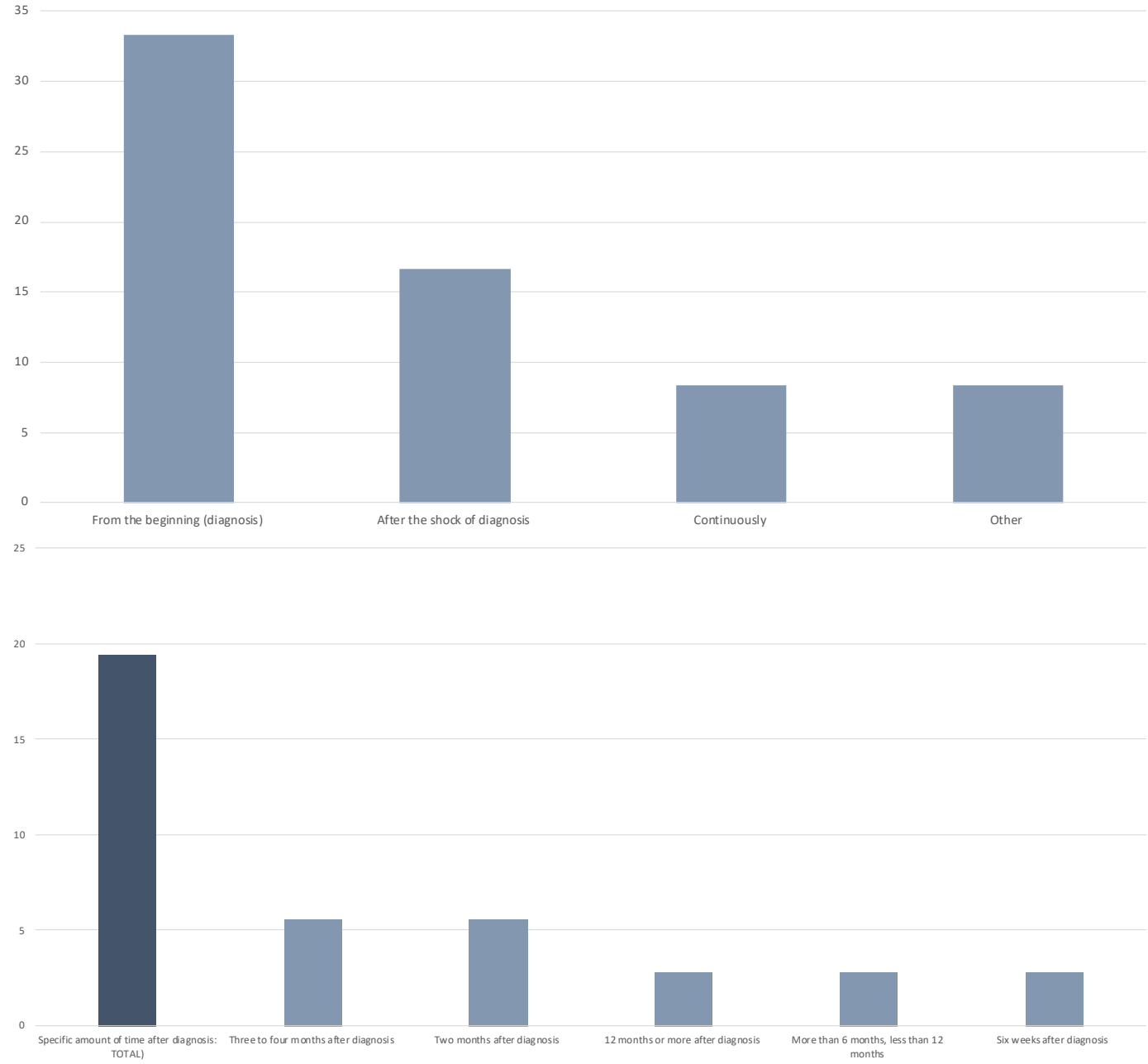


Figure 6.6: Timing of information

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=15, 41.67%). There were eleven participants (30.56%) that described an overall positive experience with the exception of one or two occasions and five participants (13.89%) who described an overall negative experience.

Where participants described a positive experience, this related to health professional communication as holistic (two way, supportive and comprehensive conversations (n=12, 33.33%). Where participants described a negative experience, this related to health professional communication being limited in relation to their understanding of the condition (n=11, 30.56%).

In relation to subgroup variations, participants in the *Aged 55 to 64* (12.50%), *ATTR-cardiac* (22.22%), and *Regional or remote* (22.22%) subgroups described health professional communication as holistic less frequently than the general population (33.33%), while those in the *AL amyloidosis* (60.00%) subgroup described this more frequently.

Participants in the *Mid to low SEIFA* subgroup described health professional communication as limited in relation to their understanding of the

condition less frequently (18.18%) than the general population (30.56%).

Overall, participants in the subgroups *ATTR-cardiac* (55.56%), *All cardiac* (52.00%), and *Male* (54.55%) described health professional communication as overall positive more frequently than the general population (41.67%), while those in the subgroups *Female* (21.43%), and *Carer* (12.50%) described this less frequently.

Participants in the *Female* subgroup described health professional communication as positive with the exception of one or two occasions more frequently (42.86%) than the general population (30.56%).

Overall positive

Good. Everyone is trying to do their best, and the conveyance of that information from various people-- I'm talking about cardiologists. I'm talking about haematologists. I'm talking about other specialists, which I've gone to them. We've talked about exercise. We've talked about all these things. I've found it to be good, helpful, and receptive. I have no complaints, not at all. Participant 001AL

The ones that I'm dealing with? Supportive and informative, but not with information overload. Only enough to maybe make me think a little bit more about the disease and do a little bit of research myself. They've not been holding back information, but not wanting to alarm me, basically. Participant 001ATR

Well, I think the medical treatments been first class. I think to the time of my having a problem, which was really when I had the February check-up to diagnosis since September is just a bit over six months and that's kind of-- Based on the information I saw in one of the workshops I attended, that's probably best, best on outcomes, some people have gotten much longer periods. I've been happy with- extremely happy with my GP, my family and my haematologist. Participant 011ATR

Overall positive with the exception of one or two occasions

It's been a little bit mixed. My GP was really good. She didn't diagnose amyloidosis, but she's always been someone who, if it's five things, you get things tested. I've got a lot to be thankful to her for picking up the low blood albumin in the first place. The renal physician, I didn't feel a connection to really. He's a fairly elderly chap and he always struck me as being a little bit- what's the word? Treating you a bit like, not a child, but he wasn't really forthcoming with good science. It was, 'Oh yes, I've treated a lot of these people and the best thing to do is to just wait. We'll check every couple of months what's happening with your urine and your blood.' I just didn't feel confident in what he was saying to me, particularly as I was learning quite a bit at the time. My haematologist though has been great. He's always been really upfront about what's happening, what the risks are, what the different treatments were likely to do, like when I went on to the cyclophosphamide dexamethasone and thalidomide. Participant 002AL

90% of it's been very good, 10%, it's been a few GPs who didn't really know where they were at with it or they've never heard of it. A couple of them didn't believe, one still doesn't believe there's any such thing. Participant 002ALX

Mixed really, I would say. My GP since hasn't really had much information about it, hasn't had any brochures to give me or anything like that. NAME DOCTOR, I keep referring back to him, but he's been wonderful. Also, we have a couple of meetings, gatherings, discussion groups at the PA hospital which have been-- I think there's only one and then the second one had to be cancelled because of the Coronavirus. That was extremely helpful and very, very, very helpful, people there running it, extremely helpful and very welcoming and putting you at your ease. Participant 003ALX

Overall negative

It was a little irregular. That can be frustrating because of the lack of awareness. Then they go to a practitioner, lack of awareness from the public. There isn't enough literature, but you couldn't look without knowing what it is, to begin with. You could research weight loss or diarrhoea. Amyloidosis is a good imitator of other diseases. I think it doesn't help. I'm glad Australia has more, but I think general education to the medical profession can be- the number is quite-- The number of times I've been into the hospital, three different hospitals that I go to here and the doctors who see me will go, 'We heard about in med school there is really not one expert here. Participant 002ATR

Health professionals, amyloidosis and they'd almost say, 'Well, what's that? I learned about that in med school, but it wasn't something of great relevance because it was a because it's relatively rare condition'. They, in turn, have to re-educate themselves perhaps on their knowledge about this. From there, proper treatments have to be given by that relevant health professional, like the GP, the lung specialist, the hospice. They really have to brush up on their knowledge and to tailor the treatment that I'll receive. The heart has tube in it because amyloidosis affects the heart. They used to tailor the treatment to look after my heart. Lung specialist has to ensure that I don't get a food on the lungs, look after my lungs in that respect. They'd be most relevant to the healing but again tailor any treatment that might be necessary to my condition because, once again, it's a rare condition and the treatment as such becomes I think specific to the conditions. Participant 006AL

Terrible. Except for the people at the NAME HOSPITAL. No one else knows about it. Participant 009ATR

Holistic (Two way, supportive and comprehensive conversations)

Since we've moved up here and being with NAME CLINICIAN, you just can't fault the system. He's been so good. If we've asked any questions, he's taken the time and explained everything in plain English, which has been a breath of fresh air. NAME CLINICIAN, he is just awesome. Participant 003CA

If I have a problem about anything, I can ring up the NAME HOSPITAL, and I'll say-- I've got a problem at the moment, actually. I've got a cancer beside my ear, a lump beside my ear. I went to my GP. He had scans done, and I said, 'Look, can you send the results to the NAME HOSPITAL Amyloid Clinic?' Anyway, as soon as I got the results, they got it as well, and I rang them up the next day. She says, 'Yes, we know. Everything's being organized.' I cannot complain. I've got no complaints about the NAME HOSPITAL. Participant 005AL

Pretty good. Pretty good, yes. I go down to LOCATION METROPOLITAN every six months and I see my heart specialist every six months, they're both fully in charge of the heart part of it and the amyloid part. They're keeping as much as an eye on me as possibly I suppose. Either of those places I can ring up or get in touch with if I need certain answers and questions. I'd talk to the amyloid clinic in LOCATION METROPOLITAN to email reasonably often about if I've got any questions come up whether I want to know something about them. They'll then they'll find the answer for me and send it back, or get someone to email, usually email, with the information I want. Participant 008ATR

Limited in understanding

Health professionals, amyloidosis and they'd almost say, 'Well, what's that? I learned about that in med school, but it wasn't something of great relevance because it was a because it's relatively rare condition'. They, in turn, have to re-educate themselves perhaps on their knowledge about this. From there, proper treatments have to be given by that relevant health professional, like the GP, the lung specialist, the hospice. They really have to brush up on their knowledge and to tailor the treatment that I'll receive. Participant 006AL

It's been really good once I found my specialist. Initially, it wasn't great because I didn't have anyone to ask or talk to, but once I actually got through the gatekeepers of referrals and things and got in a room with a specialist, it's been excellent from that point forward. Participant 006ATR

Terrible. Except for the people at the NAME HOSPITAL. No one else knows about it. Participant 009ATR

Table 6.7: Healthcare professional communication

Health professional communication	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	12	33.33	4	22.22	8	32.00	6	60.00	2	25.00	6	27.27	6	42.86	2	22.22	10	37.04
Participant describes health professional communication as limited in relation to their understanding of the condition	11	30.56	5	27.78	6	24.00	3	30.00	3	37.50	6	27.27	5	35.71	2	22.22	9	33.33
Overall positive	15	41.67	10	55.56	13	52.00	4	40.00	1	12.50	12	54.55	3	21.43	4	44.44	11	40.74
Overall positive, with the exception of one or two occasions	11	30.56	4	22.22	6	24.00	4	40.00	3	37.50	5	22.73	6	42.86	2	22.22	9	33.33
Overall negative	5	13.89	3	16.67	4	16.00	1	10.00	1	12.50	3	13.64	2	14.29	2	22.22	3	11.11

Health professional communication	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	12	33.33	1	12.50	8	42.11	3	37.50	5	35.71	5	35.71	4	36.36	8	32.00
Participant describes health professional communication as limited in relation to their understanding of the condition	11	30.56	2	25.00	5	26.32	3	37.50	5	35.71	3	21.43	2	18.18	9	36.00
Overall positive	15	41.67	3	37.50	8	42.11	4	50.00	7	50.00	7	50.00	5	45.45	10	40.00
Overall positive, with the exception of one or two occasions	11	30.56	2	25.00	5	26.32	3	37.50	4	28.57	4	28.57	3	27.27	8	32.00
Overall negative	5	13.89	1	12.50	3	15.79	1	12.50	2	14.29	2	14.29	1	9.09	4	16.00

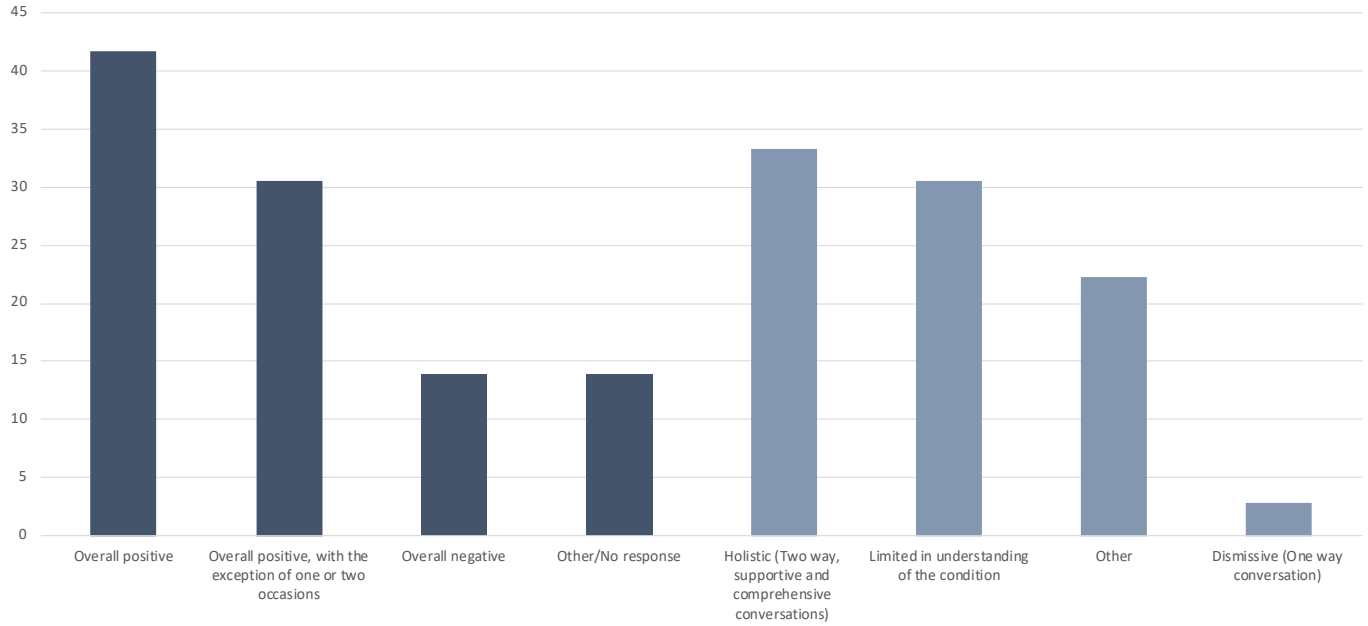


Figure 6.7: Healthcare professional communication

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, four scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.8.

Overall, the participants in this PEEK study had an average score for **'Partners in health: knowledge'** (Median = 28.00, IQR = 4.25), **'Partners in health: recognition and management of symptoms'** (Mean = 20.68, SD = 2.47), **'Partners in health: adherence to treatment'** (Median = 16.00, IQR = 1.00), and **'Partners in health: total score'** (Mean = 81.04, SD = 8.66) were in the highest quintile indicating very good recognition and management of symptoms, and very good adherence to treatment.

The average scores for **'Partners in health: coping'** (Median = 18.50, IQR = 7.50), was in the second highest quintile indicating good knowledge, coping and overall knowledge and confidence for managing their own health.

Comparisons of Partners in health have been made based on **Participant type** (Figures 6.8 to 6.12, Table

6.9), **Gender** (Figures 6.13 to 6.17, Tables 6.10 to 6.11), **Location,** (Figures 6.18 to 6.22, Tables 6.12 to 6.13), **Age** (Figures 6.23 to 6.27, Tables 6.14 to 6.17), **Education** (Figures 6.28 to 6.32, Tables 6.18 to 6.19), and **SEIFA** (Figures 6.33 to 6.37, Tables 6.20 to 6.21).

The 'Partners in health: knowledge' scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. Participants in this study had excellent knowledge about their condition and treatments

The 'Partners in health: coping' scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). Participants in this study had very good ability to manage the effects of their health condition on emotional well-being, social life and healthy behaviours.

The 'Partners in health: treatment' scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. Participants in this study had excellent recognition and management of symptoms.

The 'Partners in health: recognition and management of symptoms' scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. Participants in this study had an excellent ability to adhere to treatments and communicate with healthcare professionals.

The 'Partners in health: total score' measures the overall knowledge, coping and confidence for managing their own health. Participants in this study had excellent overall knowledge, coping and confidence for managing their own health.

Table 6.8: Partners in health summary statistics

Partners in health scale (n=28)	Mean	SD	Median	IQR	Possible range	Quintile
Partners in health: knowledge	27.36	3.53	28.00	4.25	0 to 32	5
Partners in health: coping	17.68	4.46	18.50	7.50	0 to 24	4
Partners in health: recognition and management of symptoms*	20.68	2.47	21.00	4.25	0 to 24	5
Partners in health: adherence to treatment	15.32	0.98	16.00	1.00	0 to 16	5
Partners in health: total score*	81.04	8.66	82.00	12.50	0 to 96	5

Comparisons of Partners in health scales by participant type

Participant type were grouped according to diagnosis; *ATTR-cardiac* group include participants diagnosed with hereditary or wild type ATTR (n=18, 50.00%). *All cardiac* includes all participants diagnosed with amyloidosis that have cardiac involvement, this group includes participants diagnosed with AL amyloidosis and ATTR (n=25, 64.44%). The *AL amyloidosis* group includes all participants diagnosed with AL amyloidosis, including any organ involvement (n=10, 27.78%). The final participant type are *Carers* to people with any type of amyloidosis (n=8, 22.22%).

The assumptions for normality of residuals was not met for a one-way ANOVA, a Kruskal-Wallis test was used (Table 6.9).

No significant differences were observed between participants by Participant type for any of the Partners in health scales.

Table 6.9: Partners in health by Participant type Kruskal-Wallis test and summary statistics

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	ATTR-cardiac	18	50.00	28.00	4.75	0.10	2	0.9520
	All-cardiac	25	69.44	28.00	4.00			
	AL amyloidosis	10	27.78	28.00	3.00			
Coping	ATTR-cardiac	18	50.00	18.00	7.50	0.48	2	0.7874
	All-cardiac	25	69.44	18.00	8.00			
	AL amyloidosis	10	27.78	20.00	6.00			
Recognition and management of symptoms	ATTR-cardiac	18	50.00	21.00	2.75	0.43	2	0.8058
	All-cardiac	25	69.44	21.00	3.00			
	AL amyloidosis	10	27.78	20.00	4.50			
Adherence to treatment	ATTR-cardiac	18	50.00	16.00	1.00	0.04	2	0.9803
	All-cardiac	25	69.44	16.00	1.00			
	AL amyloidosis	10	27.78	15.50	1.00			
Total score	ATTR-cardiac	18	50.00	82.00	11.50	0.06	2	0.9691
	All-cardiac	25	69.44	83.00	13.00			
	AL amyloidosis	10	27.78	83.00	12.00			

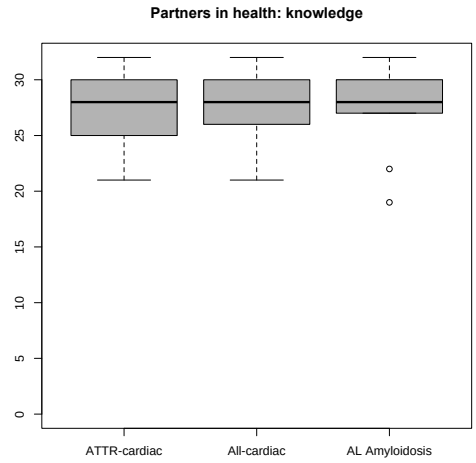


Figure 6.8: Boxplot of 'Partners in health: knowledge' by participant type

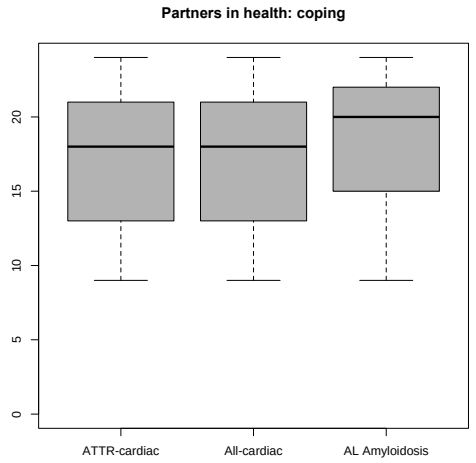


Figure 6.9: Boxplot of 'Partners in health: coping' by participant type

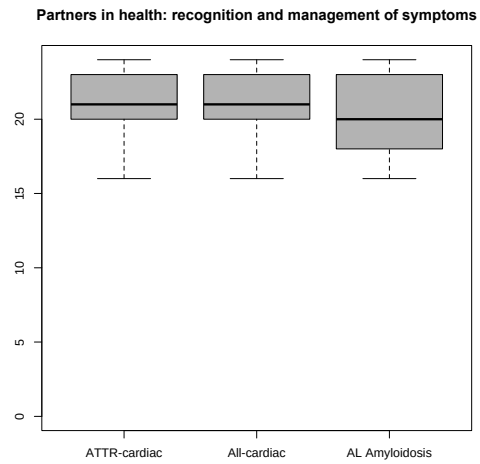


Figure 6.10: Boxplot of 'Partners in health: recognition and management of symptoms' by participant type

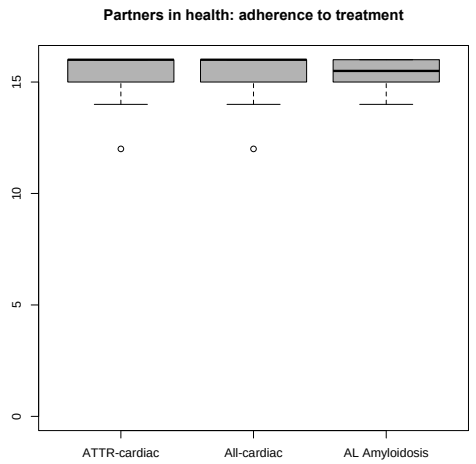


Figure 6.11: Boxplot of 'Partners in health: adherence to treatment' by participant type

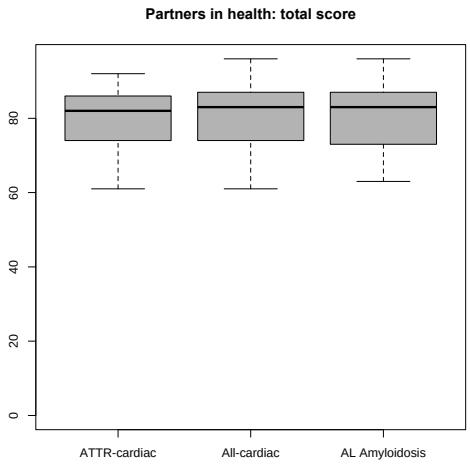


Figure 6.12: Boxplot of 'Partners in health Total score' by participant type

Comparisons of Partners in health scales by Gender

Comparisons were made by **Gender**, between males (n=21, 675.00) and females (n=7, 25.00%).

Boxplots of each Partners in health scale by **Gender** are displayed in Figures 6.13 to 6.17 summary statistics are displayed in Tables 6.10 and 6.11. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.11).

No significant differences were observed between male and female participants for any of the Partners in health scales.

Table 6.10: Partners in health by Gender summary statistics and two sample t-test

Partners in health scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Recognition and management of symptoms	Female	7	25.00	21	3	-0.04	26	0.9657
	Male	21	75.00	21	2			
Total score	Female	7	25.00	79	10	0.56	26	0.5805
	Male	21	75.00	82	8			

Table 6.11: Partners in health by Gender summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Knowledge	Female	7	25.00	25	6	106.00	0.0863
	Male	21	75.00	28	3		
Coping	Female	7	25.00	20	2	63.00	0.5932
	Male	21	75.00	18	9		
Adherence to treatment	Female	7	25.00	16	1	74.00	1.0000
	Male	21	75.00	16	1		

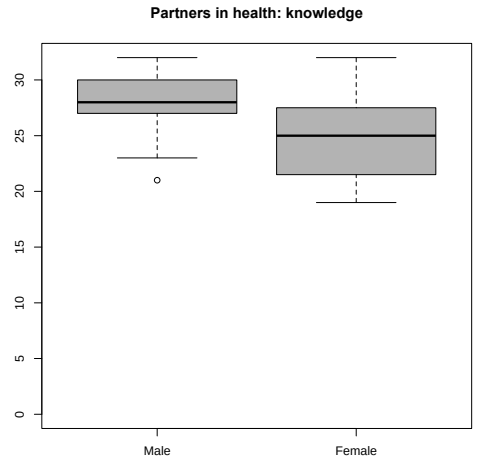


Figure 6.13: Boxplot of 'Partners in health: knowledge' by Gender

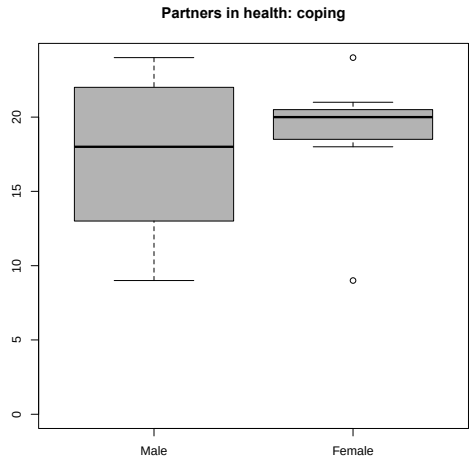


Figure 6.14: Boxplot of 'Partners in health: coping' by Gender

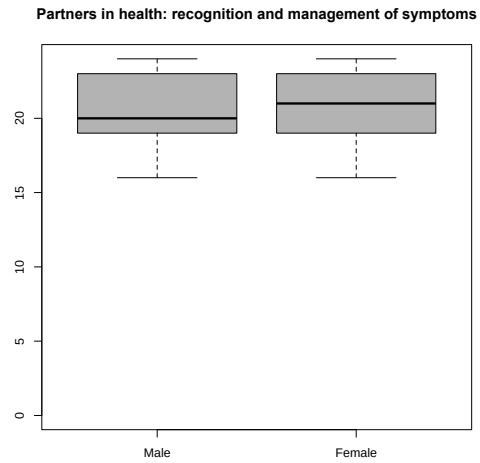


Figure 6.15: Boxplot of 'Partners in health: recognition and management of symptoms' by Gender

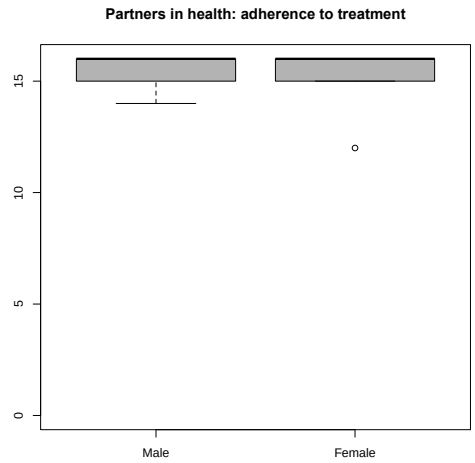


Figure 6.16: Boxplot of 'Partners in health: adherence to treatment' by Gender

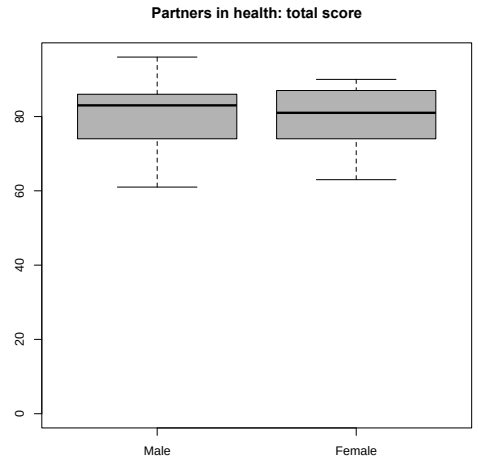


Figure 6.17: Boxplot of 'Partners in health Total score' by Gender

Comparisons of Partners in health scales by Location

The **Location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics, those living in a major city, *Metropolitan* (n=22, 78.57%) were compared to those living in regional or rural areas, *Regional or remote* (n=6, 21.43%).

Boxplots of each Partners in health scale by **Location** are displayed in Figures 6.18 to 6.22, summary statistics are displayed in Tables 6.12 to 6.13. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.13).

No significant differences were observed between participants that lived in metropolitan areas compared to those that lived in regional or remote areas for any of the Partners in health scales.

Table 6.12: Partners in health by Location summary statistics and two sample t-test

Partners in health scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Coping	Regional or remote	6	21.43	19.00	4.20	0.81	26	0.4237
	Metropolitan	22	78.57	17.32	4.56			
Recognition and management of symptoms	Regional or remote	6	21.43	20.83	2.04	0.17	26	0.8661
	Metropolitan	22	78.57	20.64	2.61			
Total score	Regional or remote	6	21.43	83.00	9.67	0.62	26	0.5409
	Metropolitan	22	78.57	80.50	8.53			

Table 6.13: Partners in health by Location summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Knowledge	Regional or remote	6	21.43	29.00	3.50	77	0.5716
	Metropolitan	22	78.57	28.00	4.75		
Adherence to treatment	Regional or remote	6	21.43	15.00	1.50	45	0.1982
	Metropolitan	22	78.57	16.00	1.00		

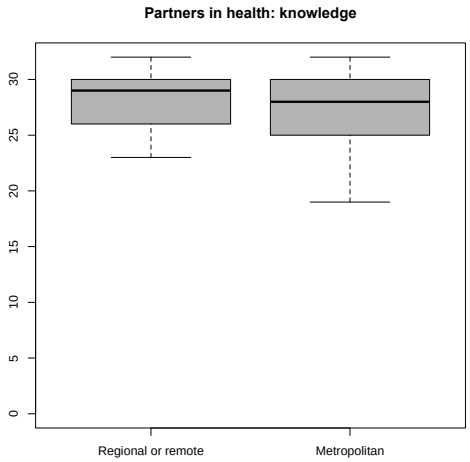


Figure 6.18: Boxplot of 'Partners in health: knowledge' by Location

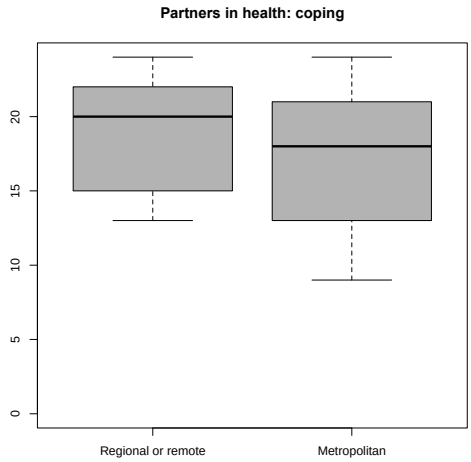


Figure 6.19: Boxplot of 'Partners in health: coping' by Location

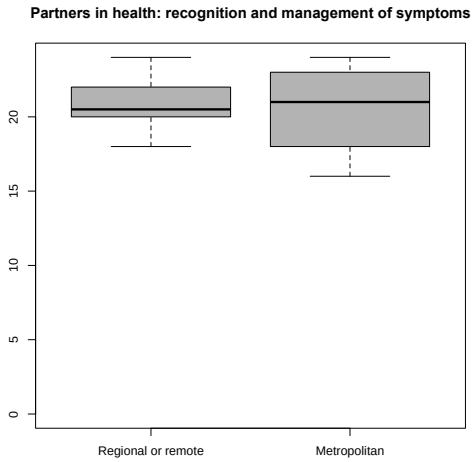


Figure 6.20: Boxplot of 'Partners in health: recognition and management of symptoms' by Location

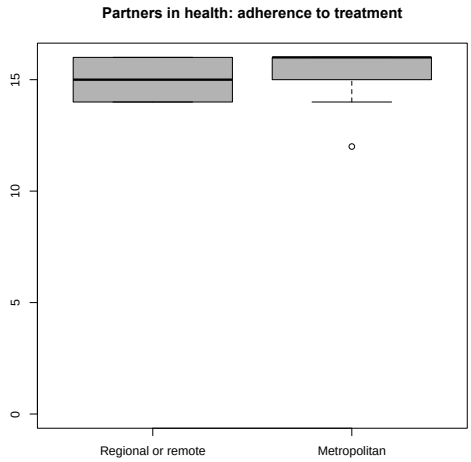


Figure 6.21: Boxplot of 'Partners in health: adherence to treatment' by Location

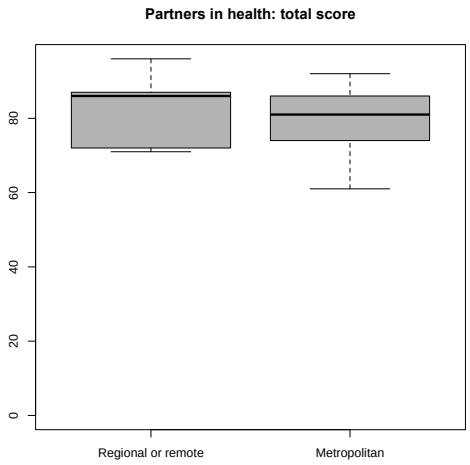


Figure 6.22: Boxplot of 'Partners in health Total score' by Location

Comparisons of Partners in health scales by Age

Participants were groups according to **Age,** with comparisons made between participants *Aged 55 to 64* (n=6, 22.22%), *Aged 65 to 74* (n=13, 48.15%), and *Aged 75 or older* (n=8, 29.63%). One participant was aged in the 25 to 34 year old age bracket and was excluded from age comparisons.

Boxplots of each Partners in health scale by **Age** are displayed in Figures 6.23 to 6.27, summary statistics are displayed in Tables 6.14 and 6.16.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.14). A Tukey HSD test was used post hoc to identify the source of any differences identified in the one-way ANOVA test (Table 6.15).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.16). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal-Wallis test (Table 6.17).

A one way ANOVA test indicated a statistically significant difference in the **'Partners in health scale'** scale between groups, [$F(2, 26) = 5.92$, $p = 0.0082$] (Table 6.17). Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the *Aged 65 to 74* subgroup (Mean = 85.08, SD = 7.20) was significantly higher compared to participants in the *Aged 55 to 64* subgroup (Mean = 72.50, SD = 8.96, p = 0.0059).

A Kruskal-Wallis test indicated a statistically significant difference in the **'Partners in health scale'** scale between groups, [$\chi^2(2) = 7.15$, $p = 0.0280$]. Wilcoxon rank sum tests between groups indicated that participants in the *Aged 65 to 74* subgroup (Median = 54.29, IQR = 15.00), scored significantly higher than participants in the *Aged 55 to 64* subgroup (Median = 22.86, IQR = 15.00, p = 0.0230).

The 'Partners in health: coping' scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in the *Aged 65 to 74* subgroup scored higher than participants in the *Aged 55 to 64* subgroup. This indicates that participants in the *Aged 65 to 74* subgroup, had an excellent ability to manage the effects of their health condition, compared to a moderate ability to manage for participants in the *Aged 55 to 64* subgroup.

The 'Partners in health: total score' measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the *Aged 65 to 74* subgroup scored higher than participants in the *Aged 55 to 64* subgroup. This indicates that participants in the *Aged 65 to 74* subgroup, had excellent overall knowledge, coping and confidence for managing their own health, compared to very good overall knowledge, coping and confidence for participants in the *Aged 55 to 64* subgroup.

Table 6.14: Partners in health by Age ANOVA test and summary statistics

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Knowledge	Aged 55 to 64	6	22.22	25.00	3.74	Between groups	68.10	2	34.05	3.067	0.0651
	Aged 65 to 74	13	48.15	28.92	2.25	Within groups	266.40	24	11.1		
	Aged 75 and older	8	29.63	26.75	4.40	Total	334.50	26			
Recognition and management of symptoms	Aged 55 to 64	6	22.22	19.33	2.34	Between groups	24.69	2	12.345	2.245	0.1280
	Aged 65 to 74	13	48.15	21.69	2.14	Within groups	131.98	24	5.499		
	Aged 75 and older	8	29.63	20.38	2.67	Total	156.67	26			
Total score	Aged 55 to 64	6	22.22	72.50	8.96	Between groups	651.70	2	325.90	5.92	0.0082*
	Aged 65 to 74	13	48.15	85.08	7.20	Within groups	1321.90	24	55.10		
	Aged 75 and older	8	29.63	81.75	6.52	Total	1973.60	26			

Table 6.15: Partners in health by Age post hoc Tukey HSD test

Partners in health scale	Group	Difference	Upper	Lower	p adjusted
Total score	Aged 65 to 74 - Aged 55 to 64	12.58	3.43	21.72	0.0059*
	Aged 75 and older - Aged 55 to 64	9.25	-0.76	19.26	0.0739
	Aged 75 and older - Aged 65 to 74	-3.33	-11.66	5.00	0.5855

Table 6.16: Partners in health by Age Kruskal-Wallis test and summary statistics

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	c^2	dF	p-value
Knowledge	Aged 55 to 64	6	22.22	22.86	13.50	7.15	2	0.0280*
	Aged 65 to 74	13	48.15	54.29	20.00			
	Aged 75 and older	8	29.63	22.86	21.00			
Adherence to treatment	Aged 55 to 64	6	22.22	22.86	15.00	5.23	2	0.0731
	Aged 65 to 74	13	48.15	54.29	15.00			
	Aged 75 and older	8	29.63	22.86	16.00			

Table 6.17: Partners in health by Age post hoc pairwise Wilcoxon rank sum test

Partners in health scale	Group	Aged 55 to 64	Aged 65 to 74
Knowledge	Aged 65 to 74	0.0230*	-
	Aged 75 and older	0.089	0.826

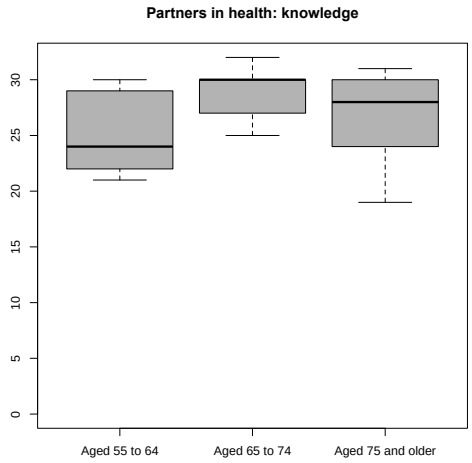


Figure 6.23: Boxplot of 'Partners in health: knowledge' by age

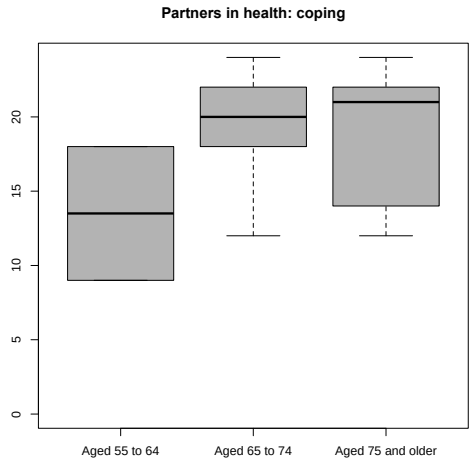


Figure 6.24: Boxplot of 'Partners in health: coping' by age

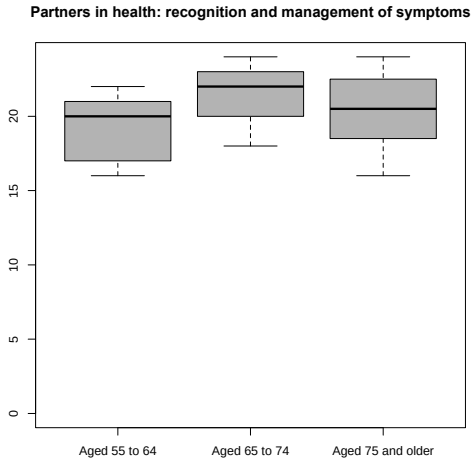


Figure 6.25: Boxplot of 'Partners in health: recognition and management of symptoms' by age

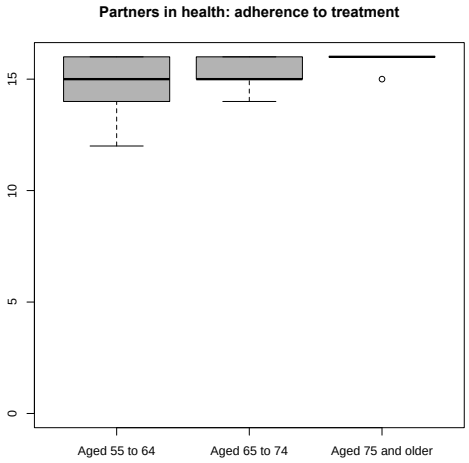


Figure 6.26: Boxplot of 'Partners in health: adherence to treatment' by age

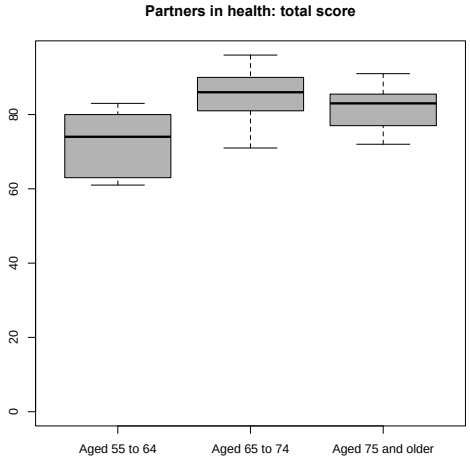


Figure 6.27: Boxplot of 'Partners in health Total score' by age

Comparisons of Partners in health scales by Education

Education status was collected only for participants diagnosed with amyloidosis (n=28). Comparisons were made by **Education** status, between those with a university qualification, *University* (n= 14, 50.00%), and those with trade or high school qualifications, *Trade or high school* (n=14, 50.00%).

Boxplots of each Partners in health scale by **Education** are displayed in Figures 6.28 to 6.32, summary statistics are displayed in Tables 6.18 to 6.19. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.18), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.19).

No significant differences were observed between participants in the *Trade or high school* subgroup compared to those in the *University* subgroup for any of the Partners in health scales.

Table 6.18: Partners in health by Education summary statistics and two sample t-test

Partners in health scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Knowledge	Trade or high school	14	50.00	26.79	4.04	-0.85	26	0.4019
	University	14	50.00	27.93	2.97			
Recognition and management of symptoms	Trade or high school	14	50.00	20.07	2.67	-1.32	26	0.1980
	University	14	50.00	21.29	2.16			
Total score	Trade or high school	14	50.00	80.43	8.92	-0.36	26	0.7181
	University	14	50.00	81.64	8.68			

Table 6.19: Partners in health by Education summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Coping	Trade or high school	14	50.00	20.00	7.50	114.00	0.4734
	University	14	50.00	18.00	5.75		
Adherence to treatment	Trade or high school	14	50.00	16.00	1.00	96.50	0.9589
	University	14	50.00	16.00	1.00		

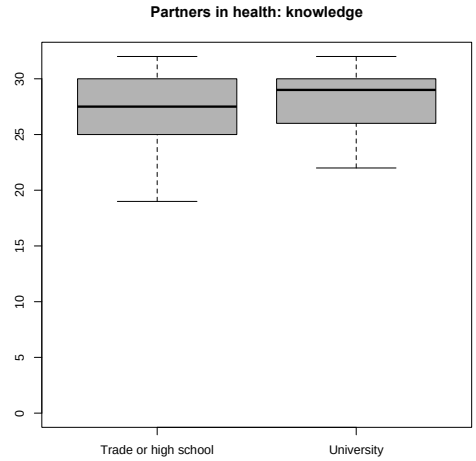


Figure 6.28: Boxplot of 'Partners in health: knowledge' by education

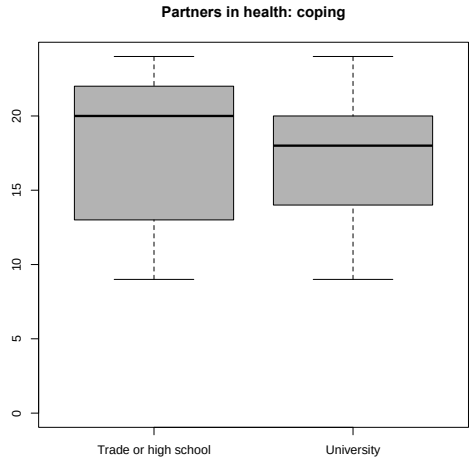


Figure 6.29: Boxplot of 'Partners in health: coping' by education

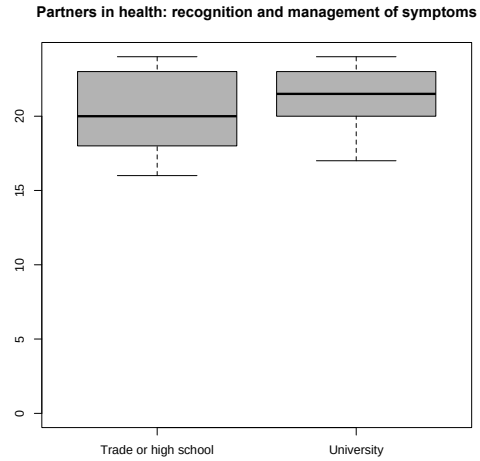


Figure 6.30: Boxplot of 'Partners in health: recognition and management of symptoms' by education

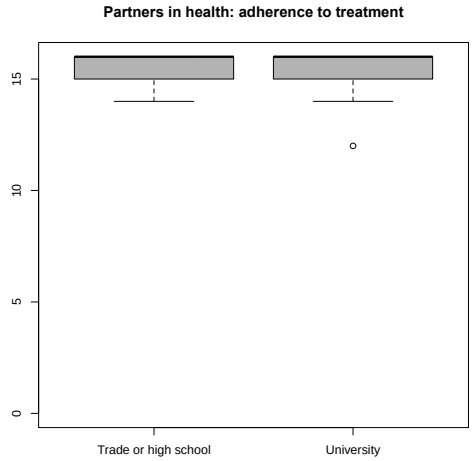


Figure 6.31: Boxplot of 'Partners in health: adherence to treatment' by education

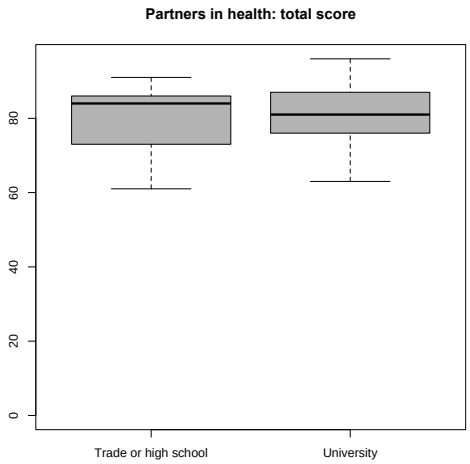


Figure 6.32: Boxplot of 'Partners in health Total score' by education

Comparisons of Partners in health scales by SEIFA

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10, *Higher SEIFA* (n=20, 71.43%) compared to those with a mid to low SEIFA score of 1-6, *Mid to low SEIFA* (n=8, 28.57%).

Boxplots of each Partners in health scale by **SEIFA** are displayed in Figures 6.33 to 6.37, summary statistics are displayed in Tables 6.20 to 6.21. A two-sample t-test was used when assumptions for normality and variance were met (Table 6.20), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.21).

No significant differences were observed between participants in the *Mid to low SEIFA* subgroup compared to those in the *Higher SEIFA* subgroup for any of the Partners in health scales.

Table 6.20: Partners in health by SEIFA summary statistics and two sample t-test

Partners in health scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Coping	Mid to low SEIFA	8	28.57	18.88	3.31	0.89	26	0.3798
	Higher SEIFA	20	71.43	17.20	4.84			
Total score	Mid to low SEIFA	8	28.57	83.00	7.48	0.75	26	0.4582
	Higher SEIFA	20	71.43	80.25	9.15			

Table 6.21: Partners in health by SEIFA summary statistics and Wilcoxon rank sum tests with continuity correction

Partners in health scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low SEIFA	8	28.57	28.50	3.50	94.00	0.4879
	Higher SEIFA	20	71.43	28.00	5.00		
Recognition and management of symptoms	Mid to low SEIFA	8	28.57	20.50	1.50	77.50	0.9183
	Higher SEIFA	20	71.43	21.50	5.00		
Adherence to treatment	Mid to low SEIFA	8	28.57	15.50	2.00	65.50	0.4248
	Higher SEIFA	20	71.43	16.00	1.00		

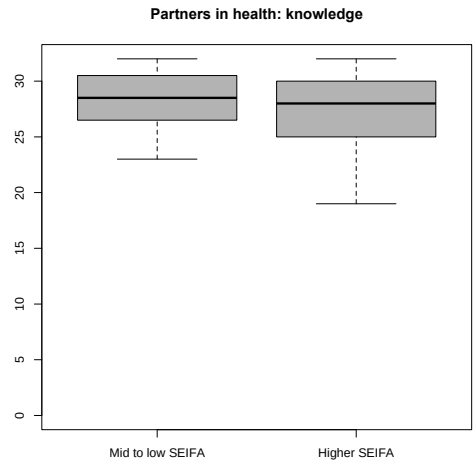


Figure 6.33: Boxplot of 'Partners in health: knowledge' by SEIFA

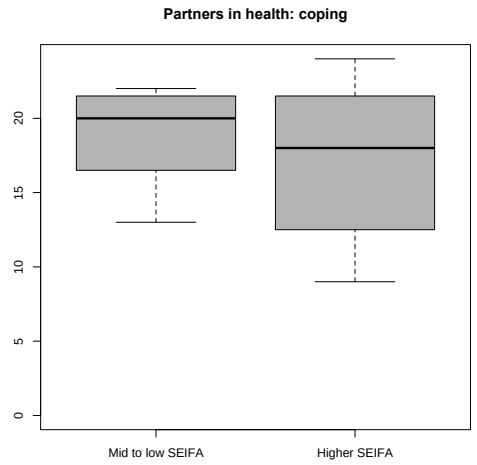


Figure 6.34: Boxplot of 'Partners in health: coping' by SEIFA

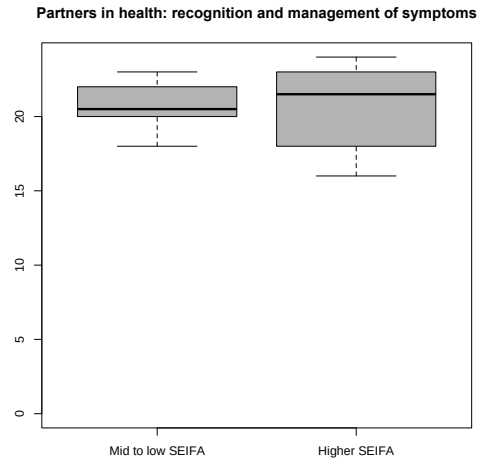


Figure 6.35: Boxplot of 'Partners in health: recognition and management of symptoms' by SEIFA

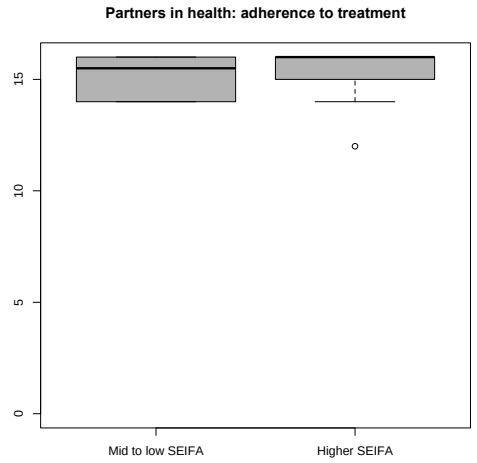


Figure 6.36: Boxplot of 'Partners in health: adherence to treatment' by SEIFA

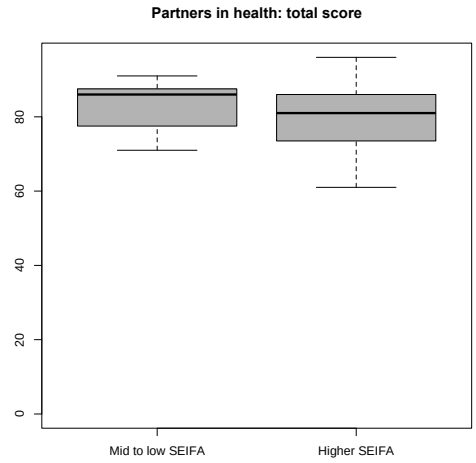


Figure 6.37: Boxplot of 'Partners in health Total score' by SEIFA

Ability to take medicine as prescribed

Participants were asked in general how good they were at taking medicine as prescribed and sticking to it.

The majority of participants responded that they took medicine as prescribed all the time (n=23, 82.14%)

Table 6.22: Ability to take medicine as prescribed

Ability to take medicine as prescribed	Number (n=28)	Percent
Never	0	0.00
Rarely	0	0.00
Sometimes	1	3.57
Most of the time	4	14.29
All of the time	23	82.14

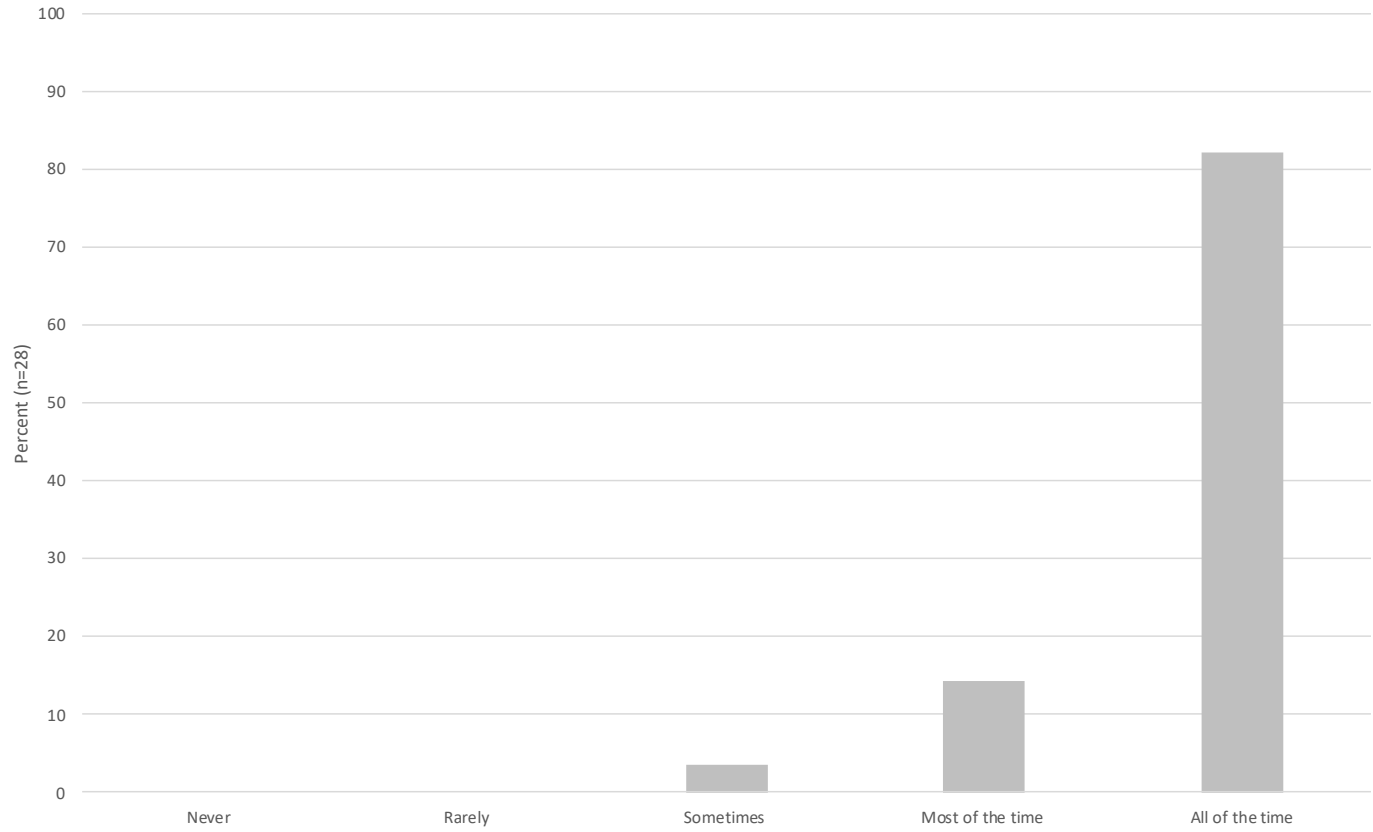


Figure 6.38: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=27, 75.00%), disease management (n=26, 72.22%), and disease cause (n=22, 61.11%) were most frequently given to participants by healthcare professionals, and information about psychological or social support (n=8, 22.22%), and complementary therapies (n=4, 11.11%) were given least often (Table 6.23, Figure 6.39).

In relation to subgroup variations, participants in the *University* subgroup (71.43%) were given for information about disease cause more often than the general population (61.11%).

Participants in the *Male* (86.36%), *Metropolitan* (88.89%), and *University* (100.00%) subgroups were given for information about treatment options more often than the general population (75.00%), while *Female* (57.14%), *Trade or high school* (57.14%), and *University* (57.14%) subgroups were given this information less often.

Participants in the *AL amyloidosis* (90.00%), and *University* (92.86%) subgroups were given for information about disease management more often than the general population (72.22%), while participants in the *ATTR-cardiac* (61.11%), *Trade or high school (*50.00%). subgroups were given this information less often.

Participants in the *ATTR-cardiac* (72.22%), *All cardiac* (64.00%), *Male* (63.64%), *Aged 65 to 74* (63.16%) and *University* (64.29%) subgroups were given for information about clinical trials more often than the general population (52.78%), while participants in the *AL amyloidosis* (40.00%), *Female* (35.71%) and *Metropolitan* (33.33%) subgroups were given this information less often.

Participants in the *AL amyloidosis* (60.00%) and *Higher SEIFA* (48.00%) subgroups were given information about dietary information more often than the general population (36.11%), while participants in *ATTR-cardiac* (16.67%), *Metropolitan* (11.11%), *Mid to low SEIFA* (9.09%) subgroups were given this information less often.

Participants in the *AL amyloidosis* (60.00%), *Aged 65 to 74* (57.89%) and *University* (64.29%) subgroups were given for information about physical activity more often than the general population (41.67%), while participants in the *Metropolitan* (22.22%), *Trade or high school* (28.57%), and *Mid to low SEIFA* subgroups were given this information less often.

Participants in the *Metropolitan* (44.44%) subgroup were given for information about hereditary considerations more often than the general population (27.78%).

Table 6.23: Information given by health professionals

Information topic	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Metropolitan		Regional or remote	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=27	%	n=9	%
Disease Cause	22	61.11	12	66.67	16	64.00	6	60.00	4	50.00	14	63.64	8	57.14	6	66.67	16	59.26
Treatment options	27	75.00	14	77.78	20	80.00	8	80.00	5	62.50	19	86.36	8	57.14	8	88.89	19	70.37
Disease management	26	72.22	11	61.11	17	68.00	9	90.00	6	75.00	16	72.73	10	71.43	7	77.78	19	70.37
Complementary therapies	4	11.11	1	5.56	2	8.00	2	20.00	1	12.50	3	13.64	1	7.14	2	22.22	2	7.41
How to interpret test results	9	25.00	6	33.33	8	32.00	3	30.00	0	0.00	7	31.82	2	14.29	0	0.00	9	33.33
Clinical trials	19	52.78	13	72.22	16	64.00	4	40.00	2	25.00	14	63.64	5	35.71	3	33.33	16	59.26
Dietary information	13	36.11	3	16.67	7	28.00	6	60.00	4	50.00	7	31.82	6	42.86	1	11.11	12	44.44
Physical activity	15	41.67	7	38.89	12	48.00	6	60.00	2	25.00	10	45.45	5	35.71	2	22.22	13	48.15
Psychological/social support	8	22.22	4	22.22	4	16.00	2	20.00	2	25.00	5	22.73	3	21.43	1	11.11	7	25.93
Hereditary considerations	10	27.78	6	33.33	9	36.00	3	30.00	1	12.50	6	27.27	4	28.57	4	44.44	6	22.22

Information topic	All participants		Aged 55 to 64		Aged 65 to 74		Aged 74 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Disease Cause	22	61.11	5	62.50	13	68.42	3	37.50	8	57.14	10	71.43	7	63.64	15	60.00
Treatment options	27	75.00	7	87.50	14	73.68	5	62.50	8	57.14	14	100.00	8	72.73	19	76.00
Disease management	26	72.22	4	50.00	15	78.95	6	75.00	7	50.00	13	92.86	8	72.73	18	72.00
Complementary therapies	4	11.11	1	12.50	2	10.53	1	12.50	1	7.14	2	14.29	2	18.18	2	8.00
How to interpret test results	9	25.00	2	25.00	5	26.32	2	25.00	6	42.86	3	21.43	3	27.27	6	24.00
Clinical trials	19	52.78	3	37.50	12	63.16	3	37.50	8	57.14	9	64.29	6	54.55	13	52.00
Dietary information	13	36.11	2	25.00	8	42.11	3	37.50	4	28.57	5	35.71	1	9.09	12	48.00
Physical activity	15	41.67	1	12.50	11	57.89	2	25.00	4	28.57	9	64.29	3	27.27	12	48.00
Psychological/social support	8	22.22	2	25.00	4	21.05	1	12.50	1	7.14	5	35.71	1	9.09	7	28.00
Hereditary considerations	10	27.78	3	37.50	5	26.32	2	25.00	5	35.71	4	28.57	4	36.36	6	24.00

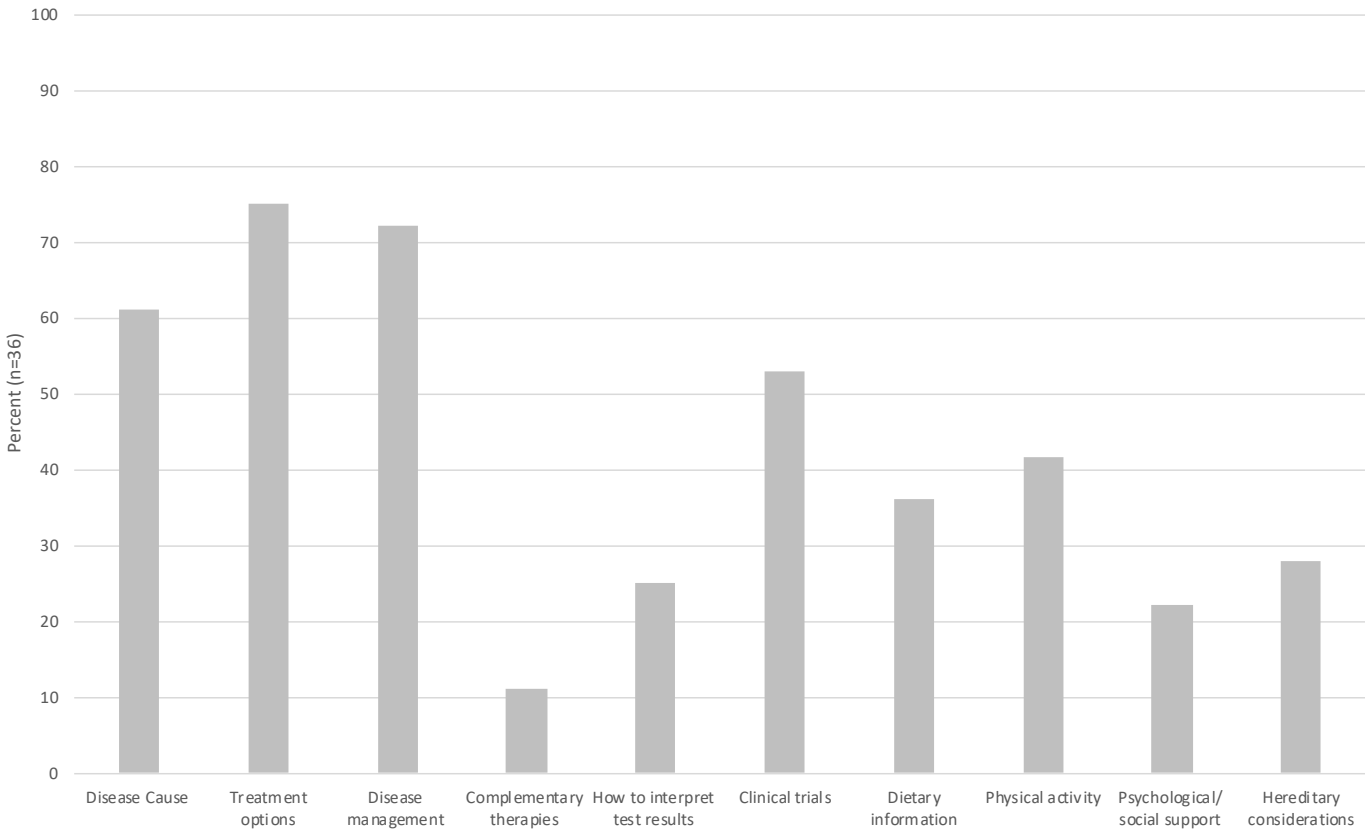


Figure 6.39: Information given by health professionals

Information searched independently

Participants were then asked, after receiving information from healthcare professionals, what information did they need to search for independently? Information about disease management (58.33%), disease cause (55.56%), and treatment options (55.56%) were most often searched for independently by participants. Psychological and social support (27.78%), and hereditary considerations (30.56%) were least searched for (Table 6.24, Figure 6.40).

In relation to subgroup variations, participants in the *ATTR-cardiac* (66.67%), *Metropolitan* (66.67%) and *Mid to low SEIFA* (72.73%) subgroups (71.43%) were searched for information about disease cause more often than the general population (55.56%), while participants in the *AL amyloidosis* (20.00%) subgroup searched for this information less often.

Female (71.43%) participants searched for information about treatment options more often than the general population (55.56%), while participants in the *AL amyloidosis* (30.00%), *Male* (45.45%), *Metropolitan* (44.44%) and *Trade or high school* (42.86%) subgroups searched for this information less often.

Participants in the *Aged 65 to 74* (47.37%), *Trade or high school* (42.86%) subgroups searched for information about Disease management less often than the general population (58.33%).

Participants in the *Female* (57.14%), *Mid to low SEIFA (54.55%)* subgroups searched for information about Complementary therapies more often than the general population (41.67%), while participants in the *AL amyloidosis* (20.00%*), Aged 65 to 74* (31.58%), *Trade or high school (*28.57%) searched for this information less often.

Participants in the *ATTR-cardiac* (61.11%), *Mid to low SEIFA* (72.73%) subgroups searched for information about clinical trials more often than the general population (50.00%), while *Female* participants (35.71%), searched for this information less often.

Participants in the *Mid to low SEIFA* (54.55%) subgroup searched for information about dietary information more often than the general population (38.89%).

Participants in the *Amyloidosis* (20.00%) subgroup searched for information about physical *activity* less often than the general population (36.11%).

Participants in the *Metropolitan* (44.44%) subgroup searched for information about psychological/social support more often than the general population (27.78%), while participants in the *ATTR-cardiac* (16.67%), *All cardiac* (16.00%), *AL amyloidosis* (10.00%) and *University* (7.14%) subgroups searched for this information less often.

Participants in the *Metropolitan* (44.44%), *Mid to low SEIFA* (54.55%) subgroups searched for information about hereditary considerations more often than the general population (30.56%), while participants in the *Higher SEIFA* (20.00%) subgroup, searched for this information less often.

Table 6.24: Information searched for independently

Information topic	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Metropolitan		Regional or remote	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=27	%	n=9	%
Disease Cause	20	55.56	12	66.67	14	56.00	2	20.00	6	75.00	11	50.00	9	64.29	6	66.67	14	51.85
Treatment options	20	55.56	10	55.56	13	52.00	3	30.00	7	87.50	10	45.45	10	71.43	4	44.44	16	59.26
Disease management	21	58.33	11	61.11	15	60.00	5	50.00	5	62.50	12	54.55	9	64.29	6	66.67	15	55.56
Complementary therapies	15	41.67	8	44.44	10	40.00	2	20.00	5	62.50	7	31.82	8	57.14	4	44.44	11	40.74
How to interpret test results	15	41.67	8	44.44	11	44.00	4	40.00	3	37.50	9	40.91	6	42.86	3	33.33	12	44.44
Clinical trials	18	50.00	11	61.11	14	56.00	4	40.00	3	37.50	13	59.09	5	35.71	5	55.56	13	48.15
Dietary information	14	38.89	6	33.33	9	36.00	4	40.00	4	50.00	9	40.91	5	35.71	4	44.44	10	37.04
Physical activity	13	36.11	7	38.89	9	36.00	2	20.00	4	50.00	8	36.36	5	35.71	3	33.33	10	37.04
Psychological/social support	10	27.78	3	16.67	4	16.00	1	10.00	6	75.00	5	22.73	5	35.71	4	44.44	6	22.22
Hereditary considerations	11	30.56	5	27.78	8	32.00	3	30.00	3	37.50	6	27.27	5	35.71	4	44.44	7	25.93

Information topic	All participants		Aged 55 to 64		Aged 65 to 74		Aged 74 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Disease Cause	20	55.56	8	100.00	10	52.63	2	25.00	7	50.00	7	50.00	8	72.73	12	48.00
Treatment options	20	55.56	6	75.00	11	57.89	2	25.00	6	42.86	7	50.00	7	63.64	13	52.00
Disease management	21	58.33	7	87.50	9	47.37	4	50.00	6	42.86	10	71.43	7	63.64	14	56.00
Complementary therapies	15	41.67	6	75.00	6	31.58	2	25.00	4	28.57	6	42.86	6	54.55	9	36.00
How to interpret test results	15	41.67	4	50.00	8	42.11	3	37.50	7	50.00	5	35.71	4	36.36	11	44.00
Clinical trials	18	50.00	6	75.00	8	42.11	3	37.50	8	57.14	7	50.00	8	72.73	10	40.00
Dietary information	14	38.89	5	62.50	8	42.11	0	0.00	5	35.71	5	35.71	6	54.55	8	32.00
Physical activity	13	36.11	4	50.00	6	31.58	2	25.00	4	28.57	5	35.71	5	45.45	8	32.00
Psychological/social support	10	27.78	2	25.00	7	36.84	1	12.50	3	21.43	1	7.14	3	27.27	7	28.00
Hereditary considerations	11	30.56	5	62.50	6	31.58	0	0.00	4	28.57	4	28.57	6	54.55	5	20.00

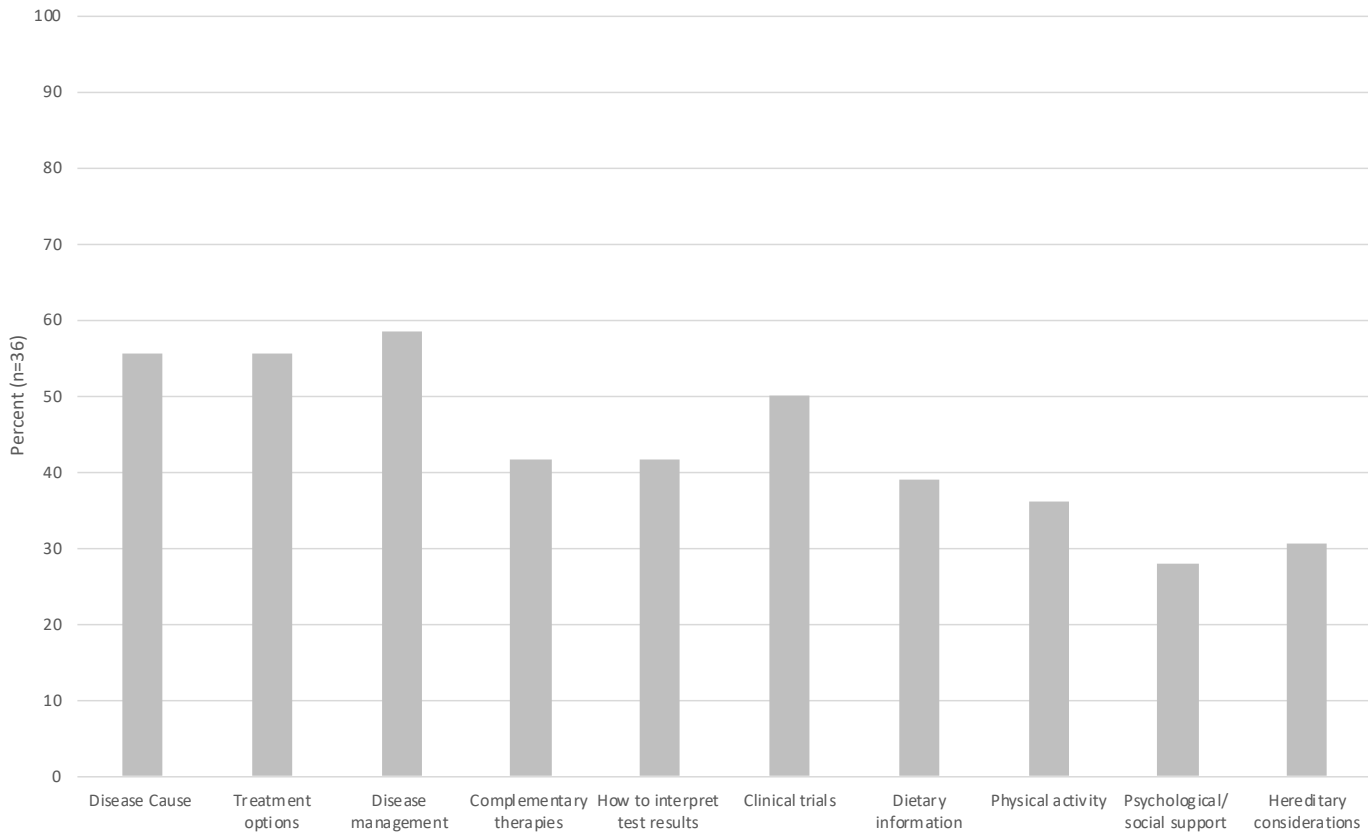


Figure 6.40: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were for psychological/social support (n=21, 58.33%), hereditary considerations genes or genomic biomarker information (n=21, 58.33%), and complementary therapies (n=20, 55.56%).

Participants were given most information either from healthcare professionals or independently for disease management (n=16, 44.44%), and treatment options (n=15, 41.67%). The topic that was most searched for independently following no information from health professionals was complementary therapies (n=12, 33.33%) (Table 6.25, Figure 6.41).

Table 6.25: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=36	%	n=36	%	n=36	%	n=36	%
Disease cause	4	11.11	12	33.33	10	27.78	10	27.78
Treatment options	4	11.11	12	33.33	15	41.67	5	13.89
Disease management	5	13.89	10	27.78	16	44.44	5	13.89
Complementary therapies	20	55.56	1	2.78	3	8.33	12	33.33
How to interpret test results	17	47.22	4	11.11	5	13.89	10	27.78
Clinical trials	9	25.00	9	25.00	10	27.78	8	22.22
Dietary information	14	38.89	8	22.22	5	13.89	9	25.00
Physical activity	15	41.67	8	22.22	7	19.44	6	16.67
Psychological/social support	21	58.33	5	13.89	3	8.33	7	19.44
Hereditary considerations	21	58.33	4	11.11	6	16.67	5	13.89

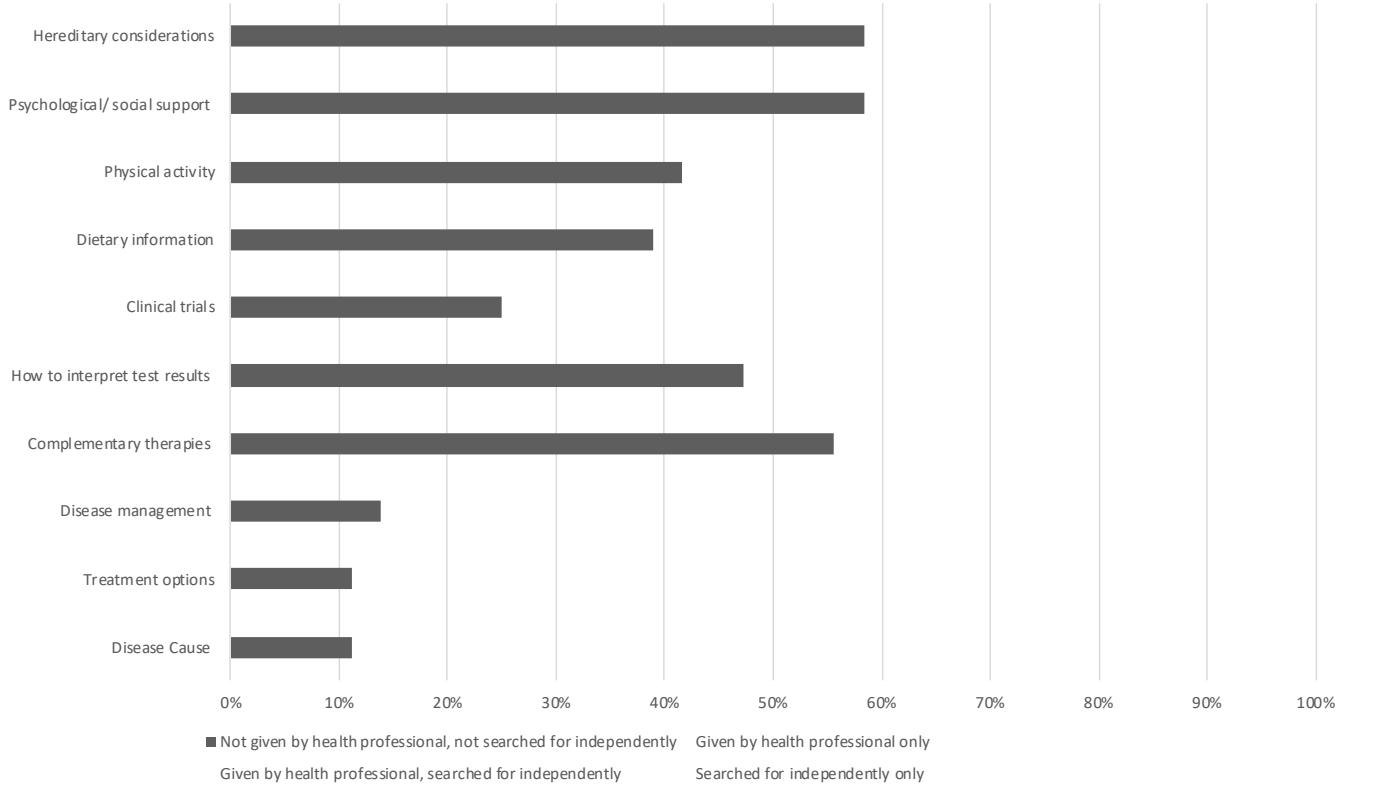


Figure 6.41: Information gaps

Accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Table 6.26 and Figure 6.42. With a weighted ranking, the higher the score, the more trusted the source of information to the participant.

Across all participants, information from the hospital or clinic where treated was most accessed, followed by information from non-profit or charities or patient organisations.

Table 6.26: Most accessed information

Information source	Weighted average (n=28)
Non-profit organisations, charity or patient organisations	3.14
Government	2.43
Pharmaceutical companies	2.89
Hospital or clinic I am being treated in	3.79
Medical journals	2.75

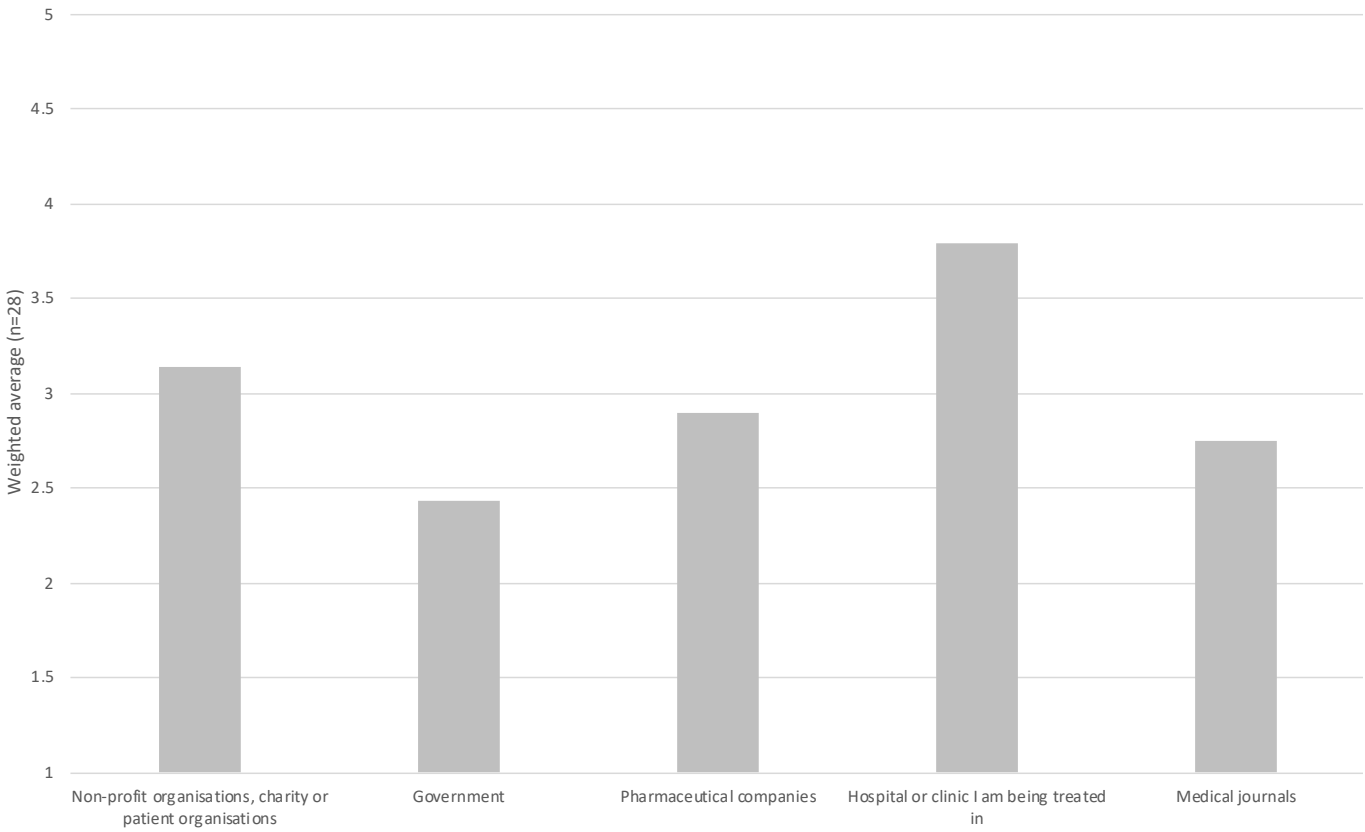


Figure 6.42: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were eleven participants (39.29%) that had accessed 'My Health Record', while 15 (53.57%) had not, two participants did not know what it is (7.14%), and four participants (4.00%) were not sure.

Of those that had accessed 'My Health Record', five participants (45.45%) found it good or acceptable, six participants (54.54%) found it poor, or very poor.

Table 6.27: Accessed 'My Health Record'

Accessed "My health record"	Number (n=28)	Percent
Yes	11	39.29
No	15	53.57
I am not sure	2	7.14

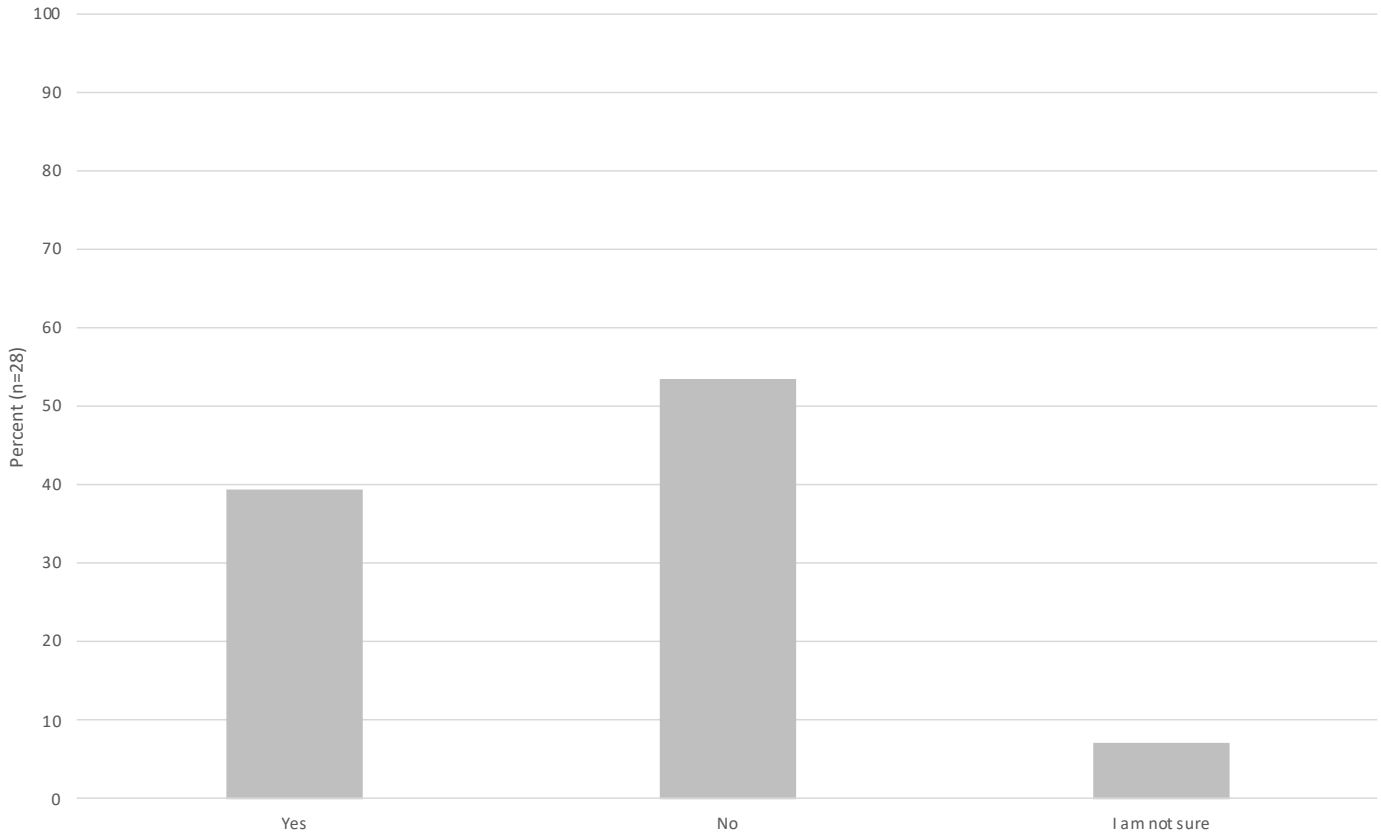


Figure 6.43: Accessed 'My Health Record'

Table 6.28: How useful was 'My Health Record'

How useful was "My health record"	Number (n=11)	Percent
Very poor	2	18.18
Poor	4	36.36
Acceptable	4	36.36
Good	1	9.09
Very good	0	0.00

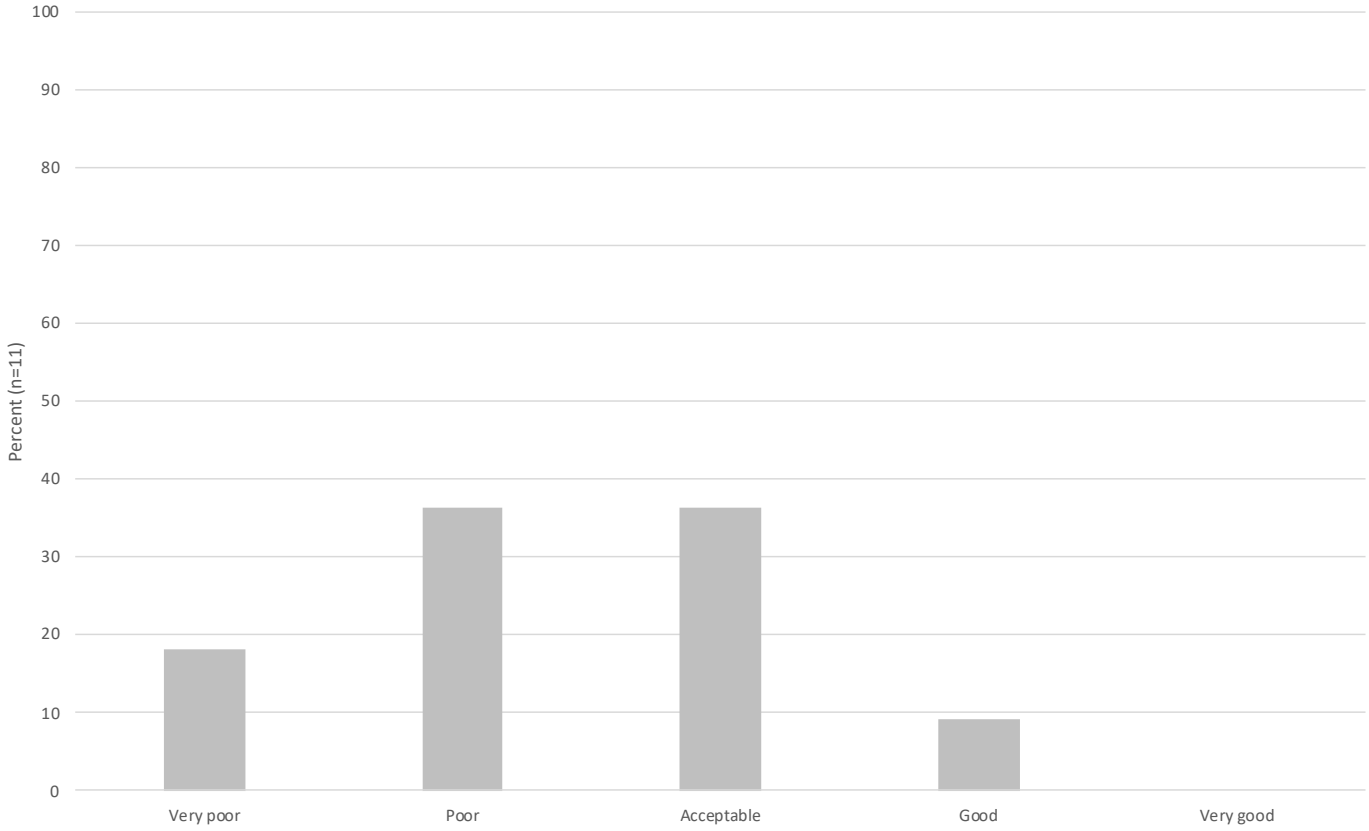


Figure 6.44: How useful was 'My Health Record'

Section 7

Care and support

Section 7 Summary: Care and support

Care coordination

- The **"Care coordination: communication"** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, the participants in this study scored in the middle of the scale, indicating that participants had moderate communication with healthcare professionals.

- The **"Care coordination: navigation"** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, the participants in this study had good navigation of the healthcare system.

- The **"Care coordination: total score"** scale measures communication, navigation and overall experience of care coordination. On average, participants in this study had very good communication, navigation and overall experience of care coordination.

- The **"Care coordination: care coordination global measure"** scale measures the participants overall rating of the coordination of their care. On average, participants in this study rated their care coordination as very good.

- The **"Care coordination: Quality of care global measure"** scale measures the participants overall rating of the quality of their care. On average, participants in this study rated their quality of care as excellent.

Experience of care and support

- In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most frequent description of care and support was family and friends (n=19, 52.78%). This was followed by receiving support through a hospital or clinical setting (n=14, 38.89%); through face-to-face peer support (n=10, 27.78%); through charities (n=7, 19.44%). There were seven participants that described finding or accessing support as challenging (19.44%).

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

Overall, the participants in this PEEK study had an average score in the highest quintile for **"Care coordination: Quality of care global measure"** (Median = 9.00, IQR = 1.00) indicating excellent quality of care.

On average, the scores for **"Care coordination: Navigation"** (Mean = 27.56, SD = 3.78), "**Care coordination: total score"** (Mean **=** 69.72, SD = 9.15), **"Care coordination: care coordination global measure"** (Median = 8.00, IQR = 2.00), were in the second highest quintile, indicating good navigation of the healthcare system, and overall care coordination.

On average, the score for "**Care coordination: communication"** (Mean = 42.17, SD = 7.11) was in the middle of the scale, indicating moderate communication.

The **"Care coordination: communication"** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, the participants in this study scored in the middle of the scale, indicating that participants had moderate communication with healthcare professionals.

The **"Care coordination: navigation"** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, the participants in this study had good navigation of the healthcare system.

The **"Care coordination: total score"** scale measures communication, navigation and overall experience of care coordination. On average, participants in this study had very good communication, navigation and overall experience of care coordination.

The **"Care coordination: care coordination global measure"** scale measures the participants overall rating of the coordination of their care. On average, participants in this study rated their care coordination as very good.

The **"Care coordination: Quality of care global measure"** scale measures the participants overall rating of the quality of their care. On average, participants in this study rated their quality of care as excellent.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=36)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	42.17	42.17	42.00	11.00	13 to 65	3
Navigation*	27.56	27.56	27.00	5.00	7 to 35	4
Total score*	69.72	69.72	72.00	12.50	20 to 100	4
Care coordination global measure	7.92	7.92	8.00	2.00	1 to 10	4
Quality of care global measure	8.44	8.44	9.00	1.00	1 to 10	5

*Normal distribution use mean and SD as measure of central tendency

Comparisons of Care coordination scales by Participant type

Participant type were grouped according to diagnosis. The *ATTR-cardiac* group includes participants diagnosed with hereditary or wild type ATTR (n=18, 50.00%). *All cardiac* includes all participants diagnosed with amyloidosis that have cardiac involvement, this group includes participants diagnosed with AL amyloidosis and ATTR (n=25, 64.44%).

The *AL amyloidosis* group includes all participants diagnosed with AL amyloidosis, including any organ involvement (n=10, 27.78%). The final participant type are *Carers* to people with any type of amyloidosis (n=8, 22.22%).

Boxplots of each Care coordination scale by **Participant type** are displayed in Figures 7.1-7.5, summary statistics are displayed in Tables 7.2 and 7.3.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.2).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.3). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal-Wallis test (Table 7.4).

A Kruskal-Wallis test indicated a statistically significant difference in the **"Care coordination: Navigation"** scale between groups, $\chi^2(3) = 9.05$, p = 0.0287. Wilcoxon rank sum tests between groups indicated that participants in the *All cardiac* subgroup (Median = 28.00, IQR = 5.00), scored significantly higher than participants in the *Carer* subgroup (Median = 24.00, IQR = 1.75, p = 0.0300), and participants in the *AL amyloidosis* subgroup (Median = 29.00, IQR = 3.50), scored significantly higher than participants in the *Carer* subgroup (Median = 24.00, IQR = 1.75, p = 0.0250).

A Kruskal-Wallis test indicated a statistically significant difference in the **"Care coordination: Total score"** scale between groups, $\chi^2(3) = 8.95$, p = 0.0220. Wilcoxon rank sum tests between groups indicated that participants in the *AL amyloidosis* subgroup (Median = 74.00, IQR = 3,25), scored significantly higher than participants in the *Carer* subgroup (Median = 61.00, IQR = 3.50, p = 0.0220).

The **"Care coordination: navigation"** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in the *All cardiac* and *AL amyloidosis* subgroups scored higher than participants in the *Carer* subgroup. However, all participants scored in the same range, this indicates that participants had good navigation of the healthcare system.

The **"Care coordination: total score"** scale measures communication, navigation and overall experience of care coordination. On average, participants in the *AL amyloidosis* subgroup scored higher than participants in the *Carer* subgroup. This indicates that participants in the *AL amyloidosis* subgroup, had very good communication, navigation and overall experience of care coordination, compared to moderate communication and navigation for participants in the *Carer* subgroup.

Table7.2: Care coordination by Participant type ANOVA test and summary statistics

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	ATTR-cardiac	18	50.00	42.17	8.49	Between groups	278.60	3	92.88	1.87	0.1440
	All-cardiac	25	69.44	43.12	7.42	Within groups	2826.40	57	49.59		
	AL amyloidosis	10	27.78	45.60	3.44	Total	3105.00	60			
	Carer	8	22.22	37.88	4.97						

Table 7.3: Care coordination by Participant type Kruskal-Wallis test and summary statistics

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	c^2	dF	p-value
Navigation	ATTR-cardiac	18	50.00	27.50	5.25	9.05	3	0.0287*
	All-cardiac	25	69.44	28.00	5.00			
	AL amyloidosis	10	27.78	29.00	3.50			
	Carer	8	22.22	24.00	1.75			
Total score	ATTR-cardiac	18	50.00	72.00	12.25	8.95	3	0.0299*
	All-cardiac	25	69.44	73.00	5.00			
	AL amyloidosis	10	27.78	74.00	3.25			
	Carer	8	22.22	61.00	3.50			
Care coordination global measure	ATTR-cardiac	18	50.00	8.50	1.00	5.02	3	0.1706
	All-cardiac	25	69.44	8.00	1.00			
	AL amyloidosis	10	27.78	8.50	1.00			
	Carer	8	22.22	6.50	2.50			
Quality of care global measure	ATTR-cardiac	18	50.00	9.00	1.00	0.06	2	0.9691
	All-cardiac	25	69.44	9.00	1.00			
	AL amyloidosis	10	27.78	9.00	1.50			
	Carer	8	22.22	8.00	2.00			

Table 7.4: Care coordination by Participant type post hoc pairwise Wilcoxon rank sum test

Care coordination scale	Type	ATTR-cardiac	All-cardiac	AL amyloidosis
Navigation	All-cardiac	0.8530	-	-
	AL amyloidosis	0.5830	0.5830	-
	Carer	0.0550	0.0300*	0.0250*
Total score	All-cardiac	0.6570	-	-
	AL amyloidosis	0.3030	0.3540	-
	Carer	0.1170	0.0550	0.0220*

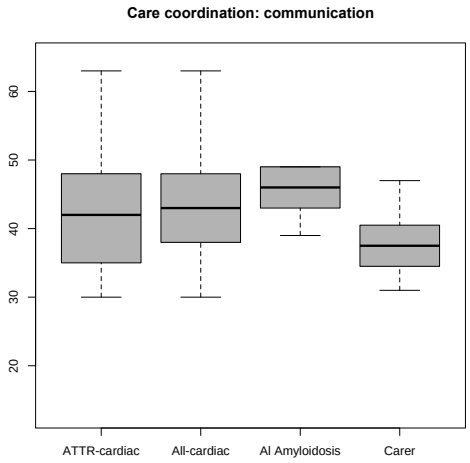


Figure 7.1: Boxplot of "Care coordination: Communication" by Participant type

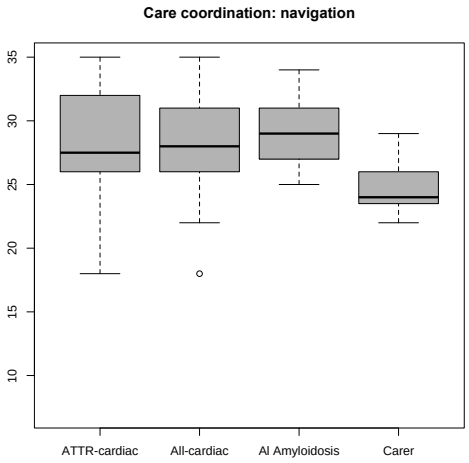


Figure 7.2: Boxplot of "Care coordination: Navigation" by Participant type

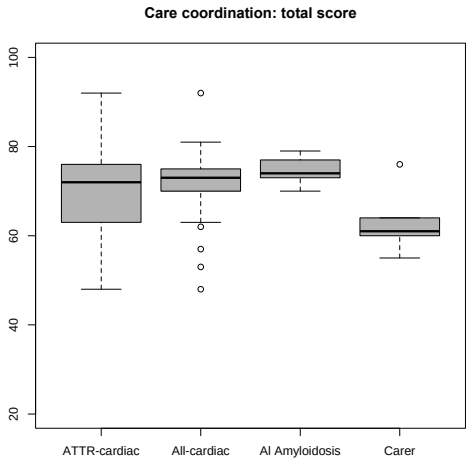


Figure 7.3: Boxplot of "Care coordination: Total score" by Participant type

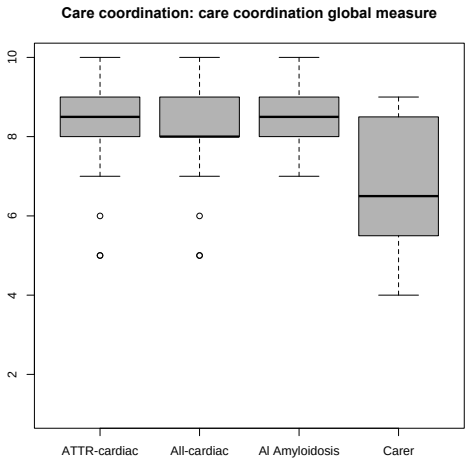


Figure 7.4: Boxplot of "Care coordination: Care coordination global measure" by Participant type

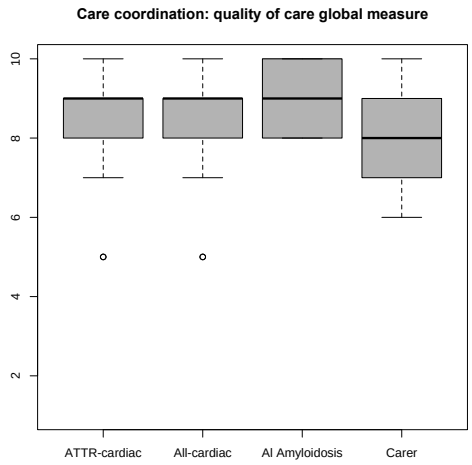


Figure 7.5: Boxplot of "Care coordination: Quality of care global measure" by Participant type

Comparisons of Care coordination scales by Gender

Comparisons were made by **Gender**, between *Males* (n=22, 61.11) and *Females* (n=14, 38.89%).

Boxplots of each Care coordination scale by **Gender** are displayed in Figures 7.6 to 7.10, summary statistics are displayed in Tables 7.5 to 7.6. A two-sample t-test was used when assumptions for normality and variance were met (Table 7.5), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.6).

A two sample t-test indicated that the mean score for the **"Care coordination Total score"** [t(34) = 2.21 p = 0.0341] was significantly higher for *Male* participants (Mean = 72.72, SD = 9.15) compared to *Female* participants (Mean = 65.71, SD = 7.88).

The "Care coordination: total score" scale measures communication, navigation and overall experience of care coordination. On average, *Male* participants in the scored higher than participants in the *Female* participants. This indicates that *Male* participants, had very good communication, navigation and overall experience of care coordination, compared to moderate communication and navigation for *Female* participants.

Table 7.5: Care coordination by Gender summary statistics and two sample t-test

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	t	dF	p-value
Communication	Female	14	38.89	39.29	5.70	2.02	34.00	0.0509
	Male	22	61.11	44.00	7.42			
Navigation	Female	14	38.89	26.43	3.50	1.45	34.00	0.1559
	Male	22	61.11	28.27	3.84			
Total score	Female	14	38.89	65.71	7.88	2.21	34.00	0.0341*
	Male	22	61.11	72.27	9.15			

Table 7.6: Care coordination by Gender summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	W	p-value
Care coordination global measure	Female	14	38.89	8.00	2.75	181.00	0.3725
	Male	22	61.11	8.00	1.00		
Quality of care global measure	Female	14	38.89	8.50	1.75	171.50	0.5684
	Male	22	61.11	9.00	1.00		

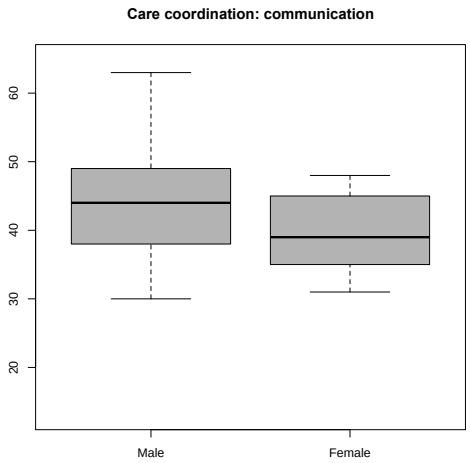


Figure 7.6: Boxplot of "Care coordination: Communication" by gender

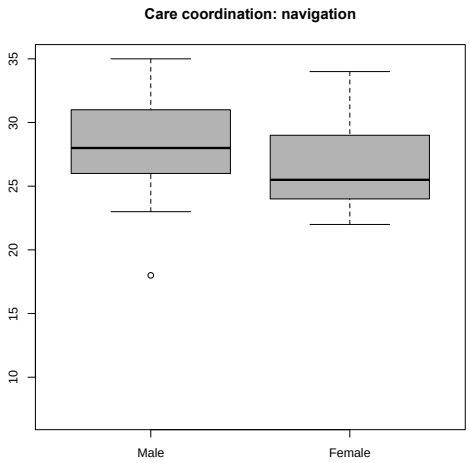


Figure 7.7: Boxplot of "Care coordination: Navigation" by gender

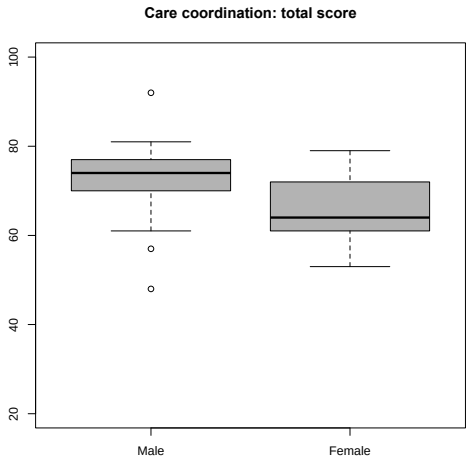


Figure 7.8: Boxplot of "Care coordination: Total score" by gender

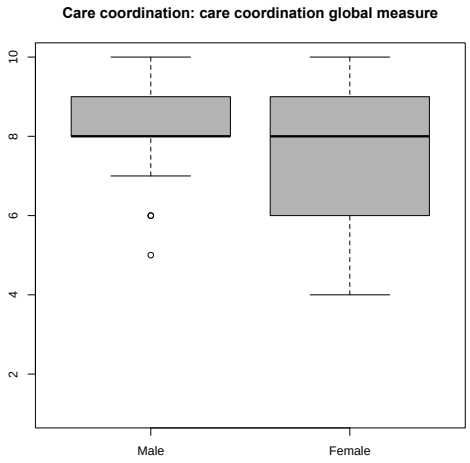


Figure 7.9: Boxplot of "Care coordination: Care coordination global measure" by gender

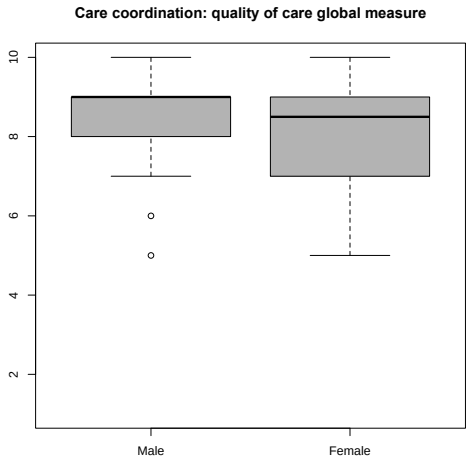


Figure 7.10: Boxplot of "Care coordination: Quality of care global measure" by gender

Comparisons of Care coordination scales by location

The **Location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics, those living in a major city, *Metropolitan* (n=27, 75.00%) were compared to those living in regional/rural areas, *Regional or remote* (n=9, 25.00%).

Boxplots of each Care coordination scale by **location** are displayed in Figures 7.11 to 7.15, summary statistics are displayed in Tables 7.7 to 7.8.
A two-sample t-test was used when assumptions for normality and variance were met (Table 7.7), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.8).

No significant differences were observed between participants in the *Regional or remote* subgroup compared to those in the *Metropolitan* subgroup for any of the Care coordination scales.

Table 7.7: Care coordination by location summary statistics and two sample t-test

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	9	25.00	41.67	6.00	-0.24	34	0.8115
	Metropolitan	27	75.00	42.33	7.54			
Navigation	Regional or remote	9	25.00	26.67	3.00	-0.81	34	0.4227
	Metropolitan	27	75.00	27.85	4.01			
Total score	Regional or remote	9	25.00	68.33	7.58	-0.52	34	0.6064
	Metropolitan	27	75.00	70.19	9.71			

Table 7.8: Care coordination by location summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	W	p-value
Care coordination global measure	Regional or remote	9	25.00	8.00	3.00	83.00	0.1500
	Metropolitan	27	75.00	8.00	1.00		
Quality of care global measure	Regional or remote	9	25.00	8.00	2.00	91.50	0.2652
	Metropolitan	27	75.00	9.00	1.50		

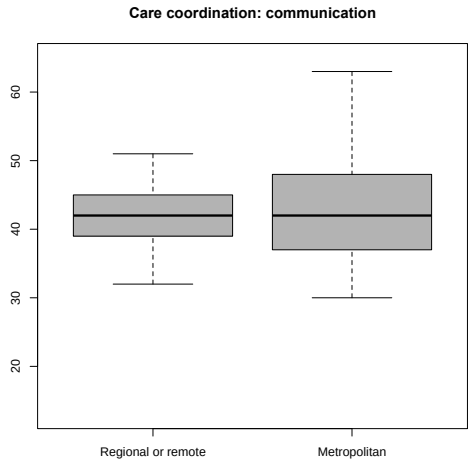


Figure 7.11: Boxplot of "Care coordination: Communication" by location

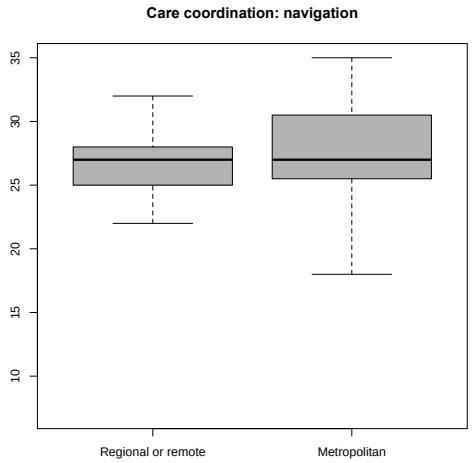


Figure 7.12: Boxplot of "Care coordination: Navigation" by location

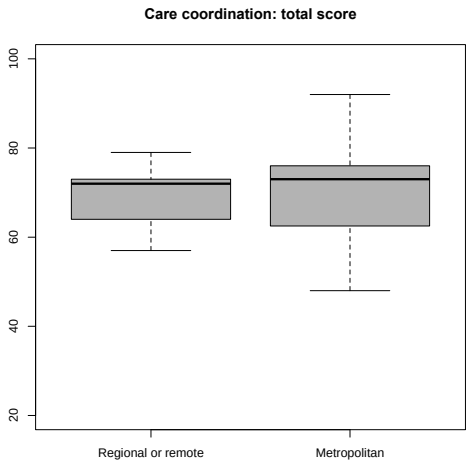


Figure 7.13: Boxplot of "Care coordination: Total score" by location

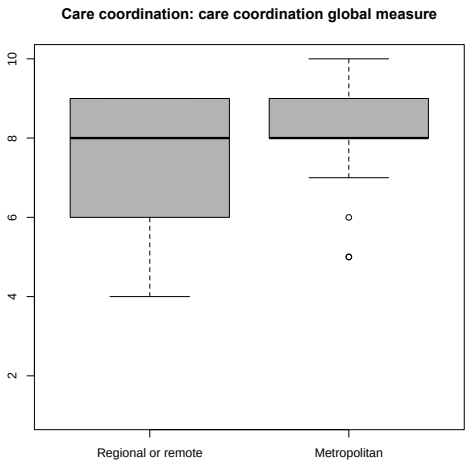


Figure 7.14: Boxplot of "Care coordination: Care coordination global measure" by location

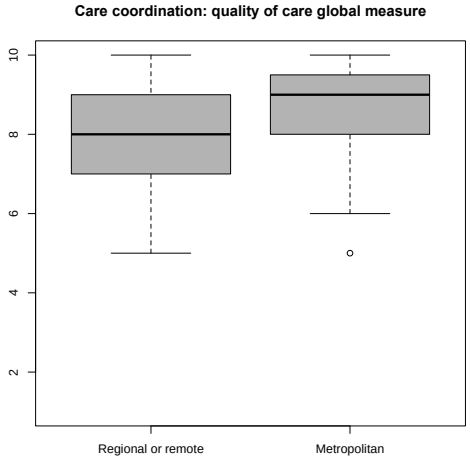


Figure 7.15: Boxplot of "Care coordination: Quality of care global measure" by location

Comparisons of Care coordination scales by age

Participants were groups according to **age,** with comparisons made between participants *Aged 55 to 64* (n=8, 22.86%), *Aged 65 to 74* (n=19, 54.29%), and *Aged 75 or older* (n=8, 22.86%). One participant was aged in the 25 to 34 year old age bracket and was excluded from age comparisons.

Boxplots of each Care coordination scale by **age** are displayed in Figures 7.16 to 7.20, summary statistics are displayed in Tables 7.9 and 7.10.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.9).

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.10).

No significant differences were observed between participants by age for any of the Care coordination scales.

Table 7.9: Care coordination by Age ANOVA test and summary statistics

Care coordination scale	Group	Number (n=35)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Navigation	Aged 55 to 64	8	22.86	25.63	5.42	Between groups	45.90	2	22.93	1.63	0.2120
	Aged 65 to 74	19	54.29	27.89	3.33	Within groups	450.50	32	14.08		
	Aged 75 or older	8	22.86	28.88	2.53	Total	496.40	34			

Table 7.10: Care coordination by Age Kruskal-Wallis test and summary statistics

Care coordination scale	Group	Number (n=35)	Percent	Mean	SD	c^2	dF	p-value
Navigation	*Aged 55 to 64*	8	22.86	33.50	11.00	5.69	2	0.0581
	Aged 65 to 74	19	54.29	43.00	9.50			
	Aged 75 or older	8	22.86	46.00	9.25			
Total score	*Aged 55 to 64*	8	22.86	60.50	16.00	5.10	2	0.0779
	Aged 65 to 74	19	54.29	73.00	12.50			
	Aged 75 or older	8	22.86	73.00	6.75			
Care coordination global measure	*Aged 55 to 64*	8	22.86	8.00	1.50	0.80	2	0.6705
	Aged 65 to 74	19	54.29	8.00	1.50			
	Aged 75 or older	8	22.86	8.50	1.25			
Quality of care global measure	*Aged 55 to 64*	8	22.86	8.00	1.50	0.24	2	0.8884
	Aged 65 to 74	19	54.29	9.00	1.00			
	Aged 75 or older	8	22.86	8.50	2.25			

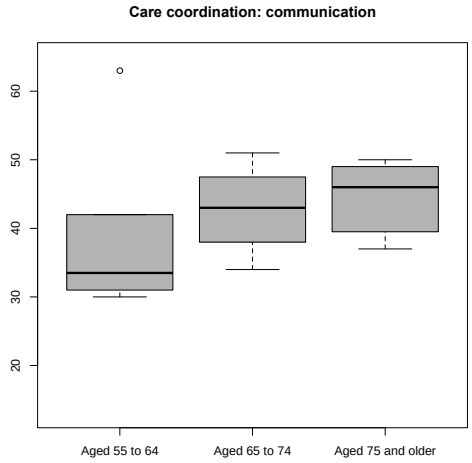


Figure 7.16: Boxplot of "Care coordination: Communication" by age

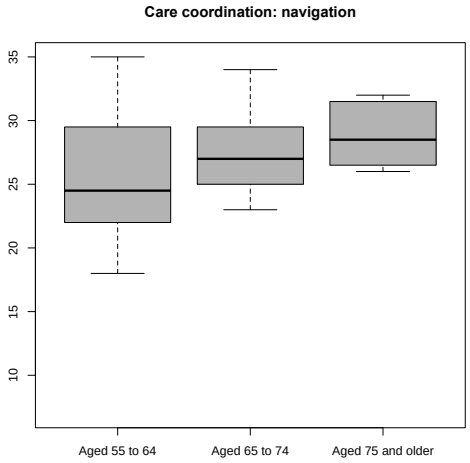


Figure 7.17: Boxplot of "Care coordination: Navigation" by age

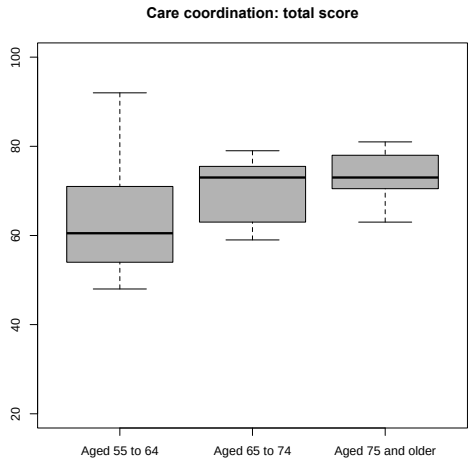


Figure 7.18: Boxplot of "Care coordination: Total score" by age

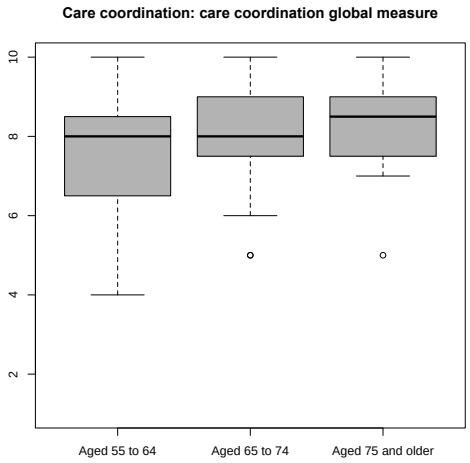


Figure 7.19: Boxplot of "Care coordination: Care coordination global measure" by age

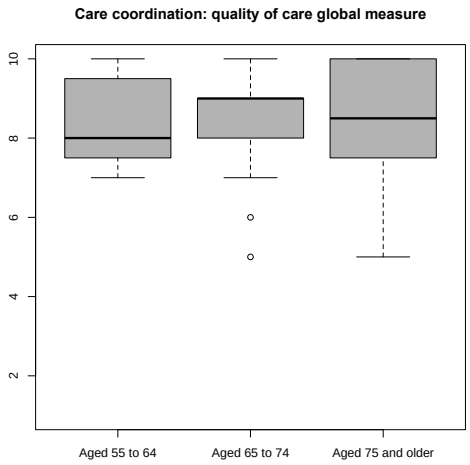


Figure 7.20: Boxplot of "Care coordination: Quality of care global measure" by age

Comparisons of Care coordination scales by education

Education status was collected only for participants diagnosed with amyloidosis (n=28). Comparisons were made by **education** status, between those with a university qualification, *University* (n= 14, 50.00%), and those with trade or high school qualifications, *Trade or high school* (n=14, 50.00%).

Boxplots of each Care coordination scale by **education** are displayed in Figures 7.21 to 7.25, summary statistics are displayed in Tables 7.11 to 7.12.

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.11), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.12).

No significant differences were observed between participants in the *Trade or high school* subgroup compared to those in the university subgroup for any of the Care coordination scales.

Table 7.11: Care coordination by education summary statistics and two sample t-test

Care coordination scale	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Communication	Trade or high school	14	50.00	42.21	6.60	-0.86	26	0.3977
	University	14	50.00	44.57	7.85			
Navigation	Trade or high school	14	50.00	27.71	4.03	-0.90	26	0.3760
	University	14	50.00	29.00	3.51			

Table 7.12: Care coordination by education summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=28)	Percent	Median	IQR	W	p-value
Total score	Trade or high school	14	50.00	71.50	7.75	66.00	0.1463
	University	14	50.00	74.50	6.00		
Care coordination global measure	Trade or high school	14	50.00	9.00	1.00	112.00	0.5144
	University	14	50.00	8.00	1.00		
Quality of care global measure	Trade or high school	14	50.00	9.00	1.75	91.50	0.7742
	University	14	50.00	9.00	1.00		

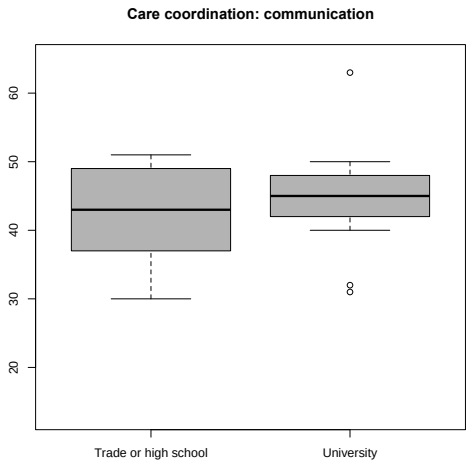


Figure 7.21: Boxplot of "Care coordination: Communication" by education

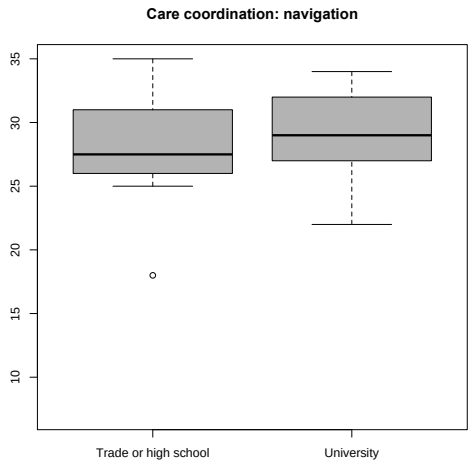


Figure 7.22: Boxplot of "Care coordination: Navigation" by education

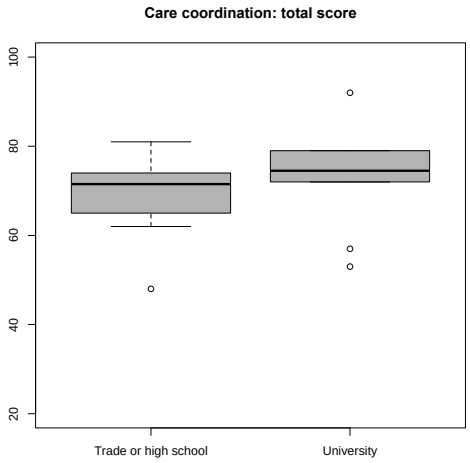


Figure 7.23: Boxplot of "Care coordination: Total score" by education

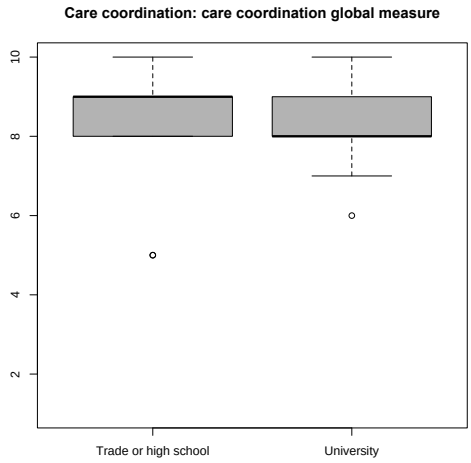


Figure 7.24: Boxplot of "Care coordination: Care coordination global measure" by education

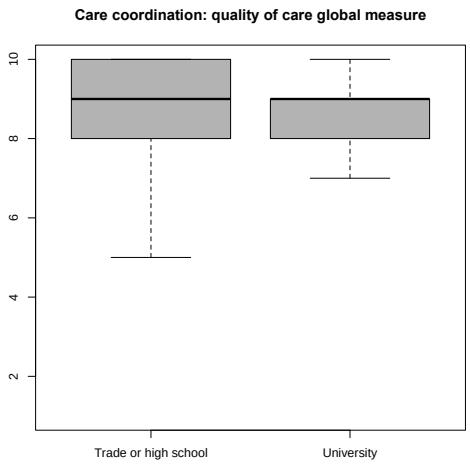


Figure 7.25: Boxplot of "Care coordination: Quality of care global measure" by education

Comparisons of Care coordination scales by SEIFA

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10, *Higher SEIFA* (n=25, 69.44%) compared to those with a mid to low SEIFA score of 1-6, *Mid to low SEIFA* (n=11, 30.56%).

Boxplots of each Care coordination scale by **SEIFA** are displayed in Figures 7.26 to 7.30, summary statistics are displayed in Tables 7.13 to 7.14.

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.13), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.14).

No significant differences were observed between participants in the *Mid to low SEIFA* subgroup compared to those in the *Higher SEIFA* subgroup for any of the Care coordination scales.

Table 7.13: Care coordination by SEIFA summary statistics and two sample t-test

Care coordination scale	Group	Number (n=36)	Percent	Mean	SD	T	dF	p-value
Communication	Mid to low SEIFA	11	30.56	42.55	5.99	0.21	34	0.8356
	Higher SEIFA	25	69.44	42.00	7.66			
Navigation	Mid to low SEIFA	11	30.56	28.27	4.13	0.75	34	0.4576
	Higher SEIFA	25	69.44	27.24	3.65			
Total score	Mid to low SEIFA	11	30.56	70.82	7.41	0.47	34	0.6405
	Higher SEIFA	25	69.44	69.24	9.93			

Table 7.14: Care coordination by SEIFA summary statistics and Wilcoxon rank sum tests with continuity correction

Care coordination scale	Group	Number (n=36)	Percent	Median	IQR	W	p-value
Care coordination global measure	Mid to low SEIFA	11	30.56	9.00	3.00	135.50	0.9574
	Higher SEIFA	25	69.44	8.00	1.00		
Quality of care global measure	Mid to low SEIFA	11	30.56	9.00	1.50	123.00	0.6191
	Higher SEIFA	25	69.44	9.00	1.00		

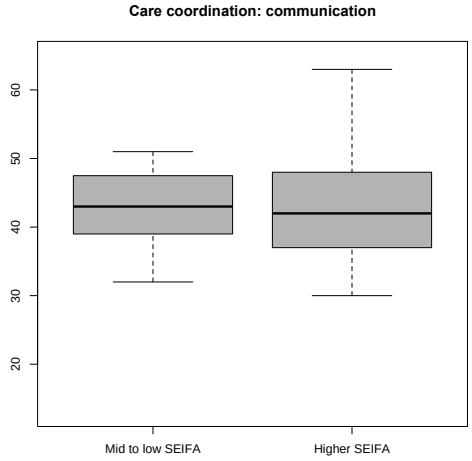


Figure 7.26: Boxplot of "Care coordination: Communication" by SEIFA

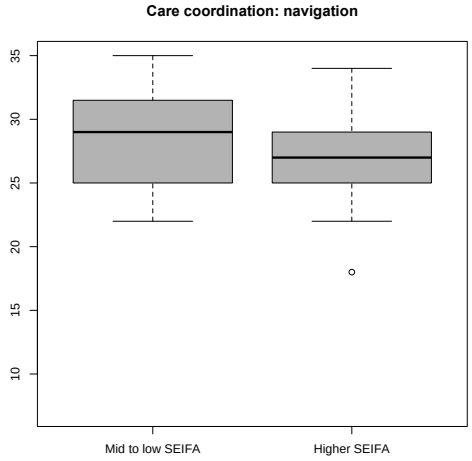


Figure 7.27: Boxplot of "Care coordination: Navigation" by SEIFA

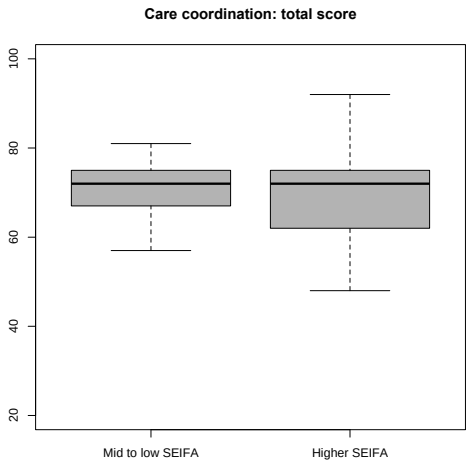


Figure 7.28: Boxplot of "Care coordination: Total score" by SEIFA

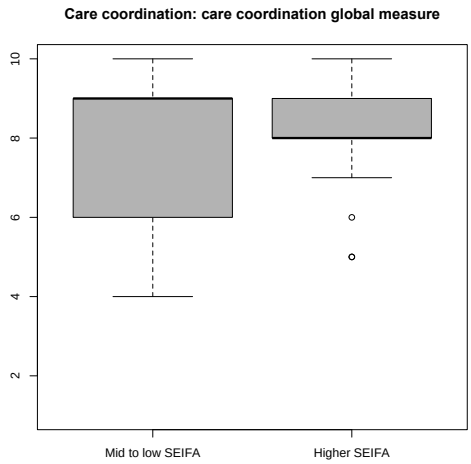


Figure 7.29: Boxplot of "Care coordination: Care coordination global measure" by SEIFA

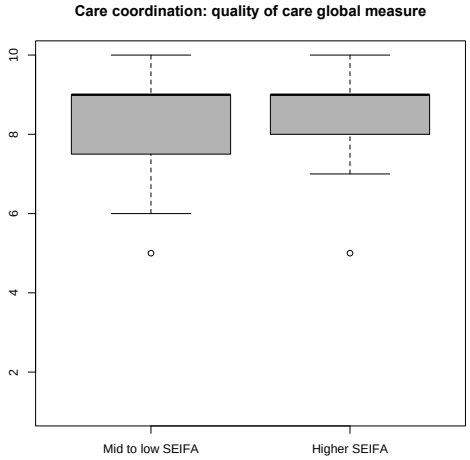


Figure 7.30: Boxplot of "Care coordination: Quality of care global measure" by SEIFA

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services.

The most common description of care and support was family and friends (n=19, 52.78%). This was followed by receiving support through a hospital or clinical setting (n=14, 38.89%); through face-to-face peer support (n=10, 27.78%); through charities (n=7, 19.44%). There were seven participants described the challenges of finding or accessing support (19.44%).

In relation to subgroup variations, participants in the *Carer* (37.50%), and *Aged 65 to 74* (42.11%) subgroups described receiving support from family and/or friends less frequently than the general population (52.78%), while those in the *Aged 75 or older* (75.00%), *Trade or high school* (64.29%), and *Mid to low SEIFA* (63.64%) subgroups described this more frequently.

Participants in the *Aged 65 to 74* (52.63%), *University* (57.14%), and *Regional or remote* (55.56%) subgroups described receiving support from a hospital or clinical setting more frequently than the general population (38.89%), while those in the subgroups *Aged 55 to 64* (25.00%), *Aged 75 or older* (12.50%) and *Trade or high school* (21.43%) described this less frequently.

Participants in the *AL amyloidosis* (70.00%) subgroup described receiving support through peer support more frequently than the general population (27.78%), while those in the subgroups *ATTR-cardiac* (5.56%), *Aged 55 to 64* (12.50%), and *Regional or remote* (11.11%) described this less frequently.

Participants in the *AL amyloidosis* (30.00%), *Regional or remote* (44.44%), and *Mid to low SEIFA* (45.45%) described receiving support through charities more frequently than the general population (19.44%), while those in the *Higher SEIFA* (8.00%) subgroup described it less frequently.

Participants in the *University* (35.71%) subgroup described the challenged of finding or accessing support more frequently than the general population (19.44%), while those in the *Trade or high school* (7.14%), and *Mid to low SEIFA* (9.09%) subgroups described this less frequently.

Family/friends

Well, I haven't needed any support or care from the outside. I just generally got my normal family support. My family is concerned, and they're a little bit in the dark about the long-term situation as well. But it's like any illness, terminal or chronic. It's just what life deals out to you sometimes. So, I haven't required any external help and support because I've not needed it because I'm early in the diagnosis. Participant 001ATR

Most of it's been from my wife. Certainly, the church I attended in LOCATION considered me to be their miracle. I had tremendous support from the people there, I've had great support from friends and family in that period. Participant 002ALX

Since I have been diagnosed, I've gotten support mainly from many friends and family. Friends that we got a long relationship with or some new as well that are like-minded in terms of helping me out. Participant 002ATR

Charities

Friends of Amyloid, that we call it-- I look after NAME HOSPITAL Friends of Amyloid. We've got a couple of sub—I ORGANISE EVENTS for NAME HOSPITAL. I wouldn't be going over my head by saying that. There's another lady who organises three-monthly morning tea. We have, let's see, Leukaemia Foundation, who also have amyloid patients. We have a morning tea combined with every three months, and we all-- It's for patients and carers, husbands and wives. Participant 005AL

The Amyloidosis Association has been our biggest support when we need something. Like what I had said, my family has been brilliant. Participant 009ATR

Only in as much as participating workshops and events and talking to other people with similar conditions. Participant 011ATR

Hospital or clinical setting

NAME CLINIC, they have various seminars, et cetera, that I attend and also help organise or coordinate the support group which we meet every two months under the banner of NAME CLINIC. I find that helpful just talking to people without doing specifics, just talk to see how we're going, et cetera. Participant 001ALX

No, we haven't had any extra really. It's really been specialists and he's had to occasionally have a GP visit, but no, we haven't resorted to any other care at this stage at all. Participant 001CA

Well, medical that's really it. Participant 002CA

Peer support (Face-to-face)

Both of wife and myself have been going to things, morning teas usually by the Leukaemia Foundation. Also, our own group where we just have the amyloidosis group. As I said, we have morning teas in various places. We have 20, 30 people turn up to those. People have got different problems and that's done as a round table. A few lies are told and a few laughs and [unintelligible 00:41:18] as well or had. It's quite a supportive group really and we send the emails to one another. My wife's involved with all of those things. The kids, obviously, aren't because they're working and they're not here in LOCATION REGIONAL. Participant 003AL

My husband is supportive. It's just the two of us at home now. With the support group I've maybe been to two of them I suppose. The social support group has been incredibly supportive. Really wonderful. I'll come away feeling quite uplifted really just the camaraderie is amazing really, the general sort of we're in this together, we'll support each other, we'll pull through somehow or rather and those who eventually won't pull through, the support is amazing. It's lovely. It's just really lovely.

Probably my main support would be those groups, amyloid groups. Participant 003ALX

Now, I know that NAME HUSBAND really enjoys the amyloid group that gets together and that's really important to him. It's really important that he didn't feel alone because it is rare, it's hard to find anybody that knows anything about it. I know that if ever we went to a doctor, we'd have to explain to them what it was all about because at that stage, they had no idea. That group has been really, really important to NAME HUSBAND. Participant 003CA

Challenges of finding or accessing support

I think the answer is that there is almost more that could be done to assist us. Just to provide better assistance. Because life always has to explain to different aspects in the situation and everybody also is different will be affected in different ways. Just a matter, again, to discover what is going on inside and also doctor patients may we require further assistance. Participant 005ATR

The trouble with accessing psychological services in this country is they're extremely expensive. I think NAME HUSBAND might have said when he was speaking to you that he's a psychologist. Actually, when I told him that I wanted to speak to a psychologist, he said, 'Oh, you can speak to me.' He's completely missing the point that it was him I needed to talk about. I think that's the main barrier, is that the cost barrier and it takes a long time to-- I saw somebody at the very beginning and then I didn't feel I was getting anywhere, so, I was fine, then I went through another difficult patch. I guess as you adjust to the changes in your relationship because that changes completely, it's not husband or wife anymore. Your physical relationship has changed because one of you is telling the other all the time what to do and what they shouldn't do. Participant 002CA

Yes, care is a really important thing. I think the system is there, but I don't think there's enough money in it to allow people to do the things that they need to do. I've been assessed by the aged care people. Once I-- she walked in and looked at me like, 'I could tell. What's wrong with you? You're just looking for some handouts.' Participant 013ATR

Table 7.15: Experience of care and support

Care and support received	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes receiving support from family/friends	19	52.78	11	61.11	14	56.00	5	50.00	3	37.50	11	50.00	8	57.14	5	55.56	14	51.85
Participant describes receiving support from a hospital or clinical setting	14	38.89	7	38.89	10	40.00	4	40.00	3	37.50	9	40.91	5	35.71	5	55.56	9	33.33
Participant describes receiving support through peer support (Face-to-face)	10	27.78	1	5.56	5	20.00	7	70.00	2	25.00	6	27.27	4	28.57	1	11.11	9	33.33
Participant describes receiving support through charities	7	19.44	3	16.67	6	24.00	3	30.00	1	12.50	5	22.73	2	14.29	4	44.44	3	11.11
Participant describes challenges of finding or accessing support	7	19.44	5	27.78	6	24.00	1	10.00	1	12.50	5	22.73	2	14.29	1	11.11	6	22.22

Care and support received	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes receiving support from family/friends	19	52.78	5	62.50	8	42.11	6	75.00	9	64.29	7	50.00	7	63.64	12	48.00
Participant describes receiving support from a hospital or clinical setting	14	38.89	2	25.00	10	52.63	1	12.50	3	21.43	8	57.14	5	45.45	9	36.00
Participant describes receiving support through peer support (Face-to-face)	10	27.78	1	12.50	6	31.58	3	37.50	3	21.43	5	35.71	2	18.18	8	32.00
Participant describes receiving support through charities	7	19.44	1	12.50	5	26.32	1	12.50	4	28.57	2	14.29	5	45.45	2	8.00
Participant describes challenges of finding or accessing support	7	19.44	2	25.00	3	15.79	2	25.00	1	7.14	5	35.71	1	9.09	6	24.00

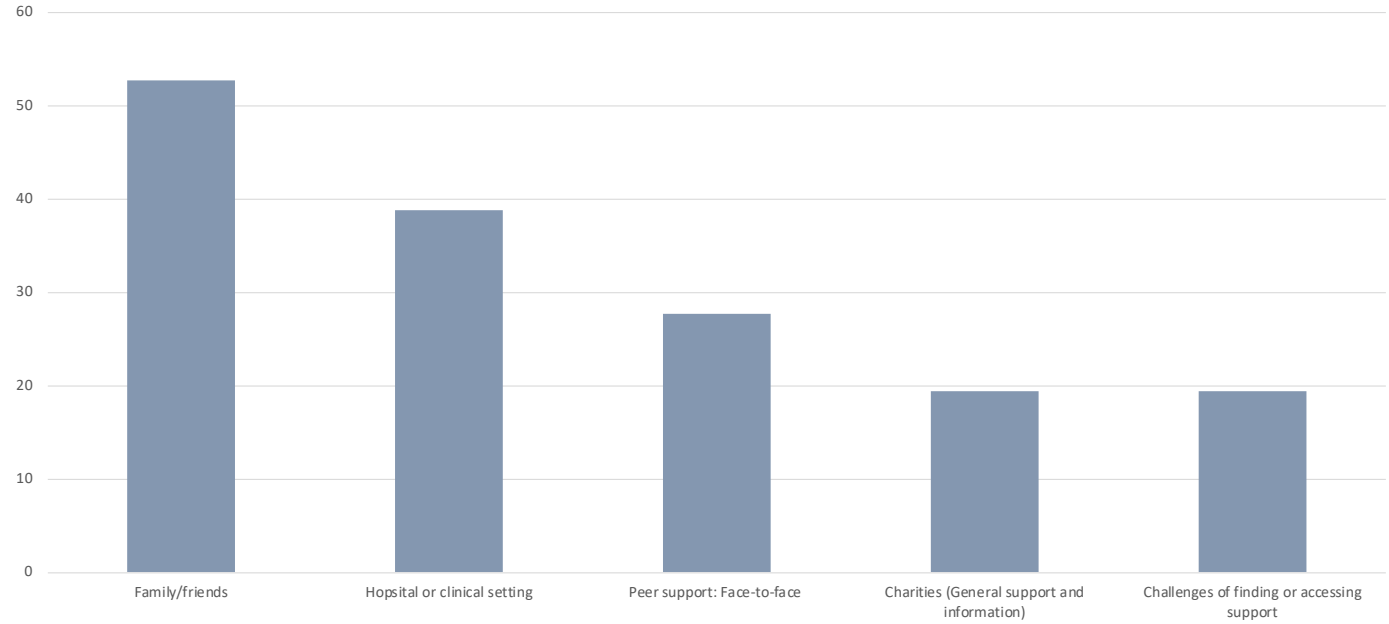


Figure 7.31: Experience of care and support

Section 8

Quality of life

Section 8 Summary: Quality of life

Experience of quality of life

- In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 19 participants (52.78%) that described a negative impact on quality of life and seven participants (19.44%) that felt that there had been minimal impact on their quality of life. The most common themes in relation to having a negative impact on quality of life included a reduced capacity for physical activity (n=15, 41.67%) and emotional strain on family or a change in relationship dynamics (n=13, 36.11%). There were also eight participants (22.22%) that described a negative impact as they are unable to travel or need to adapt significantly in order to travel. In addition, six participants (16.67%) described a negative impact as a result of fatigue, and another six (16.67%) noted a negative impact due to reduced social interaction. There were four participants (11.11%) that described a negative impact on their quality of life due to an inability to work or needing to make changes with their work.

Impact on mental health

- In the structured interview, participants were asked to share any impact on their emotional and mental health as a result of their condition. The most common theme that participants reported was experiencing at least some impact on their mental and emotional health (n=20, 55.56%). There were also seven participants (19.44%) that described experiencing no impact on their mental and emotional health overall.

Regular activities to maintain mental health

- In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common way that participants reported managing their mental and emotional health was by using coping strategies such as remaining social, making lifestyle changes or having hobbies (n=10, 27.78%). There were nine participants (25.00%) that described the importance of physical exercise in maintaining their mental health and seven (19.44%) that described the importance of family and friends in this endeavour. Other common themes included consulting a mental health professional (n=6, 16.67%), experiencing an impact but not using any activities to maintain their mental health (n=5, 13.89%) and not doing any activities to maintain their mental health as they have experienced no impact (n=4, 11.11%).

Regular activities to maintain health

- In the structured interview, participants were asked to share some of the things they needed to do every day to maintain their health. The most common way that participants reported managing their health was by understanding their limitations (n=15, 41.67%). There were 10 participants (27.78%) that described staying physically active and nine (25.00%) that described the importance of complying with treatment. Other common themes included maintaining a healthy diet (n=7, 19.44%) and the importance of self-care, for example getting more rest or seeking support for housework (n=5, 13.89%).

Impact on relationships

- In the structured interview, participants were asked whether their condition had affected their personal relationships. The most common themes in relation to impact on relationships was participants describing their relationships with family being strengthened (n=6, 16.67%) and experiencing changing dynamics in their relationships due to added anxiety, exacerbations and/or physical limitations (n=6, 16.67%).

- Overall, there were nine participants (25.00%) that described a negative impact on relationships, eight participants (22.22%) that reported a positive impact on relationships and seven participants (19.44%) that felt that relationships had not been impacted. There were also five participants (13.89%) who noted an impact on their relationships but did not feel it was positive or negative overall.

Burden on family

- In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Where participants described there was no additional burden, this was primarily described in general terms, with no specific examples provided (n=11, 30.56%). On the other hand, where participants felt there was an additional burden, this was primarily described in relation to the additional mental or emotional strain placed on their family (n=7, 19.44%), the extra household duties and responsibilities their family needed to take on (n=6, 16.67%) and as a burden in general, with no specific examples (n=4, 11.11%).

- Overall, there were 16 participants (44.44%) that felt there was an additional burden and 11 participants (30.56%) that reported no additional burden.

Experience of anxiety related to disease progression

- The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Overall the participants had a mean total score of 33.19 (SD = 9.92), which corresponds to moderate levels of anxiety.

Experience of quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 19 participants (52.78%) that described a negative impact on quality of life and seven participants (19.44%) that felt that there had been minimal impact. The most common themes in relation to having a negative impact on quality of life included a reduced capacity for physical activity (n=15, 41.67%) and emotional strain on family or a change in relationship dynamics (n=13, 36.11%). There were also eight participants (22.22%) that described a negative impact as they are unable to travel or need to adapt significantly in order to travel. In addition, six participants (16.67%) described a negative impact as a result of fatigue, and another six (16.67%) noted a negative impact due to reduced social interaction. There were four participants (11.11%) that described a negative impact on their quality of life due to an inability to work or needing to make changes with their work and four participants (19.44%) who described a minimal impact but didn't specify a reason.

In relation to subgroup variations, participants in the *AL amyloidosis* (30.00%), *Carer* (12.50%), *Aged 55 to 64* (25.00%), *Aged 75 or older* (25.00%), and *Female* (28.57%) subgroups described a negative impact on their quality of life as a result of reduced physical activity less frequently than the general population (41.67%), while those in the *ATTR-cardiac* (61.11%), *All-cardiac* (52.00%), *Aged 65 to 74* (52.63%), and *Mid to low SEIFA* (54.55%) subgroups described this more frequently.

Participants in the *AL amyloidosis* (20.00%), *Aged 75 or older* (25.00%), and *Trade or high school* (21.43%) subgroups described experiencing a negative impact as the result of emotional strain on their family or a change in relationship dynamics less frequently than the general population (36.11%), while those in the *Carer* (50.00%) subgroup described this more frequently.

Those in the *ATTR-cardiac* (33.33%) and *Regional or remote* (33.33%) subgroups described a negative impact on their quality of life as a result of being unable to travel or needing to make significant adaptations in order to travel more frequently than the general population (22.22%), whereas participants in the *AL amyloidosis* subgroup did not describe this at all.

Participants in the *Aged 65 to 74* (31.58%) subgroup described experiencing a negative impact as a result of fatigue more frequently than the general population (16.67%). No participants in the *Carer* (0.00%)*, Aged 55 to 64* (0.00%)*,* or *Aged 75 or older* (0.00%) subgroups.

Participants in the *Female* (28.57%). subgroup describe a negative impact on their quality of life as a result of reduced social interactions more frequently than the general population (16.67%). Participants in the *Aged 75 or older (0.00%)* subgroup did not describe this at all.

Those in the *Female* (21.43%) subgroup described a negative impact on their quality of life as a result of an inability to work or changes with their work more frequently than the general population (11.11%). Participants in the *AL amyloidosis* (00.00%), *Aged 75 or older* (0.00%), or *Regional or remote* (0.00%) subgroups did not describe this at all.

Participants in the *Aged 75 or older* (25.00%), and *Trade or high school* (21.43%) subgroups described experiencing a minimal impact on their quality of life ore frequently than the general population (11.11%), whereas participants in the *Carer* (0.00%), and *Mid to low SEFIA* (0.00%) subgroups did not describe this at all.

Overall, participants in the *AL amyloidosis* (40.00%), *Aged 55 to 64* (37.50%), and *Aged 75 or older* (25.00%) subgroups described a negative impact on their quality of life less frequently than the general population (52.78%), whereas those in the *Aged 65 to 74* (68.42%) subgroup described this more frequently.

Participants in the *Mid to low SEIFA* (9.09%) subgroup described a minimal impact on quality of life less frequently than the general population (19.44%), whereas those in the *AL amyloidosis* (30.00%), and *Aged 75 or older* (50.00%) subgroups described this more frequently. Participants in the *Carer* (0.00%) subgroup did not describe this at all.

Negative impact: Reduced capacity for physical activity

My main issue is I don't have my energy levels. I tire very quickly. I've now designed-- I do things in the morning. In the afternoons, I don't normally plan to do much because I often have a rest, et cetera. One surprising thing is, this is a mystery to everybody, I can't walk very far without the aid of a walking stick or something. I have now managed to walk five kilometres every Saturday morning with ParkRun with two walking poles. At the end of it, I am very knackered, and I have rest for an hour or two afterwards to recover. Participant 001ALX

We rarely go anywhere, we can't walk very fast, and he's very tired very quickly, and he has to go to bed with because he's just lazy but out we can't-- We really can't do anything. I tried taking him on a cruise boat Christmas. We were restricted to the ship because he couldn't get on and off the stages because of his instability. He has to rest a lot; he can't do a lot anymore. He's very tired very quickly. Participant 009ATR

Look, there's so many things, I just keep kicking off things that I can't do anymore, and gardening is starting to become difficult and I'm a very keen gardener. My wife keeps saying we'll get someone in to do that and I say, 'Well, how can I do that? Can I stand there, tell him exactly which branches I want cut?' I still want to do all that. Participant 013ATR

Negative impact: Emotional strain on family/ change in family dynamics

Emotionally, it was quite a challenge because I had to walk fairly carefully as to when I talked about things, and when I knew just to leave things alone. It required a lot of respect for one another. Participant 001CA

For the families, they give them a lot of observing to do. They don't know what to do because there's so many conditions that they can't even keep track of. Medication and steps, so I'll deal with the medication that I take. If I say no sugar, if I'm going through and take this drink--. If I have diarrhoea, I'll take a drink with some glucose. All the time, they are coming along, but they find it cumbersome because unless I tell them what it is, they don't know. Participant 002ATR

She's, 'Oh no, don't worry I can spend time with you.' That affects me that way, and you just got to be careful. We obviously always take the escalator or the lift, that's why we just had to move houses in the last two years. Our house was a town house, two-storey, well just a small set of stairs were a burden, and my wife loved that house, but unfortunately, we moved. That's also another load on the family. Puts on another strain, and so the condition is governing both people, it's just not governing one person. Participant 003ATR

Negative impact: Unable to/must adapt significantly to travel

NAME HUSBAND's quality of life, well, because he was having chemotherapy so regularly, we couldn't go very far. It was not easy to travel and, of course, most people retire to go do the things they didn't have time to do, to have a trip away, we would have to try and coordinate it so that it was his week off and we'd get about 12, 14 days there where we could go and do something but that was from the perspective of being able to travel, it really did clip our wings a little bit. We're both from LOCATION OVERSEAS, so that stopped us from getting back to see everybody as much as we would like to have. Participant 001CA

Yes, it's affected, I think we saved up a bit of money to get back to Europe again, and my wife's too worried after what happened in LOCATION OVERSEAS. It's probably restricted long-distance travel. Too much of a risk. Participant 007ATR

As I said, the travel, I can't do overseas travel at the moment, and I don't know whether I will be able to. I need to have a knee operation. I can't have that because of the heart. That means I can't walk around pretty good. I'll just probably take that, otherwise I would have had that a couple of years ago. Participant 008ATR

Negative impact: Fatigue

My main issue is I don't have my energy levels. I tire very quickly. I've now designed-- I do things in the morning. In the afternoons, I don't normally plan to do much because I often have a rest, et cetera. Participant 001ALX

Quality of life? The AL specifically impacts my sleep, and overall energy levels, and so to the extent that I'm awake all night. The first night after treatment, my wife goes and sleeps in the other room. That's fine, but it's an impact. Participant 004AL

I need to go to bed at seven o'clock each evening because I cannot stay up for more than that and the only thing that I want to do is to sleep every day. It's hard, I cannot enjoy a day. Participant 005ATR

Negative impact: Reduced social interactions

It's frustrating. Only thing I can do now is hang out with people who will have lunch. Then, I can't commit because I may commit tomorrow for a lunch appointment but then I'll have diarrhoea all day and wouldn't be able to go. When you go out to eat, you need to know where the quickest bathroom or toilet is. Participant 002ATR

I guess overall impact of being able to mix with people in an open way is probably more psychological than physical, but I'm terribly aware of my compromised immunoglobulin and any white cell count issues. I tend to hold back a little bit in social scenes, but really, I can still do most things I want to do but at a different pace, or merely to take a little more planning. It's more a developing strategy to cope than being unable to cope. Participant 004AL

It was really bad. For me, to a certain extent social aspects was a big thing. We basically didn't do a lot of things socially, that we used to do. We had lots of friends that we'd will always go out with them a lot. Well, he couldn't do that. He wouldn't, in the end we just didn't, more or less do that… I missed just going to work, talking to people and going out for lunches and everything like that, so, yes, it impacted on my life like that. As I said, it impacted on our social lives, left, right and centre. It was very, very, very hard, just that way. Participant 004CA

Negative impact: Inability to work/changes to work

It affects significantly. Being an active person, being a mover and a shaker, being in the corporate world, you do a lot. You're constantly on the move, you're constantly engaging in either corporate or community, very active in the community, in the charitable side of things as well as in the corporate and media. Having the disease and the treatment, it limits me down to barely 1% of what I used to do. Participant 002ATR

It's affected a lot professionally, NAME INTRERVIEWER, a lot, a lot, a lot. Certainly, my family. My wife is the only person who knows exactly what is going on because we live together and she can see but the people around, we try a bit, but they really don't care about the future of the consequences that. Participant 005ATR

I miss work terribly. I miss-- I love people, and I love interacting with people, and that all stopped for me, because I couldn't get out and I didn't feel confident driving the car in the beginning and stuff like that. Participant 012ATR

Negative impact overall

Well, I guess it changes your way of life. It changes your way of life completely. I guess that would have to be a completely individual thing too, because depending on the age you are when you get it, how disabled you are by it. All those things would impact on that. We had made travel commitments into the future, which we were able to keep, but we're not making any travel commitments anymore because NAME HUSBAND just doesn't feel that he can, because he doesn't know how he's going to feel when-- If you pay for something in advance and he's over 80, so travel insurance becomes more difficult to get anyway. Participant 002CA

Well, with the amyloidosis, I had to give up work, so literally, yes for me, but for him, it was more or less was suffering from him. Because he was this man that was very physically active in all respects. A man that-- He used to surf, he used to boat, he used to duck dive. He did everything. He was very, very physically fit, and literally, he just became frailer, frailer, and frailer. Literally, he was still lucky enough that he could get in his car and drive, but then the day that he couldn't get in his car, that was terrible. Participant 004CA

A lot. It affects a lot. My life has changed. I know that I'm still being the same person, I'm the same person, I know, but all the things around me have changed. The things I wanted to do in my life but have been working hard to achieve, to complete, now I cannot do anymore at the level I wanted to do…I need to go to bed at seven o'clock each evening because I cannot stay up for more than that and the only thing that I want to do is to sleep every day. It's hard, I cannot enjoy a day. Participant 005ATR

Minimal impact on quality of life

I'm fully aware of that. There is an effect. As I say, either the condition of amyloidosis or the therapies or the drugs or whatever it is, there is an effect. I'm aware of that, and I try as best I can to control that, and I suppose my feeling of that is that yes, others might not be quite as happy with it as I am, but it's happened. It doesn't affect, to any extensive extent, that it does anything major. Participant 001AL

My exercise is really probably lessened. So, I would say the quality of life now is-- I've lost weight and I've lost a lot of muscle mass. So, my strength and stamina is not as great as it was. But other than that, it hasn't really impacted significantly on my quality of life. My life is good. Life is good, really. Yes. Sometimes it's very good, sometimes it's good. So, on an average, it's good. My life is good. Participant 001ATR

I think that first 12 months, it's had very little effect on my life, on my general well-being, everything else. I think a lot of it has got to do with attitude at the end of the day. Participant 002ALX

Table 8.1: Experience of quality of life

Impact on quality of life	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	15	41.67	11	61.11	13	52.00	3	30.00	1	12.50	11	50.00	4	28.57	3	33.33	12	44.44
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	13	36.11	7	38.89	9	36.00	2	20.00	4	50.00	7	31.82	6	42.86	3	33.33	10	37.04
Participant describes negative impact on quality of life as they are unable to travel or need to adapt significantly in order to travel	8	22.22	6	33.33	6	24.00	0	0.00	2	25.00	5	22.73	3	21.43	3	33.33	5	18.52
Participant describes negative impact on quality of life as a result of fatigue	6	16.67	4	22.22	5	20.00	2	20.00	0	0.00	5	22.73	1	7.14	2	22.22	4	14.81
Participant describes negative impact on quality of life due to reduced social interaction	6	16.67	3	16.67	4	16.00	1	10.00	2	25.00	2	9.09	4	28.57	2	22.22	4	14.81
Participant describes negative impact on quality of life due to inability to work or needing to make changes with their work	4	11.11	3	16.67	3	12.00	0	0.00	1	12.50	1	4.55	3	21.43	0	0.00	4	14.81
Participant describes minimal impact on quality of life	4	11.11	2	11.11	3	12.00	2	20.00	0	0.00	3	13.64	1	7.14	1	11.11	3	11.11
Participant describes an overall negative impact on quality of life	19	52.78	11	61.11	14	56.00	4	40.00	4	50.00	13	59.09	6	42.86	5	55.56	14	51.85
Participant describes an overall minimal impact on quality of life	7	19.44	4	22.22	6	24.00	3	30.00	0	0.00	5	22.73	2	14.29	2	22.22	5	18.52

Impact on quality of life	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	15	41.67	2	25.00	10	52.63	2	25.00	7	50.00	7	50.00	6	54.55	9	36.00
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	13	36.11	3	37.50	8	42.11	2	25.00	3	21.43	6	42.86	4	36.36	9	36.00
Participant describes negative impact on quality of life as they are unable to travel or need to adapt significantly in order to travel	8	22.22	1	12.50	4	21.05	2	25.00	3	21.43	3	21.43	2	18.18	6	24.00
Participant describes negative impact on quality of life as a result of fatigue	6	16.67	0	0.00	6	31.58	0	0.00	3	21.43	3	21.43	2	18.18	4	16.00
Participant describes negative impact on quality of life due to reduced social interaction	6	16.67	1	12.50	4	21.05	0	0.00	1	7.14	3	21.43	2	18.18	4	16.00
Participant describes negative impact on quality of life due to inability to work or needing to make changes with their work	4	11.11	1	12.50	3	15.79	0	0.00	1	7.14	2	14.29	2	18.18	2	8.00
Participant describes minimal impact on quality of life	4	11.11	1	12.50	1	5.26	2	25.00	3	21.43	1	7.14	0	0.00	4	16.00
Participant describes an overall negative impact on quality of life	19	52.78	3	37.50	13	68.42	2	25.00	7	50.00	8	57.14	6	54.55	13	52.00
Participant describes an overall minimal impact on quality of life	7	19.44	1	12.50	2	10.53	4	50.00	4	28.57	3	21.43	1	9.09	6	24.00

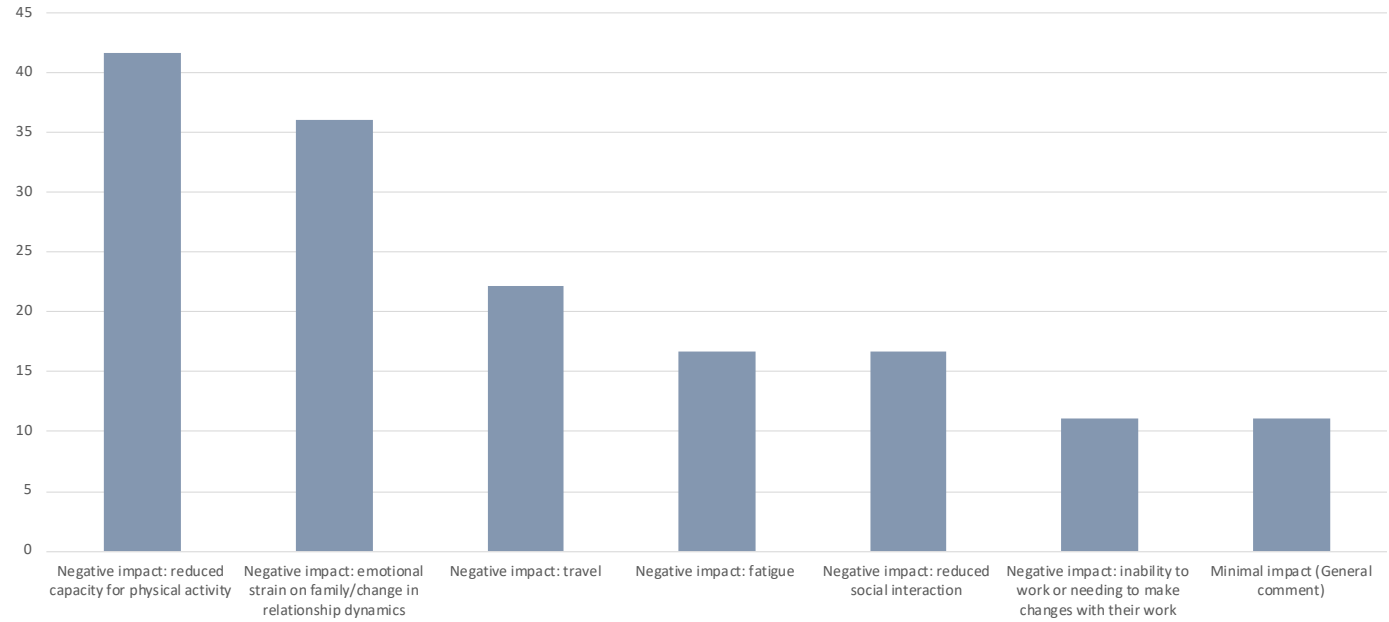


Figure 8.1: Experience of quality of life

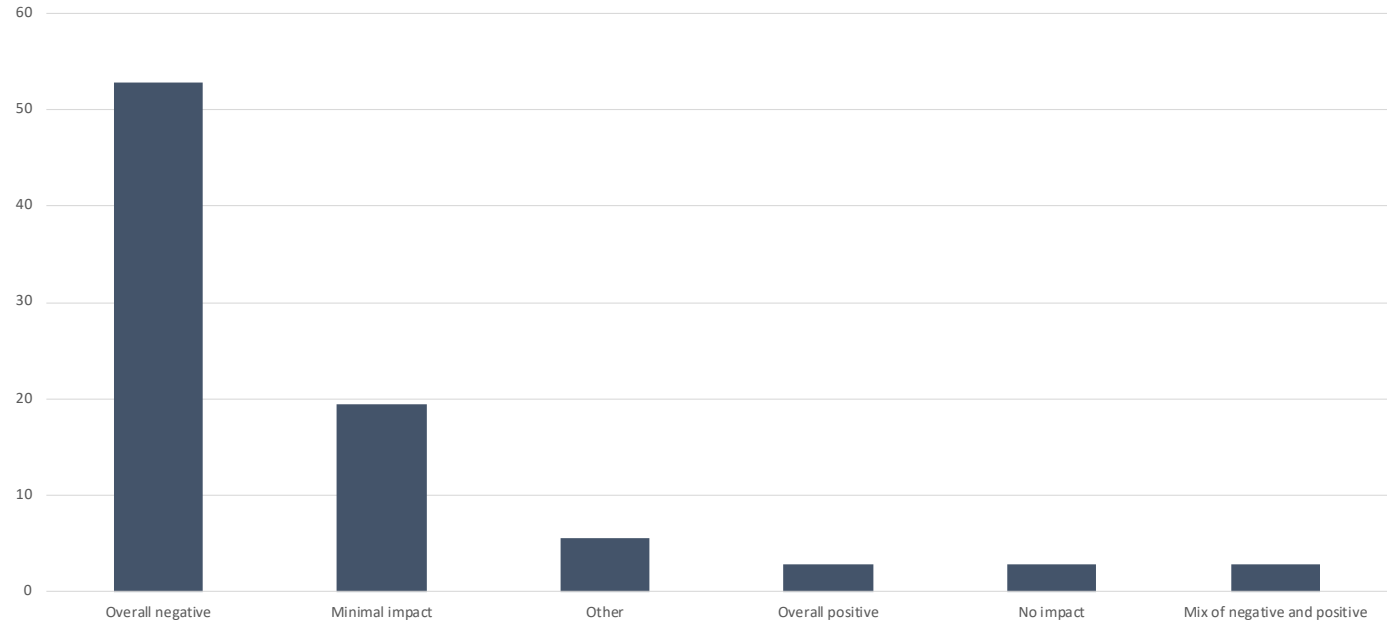


Figure 8.2: Experience of quality of life (Positive/Negative overall)

Impact on mental health

In the structured interview, participants were asked to share any impact on their emotional and mental health as a result of their condition. The most common theme that participants reported was experiencing at least some impact on their mental and emotional health (n=20, 55.56%). There were also seven participants (19.44%) that described experiencing no impact on their mental and emotional health overall.

In relation to subgroup variations, participants in the *Regional or remote* (44.44%) subgroup described at least some impact on their mental health less frequently than the general population (55.56%).

Participants in the *AL amyloidosis* (30.00%), and *Trade or high school* (35.71%) subgroups described overall no impact on their mental health more frequently than the general population (19.44%). Participants in the *Carer* (0.00%), and *Mid to low SEIFA* (0.00%) subgroups did not describe this at all.

Impact on mental health

Certainly, in the early times it did before, when I was waiting over a month or whatever it was to

have it really explained to me what amyloid basically is. I was very anxious, particularly at that time my husband was in LOCATION actually with our eldest son there. I was dealing with it on my own. Participant 003ALX

It has had an effect. With NAME HUSBAND getting more and more frail and that is between age and amyloid, I think, but yes, it has had an effect on our relationship, certainly our marital relationship. That was one of the first things that went before he was even diagnosed. Just finding ways around still loving each other without loving each other, not to put too fine a point on it, that has been an interesting journey. Participant 003CA

Yes, it does. You can't help it. Anytime you're faced with mortality, you have to contemplate mortality, it becomes an issue that weighs upon your mind. Participant 004AL

No impact on mental health

No. I don't think it affects my emotional health. I know my limits and I'll work within my limits. Participant 001ALX

I haven't noticed it. No, I don't think it has, but that's all right, I'll always be put right. Participant 003AL

No, I don't think so. I've just accepted that that's what it is. Participant 008ATR

Table 8.2: Impact on mental health

Impact on mental health	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	20	55.56	10	55.56	15	60.00	6	60.00	4	50.00	13	59.09	7	50.00	4	44.44	16	59.26
Participant gives a description suggesting that overall, there was no impact on mental health	7	19.44	4	22.22	5	20.00	3	30.00	0	0.00	5	22.73	2	14.29	1	11.11	6	22.22

Impact on mental health	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	20	55.56	4	50.00	10	52.63	5	62.50	7	50.00	9	64.29	7	63.64	13	52.00
Participant gives a description suggesting that overall, there was no impact on mental health	7	19.44	1	12.50	4	21.05	2	25.00	5	35.71	2	14.29	0	0.00	7	28.00

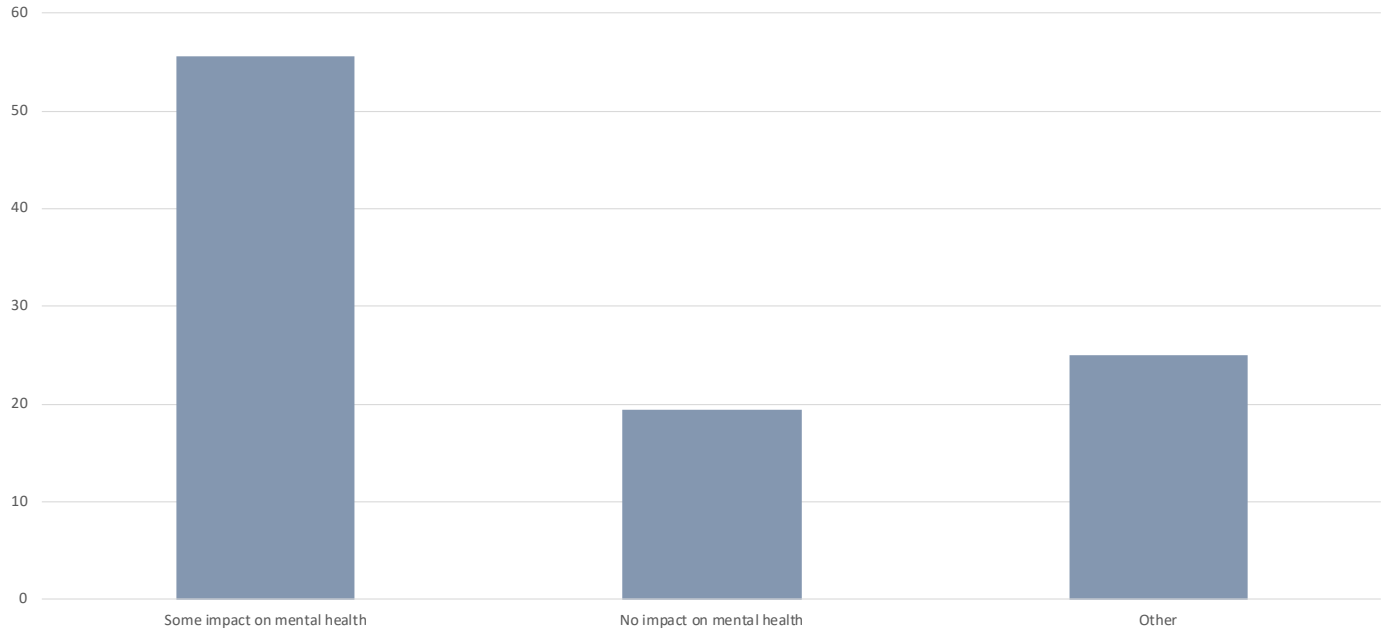


Figure 8.3: Impact on mental health

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common way that participants reported managing their mental and emotional health was by using coping strategies such as remaining social, making lifestyle changes or having hobbies (n=10, 27.78%). There were nine participants (25.00%) that described the importance of physical exercise in maintaining their mental health and seven (19.44%) that described the importance of family and friends in this endeavour. Other common themes included consulting a mental health professional (n=6, 16.67%), experiencing an impact but not using any activities to maintain their mental health (n=5, 13.89%) and not doing any activities to maintain their mental health as they have experienced no impact (n=4, 11.11%).

In relation to subgroup variations, participants in the *Regional or remote* (55.56%) subgroup described using coping strategies such as remaining social, making lifestyle changes or doing hobbies to maintain their mental health more frequently than the general population (27.78%).

Participants in the Male (9.09%), and *University* (14.29%) subgroups described using physical activities to maintain their mental health less frequently than the general population (25.00%), while those in the *Carer* (37.50%), *Aged 75 or older* (50.00%), and *Female* (50.00%) subgroups described this more frequently. Participants in the *Aged 55 to 64* (0.00%) did not describe this at all.

Participants in the *Regional or remote* (33.33%) subgroup described the important of friends or family in maintaining their mental health more frequently than the general population (19.44%).

Participants in the *ATTR-cardiac* (27.78%), *Aged 55 to 64* (37.50%) and *University* (28.57%) subgroups described consulting with a mental health professional more frequently than the general population (16.67%). Participants in the *AL amyloidosis* (0.00%) and *Aged 75 or older* (0.00%) subgroups did not describe this at all.

Participants in *AL amyloidosis* (30.00%), and *Aged 75 or older* (25.00%) subgroups who described experiencing an impact on their mental health and undertaking no activities to maintain it more frequently than the general population (13.89%). No participants in the *Carer* (0.00%), *Aged 55 to 64* (0.00%) *Female* (0.00%), or *Regional or remote* (0.00%) subgroups described this at all.

Participants in the *Trade or high school* (21.43%) subgroup described experiencing no impact on their mental health and therefore undertaking no activities to maintain it more frequently than the general population (11.11%), while no participants in the *Carer* (0.00%), *Aged 75 or older* (0.00%) or *Mid to low SEIFA* (0.00%) subgroups described this at all.

Uses coping strategies to maintain mental health

We have a dog who gets me out to the park, and I walk twice a day with him. He's hilarious, so I smile a lot and laugh. I sing in a choir when we're allowed to sing, which hasn't been for the last three and a half months. I play tennis. I keep myself physically active and outdoors doing useful things. In my capacity in the choir, I'm a volunteer in the choir…Those things give me a sense of achievement and a sense of worth, because you don't really feel a sense of achievement when someone's not getting better and you can't do anything to make them better. Participant 002CA

I've gone into the business of making family trees as a side effect of that. Also, all through my life, I've written verse, I call it poetry, but I write more verse now as a way of releasing pressure and stress. It's not flat. It's just a way of concentrating the mind and seeing things in a different, non-personal perspective, which helps a lot, I find. Participant 004AL

Some days, I'll way up and be full of life and want to do things. Other days, I'll wake up and NAME WIFE just looks up me, and you can see her saying, 'This is a sad day.' She'll quietly go out and book a couple of tickets to go to see a movie or something like that. It does really affect me anyway. Participant 013ATR

Does physical exercise to maintain mental health

We do have three acres of land here that we garden so I'm still able to do that. I walk, I go to a Yogalates class, which is a combination of yoga and pilates when we're not isolated for COVID-19 and I hope to get back to that, that's a once a week event. So, no, I have been cautious of making sure I keep my interests alive and active as much as I possibly can. Participant 001CA

Mentally I'm okay. What helps me is getting up outdoors walking. I think I'd go crazy if I couldn't do that, particularly with this lockdown stuff as well happening at the moment. I don't have any friends that I would particularly discuss it in depth with that could understand my anxiety or my mental situation, so I deal with it myself. I'm quite okay, I think. I know you're not supposed to internalise a lot of things that's not good for your health. Comes out in some other form or sort of thing. Participant 003ALX

My wife does lots of things, and I try to make sure she does her little yoga and all those sort of things, then I try to get more--I've had to drop the exercise routine which regards the gym work and stuff, but I just try and do swimming, a little bit of walking, or things like that. They give me peace of mind. Participant 003ATR

Importance of family and friends in maintaining mental health

It hasn't looked- because I am retired, I play golf and it clashes with his appointments and trips to LOCATION METROPOLITAN, I've been able to do that, and that network of women has been extraordinarily supportive. Checking in on me when we lived in LOCATION METROPOLITAN, I would get messages from the secretary just checking out that everything was going all right. That's lovely. I'm also the president of a small community group and that group of people has just been outstanding in their emotional support of me. Participant 001CA

It takes an expert to assess that I suppose, but I haven't done anything as far as my emotional health, except trying to cultivate a circle of people to what everyone recommends. You keep a group of people together, close friends that you think are most important, and my wife. I go back to LOCATION OVERSEAS and see my son every so often and my grandkids. Participant 007ATR

I'm lucky my wife is very good at- when she says we go down, she can hit me in the back and get me back in the right direction, steer me the right way. Participant 009ATR

Consults a mental health professional

I do talk to mental health professionals on occasions, not regularly, but I have contacted them in the past when I've needed to. I'm also lucky in that, a few people in my personal life at home that I talk to about things and rely on when I need to. My own friends privately and mental health professionals, I suppose. It's definitely something I'm aware of and monitor. Participant 006ATR

I've had a counsellor come and visit me from Aged Care. He comes every few months and we sit down and have a chat. He talks about different things, the change in my life. He has a look at how I've lived for a couple of months. What problems I've had and then we discuss them when he's here. He puts me on the right track. Participant 009ATR

The depression is the anxiety. That on top of previously diagnosed depression and things, it's all compounding one on top of the other and I have been talking to a counsellor and I'm happy to, in these days I don't mind talking about it at all, I've been talking to counsellors about it. Some day is good some day is bad, and that's the only thing I can say. Some day is good, some day is bad. Participant 015ATR

Experiences impact on mental health, but does no activities to address it

Well, I think my answer to my last question would be the same. Yes, it does affect it. I'm aware of it. Fortunately, or unfortunately, I have reasonable knowledge in the field. It's awareness, and then you take some actions to do that. I haven't seen any professional in that area at all ever about that, only because I'm aware what somebody else can tell me in the field of, particularly, psychology...I'm self-managed in that area. Participant 001AL

Maybe sometimes I feel that fear emotional but just at the sight of the family trying to cope with the pain. I don't want to lie. I'm saying this is what I feel, makes me feel in this way but that doesn't mean that it's putting me down, just how it is. You mustn't be sad, you have to say, 'Maybe it detaches me a little bit emotionally to try it, but I'm okay. I'm okay, I'm not scared, I'm not dead, I can deal with this.'. Participant 005ATR

My wife just said it's affected my mental health, so I guess it has. I'll have to tell her to go away. Go away. Yes, I guess it has-- not severely, but mentally and emotionally. You do know it's a life-threatening condition, and you think about it a lot, especially if you start not feeling too well. Yes, it affects you, so it has affected me, yes. Participant 017ATR

No activities to maintain mental health as have not experienced any impact

I haven't noticed it. No, I don't think it has, but that's all right, I'll always be put right. Participant 003AL

It is day by day, get on with it, you're all right. I know the things I'm feeling are normal and very common. There's never been a day where I just want to stay cuddled up in bed, put it that way. Participant 004ATR

No, I don't think so. I've just accepted that that's what it is. Participant 008ATR

Table 8.3: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	10	27.78	4	22.22	5	20.00	3	30.00	3	37.50	6	27.27	4	28.57	5	55.56	5	18.52
Participant describes the importance of physical exercise	9	25.00	4	22.22	5	20.00	2	20.00	3	37.50	2	9.09	7	50.00	2	22.22	7	25.93
Participant describes the importance of family and friends in maintaining their mental health	7	19.44	4	22.22	5	20.00	1	10.00	2	25.00	3	13.64	4	28.57	3	33.33	4	14.81
Participant describes consulting a mental health professional	6	16.67	5	27.78	5	20.00	0	0.00	1	12.50	5	22.73	1	7.14	2	22.22	4	14.81
Participant describes an impact on their mental health but no activities to maintain it	5	13.89	2	11.11	5	20.00	3	30.00	0	0.00	5	22.73	0	0.00	0	0.00	5	18.52
Participant describes no activities to maintain mental health	4	11.11	3	16.67	4	16.00	1	10.00	0	0.00	3	13.64	1	7.14	1	11.11	3	11.11

Regular activities to maintain mental health	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	10	27.78	2	25.00	6	31.58	2	25.00	3	21.43	4	28.57	4	36.36	6	24.00
Participant describes the importance of physical exercise	9	25.00	0	0.00	5	26.32	4	50.00	4	28.57	2	14.29	3	27.27	6	24.00
Participant describes the importance of family and friends in maintaining their mental health	7	19.44	1	12.50	4	21.05	1	12.50	2	14.29	3	21.43	3	27.27	4	16.00
Participant describes consulting a mental health professional	6	16.67	3	37.50	2	10.53	0	0.00	1	7.14	4	28.57	2	18.18	4	16.00
Participant describes an impact on their mental health but no activities to maintain it	5	13.89	0	0.00	3	15.79	2	25.00	3	21.43	2	14.29	2	18.18	3	12.00
Participant describes no activities to maintain mental health	4	11.11	1	12.50	3	15.79	0	0.00	3	21.43	1	7.14	0	0.00	4	16.00

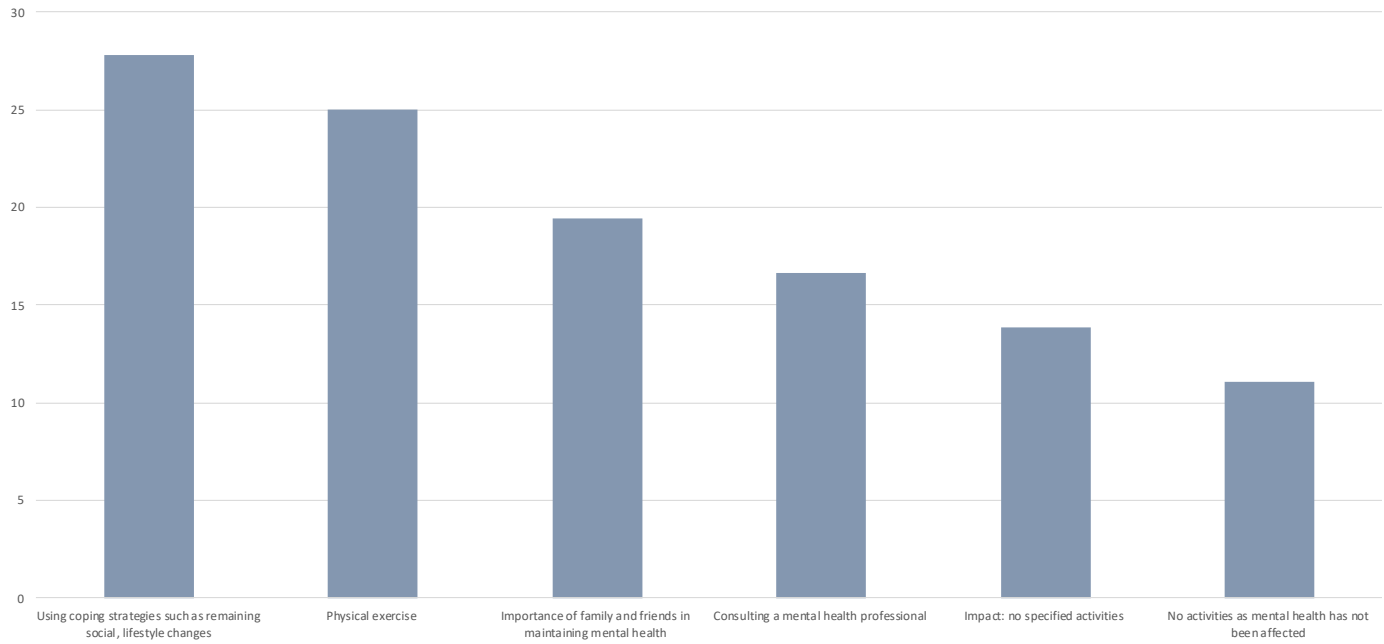


Figure 8.4: Regular activities to maintain mental health

Regular activities to maintain health

In the structured interview, participants were asked to share some of the things they needed to do every day to maintain their health. The most common way that participants reported managing their health was by understanding their limitations (n=15, 41.67%). There were 10 participants (27.78%) that described staying physically active and nine (25.00%) that described the importance of complying with treatment. Other common themes included maintaining a healthy diet (n=7, 19.44%) and the importance of self-care, for example getting more rest or seeking support for housework (n=5, 13.89%).

In relation to subgroup variations, participants in the *AL amyloidosis* (30.00%), *Carer* (25.00%), *Female* (28.57%), *Trade or high school* (28.57%), and *Mid to low SEIFA* (27.27%) subgroups described the importance of understanding their limitations less frequently than the general population (41.67%), while those in the *ATTR-cardiac* (55.56%) and *University* (64.29%) subgroups described this more frequently.

Participants in the *Aged 55 to 64* (12.50%), and *Trade or high school* (14.29%) subgroups described staying physically active as a way to maintain their general health less frequently than the general population (27.78%), while those in the *University* (42.86%) subgroup described this more frequently.

Participants in the *Carer* (12.50%), *Trade or high school* (14.29%), and *Regional or remote* (11.11%) subgroups described the importance of complying with treatment less frequently than the general population (25.00%), while those in the *University* (42.86%) and *Higher SEIFA* (32.00%) subgroups described this more frequently.

Those in the *AL amyloidosis* (40.00%) subgroup described maintaining a healthy diet more frequently than the general population (19.44%), while participants in the *Aged 55 to 64* (0.00%) and *Mid to low SEIFA* (0.00%) subgroups did not describe this at all.

Participants in the *ATTR-cardiac* (27.78%), *Aged 55 to 64* (25.00%), and *University* (35.71%) subgroups described the importance of self-care in maintaining their general health – for example, getting more rest or seeking support for housework. This is more frequently than the general population (13.89%), while participants in the *AL amyloidosis* (0.00%), *Carer* (0.00%) or *Trade or high school* (0.00%) subgroups did not describe this at all.

Understanding their limitations

The only thing is watch what activities I do and that I don't overdo things. When I do overdo things, I know I've got to stop. For example, we're part owners of a property down at LOCATION REGIONAL and we have working bees down there, et cetera. Sometimes, well, I know I can only do so much, so I'll sit, and I'll supervise the rest of it. Participant 001ALX

One of the things I have noticed, is not to overdo things, because the next day you might as well have the day off. Spend a couple of hours in the garden, and sometimes you do an hour at a time and do ride-on mowing. That's not a problem I can do that for several hours. There are things like climbing ladders to prune things, I do no more than an hour these days, because otherwise, typically, I have muscle pain where it will stop me doing things the next day. Participant 003AL

Slow down. I just take things slower. If I take the dog for a walk, I take the dog, it's now a casual walk it's not like a walk of pace. If I go to lift the grandkids, I make sure that that I can, that I'm not over stressed. I don't go bouncing on a trampoline with them chances are the heart will keep bugging me up, but I still do stuff them. Participant 004ATR

Staying physically active

I think just keep physically and mentally active. I'm really not that badly affected by the amyloid now. My kidneys are not 100% but they're as perfect as they could be probably at my age anyway. I don't feel any organ effects from having amyloidosis and I just like to keep myself fairly fit and active and just appreciate the good health whilst I've got it really. Participant 002AL

Well, that's true. I went and bought an electric e-bike. I still do the same amount of cycling on four days a week. I do a bit 200 kilometres a week so-. Participant 007ATR

Since I've started going to the gym for now, I don't get that incredible tiredness. I'm looking forward to it, I go to the gym. I come home and I'm worn out at the gym and I may go to sleep. I probably force myself to have an hour's nap in the middle of the day, because I know that if I don't, by seven o'clock,

I'll be sitting in the chair with my mouth open, snoring. Participant 013ATR

Importance of complying with treatment

The doctors will prescribe to do them together but then I find that having them together does not work so I delay taking one medicine to the other and then checking with the doctor, they try to find the best. It's all the medication gets in, in the right time…Two is have a plan and stick by it in terms of medication wise, taking your medication and reduce exposure to people who are unwell. Participant 002ATR

When I wake up in the morning, I'm parched. Probably I don't drink so much water because I do take tablets, I need to take a range of tablets both for amyloidosis and heart and so on just to maintain a healthier body, so they're the main things that I need to do. Participant 006AL

Mainly take my medication really, that's the main thing. Participant 006ATR

Maintaining a healthy diet

At this point in time with NAME HUSBAND's treatment it is diet and this low potassium diet, that's a huge focus on the household and it is for me. NAME HUSBAND is an extraordinarily good cook, but I just plan the meals around this low potassium. Participant 001CA

There's nothing I can do. Nothing I can do, nothing I have to do, except the one thing we've done from day one, is we eat very well. We avoid a lot of the processed foods. We cook everything from scratch ourselves. That's it, we eat healthy. Participant 002ALX

Managing diet so that potassium levels, sodium level, et cetera, are under a certain threshold. I have a definite low sodium diet. I have a definite low sugar diet and I have a moderate potassium intake. I keep it under 2,000 milligrams a day. Participant 004AL

Importance of self-care e.g. getting more rest

I think the thing I need to do most is get a good night's sleep, and that's helpful. I think exercise, diet, including-- I don't smoke-- including alcohol consumption, all those are important contributors to getting a good night's sleep. The acupuncture helps, being positive helps. Not getting too stressed out about things helps. All of that's important, I think. Participant 011ATR

For instance, I'll arrange my day now so that when I wake up in the morning, it affects my ability to focus and concentrate on things to some extent. Sit down at the computer and it'd take me two hours to do something I use to do in half an hour. I'd give myself some time at the start of the day where I do those more intellectual things that has to be done like paying bills and all that sort of stuff, and doing anything I've got to do on the computer, and internal stuff, ringing people, talking to people. Then as the day progresses, go have some lunch, some morning tea then some lunch. Then after lunch, I would just get incredibly tired, have to go to sleep. Participant 013ATR

One of the things that I probably haven't mentioned that comes to mind is I get tired and lethargic. I do believe that the condition affecting parts of my body or whatever. I probably need like after lunch I'll have an hour up to two hours sleep. Yes, it makes you very tired. Now, I can go without that sleep, but it eventually catches up with me as in the tiredness gets worse and worse, and I probably need to get 9 to 10 hours or sometimes more at night to sleep. Participant 016ATR

Table 8.4: Regular activities to maintain health

Regular activities to maintain health	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes the importance of understanding their limitations	15	41.67	10	55.56	12	48.00	3	30.00	2	25.00	11	50.00	4	28.57	4	44.44	11	40.74
Participant describes being physically active	10	27.78	6	33.33	8	32.00	2	20.00	2	25.00	6	27.27	4	28.57	2	22.22	8	29.63
Participant describes the importance of complying with treatment	9	25.00	6	33.33	8	32.00	2	20.00	1	12.50	6	27.27	3	21.43	1	11.11	8	29.63
Participant describes maintaining a healthy diet	7	19.44	2	11.11	4	16.00	4	40.00	1	12.50	5	22.73	2	14.29	2	22.22	5	18.52
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	13.89	5	27.78	5	20.00	0	0.00	0	0.00	4	18.18	1	7.14	1	11.11	4	14.81

Regular activities to maintain health	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes the importance of understanding their limitations	15	41.67	4	50.00	7	36.84	3	37.50	4	28.57	9	64.29	3	27.27	12	48.00
Participant describes being physically active	10	27.78	1	12.50	6	31.58	3	37.50	2	14.29	6	42.86	3	27.27	7	28.00
Participant describes the importance of complying with treatment	9	25.00	2	25.00	4	21.05	2	25.00	2	14.29	6	42.86	1	9.09	8	32.00
Participant describes maintaining a healthy diet	7	19.44	0	0.00	5	26.32	2	25.00	4	28.57	2	14.29	0	0.00	7	28.00
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	13.89	2	25.00	2	10.53	1	12.50	0	0.00	5	35.71	1	9.09	4	16.00

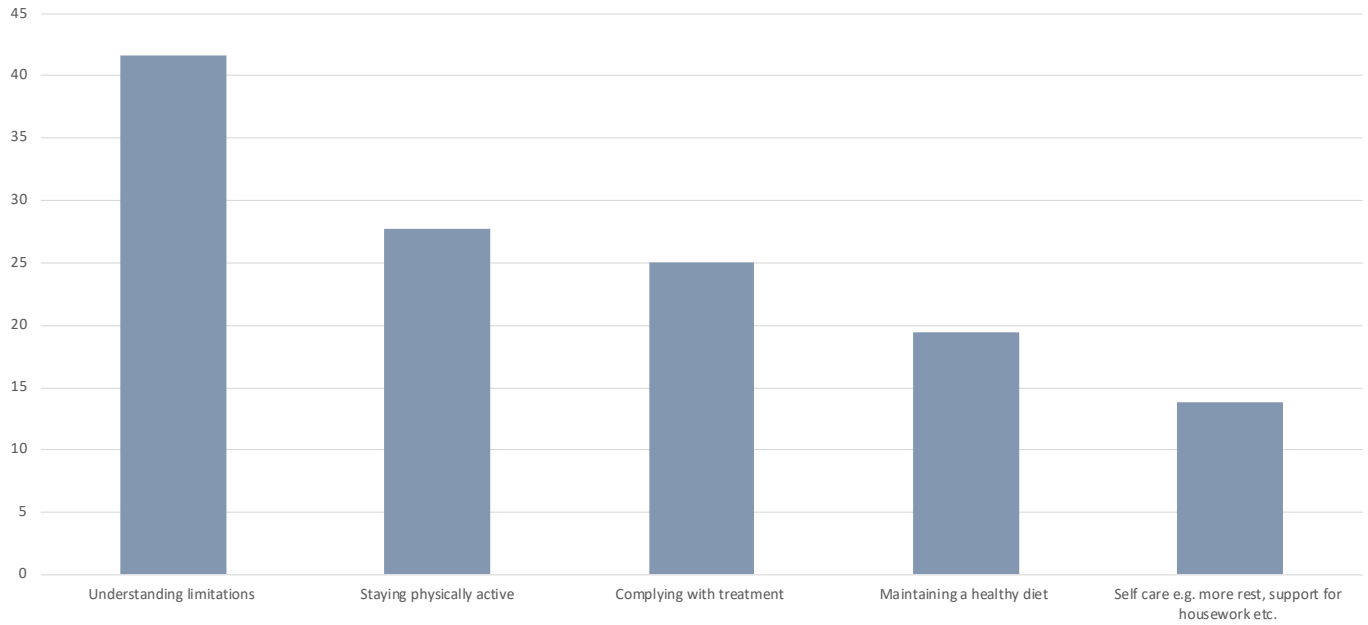


Figure 8.5: Regular activities to maintain health

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. The most common themes relating to impact on relationships was participants describing their relationships with family being strengthened (n=6, 16.67%) and experiencing changing dynamics in their relationships due to added anxiety, exacerbations and/or physical limitations (n=6, 16.67%).

Overall, there were nine participants (25.00%) that described a negative impact on relationships, eight participants (22.22%) that reported a positive impact on relationships and seven participants (19.44%) that felt that relationships had not been impacted. There were also five participants (13.89%) who noted an impact on their relationships but did not feel it was positive or negative overall.

In relation to subgroup variations, participants in the *AL amyloidosis* (30.00%) and *Regional or remote* (33.33%) subgroups described their relationships with family being strengthened more frequently than the general population (16.67%) While those in *ATTR-cardiac* (5.56%) described this less frequently.

Participants in the *Trade or high school* (35.71%), *ATTR-cardiac* (27.78%), and *Mid to low SEIFA* (27.27%) subgroups described family dynamics changing more frequently than the general population (16.67%), while those in *Carer* (0.00%), and *Aged 75 or older* (0.00%) subgroups did not describe this at all.

Overall, participants in the *Mid to low SEIFA* (45.45%) subgroup described experiencing a negative impact on their relationships more frequently than the general population (25.00%).

Participants in the *AL amyloidosis* (40.00%) and *Regional or remote* (33.33%) subgroups described a positive impact on their relationships more frequently than the general population (22.22%) while those in the subgroup *ATTR-cardiac* (11.11%) described this less frequently.

Participants in the *Mid to low SEIFA* subgroup described no impact on their relationships overall less frequently (9.09%) than the general population

(19.44%), while those in the *Aged 75 or older* subgroup described this more frequently (37.50%).

Participants in the *Trade or high* school (35.71%) subgroup described experiencing an impact on their relationships that was neither positive or negative overall more frequently than the general population (13.89%), while those in the *Carer* (0.00%), and *University* (0.00%) subgroups did not describe this at all.

Positive impact: Relationships strengthened

If anything, it might've brought us closer and more open with health issues. NAME HUSBAND was always a little distant about wanting to discuss health issues in big ways, but now, he didn't want anyone to know about it, but now he's comfortable with my friends and my networks knowing about it. With our children and grandchildren, yes, I think it's actually brought us all a lot closer. Participant 001CA

It's brought me closer to my family and some of my friends. Participant 002ALX

You know what? I think it's drawn us ever closer, particularly with my two daughters, my friends, and my grandchildren. I think it definitely has. They understand a whole lot of other things, they understand that dad or pop is not immortal. They do get to check that all is well and need to be cared for... Again, I mentioned the family reunion. I've seen cousins that I've never seen in my life, for example, and having communications with them. Talking about life's challenges has been quite cathartic as well. Now I think maybe everybody should go through one of these things and learn to value family a little more. Participant 004AL

Negative impact: Change in dynamics

I know it does. It varies depending on the relationship of family and friends, that I have with them. Immediate family, the children and so forth, it does because you don't want it to be-- they don't like to see someone they love going through the pain…For them to see the effects that they can't do anything about. Participant 002ATR

Yes, everybody looked at you. The first thing they'd say to you is, 'How are you?' They look at you first. You know what I mean? I always, sort of—how do I say this-- I've got over that phase. It used to worry me to a certain extent. Just treat me as normal, that's all, because I am normal. Put a person in a wheelchair, everybody feels sorry for him, but he doesn't feel sorry for himself. He's just-- don't treat me as somebody different. That's all. I've got over that. Participant 005AL

They might be slightly concerned about you. Some might just stay away because they don't want to interfere, but most people are pretty good, I think. Participant 014ATR

Negative impact overall

I know it does. It varies depending on the relationship of family and friends, that I have with them. Immediate family, the children and so forth, it does because you don't want it to be-- they don't like to see someone they love going through the pain-- For them to see the effects that they can't do anything about. Participant 002ATR

Our greatest concern is my girls. None of them have been tested yet because literally we thought that if they were tested and they found out they were carrying the gene, then that would be something he'd never forgive himself for. That never happened. At this stage, there's really no cure at this stage for Amyloidosis. They just watch for any symptoms and then they'll go to a doctor. But knowing that they could have it, knowing that my grandchildren could have it, it's like something just like a big black boulder sitting above you. For the girls, it's very scary because they saw how their father died. Participant 004CA

Definitely impacted personal relationships with, in terms of my love life. I don't know how to put it, but in terms of being single, at a stage where you would be maybe looking to find someone to settle down with or something. It's something if you're with someone who's somewhat terminally ill or somebody who has-- some people are even just looking for someone who has an illness and it's quite serious. It's something that impacts on that quite heavily. As well as the physical aspects with dating, a lot tricky at times. It has a pretty big impact on that. Participant 006ATR

Positive impact overall

Yes. Yes. In a good way, in some way with some of my friends, et cetera, because they're aware of my situation. I'm not one to hold back, so everyone knows that I've got it and I post on Facebook. 'This is my eighth-year remission, and this is amyloidosis day, you guys know I've got it,' et cetera. People know I've got it and they are concerned for me. 'Don't overdo it, PARTICIPANT. We know. Yes, then just don't do that PARTICIPANT.' The family is similar. Right now, that I've got four grandkids and the eldest one is 11, so they're not fully aware of what the situation is, but they know it. Apart from that, the rest of the family is aware of my issues and treat me accordingly. Participant 001ALX

If anything, strangely, through adversity comes strength and it's strengthened friendships and relationships with friends and family. We've become a little more aware of things. Participant 003CA

You know what? I think it's drawn us ever closer, particularly with my two daughters, my friends, and my grandchildren. I think it definitely has. They understand a whole lot of other things, they understand that dad or pop is not immortal. They do get to check that all is well and need to be cared for. They understand perhaps a little bit more about end of life processes because we've involved them. Participant 004AL

No impact on relationships overall

No, it hasn't. Not in my situation. No. I haven't even told my two sisters that I've got it. Some of them have been dealing with fairly other major things in their lives they don't want to hear, they don't need to hear at this stage my situation because it's not life threatening for me. When the time is right I'll tell them, but then one of them has been through horrific bushfires which recently. The other one has got other issues. Participant 003ALX

No. No. I don't have a lot of friends. My family loves me possibly more than before and I ring a lot in LOCATION and I talk with the people there, they are lovely. Actual people that I know. They treated me all the same, so, no, it's okay. No, I don't think that's a problem. Participant 005ATR

Probably not that much. I'm lucky that I have very good support in my family. No, I don't think it's made that much of a difference. Participant 017ATR

Impact on relationships, but neither positive nor negative overall

No. My sister in LOCATION METROPOLITAN is a little concerned at the moment because of the hereditary side of things, and she's about to become a grandmother. So, she's a bit concerned. She has discussed it a little bit with her son and his partner, but not to great lengths. She doesn't want to go too much into it. She's consented to be screened as well, and my sister in LOCATION METROPOLITAN has also consented. Participant 001ATR

Yes, but not in a bad way. I mean it's like, it's as my darling once said, one day she said, 'You never get sick. You're not supposed to be like this, but you are.' She's doing everything she can, so in some ways, I think it's made me stronger. I wouldn't I say it's had an -- If anything, my daughter's the one, she's a wee bit overprotective. 'You cannot do that; you can't do that.' I finally go, 'Yes, I can. I don't need you to tell me what I can and cannot do. You just help me when and where you can.' Participant 004ATR

Well, I have three children and I think it's given them a wake up. Also, I'm 73 so at some point it hurts to-- everybody understands that as you get older, you're subjected to any number of things. I guess I feel comforted by knowing there are specialists looking after the relevant areas. I'm looking after my body as best I can. My three children, I send them a health report, how it went with the treatment, how I'm feeling and so on. I'm a single person, I live alone, and I prefer it that way. Well, I just prefer it that way. Participant 006AL

Table 8.5: Impact on relationships

Impact on relationships	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes relationships with family being strengthened	6	16.67	1	5.56	3	12.00	3	30.00	2	25.00	3	13.64	3	21.43	3	33.33	3	11.11
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	6	16.67	5	27.78	6	24.00	1	10.00	0	0.00	3	13.64	3	21.43	1	11.11	5	18.52
Participant gives a description suggesting that overall, there was a negative impact on relationships	9	25.00	5	27.78	7	28.00	2	20.00	2	25.00	6	27.27	3	21.43	3	33.33	6	22.22
Participant gives a description suggesting that overall, there was a positive impact on relationships	8	22.22	2	11.11	4	16.00	4	40.00	2	25.00	4	18.18	4	28.57	3	33.33	5	18.52
Participant gives a description suggesting that overall, there no impact on relationships	7	19.44	4	22.22	5	20.00	2	20.00	1	12.50	4	18.18	3	21.43	1	11.11	6	22.22
Participant gives a description suggesting that overall, there was an impact on relationships that was neither positive nor negative	5	13.89	4	22.22	5	20.00	1	10.00	0	0.00	4	18.18	1	7.14	1	11.11	4	14.81

Impact on relationships	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes relationships with family being strengthened	6	16.67	2	25.00	3	15.79	1	12.50	1	7.14	3	21.43	1	9.09	5	20.00
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	6	16.67	2	25.00	4	21.05	0	0.00	5	35.71	1	7.14	3	27.27	3	12.00
Participant gives a description suggesting that overall, there was a negative impact on relationships	9	25.00	2	25.00	4	21.05	2	25.00	3	21.43	4	28.57	5	45.45	4	16.00
Participant gives a description suggesting that overall, there was a positive impact on relationships	8	22.22	2	25.00	5	26.32	1	12.50	2	14.29	4	28.57	2	18.18	6	24.00
Participant gives a description suggesting that overall, there no impact on relationships	7	19.44	1	12.50	3	15.79	3	37.50	3	21.43	3	21.43	1	9.09	6	24.00
Participant gives a description suggesting that overall, there was an impact on relationships that was neither positive nor negative	5	13.89	1	12.50	3	15.79	1	12.50	5	35.71	0	0.00	1	9.09	4	16.00

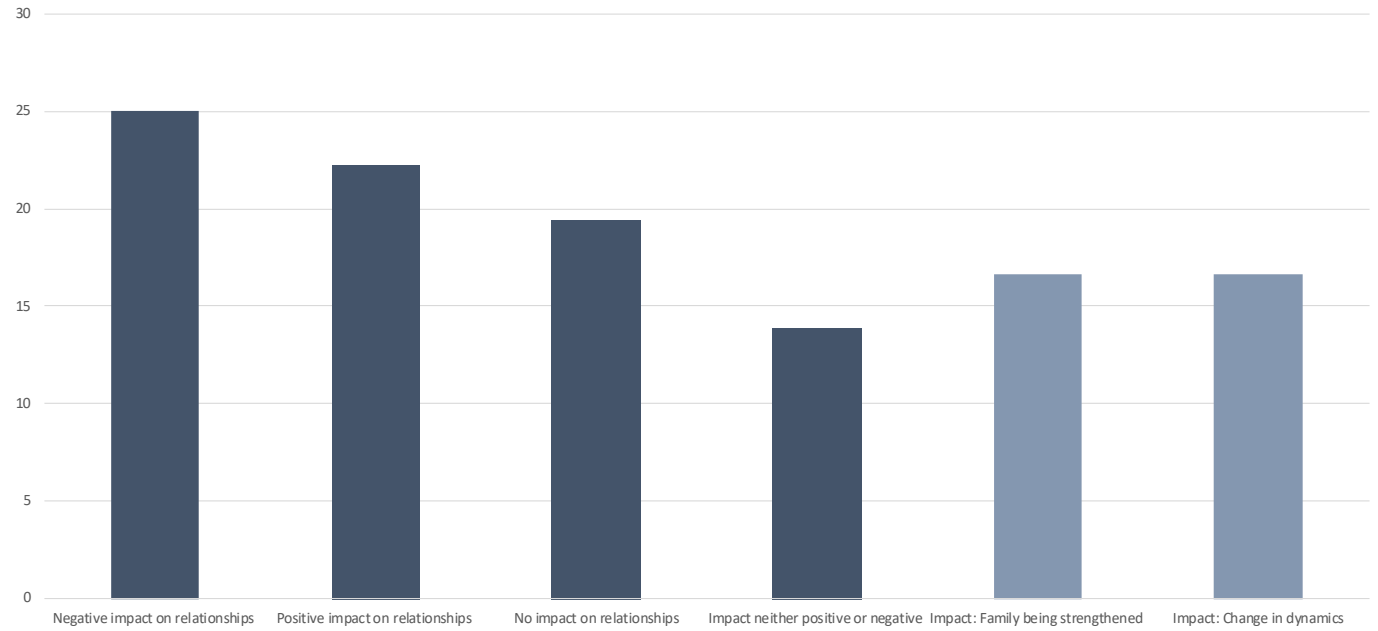


Figure 8.6: Impact on relationships

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Where participants described there was no additional burden, this was primarily described in general terms, with no specific examples provided (n=11, 30.56%). On the other hand, where participants felt there was an additional burden, this was primarily described in relation to the additional mental or emotional strain placed on their family (n=7, 19.44%), the extra household duties and responsibilities their family needed to take on (n=6, 16.67%) and as a burden in general, with no specific examples (n=4, 11.11%).

Overall, there were 16 participants (44.44%) that felt there was an additional burden and 11 participants (30.56%) that reported no additional burden.

In relation to subgroup variations, participants in the *Carer* (12.50%) and *Mid to low SEIFA* (9.09%) subgroups described no burden on family with no specific examples less frequently than the general population (30.56%), while those in the *University* (42.86%) subgroup described this more frequently.

Participants in the *AL amyloidosis* subgroup described burden on family due to mental or emotional strain more frequently (30.00%) than the general population (19.44%).

Participants in the *ATTR-cardiac* (27.78%) subgroup described burden in the form of extra household duties or responsibilities more frequently than the general population (16.67%), while those in the *AL amyloidosis* (0.00%) subgroup did not describe this at all.

Participants in the *Regional or remote* (22.22%) subgroup described their condition being a burden in general with no specific examples more frequently than the general population (11.11%), while those in the *Aged 75 or older* (0.00%) subgroup did not describe this at all.

Participants in the *Mid to low SEIFA* (54.55%) subgroup described a burden on their family overall more frequently than the general population (44.44%).

Participants in the *Carer* (12.50%) and *Mid to low SEIFA* (18.18%) subgroups described not feeling like a burden on their family less frequently than the general population (30.56%), while those in the *AL amyloidosis* subgroup described this more frequently (50.00%).

No burden: No specific examples

Not at this stage. If it is, well, bad luck, they'll just have to deal with it. And I'll have to deal with it too. But at this stage, no, it's not a burden on my family. Well, because I'm really early in the diagnosis, I'm not really as ill as what some of them are. Participant 001ATR

No, not at the moment. I don't think it was particularly at that time either. My husband did take a bit of time off work, but he wasn't burdened financially because he could take some carer's leave. Participant 002AL

No, definitely not. Participant 007ATR

Burden: mental or emotional strain on family

It can be. Oh, yes, it can be, because it affects how you feel, whether you want or need to sleep, whether the medications are there, whether I take the right medications, et cetera. Cooking, as far as I can't eat certain things sometimes. I have no appetite at all, so other people then have to eat, and I sit there and say, 'Well, I'm just not hungry.' I could eat something, and that something may be different and things like that. There is an effect. Oh, yes, there is an effect. I would say most certainly an effect. Participant 001AL

Yes. It does. Many times, where, in the medical state of mind, with so many drugs that I use, you feel that you're better off not being around because they don't have the burden of caring for you or go through the agony of watching somebody they love suffer. I'm saying that from a personal experience, as well, watching my dad suffer, watching the siblings suffer, watching my grandmother suffer through that. As a young boy, I took care of my grandmother and watching her suffering. That does affect. Friends, we limit the number of friends we hang out with. Participant 002ATR

It's more on the emotional side, that there has to be a distinct commitment for managing the issue. My wife sometimes finds it a little bit more difficult. Everybody goes through ups and downs during the day, and during the week, during the month, and my wife is no different. Participant 004AL

Burden: extra household duties and responsibilities for family

Yes, I do. Well, that's just natural, I think. You feel a burden, as I said, because you've got to limit what you can do and what you can't do. Around the house, you can do all of the simple things, but, again, one of the main reason for me going into a retirement village really was the fact that we're going to have someone come in and clip the hedges or do all of that stuff for me because, A, I couldn't do it and, B, I don't expect my wife to be out there mowing the lawn and clipping hedges. Participant 003ATR

Yes, it is, definitely. Huge. They've got to do a lot for me. They've got to- and a lot of fun they can't. Like NAME wants to go away and do a day shopping and got to make sure there's someone here with me. Because I'm prevalent to falling over, or something goes wrong, there got to be someone around all the

time. That affects her, she can't zip up and be with her friends for a day. Let be depend at home, a lot of things she's got to do. Even down to our personal banking and stuff, she's looking after a lot of that because my brain doesn't work the way it used to, I forget lots of little things and she's got to remember all those things now. Participant 009ATR

Yes, it meant I couldn't help them carry those pots up to the stairs to their apartment balcony, my daughter's back apartment balcony yesterday. I could carry some of the potting mix but not the pots. No, I'm not sure again. Maybe there're times I feel a bit--well, I'm not grumpy but not completely relaxed, yes. Participant 011ATR

Burden: No specific examples

It's a burden on my wife. I don't think it's a burden on the other three except we don't see-- well, one is living in LOCATION REGIONAL and two are up here. We don't see them every week or anything, but they're aware of it. Is it a burden on them? No, I don't think so. On my wife, definitely. Participant 001ALX

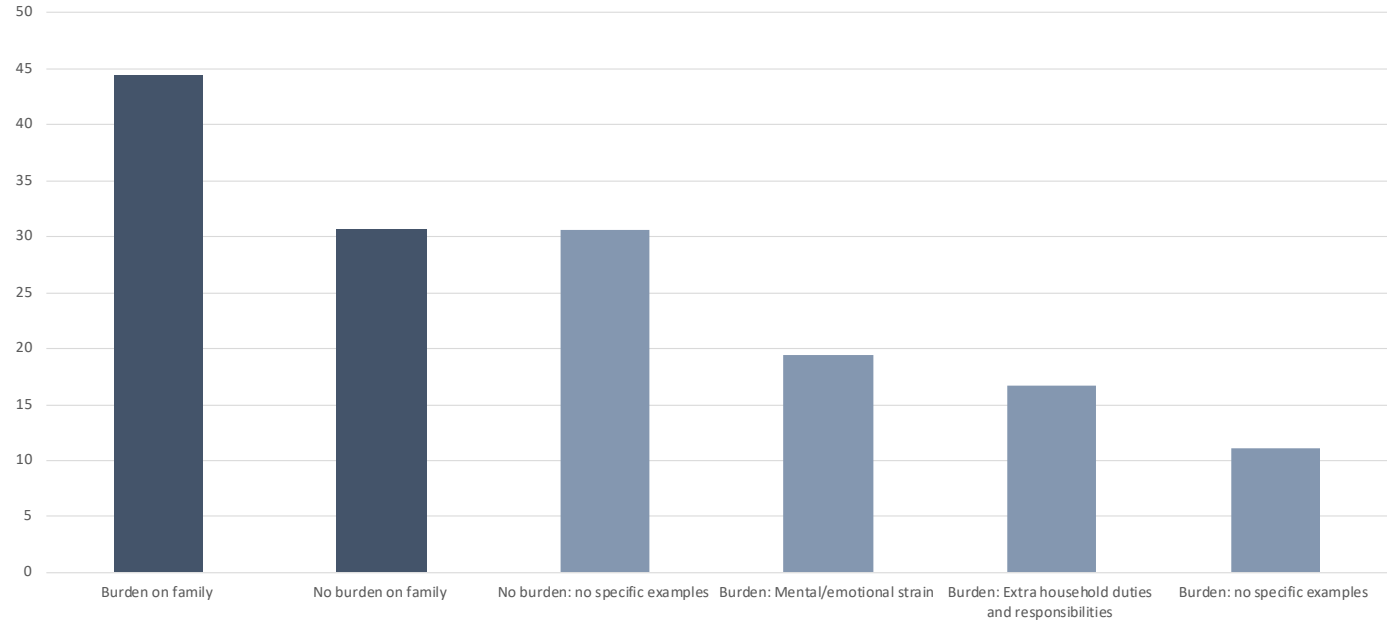
Yes. Probably a bit of extra burden on my wife. We've just accepted that's what it is and get on with life. Make the most of what's left. Participant 008ATR

Yes, probably. Participant 014ATR

Table 8.6: Burden on family

Burden on family	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes their condition not being a burden in general (No specific examples)	11	30.56	7	38.89	9	36.00	3	30.00	1	12.50	6	27.27	5	35.71	3	33.33	8	29.63
Participant describes the mental/emotional strain placed on their family	7	19.44	2	11.11	4	16.00	3	30.00	2	25.00	3	13.64	4	28.57	1	11.11	6	22.22
Participant describes extra household duties and responsibilities that their family must take on	6	16.67	5	27.78	5	20.00	0	0.00	1	12.50	4	18.18	2	14.29	1	11.11	5	18.52
Participant describes their condition being a burden in general (No specific examples)	4	11.11	2	11.11	2	8.00	1	10.00	1	12.50	3	13.64	1	7.14	2	22.22	2	7.41
Participant feels a burden on family	16	44.44	8	44.44	10	40.00	4	40.00	4	50.00	10	45.45	6	42.86	4	44.44	12	44.44
Participant does not feel a burden on family	11	30.56	5	27.78	9	36.00	5	50.00	1	12.50	7	31.82	4	28.57	3	33.33	8	29.63

Burden on family	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes their condition not being a burden in general (No specific examples)	11	30.56	2	25.00	5	26.32	3	37.50	4	28.57	6	42.86	1	9.09	10	40.00
Participant describes the mental/emotional strain placed on their family	7	19.44	2	25.00	3	15.79	2	25.00	2	14.29	3	21.43	2	18.18	5	20.00
Participant describes extra household duties and responsibilities that their family must take on	6	16.67	1	12.50	3	15.79	2	25.00	3	21.43	2	14.29	2	18.18	4	16.00
Participant describes their condition being a burden in general (No specific examples)	4	11.11	1	12.50	3	15.79	0	0.00	2	14.29	1	7.14	2	18.18	2	8.00
Participant feels a burden on family	16	44.44	3	37.50	9	47.37	4	50.00	7	50.00	5	35.71	6	54.55	10	40.00
Participant does not feel a burden on family	11	30.56	2	25.00	6	31.58	3	37.50	5	35.71	5	35.71	2	18.18	9	36.00



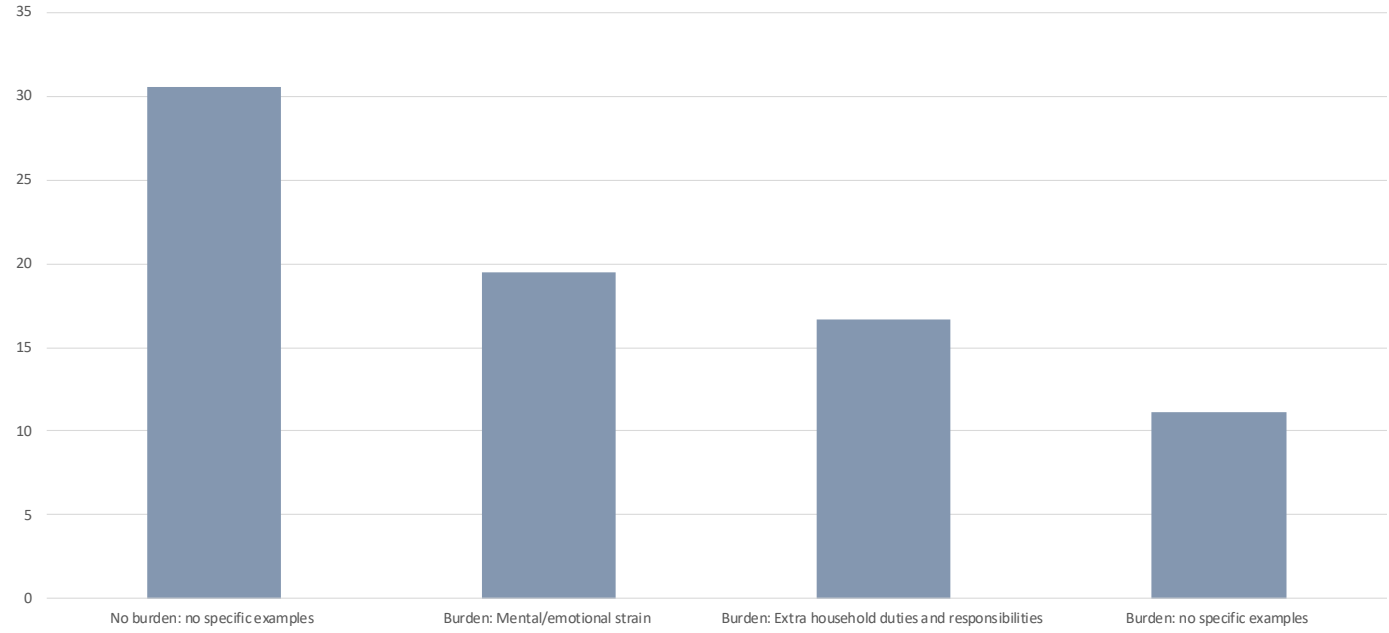


Figure 8.7: Burden on family

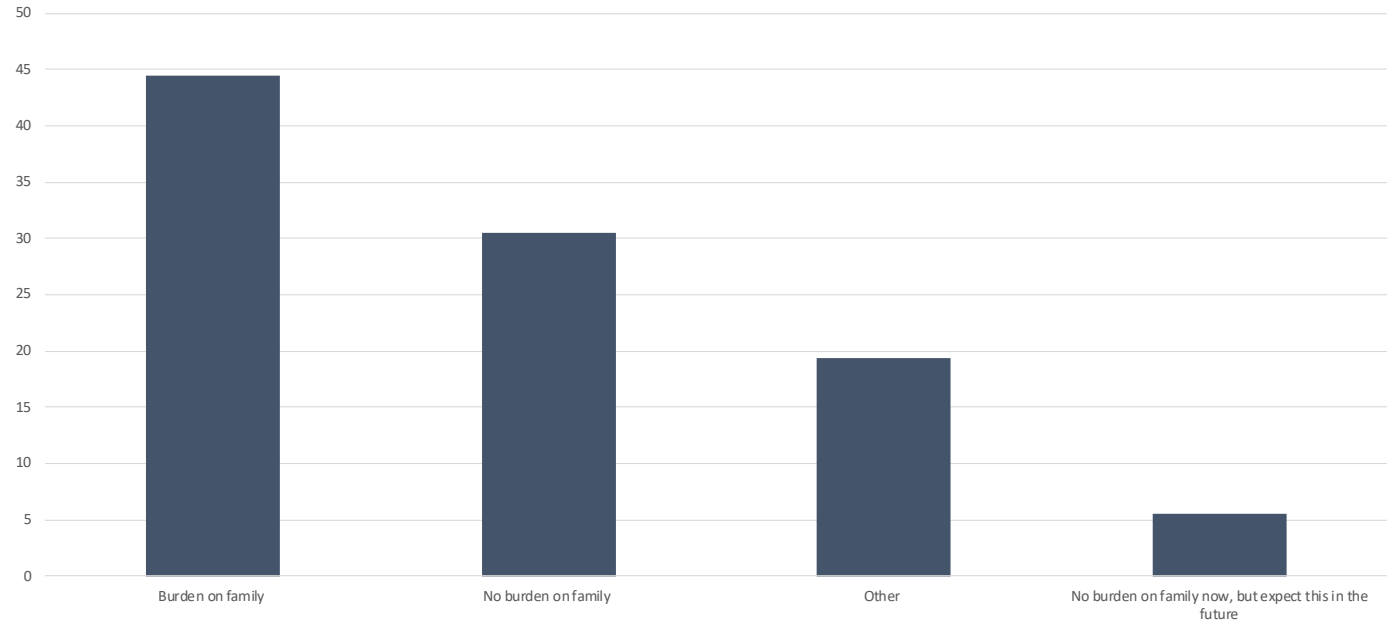


Figure 8.8: Burden on family (Additional burden/No additional burden/other)

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 11 participants (30.56%) that spoke about experiencing no cost burden as nearly everything was paid for through the health system and seven participants (19.44%) that reported a cost burden relating to time taken off work. Another seven participants (19.44%) noted a cost burden relating to treatments. Other costs described included the cost associated with parking, accommodation and travel to appointments (n=6, 16.67%), the cost of diagnostic tests and scans (n=6, 16.67%), and the cost relating to a family member taking time off work (n=4, 11.11%).

Overall, 18 participants (50.00%) reported at least some cost burden, while 13 participants (36.11%) described overall that they have experienced no cost burden.

In relation to subgroup variations, participants in the *Carer* (12.50%) subgroup described no cost burden because nearly everything was paid for through the health system less frequently than the general population (30.56%), while those in the *Aged 75 or older* (50.00%), and *Trade or high school* (50.00%)

subgroups described this more frequently. *Participants in the Aged 55 to 64* (0.00%) subgroup did not describe this at all.

Participants in the *Male* subgroup described a cost burden relating to time taken off from work less frequently (9.09%) than the general population (19.44%), while those in the *Carer* (37.50%), *Aged 55 to 64* (37.50%), and *Female* (35.71%) subgroups described this more frequently.

Participants in the *Trade or high school* (7.14%) subgroup described a burden in relation to the cost of treatments less frequently than the general population (19.44%), while those in the *Aged 55 to 64* (37.50%), and *University* (35.71%) subgroups described this more frequently. Participants in the *Mid to low SEIFA* (0.00%) subgroup did not describe this at all.

Participants in the *Aged 55 to 64* (50.00%), and *University* (28.57%) subgroups described a cost burden in relation to parking and travel to attend appointments less frequently than the general population (16.67%), while those in the *Aged 75 or older* (0.00%) subgroup did not describe this at all.

Participants in the *AL amyloidosis* (30.00%), and *University* (28.57%) subgroups described a cost burden relating to diagnostic tests and scans more frequently than the general population (16.67%), while those in *Carer* subgroup (0.00%) did not describe this at all.

Participants in the *Carer* (25.00%), and *Mid to low SEIFA* (27.27%) subgroups described a cost burden relating to a family member taking time off from work more frequently than the general population (11.11%), while those in *University* (0.00%)subgroup did not describe this at all.

Looking at the overall responses relating to whether or not they experienced any burden associated with cost, participants in the *Carer* (37.50%), *Aged 75 or older* (37.50%), and *Trade or high school* (35.71%) subgroups described experiencing at least some cost burden less frequently than the general population (50.00%), while those in the *AL amyloidosis* (60.00%), *Aged 55 to 64* (75.00%) and *University* (71.43%) subgroups described this more frequently.

Participants in the *Carer* (25.00%), and *University* (21.43%) subgroups described experiencing no cost burden overall less frequently than the general population (36.11%), while those in the *Aged 75 or older* (62.50%) and *Trade or high school* (57.14%) subgroups described this more frequently. Participants *Aged 55 to 64* (0.00%) did not describe this at all.

No cost burden: nearly everything paid for through health system

Oh, $780 from NAME PATHOLOGY COMPANY? That was done doing a lot of bloods for allergies and things like that. I had to pay that first and then submit that to Medicare. I actually showed the bill to the doctor I'm under at NAME HOSPITAL, and he was horrified with it and he phoned up NAME PATHOLOGY COMPANY and questioned the cost of it. It worked out that I was $134 out of pocket the rest was covered by Medicare. Really, I haven't been significantly out of pocket. He assured me that most things that I will have done, and treatments will be done under Medicare and not on private. Participant 001ATR

There's two costs. Obviously is monetary cost. I'm very fortunate that I'm a MILITARY PROFESSIONAL, so all mine has been covered, short of paying for some scripts. All those other costs have been covered by GOVERNMENT DEPARTMENT. That's one burden that hasn't arisen, of course. Participant 003ATR

Anyway, the doctor says, 'Hang on, don't do this, don't do that. No, you're better stay in here. You stay here. You'd be better off.' I was put on the public system just through that. Besides paying for drugs, I'm on the pension. Very little, really, very little, except for the cost of going in there, in and out. $650, I think, I pay now for my drug, which I know is terribly expensive, but it's on the PBS. Cost, really, for me, has never really been an issue. Participant 005AL

Cost burden: time off work

It certainly impacted on our general finances because I was actually doing some work on the side, and that ceased and effectively I lost my business. That initial impact was there, but since then, it hasn't had much impact on me at all, from a work or income point of view. Although, certainly, I couldn't go back and do the job I was doing. Participant 002ALX

However, because of the disease, you are debilitated from being able to function and working, you need to be honest for a job. I had to

reduce my work, the work from my own company and meeting clients and so on and so forth, so there were the cost of business, that is an income to the family, from a single income family or having fortunes. It took a huge impact in terms of the income coming in. In terms of costs to be treated, there were some things that were covered and some things they didn't. Participant 002ATR

I had stopped work, full-time work, in September 2016. I did some part-time consulting now, probably it's in the first year, it probably maybe I didn't-- When I was dealing with this new diagnosis probably it held me back a little bit in terms of promoting myself or consulting work. Participant 011ATR

Cost burden: Treatments including repeat prescriptions

Some of these drugs and some of these new drugs with the blood pressure and things, they're getting fairly expensive. All the chemotherapy treatments were on the basis of-- They were all PBS. Participant 001AL

The costs initially were that I was up for things like echocardiograph which is $200. Plus, each time I went to a treatment that was $50. Plus, the doctor's fees, which until they started bulk billing were quite substantial. I would say it cost probably about $5,000 for hospital. Participant 003AL

I'm lucky in the situation, the only costs I've come across so far, is the cost of medication and at about 150 a month, if you weren't prepared for it, it would botch you. If you didn't have the ability it would botch you. Participant 004ATR

Cost burden: Parking, travel and accommodation needed to attend medical appointments

I think parking ticket itself I think is a thousand dollars for two years or maybe 12 months; just parking at any hospital for that kind of thing. Participant 002ATR

Financially, it has been quite a drain for us, because we travelled to, well, not since COVID, but I would go to LOCATION METROPOLITAN every three months. We had the cost of airfares and things like that because I couldn't go by myself. Participant 012ATR

Unfortunately, because I can only pick it up from the hospital, it costs me half a day to travel to get it and to travel home. The cost of the travelling and the cost of the parking at some hospitals is absolutely disgustingly high. Those are my only costs up to now. I pay it, but that's my only concern. Participant 015ATR

Cost burden: Diagnostic tests and scans

The costs initially were that I was up for things like echocardiograph which is $200. Plus, each time I went to a treatment that was $50. Plus, the doctor's fees, which until they started bulk billing were quite substantial. I would say it cost probably about $5,000 for hospital. The medication was covered because it was given to me in the hospital. It looks like the medication will be covered again when I start this one, but certainly, it would have been $5,000. Participant 003AL

There was a cost, the blood tests, as you know, involved different sorts of tests I had to have or whatever. I had to have that with CLINIC NAME so I couldn't go to the hospital to have it. One of the tests that was about $85, or $87, or $90 that I had to pay. That was the cost that was absorbed. So far there hasn't been any overwhelming costs for me. Participant 003ALX

It can be quite frustrating to you due to the amount of things you have to go to as well. There's also particularly a lot of tests and scans and things, so it can build up quite quickly in terms of how much they cost. You have to get a nuclear bone scan and that's $600, and Medicare gives you back $150 or something like that. There is around testing particularly, this side of testing it's particularly expensive. Medications just because I'm on it so much, it's quite an expense as well. I don't regret it and I've responded quite a bit already, but basically, it's just the constant cost and year-round caring. It does build up quite a bit as well. It's more of a slow bleed that you'll actually take with the diagnostic tests and MRI's and things. Participant 006ATR

Cost burden: Family member taking time off work

It impacted, the early stages, very much on my wife's work, because she said she spent quite a bit of time running around after me because I couldn't drive or things like that, I was carrying problems in that field. I was in hospital a lot and she then had to move to a job where she could take adequate time off and everything. It impacted on us. Participant 002ALX

The biggest cost was us figuring we had to retire for longevity of life for NAME HUSBAND. Naturally, the medical team was surprised that he's not further along. We retired straight away. I retired within a month, and NAME HUSBAND took long service leave and annual holiday leave, then he retired mid-2016. That was the biggest thing. Participant 005CA

NAME HUSBAND had to cut back days at work to just three days and he's AGE to be able to do the other duties because I couldn't do them. Moneywise it's cost us a lot and while we covered quite a few things, there were a lot of the odd tests and things in the beginning that you had to pay, the bone scans and the MRI things and stuff like that. Participant 012ATR

At least some cost Burden overall

Well, it cost us a hell of a lot in the fact that we had income protection insurance, which we thought would be able to get us through. However, they basically turned around and just said we don't think that you'll have some will ever go back to work, so we decided to pay out a death benefit, which was about $27,000 as compared with 85% of what his normal. Literally, what they do is they just more or less, 'It's all right, we're just going to give you the death benefit. Participant 004CA

Yes, it's impacted quite a bit on our bank balance. We're retirees so we're not working, living off our superannuation and pension. It does become a bit of a strain. Participant 009ATR

The cost of treatment, the cost of testing, all those things has been borne by the PBS. It has been great. The cost of the medication isn't a problem because even though it's not on the list for being dispensed over here, I'm only paying the PBS rates for it. Unfortunately, because I can only pick it up from the hospital, it costs me half a day to travel to get it and to travel home. The cost of the travelling and the cost of the parking at some hospitals is absolutely disgustingly high. Those are my only costs up to now. I pay it, but that's my only concern. Participant 015ATR

No cost burden overall

I had to have an extensive echo specifically looking for amyloids for a cardiologist attached to the Amyloid Clinic at NAME HOSPITAL. It was done at NAME HOSPITAL, but it was done through the public system. I wasn't out of pocket for that one at all. Thus far I have not been out of pocket for anything. Participant 001ATR

Look, in our circumstance, it hasn't been an issue and I had already retired so I was not removing myself from the workforce, so I was quite prepared to be a dedicated carer. Probably, at this point in time, look, we have got very good private health. I'm not sure. I never even see an account from NAME DOCTOR now, so whether he bulk bills it, goes straight to our private health, I'm not sure. Some of his pharmaceuticals we have to cover, but it's never extraordinarily big amounts. Probably our biggest expense is driving to LOCATION METROPOLITAN every week, and we don't have to take accommodation when we go up there because we have two daughters living there. We haven't had any of those expenses. Participant 001CA

We're in the fortunate position where whatever it costs, we could pay. It's not something that we've been actually watching. Although if you added it up, there are a lot of costs. The blood pressure drug is on at the moment is $130 for 100 pills, and he takes 10 a day. That adds up. We're in a top level of a health fund. Costs, I think for us the costs are much more emotional than they are financial. Participant 002CA

Table 8.7: Cost considerations

Cost considerations	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes no cost burden and that nearly everything was paid for through the health system	11	30.56	7	38.89	10	40.00	3	30.00	1	12.50	7	31.82	4	28.57	3	33.33	8	29.63
Participant describes a cost burden in relation to needing to take time off work	7	19.44	3	16.67	3	12.00	1	10.00	3	37.50	2	9.09	5	35.71	1	11.11	6	22.22
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	7	19.44	4	22.22	6	24.00	2	20.00	1	12.50	5	22.73	2	14.29	1	11.11	6	22.22
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	16.67	4	22.22	4	16.00	1	10.00	1	12.50	3	13.64	3	21.43	1	11.11	5	18.52
Participant describes a cost burden in relation to diagnostic tests and scans	6	16.67	3	16.67	4	16.00	3	30.00	0	0.00	3	13.64	3	21.43	1	11.11	5	18.52
Participant describes a cost burden in relation to a family member needing to take time off work	4	11.11	1	5.56	1	4.00	1	10.00	2	25.00	1	4.55	3	21.43	1	11.11	3	11.11
Participant gives a description suggesting that overall, there was at least some cost burden	18	50.00	9	50.00	12	48.00	6	60.00	3	37.50	12	54.55	6	42.86	5	55.56	13	48.15
Participant gives a description suggesting that overall, there was no cost burden	13	36.11	8	44.44	11	44.00	3	30.00	2	25.00	8	36.36	5	35.71	3	33.33	10	37.04

Cost considerations	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes no cost burden and that nearly everything was paid for through the health system	11	30.56	0	0.00	7	36.84	4	50.00	7	50.00	3	21.43	3	27.27	8	32.00
Participant describes a cost burden in relation to needing to take time off work	7	19.44	3	37.50	3	15.79	1	12.50	2	14.29	2	14.29	3	27.27	4	16.00
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	7	19.44	3	37.50	2	10.53	1	12.50	1	7.14	5	35.71	0	0.00	7	28.00
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	16.67	4	50.00	2	10.53	0	0.00	1	7.14	4	28.57	2	18.18	4	16.00
Participant describes a cost burden in relation to diagnostic tests and scans	6	16.67	1	12.50	3	15.79	1	12.50	2	14.29	4	28.57	1	9.09	5	20.00
Participant describes a cost burden in relation to a family member needing to take time off work	4	11.11	1	12.50	2	10.53	1	12.50	2	14.29	0	0.00	3	27.27	1	4.00
Participant gives a description suggesting that overall, there was at least some cost burden	18	50.00	6	75.00	8	42.11	3	37.50	5	35.71	10	71.43	5	45.45	13	52.00
Participant gives a description suggesting that overall, there was no cost burden	13	36.11	0	0.00	8	42.11	5	62.50	8	57.14	3	21.43	4	36.36	9	36.00

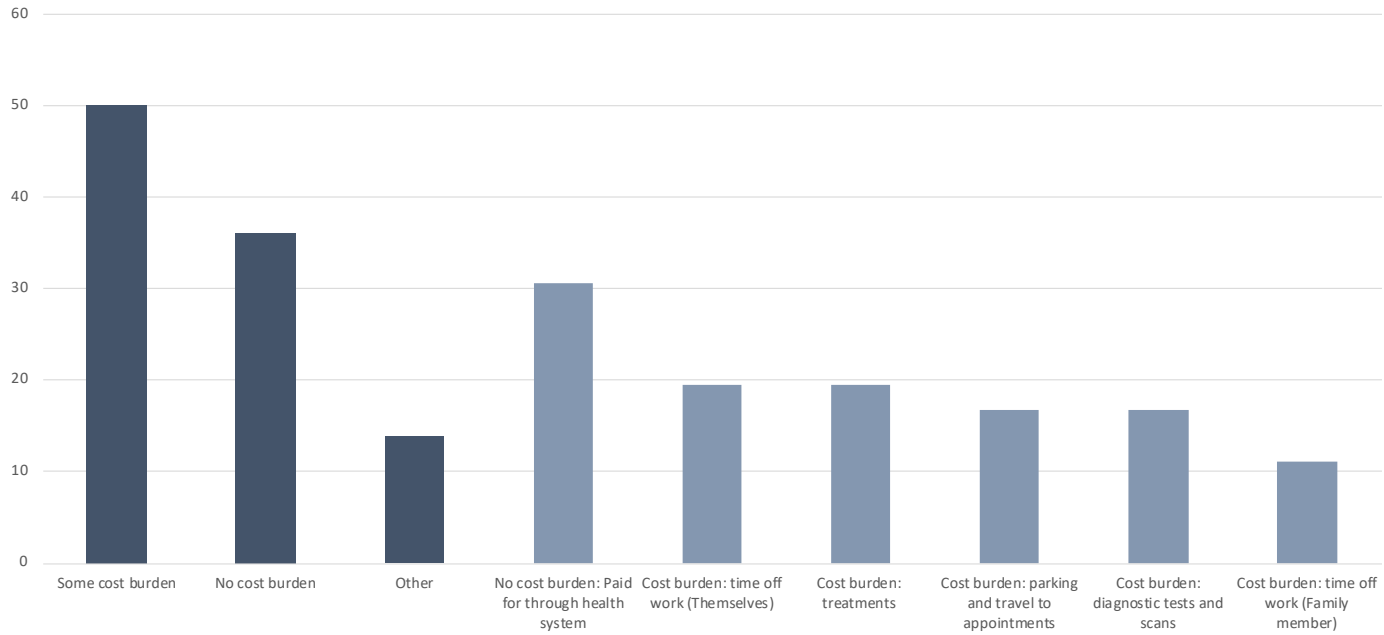


Figure 8.9: Cost considerations

Experience of anxiety related to disease progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety.

Summary statistics for the entire cohort are displayed in Table 8.8. Overall the entire cohort had a mean total score of 33.19 (SD = 9.92), which corresponds to moderate levels of anxiety.

The Fear of progression total score comparisons have been made by subgroups. Summary statistics are listed in Table 8.8.

Table 8.8: Fear of progression summary statistics

Sub-group	Count	Percent	Mean	SD	Median	IQR	Possible range	Quintile
All participants*	36	100.00	33.19	9.92	31.50	12.25	12 to 60	3

*Normal distribution use mean and SD as measure of central tendency

Comparisons of Fear of progression total score scales by Participant type

Participant type were grouped according to diagnosis; *ATTR-cardiac* group include participants diagnosed with hereditary or wild type ATTR (n=18, 50.00%). *All-cardiac* includes all participants diagnosed with amyloidosis that have cardiac involvement, this group includes participants diagnosed with AL amyloidosis and ATTR (n=25, 64.44%). The *AL amyloidosis* group includes all participants diagnosed with AL amyloidosis, including any organ involvement (n=10, 27.78%).

The final participant type are *Carers* to people with any type of amyloidosis (n=8, 22.22%).

Boxplots of each Fear of progression total score scale by **participant type** are displayed in Figures 8.10 summary statistics are displayed in Table 8.9.

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 8.9).

No significant differences were observed between participants in the by type of participant for the Fear of progression total score.

Table 8.9: Fear of progression total score by participant type ANOVA test and summary statistics

Fear of progression	Group	Number (n=36)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	ATTR-cardiac	18	50.00	36.50	9.15	Between groups	615.00	3	204.99	2.39	0.0784
	All-cardiac	25	69.44	33.88	9.26	Within groups	4894.00	57	85.86		
	AL amyloidosis	10	27.78	26.80	5.85	Total	5509.00	60			
	Carer	8	22.22	33.75	12.57						

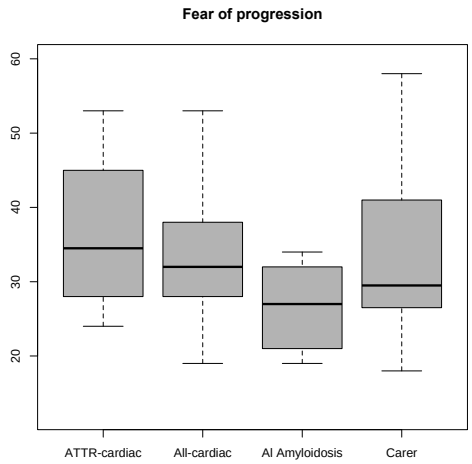


Figure 8.10: Boxplot of "Fear of progression total score" by participant type

Comparisons of Fear of progression total score scales by gender

Comparisons were made by **gender**, between males (n=22, 61.11) and females (n=14, 38.89%).

Boxplots of each Fear of progression total score scale by **gender** are displayed in Figures 8.11, summary statistics are displayed in Table 8.10. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.10).

No significant differences were observed between male and female participants in the Fear of progression total score.

Table 8.10: Fear of progression total score by gender summary statistics and two sample t-test

Fear of progression	Group	Number (n=36)	Percent	Mean	SD	T	dF	p-value
Total score	Female	14	38.89	32.64	10.32	0.26	34	0.7945
	Male	22	61.11	33.55	9.89			

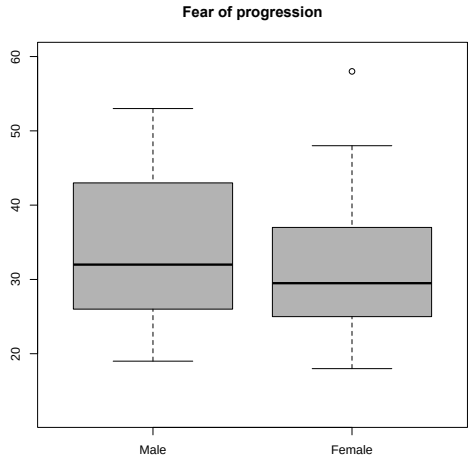


Figure 8.11: Boxplot of "Fear of progression total score" by gender

Comparisons of Fear of progression total score scales by Age

Participants were groups according to **age,** with comparisons made between participants *Aged 55 to 64* (n=8, 22.86%), *Aged 65 to 74* (n=19, 54.29%), and *Aged 75 and older* (n=8, 22.86%). One participant was aged in the 25 to 34 year old age bracket and was excluded from age comparisons.

Boxplots of each Fear of progression total score scale by **age** are displayed in Figures 8.12, summary statistics are displayed in Table 8.11.

When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 8.11).

No significant differences were observed between participants by age for any of the Fear of progression total score scales.

Table 8.11: Fear of progression total score by Age Kruskal-Wallis test

Fear of progression	Group	Number (n=35)	Percent	Median	IQR	c^2	dF	p-value
Total score	Aged 55 to 64	8	22.86	36.00	7.50	3.37	2	0.1859
	Aged 65 to 74	19	54.29	30.00	9.00			
	Aged 75 or older	8	22.86	28.50	9.00			

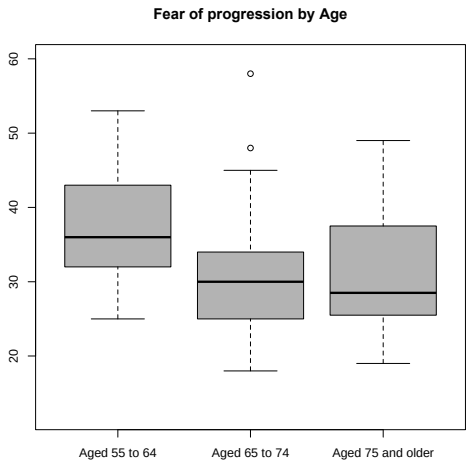


Figure 8.12: Boxplot of "Fear of progression total score" by age

Comparisons of Fear of progression total score scales by Education

Education status was collected only for participants diagnosed with amyloidosis (n=28). Comparisons were made by **education** status, between those with a university qualification, *University* (n= 14, 50.00%), and those with trade or high school qualifications, *Trade or high school* (n=14, 50.00%);

Boxplots of each Fear of progression total score scale by **education** are displayed in Figures 8.13, summary statistics are displayed in Table 8.12. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.12).

No significant differences were observed between participants by education for the Fear of progression total score.

Table 8.12: Fear of progression total score by education summary statistics and two sample t-test

Fear of progression	Group	Number (n=28)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	14	50.00	33.36	10.26	0.18	26	0.8589
	University	14	50.00	32.71	8.62			

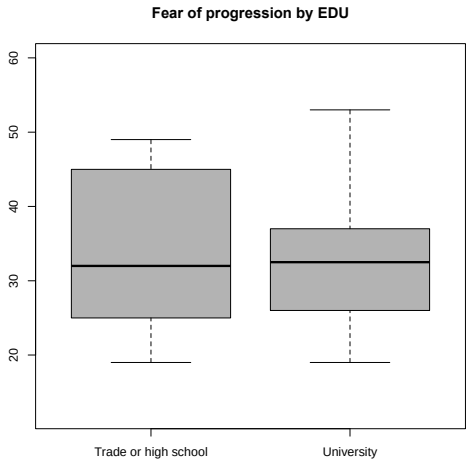


Figure 8.13: Boxplot of "Fear of progression total score" by education

Comparisons of Fear of progression total score scales by location

The **Location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics, those living in a major city, *Metropolitan* (n=27, 75.00%) were compared to those living in regional/rural areas, *Regional or remote* (n=9, 25.00%).

Boxplots of each Fear of progression total score scale by **location** are displayed in Figures 8.14, summary statistics are displayed in Table 8.13. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.13).

No significant differences were observed between participants by location for the Fear of progression total score.

Table 8.13: Fear of progression total score by location summary statistics and two sample t-test

Fear of progression	Group	Number (n=36)	Percent	Mean	SD	t	dF	p-value
Total score	Regional or remote	9	25.00	30.56	7.73	-0.92	34	0.3644
	Metropolitan	27	75.00	34.07	10.53			

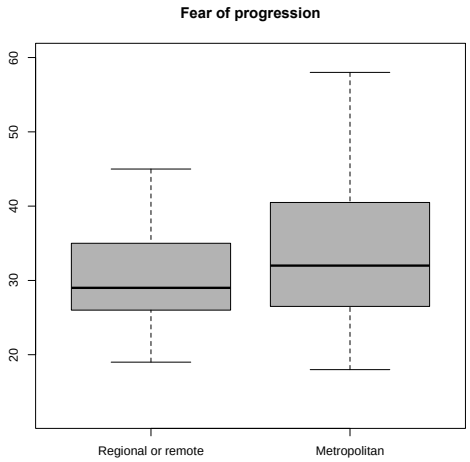


Figure 8.14: Boxplot of "Fear of progression total score" by location

Comparisons of Fear of progression total score scales by SEIFA

Comparisons were made by Socio-economic Indexes for Areas (**SEIFA**) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a higher SEIFA score of 7-10, *Higher SEIFA* (n=25, 69.44%) compared to those with a mid to low SEIFA score of 1-6, *Mid to low SEIFA* (n=11, 30.56%).

Boxplots of each Fear of progression total score scale by **SEIFA** are displayed in Figure 8.15, summary statistics are displayed in Table 8.14. Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.14).

No significant differences were observed between participants by SEIFA for the Fear of progression total score.

Table 8.14: Fear of progression total score by SEIFA summary statistics and two sample t-test

Fear of progression	Group	Number (n=36)	Percent	Mean	SD	t	dF	p-value
Total score	Mid to low advantage	11	30.56	36.36	11.41	1.28	34	0.2082
	Higher advantage	25	69.44	31.80	9.09			

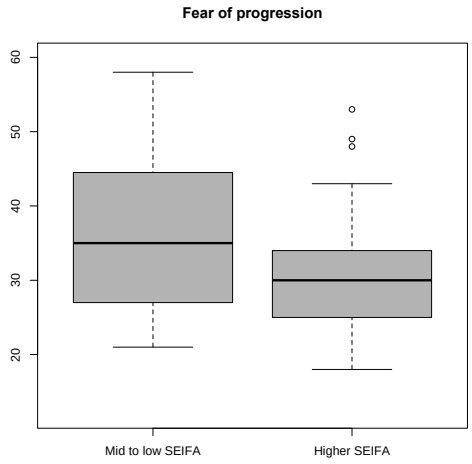


Figure 8.15: Boxplot of "Fear of progression total score" by SEIFA

Section 9

Expectations and messages to decision-makers

Section 9 Summary: Expectations and messages to decision-makers

Expectations of future treatments

- In the structured interview, participants were asked what their expectations of future treatments are. The most common theme was participants expected treatments to be more affordable (n=18, 50.00%), followed by the expectation that future treatments would be more effective (n=8, 22.22%). There were six participants (16.67%) that recommended future treatments should have fewer or less intense side effects and four participants (11.11%) that called for future treatments to be less invasive.

Expectations of future information

- Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was participants having no recommendations or feeling satisfied with the information currently available (n=7, 19.44%), and this was followed by the expectation that future information would be easier to understand (n=6, 16.67%). There were five participants (13.89%) that recommended more information to inform the community and decision-makers about the condition. There were also four participants (11.11%) who suggested future information provide more details about new treatments and trials and four participants (11.11%) that called for more details about the specific classification of their condition.

Expectations of future communication with healthcare professionals

- Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will involve health professionals having a better knowledge of the condition (n=13, 36.11%), and this was followed by no recommendations or participants feeling they had experienced good communication (n=10, 27.78%).

Expectations of future care and support

- Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was more access to support services in future (n=8, 22.22%), and this was followed by participants having no recommendations or being satisfied with the care they have received (n=6, 16.67%). There were four participants (11.11%) that recommended future care and support involving more peer support such as support groups and four participants (11.11%) that called for care and support to include more long-term condition management or care planning.

What participants are grateful for in the health system

- Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was participants expressing feeling grateful for the entire healthcare system (n=13, 36.11%). This was followed by those who were grateful for healthcare staff (n=10, 27.78%), low cost or free medical care through the government (n=10, 27.78%), timely access to treatment (n=5, 13.89%) and access to private healthcare/insurance (n=4, 11.11%).

Symptoms and aspects of quality of life

- Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported for participants with ATTR-cardiac were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and arm and leg symptoms (e.g. numbing, tingling, weakness, pain).

- The most important aspects reported for participants with AL amyloidosis were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and kidney symptoms (fatigue, loss of appetite and swelling in feet, ankles or legs).

Values for decision-making

- Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were 'How safe the medication is and weighing up the risks and benefits', and 'The severity of the side effects'. The least important were 'The financial costs to me and my family'.

Values for decision-makers

- Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The two most important values were quality of life for patients, and access for all patients to all treatments and services; the least important was economic value to government.

Time taking medication to improve quality of life

- Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n=19, 67.86%) would use a treatment for more than ten years for a good quality of life, even if it didn't offer a cure.

Message to decision-makers

- Participants were asked, 'If you were standing in front of the health minister, what would your message be in relation to your condition?'. The most common message was that treatments need to be affordable (n=10, 27.78%). This was followed by the message that there should be more clinical trials and/or new treatments (n=8, 22.22%), that there should be improved access to support and care (n=6, 16.67%), the need to take the condition seriously (n=5, 13.89%), the need to invest in professional development so that clinicians better understand the condition (n=5, 13.89%) and finally, to invest in research, including the effort to find new treatments (n=4, 11.11%).

Expectations of future treatments

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was participants expected treatments to be more affordable (n=18, 50.00%), followed by the expectation that future treatments would be more effective (n=8, 22.22%). There were six participants (16.67%) that recommended future treatments should have fewer or less intense side effects and four participants (11.11%) that called for future treatments to be less invasive.

In relation to subgroup variations, participants in the *Aged 75 or older* (37.50%) subgroup described the expectation that future treatments would be more affordable less frequently than the general population (50.00%), while those in the *Carer* (62.50%), *Aged 55 to 64* (62.50%), and *Female* (64.29%) subgroups described this more frequently.

Participants in the *Carer* (0.00%), *Female* (0.00%), and *Regional or remote* (11.11%) subgroups described the expectation that future treatments would be more effective less frequently than the general population (22.22%), while those in the *ATTR-cardiac* (33.33%), and *Male* (36.36%) subgroups described this more frequently.

Participants in the the general population (16.67%). described the expectation that future treatments would have fewer or less intense side effects, however no participants described this in the *Aged 75 or older* (0.00%) subgroup.

Participants in the *Aged 55 to 64* (25.00%), and *Female* (21.43%) subgroups described the expectation that future treatments would be less invasive more frequently than the general population (11.11%), while those in *Regional or remote* (0.00%), and *Mid to low SEIFA* (0.00) subgroups did not describe this at all.

More affordable

Well, obviously, the main would be costs to be brought down for those ones…I know it costs time to develop with these things, but those prices seem pretty high. Participant 001ALX

I think a lot of the cost, for example, some of the marker ones, not on the PBS though, I'm being charged the full amount for those, $89 a pop. Participant 003AL

Well, obviously the cost. If it ever gets to the point where some of them are paid for, that would be fantastic. Participant 012ATR

More effective

Well, the aim that I'd really love to have is some treatment that works for other types that actually gets in and effectively eats away this disease. I mean, that is a long, long, long, long way and it'll never be in my lifetime of course. To me, that would be the ideal, so that when people are diagnosed with my problem, they can go onto this treatment and say, 'Well, in two or three years if you keep taking this drug, you'll just have a normal heart instead of having a heart that only works at 30% of the average person.' To me, that would be the ideal situation. Participant 003ATR

If they could find something to dissolve amyloid in your system, and even not permanently, but just to give people a better quality of life with amyloid-free in their kidneys or heart or liver or wherever they have it. Participant 005AL

Just the cost for me and effectiveness. For somebody that has to pay for these treatments and the effectiveness, people like guarantees of course but they like best of all assurances that the benefit is going to be worth the cost. A lot of people cannot afford new treatments. Those two things together would be relevant to most people. Participant 006AL

Fewer or less intense side effects

Side effects, for me, I would like them to be known about. So, we know what's going to possibly going to happen and we can be aware of it. Participant 015ATR

It also does give you the chance to go away even if you just go for a weekend away or something like that. Yes, the least possible side effects if something was to give him really worse side effects than he has now and without any particular benefits. Participant 002CA

Well, everyone if there's new treatment there I suppose everyone expects it to not to have any side effects and to make it better as soon as possible. Participant 008ATR

Less invasive

Yes, so treatment-- a tablet is OK, I mean you just put it in the mouth. There are times that I have had to use injection, once I know-- you might look at and one's you might not. An IV drip because that would be really--The choices would be I think, for the future to see right now treatment is only for pre-transplant on the-- I know that there is post-transplant, that will be the trialled in Sweden, but they need three patients to do that. Participant 002ATR

What I would most like to see? I suppose the way it is administered. It depends if it's going to be an injection I suppose or tablets to ingest. If there was a discussion about preference for that and any side effects and I had a choice that would be something I would want to know about and have a choice in the administration of the treatment. Even if it was ongoing like a meeting with a health professional and discussion sort of thing that would be fine. I would be happy to do that. Participant 003ALX

In delivery, that is something that I would rather it be either an in-home where like taking medication, things like that. I don't like the idea of outpatients having to go into a hospital on a regular basis, because that's basically totally messing with your day and while you are trying to work, that's not good. So least invasive possible. Participant 015ATR

Table 9.1: Expectations of future treatments

Expectations of future treatments	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes the expectation that future treatment will be more affordable	18	50.00	8	44.44	11	44.00	5	50.00	5	62.50	9	40.91	9	64.29	4	44.44	14	51.85
Participant describes the expectation that future treatment will be more effective	8	22.22	6	33.33	8	32.00	2	20.00	0	0.00	8	36.36	0	0.00	1	11.11	7	25.93
Participant describes the expectation that future treatments will have fewer or less intense side effects	6	16.67	3	16.67	4	16.00	1	10.00	2	25.00	3	13.64	3	21.43	1	11.11	5	18.52
Participant describes the expectation that future treatment will be less invasive	4	11.11	2	11.11	2	8.00	1	10.00	1	12.50	1	4.55	3	21.43	0	0.00	4	14.81

Expectations of future treatments	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes the expectation that future treatment will be more affordable	18	50.00	5	62.50	10	52.63	3	37.50	7	50.00	6	42.86	5	45.45	13	52.00
Participant describes the expectation that future treatment will be more effective	8	22.22	1	12.50	4	21.05	2	25.00	4	28.57	4	28.57	2	18.18	6	24.00
Participant describes the expectation that future treatments will have fewer or less intense side effects	6	16.67	1	12.50	5	26.32	0	0.00	2	14.29	2	14.29	1	9.09	5	20.00
Participant describes the expectation that future treatment will be less invasive	4	11.11	2	25.00	1	5.26	1	12.50	1	7.14	2	14.29	0	0.00	4	16.00

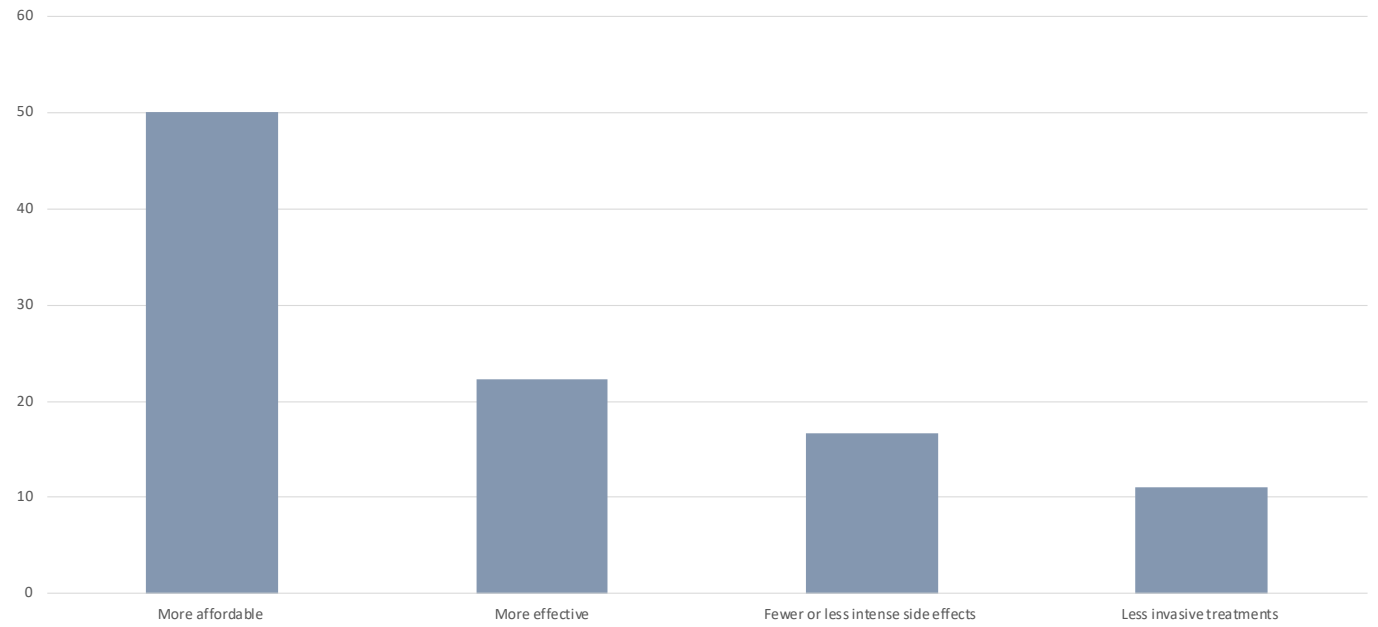


Figure 9.1: Expectations of future treatments

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was participants having no recommendations or feeling satisfied with the information currently available (n=7, 19.44%), and this was followed by the expectation that future information would be easier to understand (n=6, 16.67%). There were five participants (13.89%) that recommended more information to inform the community and decision-makers about the condition. There were also four participants (11.11%) who suggested future information provide more details about new treatments and trials and four participants (11.11%) that called for more details about the specific classification of their condition.

In relation to subgroup variations, participants in the *Regional or remote* (33.33%) subgroup described being satisfied with information or having no recommendations more frequently than the general population (19.44%).

Participants in the *AL amyloidosis* (30.00%), *Regional or remote* (33.33%), and *Mid to low SEIFA* (27.27%) subgroups described expectations that future information would be easier to understand more frequently than the general population (16.67%), while those in the *ATTR-cardiac* described this less frequently (5.56%).

Participants in the *Aged 75 or older* (25.00%) subgroup described the expectation that future information will help to inform the community and decision-makers about their condition more frequently than the general population (13.89%), whereas those in the *Regional or remote* (0.00%) subgroup did not describe this at all.

No participants in the *Carer* (0.00%), *Female* (0.00%), or *Trade or high school* (0.00%) subgroups described the expectation that future information about provide more details about new treatments and trials. Participants in the *University* (28.57%), and *Regional or remote* (22.22%) described this more frequently than the general population (11.11%).

Participants in the general population(11.11%) described expecting future information to provide more details about the specific classification of their condition, while no participants described this in the *AL amyloidosis* (0.00%) subgroup.

No recommendations/satisfied with existing information

No, I think what I have accessed is adequate information for me, personally. Participant 001ATR

I didn't find researching information difficult and if something didn't answer my question, I was comfortable with finding another source…I was comfortable with the amount of information that was out there definitely. Participant 001CA

The pamphlets they gave me when I first got diagnosed were comprehensive. They weren't full of jargon, so they were good. The information I'm getting from my doctor it's been pretty accurate... there's not much more they could say or do. Participant 004ATR

Easier to understand

I've tried reading some of the reports that are put out about the end results of the trials, et cetera, but they get too wordy and technical for us. If they're able to be summarised, maybe they are in layman's terms, et cetera. It's one or two pages. Participant 001ALX

I suppose just a very basic layman's term of description would help me a bit more. There's a little thing here I'm reading, the free light chains that fold into amyloid fibrils. That sort of thing, I guess I could-- You shouldn't Google these sorts of things, but yes, more information, more basic information as far as I'm concerned, it would be for my situation. Participant 003ALX

For one, I'm not a medical person, and two, I don't want to get it wrong. It really needs to be explained in layman's terms. 'If you have this type of amyloidosis, this is the type of medication you need. Participant 005CA

Inform the community (raise awareness)

I think more information has to be given by just normal doctors. I don't think that enough people know about Amyloidosis. I don't think education-- People need to be aware of it. The education level, whether that goes to doctors so that when someone's there, when a patient comes in and they have something that could be Amyloidosis, the

doctor needs to know that that may be Amyloidosis rather than sitting and waiting like we did for 12 weeks to find out what he had. Participant 004CA

I think more available information and more learning, I suppose. I still reckon a lot of people have never heard of the word, amyloidosis, me included, actually. Have never heard, and then I knew that a lot of people still say like, 'There's no treatment for that.' I say, 'You don't really give a damn, that is true.' It might have but and that's as far as your treatment, but available the information and for the promotion or awareness, I suppose, of information. Participant 006ATR

For me, I'm happy with it that I'm going to get back on that blinking high horse of mine, the GPs need to be informed. They really do. They've got a lot to do, it's a rare disease. Even if there is just a little something on top of their minds that says, 'Going down these lines carpal tunnel, both wrists, could be amyloids.' I want other people to get the information, not me. Participant 015ATR

New treatments and trials

The information, as I've mentioned before, comes from a variety of sources. What would interest me or what I would look for is new information. New, and that means- I'm again repeating what I've said before- is any new drugs or any trials. I think we've got to that point which I can't go. Going back, I think I'm sufficiently informed. Going forward, of course, I'll be interested in looking at anything. Participant 001AL

Interesting what the potential future developments, nearness of new drugs, or the clinical trials for new drugs that there might be. Participant 004AL

Now that the websites up, I think, the topics I'd like to see covered at would be the status of new drugs and trials, and secondly what are the tell-tale signs of worsening condition and what you should and shouldn't do. Participant 011ATR

Specific classification of condition

There are so many different amyloidosis. I don't know the diseases. Possibly a clear classification on them. Just that there is different things. You know? Simple, not too difficult, just outlining the major aspect that there is available. What could be done. Participant 005ATR

You can't go and talk to another patient that's got this, because we haven't found anyone that's got this. There's different ones around with hereditary type but it's different from mine. Participant 009ATR

Yes, I would like to see more information on actually in the eye. As I said I did a Zoom here recently which was interesting, but it didn't relate to anything of mine. There were three doctors talking. It would have related to some people and they probably would've found it wonderful but as I said, it didn't relate to me. Participant 010ATR

Table 9.2: Expectations of future information

Expectations of future information	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant has no recommendations/is satisfied with the information currently available	7	19.44	4	22.22	6	24.00	2	20.00	1	12.50	4	18.18	3	21.43	3	33.33	4	14.81
Participant describes the expectation that future information will be easier to understand	6	16.67	1	5.56	2	8.00	3	30.00	2	25.00	3	13.64	3	21.43	3	33.33	3	11.11
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	5	13.89	3	16.67	3	12.00	1	10.00	1	12.50	4	18.18	1	7.14	0	0.00	5	18.52
Participant describes the expectation that future information will provide more details about new treatments and trials	4	11.11	2	11.11	4	16.00	2	20.00	0	0.00	4	18.18	0	0.00	2	22.22	2	7.41
Participant describes the expectation that future information will provide more details on specific classifications of their condition	4	11.11	3	16.67	3	12.00	0	0.00	1	12.50	2	9.09	2	14.29	1	11.11	3	11.11

Expectations of future information	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant has no recommendations/is satisfied with the information currently available	7	19.44	1	12.50	4	21.05	2	25.00	3	21.43	3	21.43	2	18.18	5	20.00
Participant describes the expectation that future information will be easier to understand	6	16.67	2	25.00	3	15.79	1	12.50	2	14.29	2	14.29	3	27.27	3	12.00
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	5	13.89	1	12.50	1	5.26	2	25.00	2	14.29	2	14.29	1	9.09	4	16.00
Participant describes the expectation that future information will provide more details about new treatments and trials	4	11.11	1	12.50	2	10.53	1	12.50	0	0.00	4	28.57	1	9.09	3	12.00
Participant describes the expectation that future information will provide more details on specific classifications of their condition	4	11.11	1	12.50	2	10.53	1	12.50	2	14.29	1	7.14	1	9.09	3	12.00

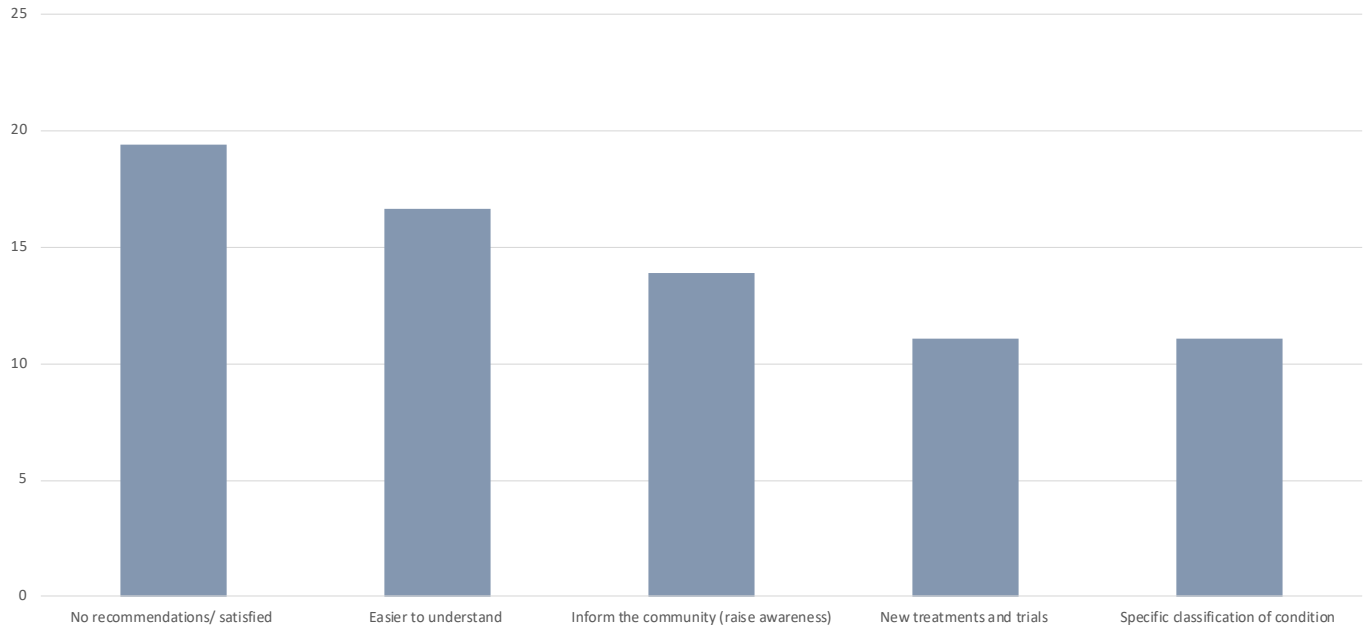


Figure 9.2: Expectations of future information

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was the expectation that future communication will involve health professionals having a better knowledge of the condition (n=13, 36.11%), and this was followed by no recommendations or participants feeling they had experienced good communication (n=10, 27.78%).

In relation to subgroup variations, participants in the *Carer* (25.00%), and *Aged 75 or older* (25.00%) subgroups described wanting health professionals to have a better knowledge of their condition less frequently than the general population (36.11%).

Participants in the *Carer* (12.50%), *Aged 55 to 64* (12.50%), and *Female* (14.29%) subgroups described having experienced good communication or having no recommendations less frequently than the general population (27.78%), while those in the *AL amyloidosis* (50.00%), *Aged 75 or older* (62.50%), *University* (47.86%), and *Regional or remote* (44.44%) subgroups described this more frequently.

Better knowledge of condition

I think health professionals should be honest when they don't know about amyloidosis and that they do reach out to keep the patients informed...I think that there needs to be more education and training for them. Participant 002ATR

The only thing in relation to health professionals is that there needs to be more education at the general practice level to be looking for this as a potential diagnosis, because I haven't met one person who hasn't been on 12 months' worth of looking and trying to find out why they were going downhill. It's more about education. Participant 002CA

I think health professionals need more knowledge about the disease itself. A lot of them don't know

about it. They've never heard of it. We've come across a couple of doctors now that- even our own neurosurgeon or neuro guy didn't know. He said, 'I've never heard of it'. Participant 009ATR

No recommendations/good communication

No. I think I'm pretty lucky that I've got good health professionals. I let my GP know what's going on. I'm trying to think. I don't recall saying, 'We should do this' or 'we should do that'. No, nothing in my case I can think of. Participant 001ALX

No. My experience is such that I wouldn't really change the people I've dealt with. It's hard to believe that I haven't run into somebody that had caused me any hustles at all. I'm big enough, I'm ugly enough to stand up for myself, and NAME wanted to do a heart biopsy, I told him he had to wait to autopsy. Participant 002ALX

No, I don't think so. I thought the way that they had NAME there that was so open 24 hours a day, practically, who have a vast knowledge of amyloidosis, that was just fantastic to know that you could pick up a phone and talk to her, and she would actually get you through to a cardiac specialist, whoever you wanted, very easily. I'd hate to see that go away, because she's a voluntary worker. As a patient, it was fantastic to know she was there. It was really good. Participant 017ATR

Table 9.3: Expectations of future healthcare professional communication

Expectations of future communication	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes the expectation that future communication will have health professionals with a better knowledge of the condition	13	36.11	8	44.44	10	40.00	3	30.00	2	25.00	7	31.82	6	42.86	3	33.33	10	37.04
Participant has no recommendations/experienced good communication	10	27.78	4	22.22	7	28.00	5	50.00	1	12.50	8	36.36	2	14.29	4	44.44	6	22.22

Expectations of future communication	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes the expectation that future communication will have health professionals with a better knowledge of the condition	13	36.11	3	37.50	8	42.11	2	25.00	6	42.86	5	35.71	4	36.36	9	36.00
Participant has no recommendations/experienced good communication	10	27.78	1	12.50	4	21.05	5	62.50	3	21.43	6	42.86	2	18.18	8	32.00

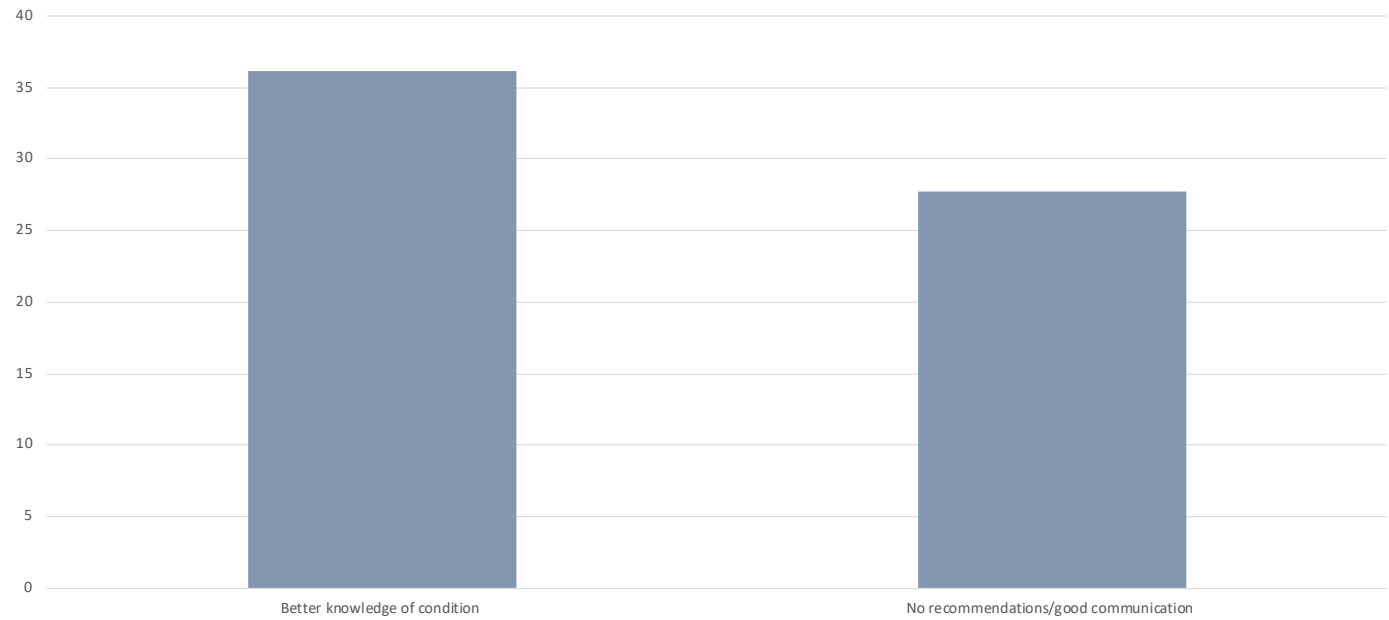


Figure 9.3: Expectations of future healthcare professional communication

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was more access to support services in future (n=8, 22.22%), and this was followed by participants having no recommendations or being satisfied with the care they have received (n=6, 16.67%). There were four participants (11.11%) that recommended future care and support involving more peer support such as support groups and four participants (11.11%) that called for care and support to include more long-term condition management or care planning.

In relation to subgroup variations, participants in the *AL amyloidosis* (10.00%), and *University* (7.14%) subgroups described wanting better access to support services in the future less frequently than the general population (22.22%), while those in the *Carer* (50.00%), *Aged 65 to 74* (36.84%), *Female* (35.71%), *Regional or remote* (44.44%) and *Mid to low SEIFA* (36.36%) subgroups described this more frequently. There were no participants in the *Aged 75 or older* (0.00%) subgroup that described this.

Participants in the *AL amyloidosis* (30.00%), and *Trade or high school* (28.57%) subgroups described having no recommendations or being satisfied with the care they have received more frequently than the general population (16.67%), while those in the *Carer* (0.00%) subgroup did not describe this at all.

No participants in the *Carer* (0.00%), *Aged 55 to 64* (0.00%), *Regional or remote* (0.00%) or *Mid to low SEIFA* (0.00%) subgroups described wanting future care and support to include more peer support. Those in the *Aged 75 or older* (25.00%) subgroup described this more frequently than the general population (11.11%).

Those in the *Aged 55 to 64* (25.00%), and *Regional or remote* (22.22%) subgroups described wanting future support and care to include more long-term condition management more frequently than the general population (11.11%), while participants in the *AL amyloidosis* (0.00%), and *Aged 75 or older* (0.00%) subgroups did not describe this at all.

Access to support services

There are people out there miles out in the country that have Amyloidosis and have to come into the hospitals. I believe that there should be accommodation for these people...I feel that there should be people that can pick them up from the airport, take them to places. Participant 004CA

I don't know what other charities there would be, but I would think probably, maybe for a lot of people, it's having someone to talk to, especially in those early days, about it, to find you to get to the right path and know what's available and how to help them would be really helpful. Participant 012ATR

Well, I think I'm pretty all right, but then a person by themselves would probably need a bit of support, someone to talk to or keep an eye on them. As it gets worse, you probably become incapacitated and you'll need probably pretty intensive care. Participant 014ATR

No recommendations

Let me think, what I would need help with? Sorry. I can't think of anything. Let me see. I get the support that NAME CLINIC they ran some services on exercises and that sort of thing and eating, and what to eat. That was good. No, I can't think of anything, sorry. Participant 001ALX

I haven't needed a lot of help. I know that it might sound big headed. To be perfectly honest, no. If it can be improved, but I don't think if there's necessarily anything not available or not at least missing to me as we're managing the disease. I think as a result of the questions you asked me, I may well ask some additional questions next time I meet NAME CLINICIAN, but no, I'm pretty comfortable with the care and the information and the like, that's been provided. Participant 004AL

No, I don't think so. I'm lucky to have a fantastic wife who cared for me fantastically. We didn't need any outside support. She might, but I didn't. Participant 017ATR

Peer support

I know recently we had to do one. We had two sessions, we had a support group meeting and an education meeting, and I think more people got on board that then-- Maybe sometimes people can't get to a local, actual physical meet up group, so maybe some more online stuff is a good idea. Participant 002AL

I think support groups are probably a big help, but again because in this case, in my case because the numbers are so small, obviously the support group is very small and it's all like people live in different areas, you've got to travel sometimes and again sometimes you can't. Meetings will be held or support groups will be held but that's not as if you can just drive 15 minutes and you're meeting a group of people, you have to drive an hour and half or whatever, but I think support groups will do. Participant 003ATR

I think I've a couple of group or, what they call it, the chat group or something in LOCATION REGIONAL where everyone can meet once a month and have a talk about their problems. Compare problems. That sort of thing, it would probably be good I reckon. It's just sort of-- I think you got to be-- If someone in the right position, they might know that and get that going. I've had three or four names. Participant 008ATR

Care planning

I think the answer is that there is almost more that could be done to assist us. Just to provide better assistance. Because life always has to explain to different aspects in the situation and everybody also is different will be affected in different ways. Just a matter, again, to discover what is going on inside and also doctor patients may we require further assistance. Understanding the feeling and what it can create, but then those patients can be as a group and also as individuals because of their own systems. Participant 005ATR

I think I would've liked more one-on-one, not one-on-one really, more feedback on the ATTR, rather than just a pamphlet, because when we searched, it's pretty tricky to get that non-medical, so we educated ourselves, me more so, because NAME HUSBAND became so overwhelmed sometimes… The thing is, if anything happens, I'll have to explain to every medical person what was used in his medicine. Especially emergency, because they're not going to just contact a cardiologist come up from LOCATION METROPOLITAN hurrying. The support team, I think has to be through the medical system, but they don't communicate, NAME HOSPITAL 1 don't communicate with the NAME HOSPITAL 2. Even with travel, they don't communicate. Participant 005CA

It's not dementia, it's not Parkinson's, so you can't treat it in the same way. That, to me, would be-- that level of care, but specifically tailored to the-- At the end of the day, so the very last day, my dad's mind was as clear as a bell, it wasn't a problem. Treat him like he's got dementia, no way, he would have thrown things at you if you could have picked him up. That's what I mean, it needs to be condition-specific care because, otherwise, if you treated me like I have dementia, I'd pick up a bowl and throw it at you because that's not what I am. That needs to be recognised when they're planning their care. Participant 014ATR

Table 9.4: Expectations of future care and support

Expectations of future care and support	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant describes the expectation that future care and support will include more access to support services	8	22.22	3	16.67	4	16.00	1	10.00	4	50.00	3	13.64	5	35.71	4	44.44	4	14.81
Participant has no recommendations/is satisfied with care received	6	16.67	3	16.67	5	20.00	3	30.00	0	0.00	5	22.73	1	7.14	1	11.11	5	18.52
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	11.11	2	11.11	4	16.00	2	20.00	0	0.00	3	13.64	1	7.14	0	0.00	4	14.81
Participant describes the expectation that future care and support will include more long-term condition management (care planning)	4	11.11	3	16.67	3	12.00	0	0.00	1	12.50	3	13.64	1	7.14	2	22.22	2	7.41

Expectations of future care and support	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant describes the expectation that future care and support will include more access to support services	8	22.22	1	12.50	7	36.84	0	0.00	3	21.43	1	7.14	4	36.36	4	16.00
Participant has no recommendations/is satisfied with care received	6	16.67	1	12.50	3	15.79	2	25.00	4	28.57	2	14.29	1	9.09	5	20.00
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	4	11.11	0	0.00	2	10.53	2	25.00	2	14.29	2	14.29	0	0.00	4	16.00
Participant describes the expectation that future care and support will include more long-term condition management (care planning)	4	11.11	2	25.00	2	10.53	0	0.00	1	7.14	2	14.29	2	18.18	2	8.00

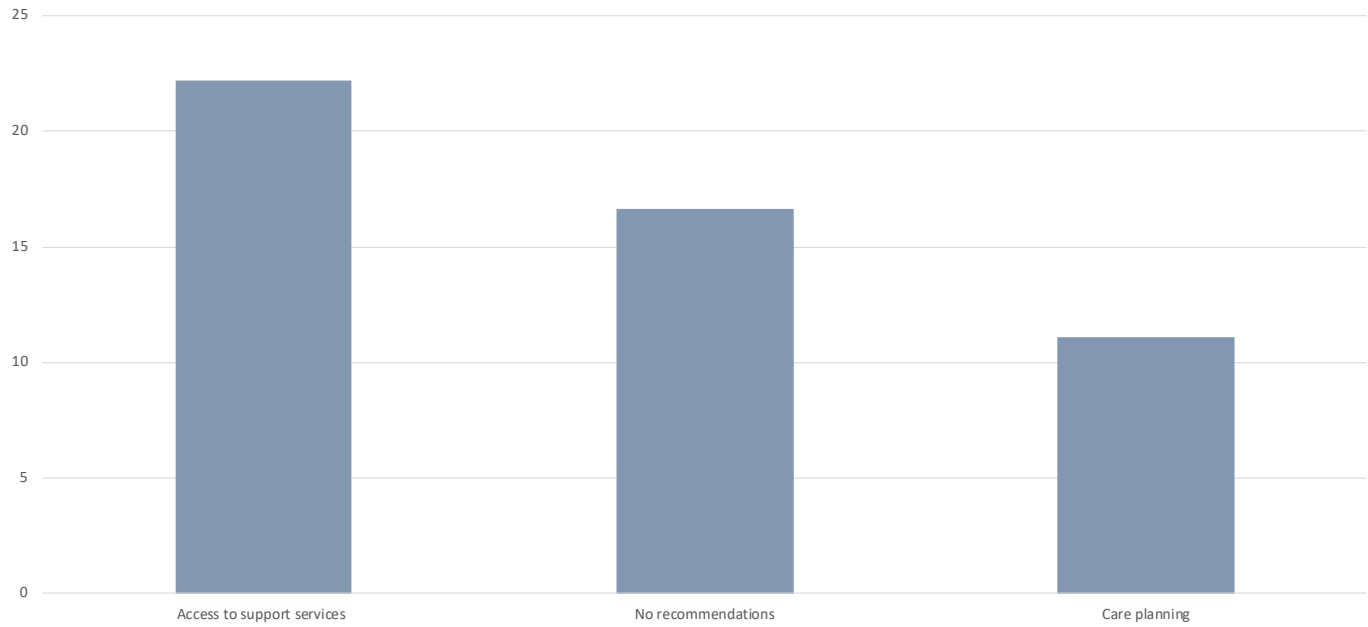


Figure 9.4: Expectations of future care and support

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was participants expressing feeling grateful for the entire healthcare system (n=13, 36.11%). This was followed by those who were grateful for healthcare staff (n=10, 27.78%), low cost or free medical care through the government (n=10, 27.78%), timely access to treatment (n=5, 13.89%) and access to private healthcare/insurance (n=4, 11.11%).

In relation to subgroup variations, participants in the *Carer* (12.50%), *Aged 55 to 64* (12.50%), and *University* (21.43%) subgroups described being grateful for the entire health system less frequently than the general population (36.11%), while those in the *AL amyloidosis* (60.00%), *Aged 75 or older* (50.00%), and *Trade or high school* (64.29%) subgroups described this more frequently.

Participants in the *Aged 65 to 74* (10.53%), and *Trade or high school* (14.29%) subgroups described being grateful for healthcare staff less frequently than the general population (27.78%), while those in the *Aged 55 to 64* (50.00%) subgroup described this more frequently.

No participants in the *Trade or high school* (0.00%), and *Mid to low SEIFA* (0.00%) subgroups described bring grateful for timely access to treatment. Participants in the *Carer* (25.00%), and *Aged 55 to 64* (25.00%) subgroup described this more frequently than the general population (13.89%).

Participants in the *AL amyloidosis* (30.00%), and *Regional or remote* (22.22%) subgroups described being thankful for access to private healthcare or insurance more frequently than the general population (11.11%), while those in *ATTR-cardiac* (0.00%) subgroup did not describe this at all.

Entire health system

Just for living in the health system that we live in basically. Thank God our taxes go to some good. Participant 001ATR

Yes, I agree with you, we've got a brilliant health system. I think people who complain about the public system in particular need a good boot up the backside because it's probably the best public health system in the world. Participant 002ALX

The Australian health system is second to none. Trust me. I'm just ever so grateful for the assistance that we've had. Participant 003CA

Healthcare staff

I think I'm particularly grateful for the quality of his oncologist and haematologist. We've always had, I think it's important to have a great trust in the person who's managing your health, especially when it's a life-threatening health condition. We have always had that, there's never been any time

we moved out of NAME CLINICIAN. We always felt he was very well connected with renal specialists and heart specialists. They actually were a team, so NAME HUSBAND felt that he was not going from one to another without communication. So, they've always been informed with NAME HUSBAND'S blood tests and progress. That's been very important to have those professionals who are helping to manage your condition, communicating, and connected to one another. Participant 001CA

The ambulance took me straight through NAME HOSPITAL and honestly, the care there was just amazing. The same at the NAME HOSPITAL, the care is just wonderful, the people doing the tests on me, the urine test, the blood tests, all the nurses, whatever, even the people at the reception, I think they chose them especially for it because they're so caring and so positive. Participant 003ALX

Now, I've just been there, I've been thankful for every time I've been in hospital or wherever that I've never come across a cranky nurse, doctor or anything like that. They've always been understanding and obliging, and we've heard some horrible misadventures in the hospital, but they've always been there, they've never been--they largely never been put down or belittled in any way like that. Participant 003ATR

Low cost/free medical care

The availability of the doctors under the PBS and the public health system, so I don't have too many expenses. For a while there, I was visiting my haematologist as a private patient, that was costing me. The day we had a meeting, it turned out not to be convenient, so I asked to be moved. I realised he also had whatever, they're called consulting rooms at NAME HOSPITAL. I asked to move to there…The cost is the biggest benefit. Participant 001ALX

Well, the amyloidosis clinic at NAME HOSPITAL because when we go there if we have any sort of a test, an echocardiogram or any sort of test, it's all covered by the health system, which means that if you weren't in the position of being able to afford specialist doctors who're running private practices, that you still have access to that kind of care, the same level of care. Participant 002CA

Heck, yes. I'm grateful to going and having a scan, and not paying for it under Medicare. I can't believe that such a sophisticated thing and people interpreting it is all under. Yes. When I look at what's happened in a place like LOCATION OVERSEAS, when I look at Australia, oh, gee-whiz! No, I'm very grateful for Medicare in Australia. Participant 007ATR

Timely access to treatment

I am extraordinarily grateful for the availability of pharmaceuticals. It was a little bit of a shock when we thought carfilzomib might be the answer to NAME HUSBAND's condition, and it wasn't going to be available. NAME HUSBAND said to NAME DOCTOR, 'we'll buy it, you just get it'. But NAME DOCTOR said it wasn't quite like that. You couldn't just go and buy it off the shelf. We were very grateful when he pleaded the case to PBS, and it did become available to NAME HUSBAND. Participant 001CA

The Australian health system is second to none. Trust me. I'm just ever so grateful for the assistance that we've had. I think being a rare thing, I think the one time we had to go over to HOSPITAL METROPOLITAN in an emergency and the minute they knew that NAME HUSBAND had been on thalidomide and had amyloid, they just picked him up and took him straight in. Participant 003CA

The thing that has always pleased and surprised me in comparison to living over in the UK with the NHS, is the speed at which things are done. I'm not talking about whether you're under a private healthcare scheme or anything like that, just going straight into the health system, the speed at which things are done is great and I am very appreciative of that, again, on a daily basis. I have heard them say on the television, 'It takes two days before somebody gets seen and has treatment for something.' Yes, and in the UK, it's three years, shut up and smile. I am always pleased for that. Participant 015ATR

Access to private healthcare/private insurance

I would agree that the health system is very good. Also, carrying private insurance, which we do. I have access pretty much immediately. Participant 001AL

We have insurance, and even meant for chronic conditions like the management for, you can go on a care plan, which we have done over the course of 2015 to now. We've gone through care plan for nutrition through our local GP, nutrition,

counselling, physios and now physio again, we haven't done it every year, but I think it's handy in that you can have the first 10 at a rebate. That has been so beneficial. Not only a GP, we didn't know that so the GP have been great in terms of, 'I think you need to go on a care plan, and this is what it will look like'. Then you can pay those components. Participant 005CA

I can look at it from both sides because I could look at the health system and be thankful that we do have a really good health system. Further, I can be very thankful that I'm a NAME INSURER client because that does cover all the costs. I'm doubly grateful. Participant 006AL

Table 9.5: What participants are grateful for in the health system

Aspects of the health system that people are grateful for	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant is grateful for the entire health system	13	36.11	6	33.33	10	40.00	6	60.00	1	12.50	8	36.36	5	35.71	3	33.33	10	37.04
Participant is grateful for healthcare staff	10	27.78	5	27.78	5	20.00	2	20.00	3	37.50	6	27.27	4	28.57	3	33.33	7	25.93
Participant is grateful for low cost/free medical care through the government	10	27.78	5	27.78	6	24.00	2	20.00	3	37.50	6	27.27	4	28.57	2	22.22	8	29.63
Participant is grateful for timely access to treatment	5	13.89	1	5.56	3	12.00	2	20.00	2	25.00	3	13.64	2	14.29	2	22.22	3	11.11
Participant is grateful for access to private healthcare/private insurance	4	11.11	0	0.00	3	12.00	3	30.00	1	12.50	3	13.64	1	7.14	2	22.22	2	7.41

Aspects of the health system that people are grateful for	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant is grateful for the entire health system	13	36.11	1	12.50	8	42.11	4	50.00	9	64.29	3	21.43	4	36.36	9	36.00
Participant is grateful for healthcare staff	10	27.78	4	50.00	2	10.53	3	37.50	2	14.29	5	35.71	2	18.18	8	32.00
Participant is grateful for low cost/free medical care through the government	10	27.78	3	37.50	4	21.05	2	25.00	3	21.43	4	28.57	3	27.27	7	28.00
Participant is grateful for timely access to treatment	5	13.89	2	25.00	2	10.53	1	12.50	0	0.00	3	21.43	0	0.00	5	20.00
Participant is grateful for access to private healthcare/private insurance	4	11.11	1	12.50	2	10.53	1	12.50	1	7.14	2	14.29	1	9.09	3	12.00

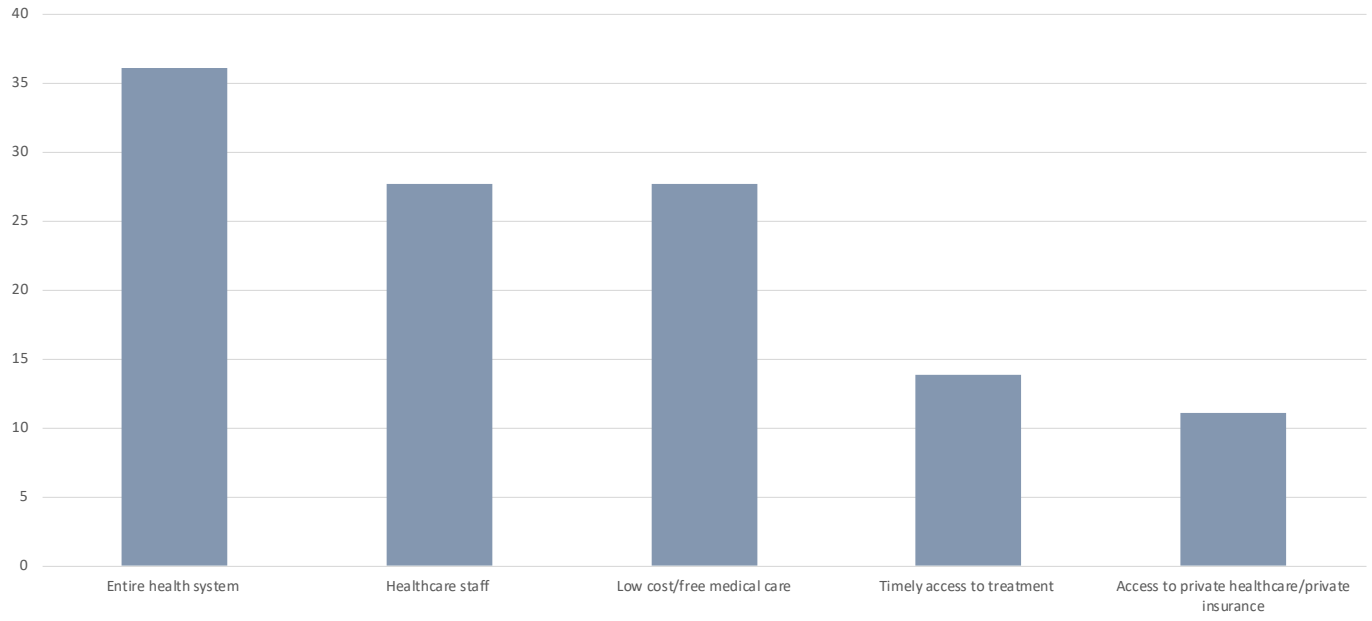


Figure 9.5: What participants are grateful for in the health system

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, were 1 is the most important and 9 is the least important. A weighted average is presented in Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects reported for participants with ATTR-cardiac were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and arm and leg symptoms (e.g. numbing, tingling, weakness, pain).

The most important aspects reported for participants with AL amyloidosis were heart and lung symptoms (e.g. short of breath, palpitations, chest pain), and kidney symptoms (fatigue, loss of appetite and swelling in feet, ankles or legs).

Table 9.6: Symptoms and aspects of quality of life ATTR-cardiac

Symptom	Weighted average (n=18)
Heart and lung symptoms (e.g. short of breath, palpitations, chest pain)	4.11
Fatigue	2.78
Arm and leg symptoms (e.g. numbing, tingling, weakness, pain)	2.94
Head and neck symptoms (e.g. light-headedness, dizziness, eye floaters)	2.33
Stomach symptoms (e.g. appetite, bloating, diarrhoea, nausea, weight loss)	2.83

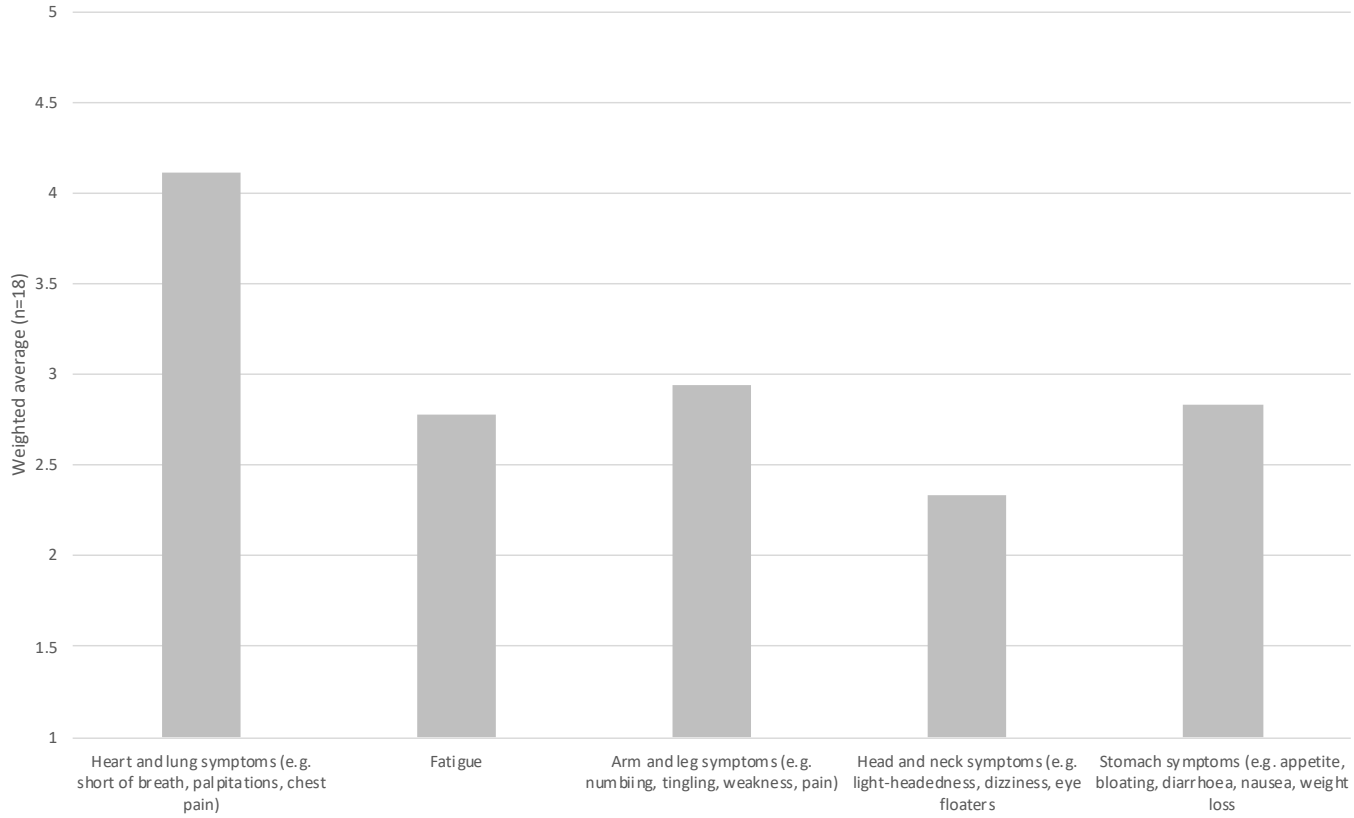


Figure 9.6: Symptoms and aspects of quality of life ATTR-cardiac

Table 9.7: Symptoms and aspects of quality of life AL amyloidosis

Symptom	Weighted average (n=10)
Heart and lung symptoms (e.g. short of breath, palpitations, chest pain)	5.33
Kidney symptoms (fatigue, loss of appetite and swelling in feet, ankles or legs)	4.22
Fatigue	3.80
Arm and leg symptoms (e.g. numbing, tingling, weakness, pain)	3.00
Head and neck symptoms (e.g. light-headedness, dizziness, eye floaters)	2.70
Stomach symptoms (e.g. appetite, bloating, diarrhoea, nausea, weight loss)	2.44

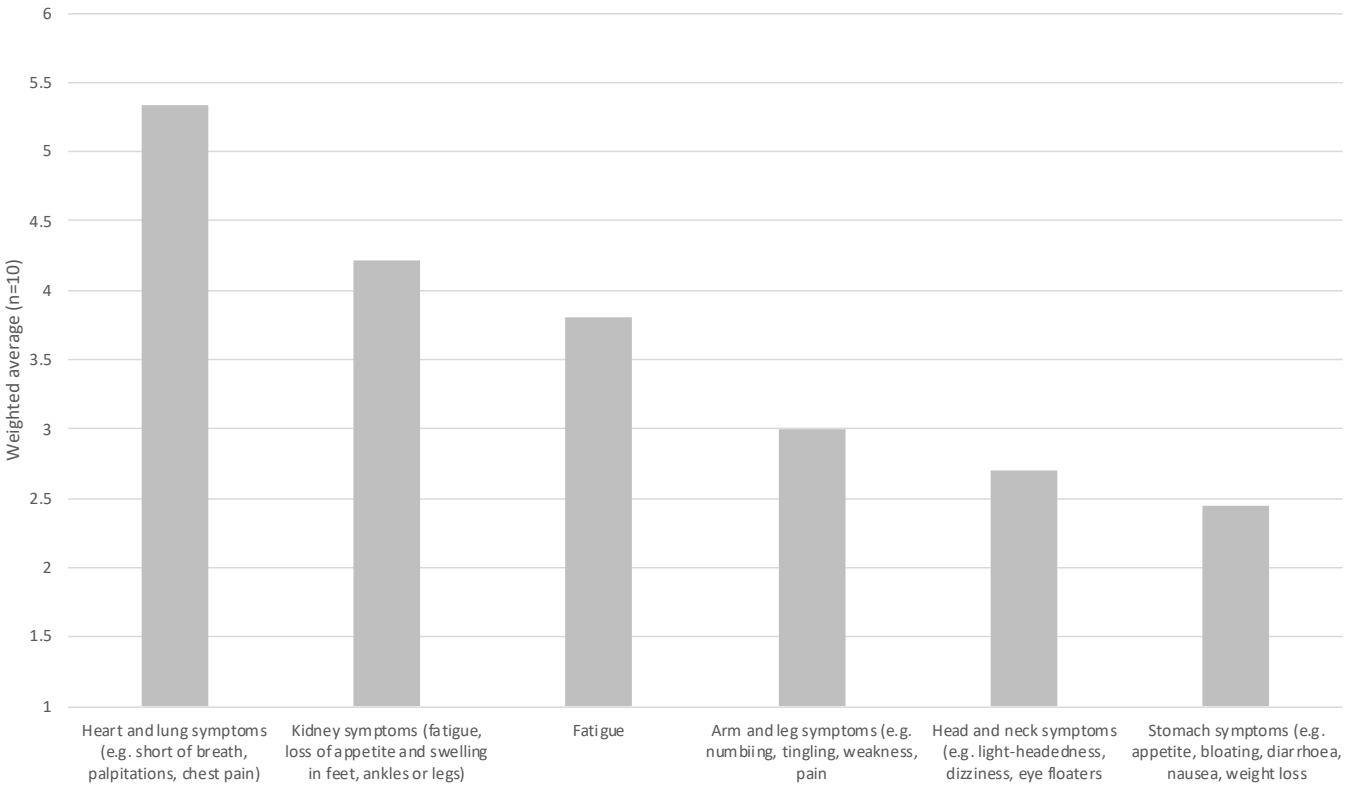


Figure 9.7: Symptoms and aspects of quality of life AL amyloidosis

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.8.

With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects were 'How safe the medication is and weighing up the risks and benefits', and 'The severity of the side effects'. The least important were 'The financial costs to me and my family'.

Table 9.8: Values in making decisions

Symptom	Weighted average (n=36)
How safe the medication is and weighing up the risks and benefits	7.06
The severity of the side effects	6.36
Time impact of the treatment on my quality of life	4.97
How the treatment is administered	4.19
How personalised the treatment is for me	4.50
The ability to include my family in making treatment decisions	3.67
My ability to follow and stick to a treatment regime	2.78
The financial costs to me and my family	2.47

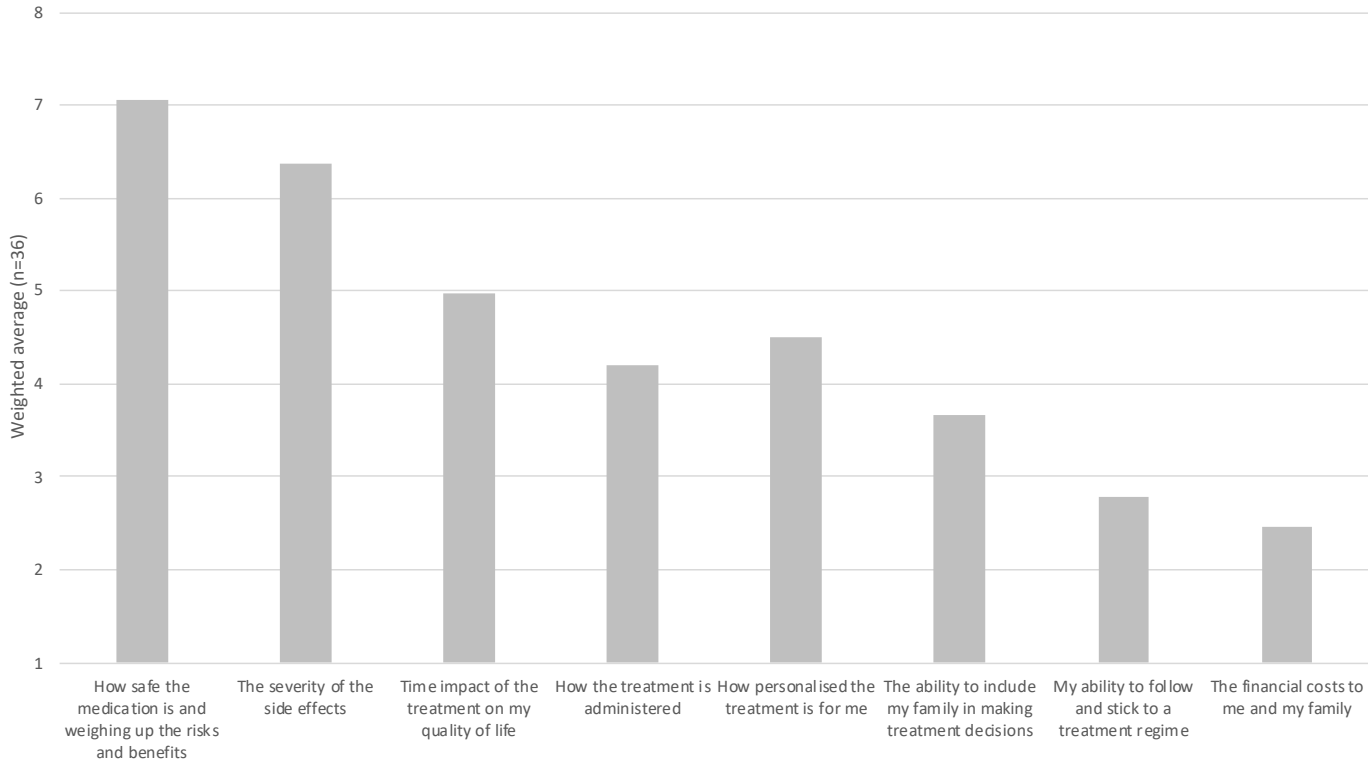


Figure 9.8: Values in making decisions

Values for decision-makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.9. With a weighted ranking, the higher the score, the greater value it is to participants. The two most important values were quality of life for patients, and access for all patients to all treatments and services; the least important was economic value to government.

Table 9.9: Values for decision-makers

Symptom	Weighted average (n=36)
Economic value to government and tax payers	1.25
Economic value to patients and their families	2.53
Quality of life for patients	4.39
Compassion	2.92
All patients being able to access all available treatments and services	3.92

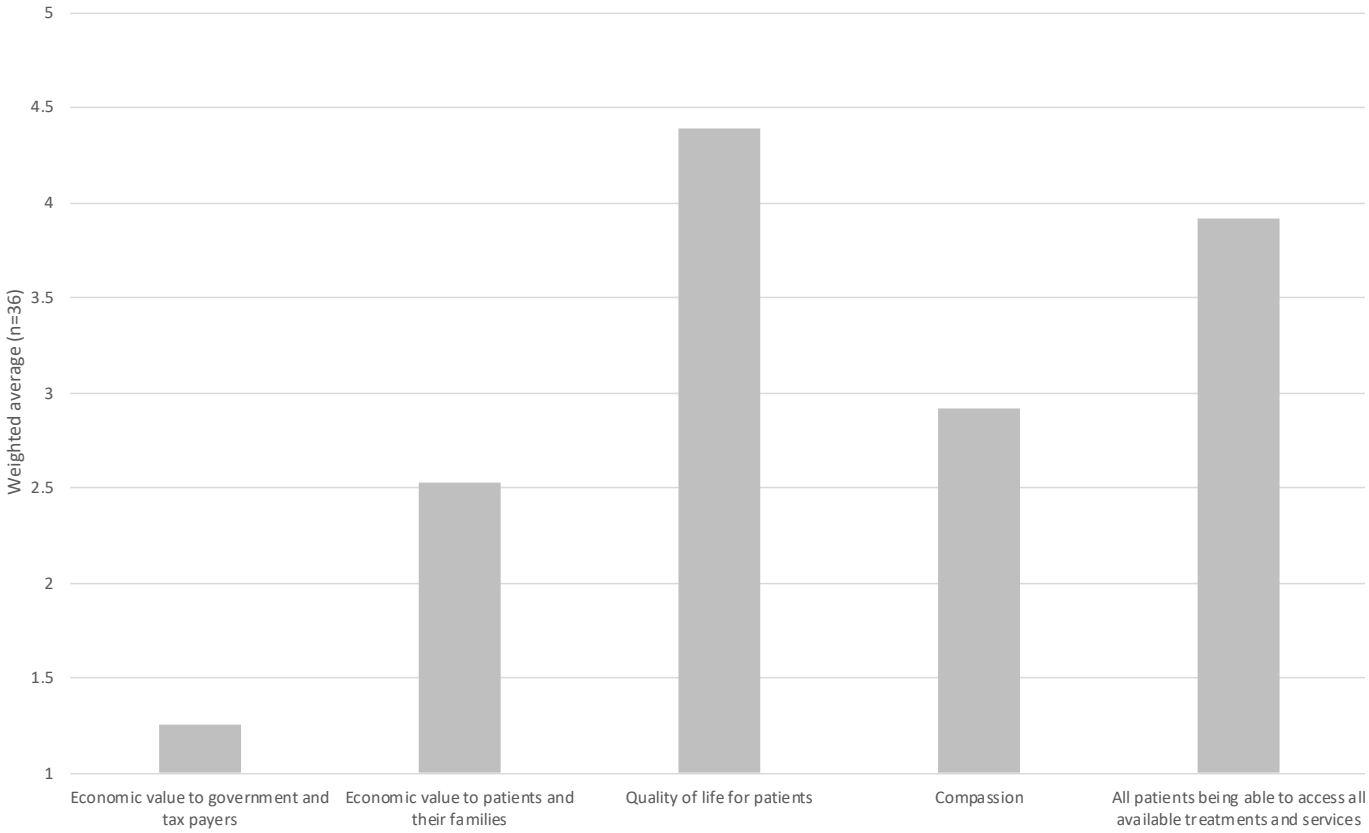


Figure 9.9: Values for decision-makers

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n=19, 67.86%) would use a treatment for more than ten years for a good quality of life, even if it didn't offer a cure.

Table 9.10: Time taking medication to improve quality of life

Time	Number (n=28)	Percent
1 to 2 years	3	10.71
3 to 4 years	2	7.14
5 to 10 years	4	14.29
More than 10 years	19	67.86

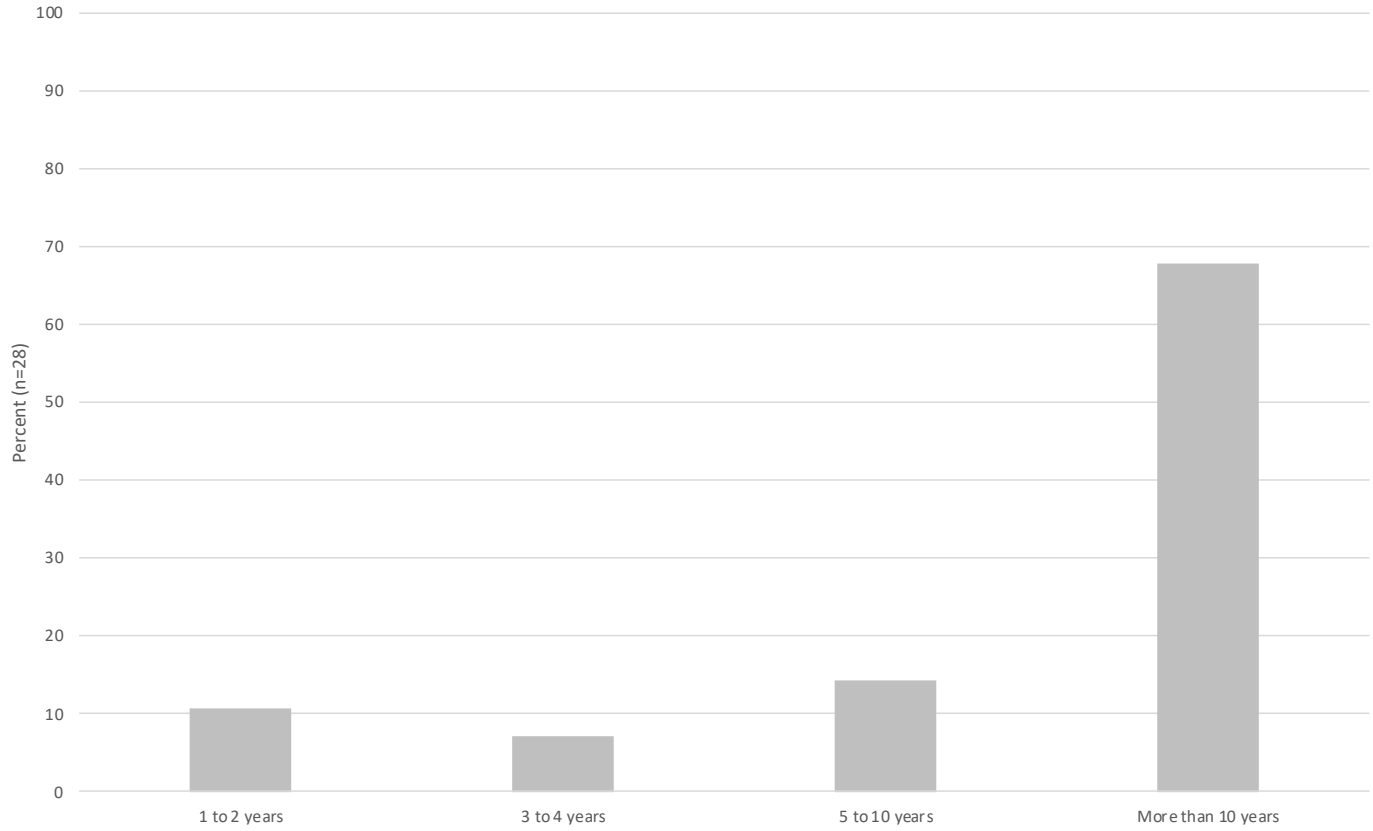


Figure 9.10: Time taking medication to improve quality of life

Messages to decision-makers

Participants were asked, 'If you were standing in front of the health minister, what would your message be in relation to your condition?' The most common message was that treatments need to be affordable (n=10, 27.78%). This was followed by the message that there should be more clinical trials and/or new treatments (n=8, 22.22%), that there should be improved access to support and care (n=6, 16.67%), the need to take the condition seriously (n=5, 13.89%), the need to invest in professional development so that clinicians better understand the condition (n=5, 13.89%) and finally, to invest in research, including the effort to find new treatments (n=4, 11.11%).

In relation to subgroup variations, participants in the *Aged 55 to 64* (50.00%), and *Regional or remote* (55.56%) subgroups described wanting treatments to be more affordable more frequently than the general population (27.78%), while those *Aged 75 or older* (0.00%) subgroup did not describe this at all.

Participants in the *AL Amyloidosis* (10.00%) subgroup described the message that there should be more clinical trials and/or new treatments less frequently than the general population (22.22%), while those in *Regional or remote* (44.44%), and *Mid to low SEIFA* (36.36%) subgroups described this more frequently. Participants in the *Aged 75 or older* (0.00%) subgroup did not describe this at all.

Those in the *ATTR-cardiac* (27.78%), *Aged 75 or older* (35.50%), and *Trade or high school* (35.71%) subgroups described the message to improve access to support and care more frequently than the general population (16.67%), while the participants in the in the *Carer* (0.00%), *Aged 55 to 64* (0.00%) and *Regional or remote* (0.00%) subgroups did not describe this at all.

No participants in the *Carer* (0.00%), *Aged 55 to 64* (0.00%), *Female* (0.00%), *Regional or remote* (0.00%) and *Mid to low SEIFA* (0.00%) subgroups described the message that decision-makers should take the condition more seriously. Participants in the *Aged 75 or older* (37.50%) subgroup described this more frequently than the general population (13.89%).

Those in the *Aged 55 to 64* (25.00%) subgroup described the message that there should be more investment in professional development so that clinicians better understand the condition more frequently than the general population (13.89%), while participants in the *Carer* (0.00%) and *Aged 75 or older* (0.00%) subgroups did not describe this at all.

No participants in the *Carer* (0.00%), *Aged 55 to 64* (0.00%) and *Regional or remote* (0.00%) subgroups described wanting to see more investment in research (including new treatments). Those in the *AL amyloidosis* (30.00%), *Aged 75 or older* (25.00%), and *Trade or high school* (21.43%) described this more frequently than the general population (11.11%).

Affordable treatments

I would say to him that medication that has been shown to be efficacious overseas, and there's plenty of data for that, that medication should be put on the PBS as soon as possible…That should be covered by PBS and that makes it affordable for everybody. Participant 003AL

Probably the big one is the cost of some of the drugs...Supporting those rare diseases is so incredibly important and the sheer cost involved of being sick. We were very fortunate to be close by really good doctors and hospitals and all of that sort of thing, but the people that have got to travel for care that is in then a huge impact on them financially. Participant 003CA

All drug treatments for all cancer patients should be free. Get rid of this, 'It costs too much' bullshit. Just give the people the drugs they need to treat what they've got. Participant 004ATR

More clinical trials and/or new treatments

I would say to him that medication that has been shown to be efficacious overseas, and there's plenty of data for that, that medication should be put on the PBS as soon as possible so that it can be utilised by people that that medication is appropriate to. Because sometimes a particular medication isn't appropriate for everybody. That should be covered by PBS and that makes it affordable for everybody. Participant 003AL

I would stand in front of the health minister and I would say, you really need to do something about getting the trials into Australia. We need to basically be able to have the same opportunities as what people do overseas. We need to be able to cut through all of the red tape and look at people's lives rather than sitting and thinking, 'oh, this is going to take this long.' People are dying. People around us are dying. Yet people overseas are having the benefits of these drugs that we never get. Please, look at it, have a look at it. Participant 008ATR

Well, I would be preaching on-- while people, I'm probably one of them, are waiting for all these drugs to be approved. You won't be here to take advantage of them and how they take too long to get things. If they have been in other countries, why can't this happen in Australia? Probably you have enough guinea pigs elsewhere that show that it does work and it's beneficial. Then they got to do it all again over here. If it was available, probably a lot of us wouldn't be able to afford it anyway. Participant 014ATR

Improve access to support and care

I would probably suggest to put some more funding available to an amyloid centre in each capital city…Because the waiting list when I was first got an appointment- and I really pushed NAME CLINICIAN to get an appointment at NAME HOSPITAL and I was I like after, and I find out this number which I was told to do. I said- went back in and I said I'd be bloody dead by the time I get an appointment at this hospital. They asked me for my Centrelink card to have available my Medicare card and my Centrelink card, and I'm thinking, 'What sort of hospital am I dealing with?'. Participant 001ATR

Access for people in regional and remote areas would be a big thing to alert the health minister to. They miss out on a lot. I have to travel a long way from LOCATION REGIONAL where I've got a lot of relations, having to drive because flying is too expensive all the way to LOCATION REGIONAL or LOCATION REGIONAL for treatment or even to LOCATION METROPOLITAN. That sort of thing would be really helpful. Regional assistance, regional specialists to visit on a regular basis. Participant 003ALX

No. I think it's Sydney, Melbourne and Brisbane that have got the centres. It must be awful for people in places like that. You're still a long way away to accessing the part from the internet and things I guess-- and dedicated, like you said, with a nurse or someone you could speak to when you can't get to your doctor, but I guess they've got to be associated with the doctors. They cannot be generalised in another state when they don't know your case or anything. They'd have to work with the doctors. The funding for that would be helpful. Participant 012ATR

Take the condition seriously

I understand that there are lots of conditions, diseases, cancers, and whatever that affects a whole lot more people than amyloidosis. The rare diseases area-- I think there are some groups and associations now which are looking at rare diseases, not only amyloidosis. The restriction I feel that we're always under is that because amyloidosis is a rare condition, the actual research, trials, funding, et cetera, would rank low priority. The clinic at NAME HOSPITAL, as a say, which seems to be the headquarters of these things, often says to me, 'Well, look, we're trying to get more funding. We're trying to get more information, but we don't rank high on the list of priorities'. Participant 001AL

Regardless, if you're affected with a cancer or a terminal disease, it is extremely important to you and your family and shouldn't be put aside and say, 'Well, of course, there's only 1 in 100,000, we won't worry too much about that.' I think that's not a very good attitude. Participant 003ATR

I reckon there's a lot more people that are affected by this than they have any idea about. I think genuinely there's probably a lot more people suffering from it than they've ever heard about what it is. It's a bigger issue than people realise. It's still incredibly-- I know it's hard because there's only so much funding to go around. I think overall, it's a pretty underfunded thing. Participant 006ATR

Invest in professional development

Well, it's not up to him really, any administrative, but I think that it comes from grassroots, it comes from the universities, it comes from some teaching within the hospital. It doesn't come from the Health Minister. He can't enforce the education towards the medical students. Participant 001ATR

The other thing I would say, again, is doctors, specialists, GPs, they lack information, they need to have it there. I don't mean this in a nasty way, even down to the chemist, the pharmacist, whatever it is, they should be able to have the alarm bell ringing. Like I said, carpal tunnel, 'Okay, we'll just double check that it isn't a problem down the line with that as well.' I can only talk about my particular version, but that's what I see. It's the education and being-- If you're given the education, then will allow you to be aware of it. Participant 015ATR

I think, first of all, there needs to be a greater awareness among specialists. There is an argument for GPs to have a better understanding of it. I know with my GP, as soon as I mention I've got this or that or whatever, he's quite quick at saying, look, 'I'll refer you to this specialist.' It is something significant-- Do you know what I mean. Participant 016ATR

Invest in research (including new treatments)

I'd thank him for it, and then suggest that it may be a little bit more for some Australian research would be appreciated. The health system itself, well, as I say, I think is the best in the world. I've looked at the health systems in a few countries around the world. Participant 002ALX

More funding for research. Amyloidosis is one of those low-- because people haven't heard about it-- the NAME HOSPITAL estimates that there's probably 10,000 people in Australia walking around undiagnosed. That's the biggest thing about amyloidosis, getting the diagnosis. They mimic so many other things. A patient goes to the doctor and says, 'I just feel lethargic. I don't know why. I'm tired all of the time.' That could be any number of things. Participant 005AL

That they need to increase the funding to try to find more things that can help with remission and stuff like that. Research, they need the money for research, I guess, because that's the way they're going to be able to help a lot more. Participant 012ATR

Table 9.11: Messages to decision-makers

Message to decision-makers	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant's message is that treatments need to be affordable	10	27.78	5	27.78	7	28.00	3	30.00	2	25.00	7	31.82	3	21.43	5	55.56	5	18.52
Participant's message is that there should be more clinical trials and/or new treatments	8	22.22	5	27.78	6	24.00	1	10.00	2	25.00	6	27.27	2	14.29	4	44.44	4	14.81
Participant's message is to improve access to support and care	6	16.67	5	27.78	5	20.00	1	10.00	0	0.00	3	13.64	3	21.43	0	0.00	6	22.22
Participant's message is to take the condition seriously	5	13.89	3	16.67	5	20.00	2	20.00	0	0.00	5	22.73	0	0.00	0	0.00	5	18.52
Participant's message is to invest in professional development so that clinicians understand the condition	5	13.89	3	16.67	4	16.00	2	20.00	0	0.00	4	18.18	1	7.14	1	11.11	4	14.81
Participant's message is to invest in research (including to find new treatments)	4	11.11	1	5.56	3	12.00	3	30.00	0	0.00	3	13.64	1	7.14	0	0.00	4	14.81

Message to decision-makers	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant's message is that treatments need to be affordable	10	27.78	4	50.00	6	31.58	0	0.00	4	28.57	4	28.57	4	36.36	6	24.00
Participant's message is that there should be more clinical trials and/or new treatments	8	22.22	2	25.00	6	31.58	0	0.00	3	21.43	3	21.43	4	36.36	4	16.00
Participant's message is to improve access to support and care	6	16.67	0	0.00	3	15.79	3	37.50	5	35.71	1	7.14	2	18.18	4	16.00
Participant's message is to take the condition seriously	5	13.89	0	0.00	1	5.26	3	37.50	2	14.29	3	21.43	0	0.00	5	20.00
Participant's message is to invest in professional development so that clinicians understand the condition	5	13.89	2	25.00	3	15.79	0	0.00	2	14.29	3	21.43	2	18.18	3	12.00
Participant's message is to invest in research (including to find new treatments)	4	11.11	0	0.00	2	10.53	2	25.00	3	21.43	1	7.14	2	18.18	2	8.00

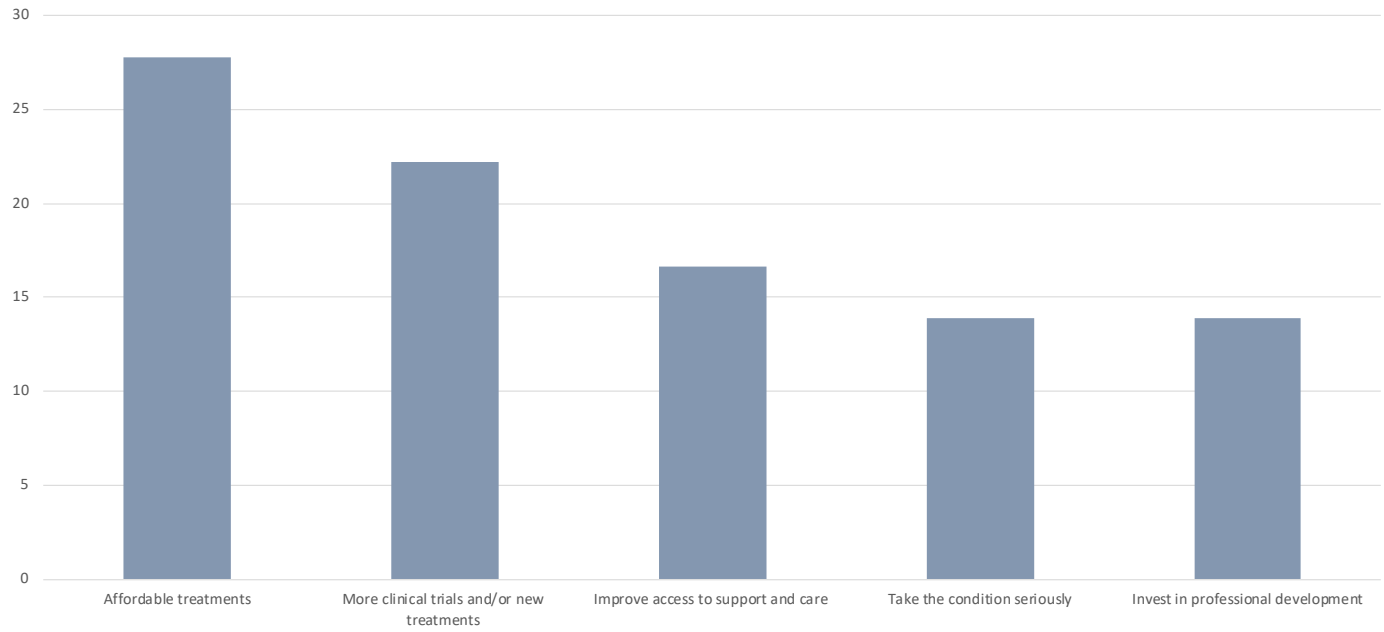


Figure 9.11: Messages to decision-makers

Section 10

Advice to others in the future

Section 10 Summary: Advice to others in the future

Advice to other patients and families in the future

- In the structured interview, participants were asked what advice they would give to other patients and their families. Six themes emerged as a result, the most frequent of which was that newly diagnosed patients should seek peer support or join support groups (n=9, 25.00%), followed by advice to seek and accept support in general (n=8, 22.22%). Other themes that emerged were to do research and ask questions (n=6, 16.67%), to find the best medical support for you (n=5, 13.89%), try to stay positive (n=4, 11.11%) and finally, to be aware of your own body and trust your instincts (n=4, 11.11%).

Advice to other patients and families in the future

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Seek peer support/join support groups

Talk to others who are in the same boat. Get support from them because those of us who do it find it very helpful realising you're not alone because it is such a rare disease. There aren't that many people around, so get in touch with people attending a group if possible or online or whatever but try. Participant 001ALX

Other patients or other people with amyloidosis to ring up and chat to each other about that is helpful. Just knowing that you're not alone in these sorts of things. There is someone out there you can reach out to, very important, very balancing. Participant 003ALX

It's good to hear that or someone'd say, 'I've got that too. What do you do? What helps you?' That makes so much of a difference. I think support groups are the most important things in the world. Participant 004CA

Seek and accept support

First of all, they are not alone. Ask. Constantly ask questions. If you are not happy, get a second opinion. If you need help, you just have to reach out and ask for it. Help for either the carers who go through a lot. Participant 002ATR

Find somebody to talk to about it so that you don't feel so alone. Just make sure you've got really good, strong networks around you, that it is okay to feel sad. It's okay to feel devastated, but it's equally okay to look for things that are joyous as well. Participant 003CA

I think through that whatever it takes, and it will be different for everybody, but take advantage of the information centres and networks the carers and your support, family support, community support. Participant 004AL

Research and ask questions

First of all, they are not alone. Ask, constantly ask questions. If you are not happy, get a second opinion. If you need help, you just have to reach out and ask for it. Help for either the carers who go through a lot. Participant 002ATR

I think through that whatever it takes, and it will be different for everybody, but take advantage of the information centres and networks the carers and your support, family support, community support. Get out there, find out everything you can. Be informed, and not just about the treatment, but about your body. Understand what's going on how you can manage that to give the treatment the optimum chance of working. Positive attitude, being informed and acting on that information. I guess getting on with life and keeping at it. Just don't give in. Participant 004AL

Self-advocate. Don't just sit back and listen and take copious notes. Self-advocate and educate yourself. That's the best advice that I could give. You don't know what questions to ask, but the more you read about it the more questions you can ask. Obviously, educate yourself so that you can understand what's being said. Get that family and friends support. They probably go hand in hand. Participant 005CA

Find the best medical support for you

Make sure you see an expert. Don't rely on your GP or some other person. It has to be someone who is specialised in the area. If you have to travel, you've got to do that because that's where the main advice comes from. Participant 001ALX

I think the biggest advice, I would say, is find the team that is going to really go in to bat for you, even if that means searching around a bit, because I'm sure a lot of people just get sent to a doctor, and they're not even aware that they're specialist people around or anything like that. I think that's really important, and having an amazing haematologist is really important. Participant 012ATR

I think accessing appropriate specialist, whether it's your haematologist and heart specialist is important. They're the two people or the two professions that it's most important to have good access to the appropriate people. That's number one. Participant 016ATR

Stay positive

I think the biggest thing in most aspects of life is attitude. Your mental approach, if you like, you've got to get it and maintain it in a positive state. I'm not sure how individuals do that, every individual does it, but that's the key, is to be positive and informed. If you throw the towel and become negative and, 'Oh woe is me,' that's not a great mindset to progress from. You've already failed in a way. Participant 004AL

Well, encouragement. We need encouragement. If I'm having a bad patch with treatments, it's not something I want to lay a burden on somebody that's only recently found out that they have amyloidosis because if they can cope with amyloidosis then it doesn't progress to the point where other people are…Goes back to meeting a guy before I went into the clinic. He mentioned that we were, in fact, going into the same place. He was younger, he still has his active lifestyle. Why should I say, 'Oh, you're going to feel like shit,.' So, encouragement. That's the bottom line. Participant 006AL

The general advice really is to relax with it. I think if you panic-- I've seen people writing in Facebook where they're panicking from day to day to day about what's happening or might not happen. You can hear, from my voice, I went past that probably 20-odd years ago. I don't panic about it. It's going to happen, let's move with it, let's do the things that need to be done. Participant 015ATR

Be aware/trust your instincts

For me, personally, I think you have to be proactive in your own health regardless of what you're diagnosed with and when you're diagnosed, and you just have to-I'd hate to be a GP. I mean, there's so many people coming in and dealing with all sorts of things that it is hard for them to pinpoint whatever. You've just got to take responsibility for your own health, and don't get pushed aside because it's in the 'too hard' basket for the medical professionals. Participant 001ATR

It's probably prior to diagnosis. If you're not comfortable with what your specialist is telling you, don't just accept that what they're telling you is true…The only-- again, it goes back down to education of specialists because my GP, both my GPs were aware of the condition because we moved from LOCATION METROPOLITAN first, both my GPs were aware of the condition when they were told that I had it. But they didn't-- there wasn't anything that clicked in the back of their head that goes, 'I know this is rare, maybe we should test this.' If you're not feeling well and the specialist tells you, you're fine find another specialist. Participant 004ATR

I would tell people, which I'm telling my family, if you find anything strange in your body or anything that's affecting you, go straight away and have a test. Participant 010ATR

Table 10.1: Advice to other patients and families in the future

Advice to others in the future	All participants		ATTR-cardiac		All cardiac		AL amyloidosis		Carer		Male		Female		Regional or remote		Metropolitan	
	n=36	%	n=18	%	n=25	%	n=10	%	n=8	%	n=22	%	n=14	%	n=9	%	n=27	%
Participant's advice is to seek peer support and/or join support groups	9	25.00	2	11.11	4	16.00	4	40.00	3	37.50	4	18.18	5	35.71	3	33.33	6	22.22
Participant's advice is to seek and accept support	8	22.22	4	22.22	6	24.00	2	20.00	2	25.00	3	13.64	5	35.71	3	33.33	5	18.52
Participant's advice is to do research and ask questions	6	16.67	2	11.11	4	16.00	2	20.00	2	25.00	3	13.64	3	21.43	3	33.33	3	11.11
Participant's advice is to find the best medical support for you (including that it is ok to seek a second opinion)	5	13.89	4	22.22	4	16.00	1	10.00	0	0.00	3	13.64	2	14.29	1	11.11	4	14.81
Participant's advice is to try and stay positive	4	11.11	1	5.56	3	12.00	3	30.00	0	0.00	4	18.18	0	0.00	1	11.11	3	11.11
Participant's advice is to be aware of your own body and trust your instincts	4	11.11	4	22.22	4	16.00	0	0.00	0	0.00	2	9.09	2	14.29	0	0.00	4	14.81

Advice to others in the future	All participants		Aged 55 to 64		Aged 65 to 74		Aged 75 or older		Trade or high school		University		Mid to low SEIFA		Higher SEIFA	
	n=36	%	n=8	%	n=19	%	n=8	%	n=14	%	n=14	%	n=11	%	n=25	%
Participant's advice is to seek peer support and/or join support groups	9	25.00	1	12.50	6	31.58	2	25.00	2	14.29	4	28.57	2	18.18	7	28.00
Participant's advice is to seek and accept support	8	22.22	3	37.50	4	21.05	0	0.00	2	14.29	4	28.57	3	27.27	5	20.00
Participant's advice is to do research and ask questions	6	16.67	2	25.00	3	15.79	1	12.50	1	7.14	3	21.43	1	9.09	5	20.00
Participant's advice is to find the best medical support for you (including that it is ok to seek a second opinion)	5	13.89	3	37.50	2	10.53	0	0.00	2	14.29	3	21.43	2	18.18	3	12.00
Participant's advice is to try and stay positive	4	11.11	1	12.50	2	10.53	1	12.50	2	14.29	2	14.29	0	0.00	4	16.00
Participant's advice is to be aware of your own body and trust your instincts	4	11.11	2	25.00	1	5.26	1	12.50	3	21.43	1	7.14	0	0.00	4	16.00

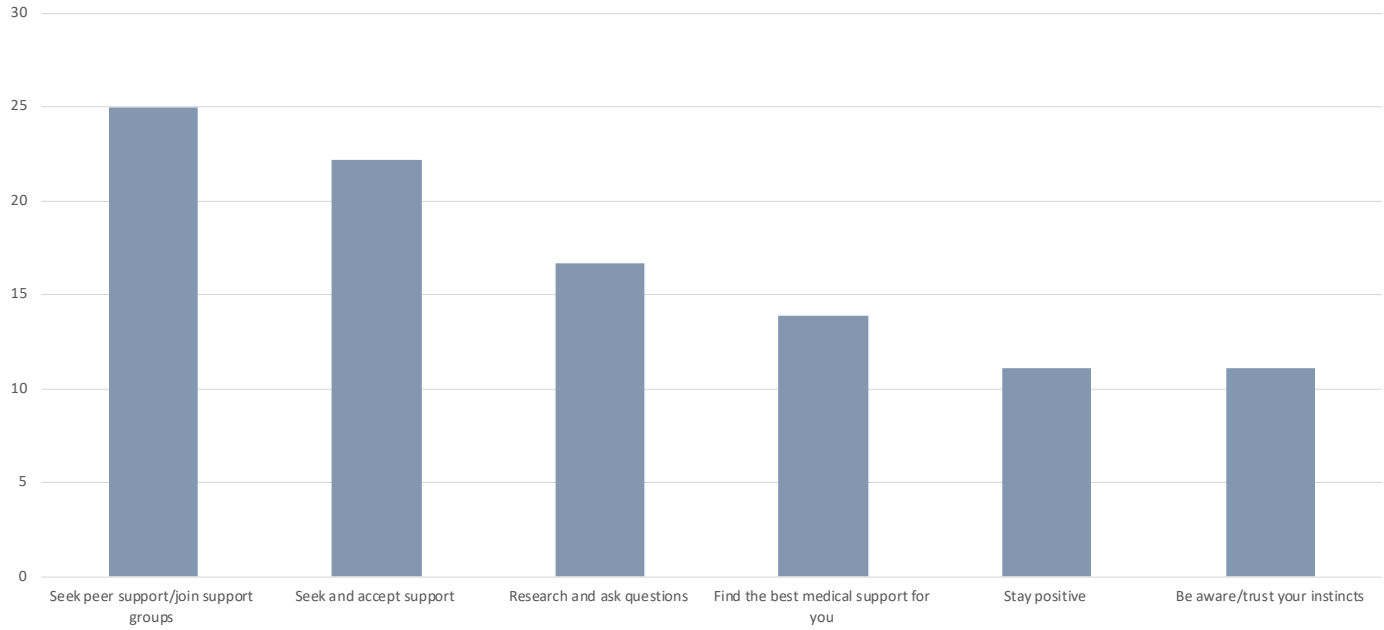

Figure 10.1: Advice to other patients and families in the future

Section 11

Discussion

Introduction

Amyloidosis is a heterogeneous disease, where amyloid deposits form and accumulate in tissues and organs of the body. It can be acquired or hereditary, localised or systemic. The amyloid deposits can accumulate in the heart, kidneys, spleen, nerves, and blood vessels [1].

There are two types of (TTR) amyloidosis, the more common is the wild type, the other is an inherited TTR mutation[2,3]. AL amyloidosis is the most commonly diagnosed type of amyloidosis[2,3].

In this PEEK study, 28 participants with amyloidosis, and 8 carers to people with amyloidosis were recruited into the study. There were 18 participants with either wild type or hereditary ATTR, and 10 participants with AL amyloidosis (seven of these with cardiac involvement). There were six participants that were carers to people with AL amyloidosis and two were carers to people with ATTR.

Amyloidosis is a rare disease; the number of cases is not known in Australia. The incidence in Queensland was estimated at 10 cases per million per year in people aged 20 years or older[4]. Autopsy data have indicated that amyloid deposits in about a quarter of individuals over 80 years old[5].

Risk factors include advanced age, male gender, family history, having dialysis, and African descent[2,3]. The median age for a wild type ATTR diagnosis is 79, though can be found in people in their forties. It is predominantly a disease found in males, with approximately 96% of cases reported in men[6]. The median age for inherited ATTR diagnosis is 67, and the proportion of males to females is approximately 70 to 30[6]. Consistent with risk factors, of the participants in this study that were diagnosed with amyloidosis, the majority were male, and aged over 65.

Other health conditions

In addition to amyloidosis, 85% of participants had at least one other condition to manage. Most commonly arrythmias (54%), other reported conditions were sleep problems or insomnia (39%), anxiety (self or doctor diagnosed – 36%), chronic pain (32%), depression (self or doctor diagnosed – 29%), hypertension (29%), chronic heart failure (21%), chronic obstructive pulmonary disease (18%), angina (10%), and diabetes (4%).

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition[7]. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%), asthma (11%), diabetes mellitus (5%), heart, stroke and vascular disease (5%), osteoporosis (4%), chronic obstructive pulmonary disease (3%), cancer (2%), and kidney disease (1%)[7]. The Australian Bureau of Statistics reports that 10% of Australians have depression or feelings of depression and 13% have an anxiety-related condition[7].

Compared to the Australian population, participants in this study had higher rates of depression, anxiety, cardiovascular disease and COPD, this may be attributed in part by the advanced age of the majority of participants.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[8]. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function[8].

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the Amyloidosis community in this PEEK study compares with the Australian population[9]. Compared to the Australian population, participants in this PEEK study on average scored similar results for the energy/fatigue, emotional well-being, and social functioning domains, they had worse scores for the physical functioning, role functioning/physical, role functioning/emotional, pain and general health domains.

Compared to baseline SF36 data from 574 participants in America with AL amyloidosis, the PEEK participants scored similar results for the Role functioning/physical, pain, general health, and energy/fatigue domains, and better in the physical functioning, social functioning, role

functioning/emotional, and emotional well-being domains[10].

Other studies of health-related quality of life in people with amyloidosis in general report lower scores compared to the general American population. A large international study reported that participants with symptomatic ATTR-CM had severely reduced health related quality of life compared to the general US population[11]. In a study of 158 participants with ATTR-CM, the lowest scoring health related quality of life domains were physical limitations, social limitations and symptom stability[6], greater physical limitations were also found in this PEEK study, however social limitations were not affected. This is similar to a comparison of 31 AL amyloidosis participants with the general USA population, where health related quality of life scores were lower, in particular for physical health[12].

Symptoms

Symptoms of amyloidosis depend on the tissues and organs affected, they are often mistaken for other more common diseases[2,3]. Symptoms of wild type and hereditary ATTR include fatigue, shortness of breath, swelling of feet and legs, heart palpitations, slow heart rate that can cause dizziness or blackouts, chest pain, sleep problems, unintentional weight loss, carpel tunnel syndrome, nerve pain, and blood in urine[2,3].

General symptoms of AL amyloidosis include loss of appetite, fatigue, unintentional weight loss, and weakness. When the heart is involved, swollen ankles, and being short of breath. The symptoms when the kidneys are involved include swollen ankles, frothy urine, and high cholesterol[2,3]. When there is nerve involvement, tingling in fingers and toes, and diarrhoea. Bruising, especially around eyes occurs with blood vessel involvement, diarrhoea from gut involvement, and swollen tongue when the tongue is involved[2,3].

Participants in this PEEK study had between zero and 13 symptoms (Median = 5.00), The most common symptoms for all participants were fatigue being short of breath, limb weakness, and light-headedness. Similar to the PEEK study, the most commonly patient reported symptoms in other studies were fatigue, oedema (swelling ankles and legs), short of breath, dizziness on standing, feeling full, weight loss, neuropathy, constipation/ diarrhoea, purpura (raccoon eyes), enlarged tongue, and weakness[13,14]. The most common symptom leading to diagnosis in this PEEK study population was excessive weight loss.

Diagnosis

ATTR-CM is an under-diagnosed condition, the diagnosis of ATTR-CM is difficult due the wide range of symptoms, it can mimic other conditions, there is a lack of awareness by physicians, there is limited access to genetic screening, and it is a rare disease[15,16]. Early diagnosis is important for effective management. Amyloidosis is diagnosed from biopsy; the Congo red staining of biopsy is the gold standard. Clinical assessments and imaging of involved organs, in particular, investigations of kidney (blood and urine tests), heart (blood tests, electrocardiogram (ECG) and echocardiography, MRI) and liver function (blood tests and ultrasound)[17].

Diagnosing the correct type of amyloidosis is important in all cases, monoclonal immunoglobulin abnormality testing may indicate AL amyloidosis but is not diagnostic. Assessment of the clinical presentation, genetic testing, immunohistochemistry , and mass spectrometry are used to identify the type[17].

Patient reported diagnostic tests collected in questionnaires completed by 341 AL amyloidosis participants included reported diagnostic tests include biopsy, bronchoscopies, cardiac catheterizations, cardiac magnetic resonance imaging, colonoscopies, computerized tomography scans, echocardiograms, electrocardiograms, endoscopies, nerve conduction tests, positron emission tomography scans, pulmonary functioning tests, and X-rays[13]. Often diagnostic tests were done before amyloidosis was suspected, and then more tests were conducted to confirm amyloidosis[45]. In this PEEK study, participants had between one and 11 diagnostic tests, (Median = 6.5). The most common diagnostic tests were blood tests, electrocardiogram, and echocardiogram.

Reasons for delays in diagnosis of amyloidosis from the patient perspective include their own interpretation of symptoms, and the time taken to seek medical attention[13]. From the healthcare side, delays can occur due to doctors that are not familiar with disease, delays in the healthcare system (for example, time to get a specialist appointment), symptoms similar to other conditions causing misdiagnosis, and the slow diagnostic process once amyloidosis is suspected[13].

In this PEEK study, about 10% of participants described having symptoms and not seeking medical attention initially but recognising the importance of those symptoms in hindsight. About half of the participants noticed symptoms and sought medical attention straight away, while about 20% delayed seeking medical attention. There were some participants that did not notice any symptoms.

Consistent with risk factors, of the participants in this study that were diagnosed with amyloidosis, the majority were male, and aged over 65.

A survey was completed by 533 participants with any type of amyloidosis diagnosis or their caregivers[11]. Time from symptoms to diagnosis was within a year for most participants (68%), and over a year for 38%[14]. The AL amyloidosis diagnostic journey was explored with 10 patient interviews, 4 clinician interviews and 341 patient surveys[13]. The time from symptoms to diagnosis was reported by clinicians on average 10 months, and by patients interviewed on average 3 years. Of the 341 survey respondents, over 70% reported diagnosis after 6 months from symptoms[13]. In a questionnaire of 158 participants with ATTR-CM , diagnosis was delayed in particular for wild type ATTR-CM, with over 40% being diagnosed more than four years after initial cardiac symptoms[6]. In addition, quantitative data from 341 participants with AL amyloidosis, those with cardiac involvement were more likely to receive a delayed diagnosis compared to those with kidney involvement[13]. Participants in this PEEK study, more than 40% of participants waited more than a year before being diagnosed, though the time between tests and receiving a diagnosis was most commonly between 2 and 3 weeks, or more than 4 weeks.

Once diagnosed, patients have reported mixed emotions. In interviews with ten participants with AL amyloidosis some were relieved to finally have a diagnosis, while others were in shock and overwhelmed by a rare disease diagnosis[13]. A survey completed by 200 AL amyloidosis participants reported feeling frightened by the diagnosis, depressed, numb, powerless, hopeless, relieved, and angry[14].

In a survey completed by 533 participants with any amyloidosis diagnosis or their caregivers, approximately half made four or more visits to a doctor before a diagnosis was made, and most commonly, the diagnosis was made by a haematologist or oncologist.[14], another study of 341 questionnaire respondents almost two thirds reported four or more doctors before diagnosis[13]. In a questionnaire of 158 participants with ATTR-CM, diagnostic delays occurred, with patients that used hospital services reporting a median of 17 hospital visits during the three year period before diagnosis[6]. In this PEEK study, the diagnosis was given most commonly by the haematologist, followed by a cardiologist. About a quarter of participants in this PEEK study described seeing 3 or more doctors before getting a diagnosis.

Biomarkers or genetic markers

Genetic testing is important in patients with a family history to confirm the diagnosis and to identify the specific mutation[18]. The most common mutations globally are Val30Met, Val122Ile, and.8 Val30Met [19]. The European Network for TTR-FAP recommends genetic counselling for individuals and families diagnosed or at risk of ATTR to detect asymptomatic carriers and avoid misdiagnosis[18].

More than half of the participants in this PEEK study didn't have many discussions about biomarkers or genetic testing with their healthcare profession, and about half knew of any mutations that they had related to their amyloidosis. Similar to this PEEK study, qualitative interviews with ATTR participants reported that they were aware that there were several mutations responsible for their condition, but often did not know which mutation they had[20].

Understanding of disease at diagnosis

The majority of participants in this PEEK study had little to no knowledge about amyloidosis before they were diagnosed. Some participants had some knowledge due to a family history of the disease, and others noted that they understood more as they lived with the condition. A theme from 10 qualitative interviews was that participants did not consider themselves seriously ill until they received an abnormal test result[13], a general lack of knowledge about the condition could account for this.

Decision-making

The decision-making process in healthcare is an important component in care of chronic or serious illness[21]. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare, highlighting the importance of

healthcare professional communication[22,23]. In addition, the role of family members in decision-making is important, with many making decisions following consultation with family[24].

When treatment options were presented to participants in this PEEK study, when multiple treatment options were discussed almost equal numbers participated in decision-making, some decided not to take part in decision-making, and others were not given an option to take part in treatment decision-making. The most important aspects to consider when making treatment decisions were quality of life, efficacy, and side effects.

Treatment

ATTR-CM requires a multidisciplinary approach to symptomatic treatment, in particular for neuropathy, weakness, autonomic dysfunction, changes in bowel function, and cardiac symptoms[25]. Treatment aims to prevent or delay the progression of disease and improve quality of life. The European Network for Transthyretin-Related Familial Amyloid Polyneuropathy recommends a full history and clinical examination and the assessment of sensorimotor function, autonomic dysfunction, cardiac function, and renal function[18]. National reference centres are recommended for early diagnosis, treatment and care and to ensure consistent treatment and care across different regions[16].

Hereditary and wild type ATTR, there are limited drugs available to slow the course of the disease such as diflunisal, a non-steroidal anti-inflammatory drug[25,26]. New promising treatments such as tafamidis[27-32], inotersen[33,34], and patisiran[35] are undergoing clinical trials. Selected patients may benefit from liver transplants[25]. There were five participants in this study that had diffusional to treat their ATTC-CM, quality of life with this treatment was average, consistent with a randomised clinical trial of diffusional that reported preservation of quality of life[26].

The treatment for AL amyloidosis is chemotherapy, similar to that used for myeloma, these include traditional chemotherapy drugs (melphalan and cyclophosphamide), corticosteroids (such as dexamethasone), and targeted therapies such as bortezomib and ixazomib, and immunosuppressants such as thalidomide and lenalidomide[36]. Selected patients may benefit from stem cell transplants[36]. Consistent with these treatment guidelines, participants in this PEEK study most commonly had the following combinations for treating AL amyloidosis: melphalan and dexamethasone; bortezomib, cyclophosphamide, dexamethasone; cyclophosphamide, thalidomide, and dexamethasone.

In a survey of 181 participants with AL amyloidosis, participants reported having chemotherapy (63%), stem cell transplantation (39%), and organ transplant (8%)[14]. In this PEEK study, of the ten participants with AL amyloidosis, 90% had chemotherapy and 20% had stem cell transplantation. The average quality of life for all treatments was in the life was distressing to a little distressing range.

Affordability of healthcare

Almost half of the Australian population have private health insurance with hospital cover[37]. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private healthcare funded hospitalisations in public hospitals rose from about 8% to 14%[37]. In this PEEK study, 82% had private insurance, which is more than the Australian population. It should also be noted that participants in this study are grateful for the low-cost medical care and access to treatment and hospital through Medicare.

Clinical trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on 22 June 2020. The search included any study that included ATTR or amyloidosis participants, was conducted in Australia, and was open for recruitment in the last ten years. A total of eight studies were identified that had a target recruitment of between 20 and 2000 participants (Median = 218), seven studies were international drug clinical trials, and a single study was exclusively conducted in Australia and was focused on transplants.

The clinical trials were conducted across Australia, with all eight studies conducted in NSW, five were conducted in Queensland, four in Victoria, three in Western Australia, two in South Australia, and one in Tasmania. None of the clinical trials were conducted in the Australian Capital City or the Northern Territory.

A survey of 533 participants with amyloidosis and their caregivers, reported that more than 70% were poorly informed about clinical trials, almost half believed that taking part in a clinical trial would be beneficial to their health and would consider taking part, and about 20% had taken part in a clinical trial.[14] Almost all of the participants in this PEEK study had discussions about clinical trials with their doctor, indicating that they were given some information about clinical trials, nearly 80% would like to take part in a suitable clinical trial, only a single participant had taken part in a clinical trial (4%).

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving[38]. Components of self-management include information, activation and collaboration[38].

Information

Information is a key component of health self-management[39,40]. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management[39,40].

In this PEEK study, information about treatment options, disease management, and disease cause were most frequently given to participants by healthcare professionals; and were also the most common topics searched for independently by the participants. In contrast, qualitative interviews with 10 ATTR-CM patients or carers, the most common topics that participants wanted to be informed about were symptoms, liver transplants, and cardiac involvement[20]. In another study of 421 questionnaire respondents, the most commonly given information was information specific to their type of amyloidosis, support groups, and clinical trial information[14]. In this PEEK study, participants accessed information most often from the hospital or clinic where treated, followed by non-profit or charities or patient organisations, consistent with reports from another amyloidosis study[14].

Activation (skills and knowledge)

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

In this PEEK study, the partners in heath questionnaire was used to measure patient activation[41]. Participants scored highly in all domains which indicated that they had excellent knowledge about their condition and treatments, they had a very good ability to manage the effects of their health condition on emotional well-being, social life and healthy behaviours. They had an excellent ability to adhere to treatments and communicate with healthcare professionals, and an excellent recognition and management of symptoms. Interviews with 10 people with ATTR or their carers reported that participants had good knowledge of the disease and symptoms, but poor knowledge about disease mechanisms, they had a good knowledge of their healthcare team and what the role of each member of their healthcare team was, and they had good adherence to medication though did not always comply with dosage[20]. The participants in this PEEK study also had a good knowledge about their healthcare team roles, and the majority had complied with their treatments and medications at all times.

Communication and collaboration

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support[39,40]. Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction[9,42-45].

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making[46].

Building a relationship with patient, families and support networks is fundamental to establishing good communication[46]. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding[46]. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands[46]. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources[46]. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

In this PEEK population, participants commonly described having a positive experience in communicating with healthcare professionals. Positive experiences were related to comprehensive, two-way, supportive conversations, and negative experiences occurred most commonly when healthcare professionals had a limited understanding of their condition. In addition, communication with health care professionals was measured using the "Care coordination: communication" scale[47]. It measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants had an average score for communication with healthcare professionals, and a good score for navigating the health system.

Participants in this PEEK study experienced support and care from family and friends, through hospital or clinical settings, peer support and charities though some reported the challenges of finding or accessing support, similar to other reports of supportive families[20] .

Anxiety and depression

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease[48].

Interviews with 10 people with ATTR-CM or their carers, reported that the condition had a negative impact on mental and physical well-being, in particular, participants were worried about future reliance on family[20]. Participants in this PEEK study, also felt the burden they placed on families and experiencing changing dynamics in their relationships due to added anxiety, exacerbations and/or physical limitations, however, the most common theme in relation to impact on relationships was participants describing their relationships with family being strengthened.

In this PEEK study, anxiety associated with amyloidosis was measured by the fear of progression questionnaire[49], participants in this study had moderate anxiety.

Characterisation

There were 36 participants in the study from across Australia, 28 diagnosed with amyloidosis, and eight carers to people with amyloidosis. The majority of participants were from Queensland and New South Wales, and most lived in major cities, they lived in all levels of advantage. Most of the of participants identified as Caucasian or white, aged mostly between 65 and 74. Half of the participants had completed some university, and most were retired.

Participants in this PEEK study were most commonly diagnosed with ATTR, either hereditary or wild type. Most of the participants also had other health conditions they had to manage, approximately 44% of the participants had anxiety and/or depression.

This is a patient population that experienced fatigue as the most common symptom leading to diagnosis. They most commonly had five or six diagnostic tests

to get their diagnosis and were diagnosed more than a year after first noticing symptoms. They had out of pocket expenses for their diagnosis, but usually the cost wasn't a significant burden. Most participants felt they had enough emotional support and information from healthcare professionals at the time of diagnosis.

This is a patient population that experienced excessive weight loss, breathlessness and tiredness as key symptoms leading to their diagnosis. Half of the participants described seeking medical attention relatively soon after they started experiencing symptoms.

This is a study cohort that described knowing nothing or very little about their condition prior to diagnosis.

This is a patient population that had conversations about treatment where multiple options were presented. They mostly took quality of life, efficacy of treatment, and side effects into consideration when making treatment decisions, their decision making had not changed over time. They commonly did not have many discussions about biomarkers and were not sure if they had any.

This is a group who felt they were treated with respect throughout their experience. They were most commonly treated for ATTR-CM with loop-acting diuretics, and doxycycline; and were most commonly treated for AL amyloidosis with melphalan and dexamethasone. Half of this study population made lifestyle changes following diagnosis, and most used complementary therapies to manage their amyloidosis

Most of the participants in this study population reported having discussions about clinical trials with their clinician and though only one had taken part in a clinical trial. Participants in this study would be willing to participate if there was a suitable trial for them.

This is a patient population that described mild side effects as fatigue and diarrhoea. They described severe side effects as pain, neuropathy, nausea and vomiting.

Within this patient population, most participants adhered to treatment at the advice of their clinician or as long as it was prescribed. They felt that evidence of stable disease and an improvement in general well-being were needed to feel like treatment was effective.

This is a patient population that primarily needed the advice of their clinician as well as information about side effects, scientific evidence and clinical advice or expertise in order to feel comfortable trying new treatments.

The cohort was split between people who did not need support to have treatment at home, and those who needed the support from family or friends, regular check-ups from a GP or nurse, and someone to call if they had a question or issue.

Participants in this study had excellent knowledge about their condition and treatments, an excellent ability to adhere to treatments and communicate with healthcare professionals, excellent recognition and management of symptoms, and a very good ability to manage the effects of their health condition on emotional well-being, social life and healthy behaviours.

This is a patient population that primarily accessed information through the internet, books, pamphlets and newsletters as well as from specific health charities. They found information from reliable sources and from their doctors helpful, and preferred to get information by talking to someone. They were most receptive to information at the time of diagnosis.

The participants in this PEEK study had very good communication, navigation and overall experience of care coordination. They mostly experienced positive communication from health care professionals with holistic, two way, and supportive conversations.

This is a patient population that experienced support and care from family and friends, through hospital or clinical settings, peer support and charities though some reported the challenges of finding or accessing support.

This is a patient population where their condition had an impact on their mental and emotional health, and it had a negative impact on their quality of life. The participants in this PEEK study had moderate levels of anxiety in relation to their condition. They managed their general health by understanding their limitations.

This is a group who would most like to control heart and lung symptoms. The most important aspect for making decisions about their own treatment was medication safety, and they thought that decision-makers should consider quality of life when making decisions about treatment for people with amyloidosis.

This is a patient population that would like future treatments to be more affordable, and more effective.

This is a study cohort did not have any recommendations for information about their condition but want more access to support services. They would like health professionals to have more knowledge of their condition.

This is a patient population that felt grateful for healthcare staff and the entire health system in general.

This is a patient population that wanted to tell patients and families in the future that they should seek peer support and join support groups, as well as seeking and accepting support in general.

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Section 12

Next steps

Next steps

At the end of each PEEK study, CCDR identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

1. **Information:** This is a patient group that is ready for information from the point of diagnosis, however decision-making about treatments is complex and there was a lack of clarity about disease progression and prognosis. This patient population would benefit from more detailed and accessible information about treatment options and discussions about what to expect in the future. This could be aided by the documentation of holistic treatment and care plans with regular revisions.

2. **Support:** A common theme was the need for specialised support and care, ideally via telephone. This patient population would benefit from a central, dedicated telehealth nurse navigator that can link patients and families to the specific services they need, based on their unique presentation of symptoms. This includes access to mental health support as close to half of the participants noted depression and/or anxiety and the largest gap in information was about psychological/social support.

3. **Quality of life:** This cohort valued the ability to exercise as a way to maintain their physical and mental health, while the biggest negative impact on quality of life was a reduced capacity for physical activity. This patient population would benefit from targeted physical programs that allow them to exercise within their limitations. This would also have positive social and psychological benefits.

2020 Amyloidosis

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2020 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 Amyloidosis 2020 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	53.47	52.50
	Role functioning/physical	37.50	25.00
	Role functioning/emotional	62.04	66.67
	Energy/fatigue*	43.33	45.00
	Emotional well-being	72.44	76.00
	Social functioning	60.76	62.50
	Pain *	59.58	55.00
	General health*	46.81	45.00
	Health change	40.28	37.50
Knowledge of condition and treatments (Partners in Health)	Knowledge	27.36	28.00
	Coping	17.68	18.50
	Recognition and management of symptoms *	20.68	21.00
	Adherence to treatment	15.32	16.00
	Total score*	81.04	82.00
Care coordination scale	Communication*	42.17	42.00
	Navigation*	27.56	27.00
	Total score*	69.72	72.00
	Care coordination global measure	7.92	8.00
	Quality of care global measure	8.44	9.00
Fear of progression	Total Score *	33.19	31.50
		Percent	
Accessed My Health Record	-	39.29	-
Participants that had discussions about biomarkers/genetic tests	-	39.29	-