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

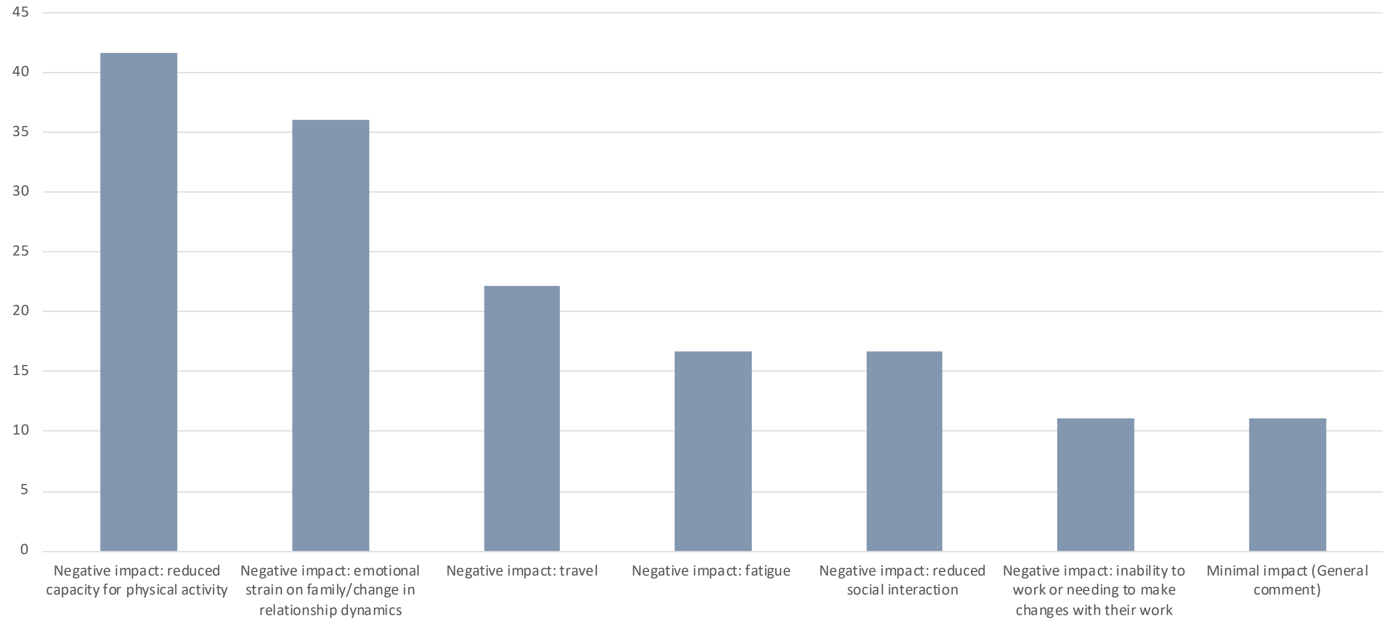


Figure 8.1: Experience of quality of life

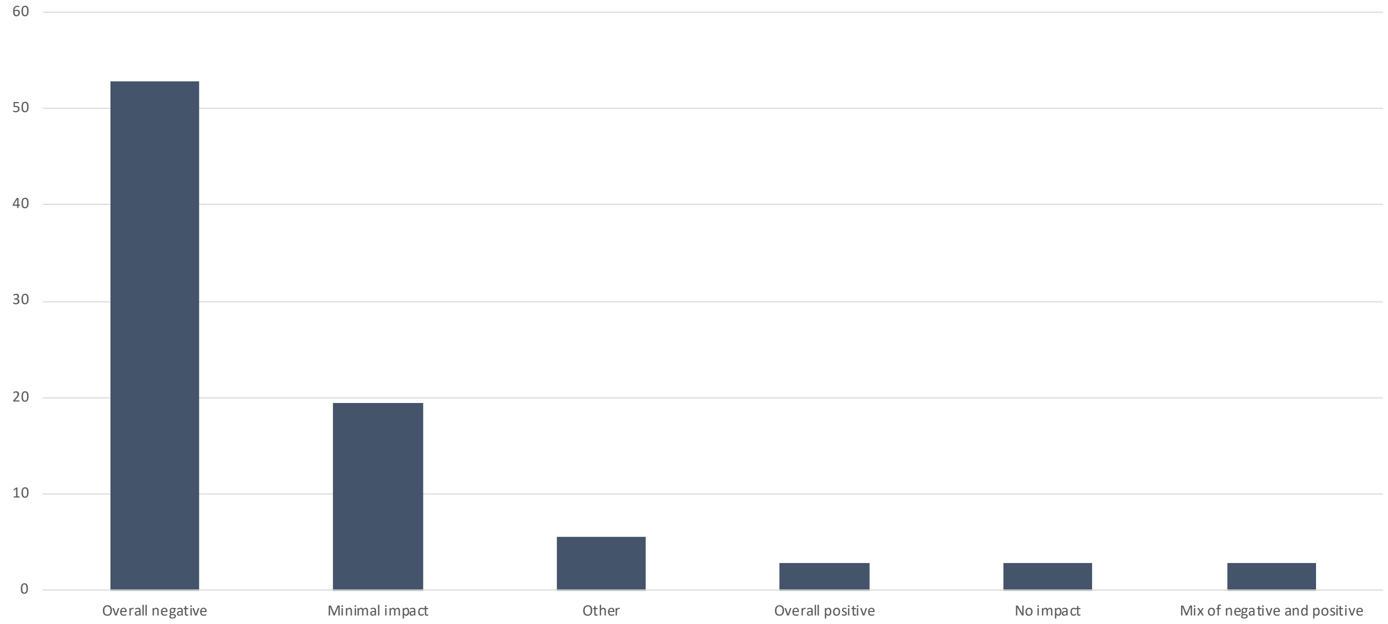


Figure 8.2: Experience of quality of life (Positive/Negative overall)

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

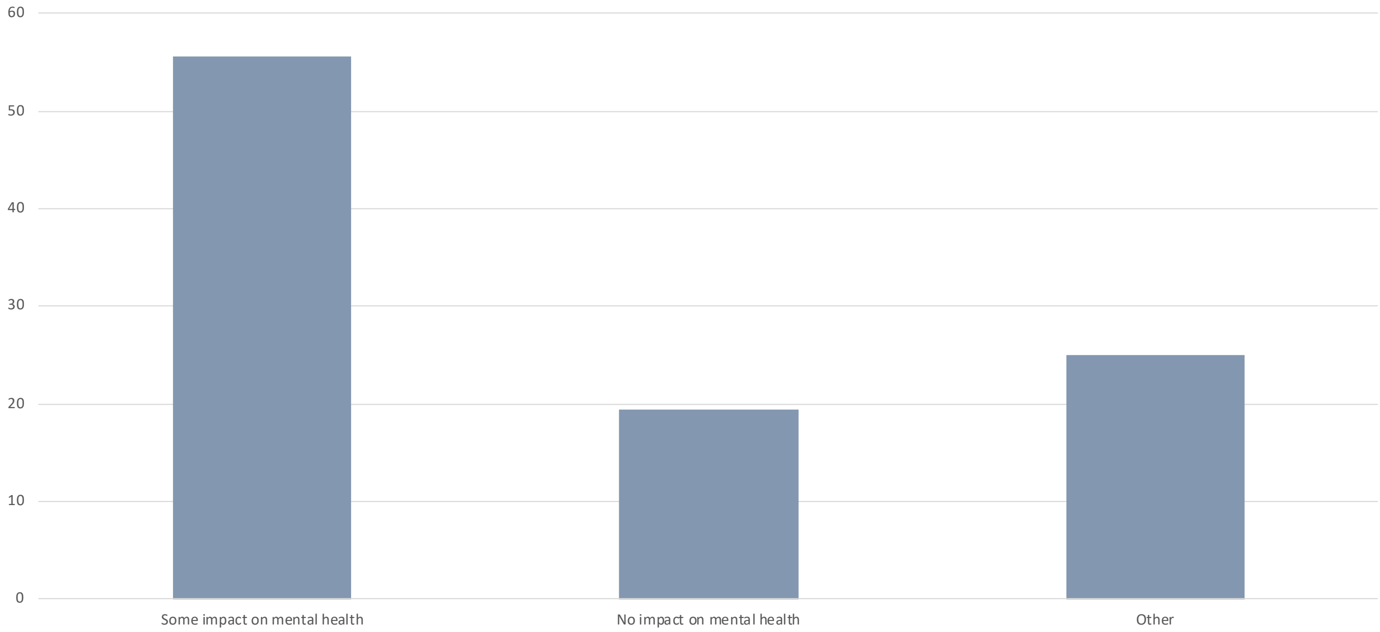


Figure 8.3: Impact on mental health

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

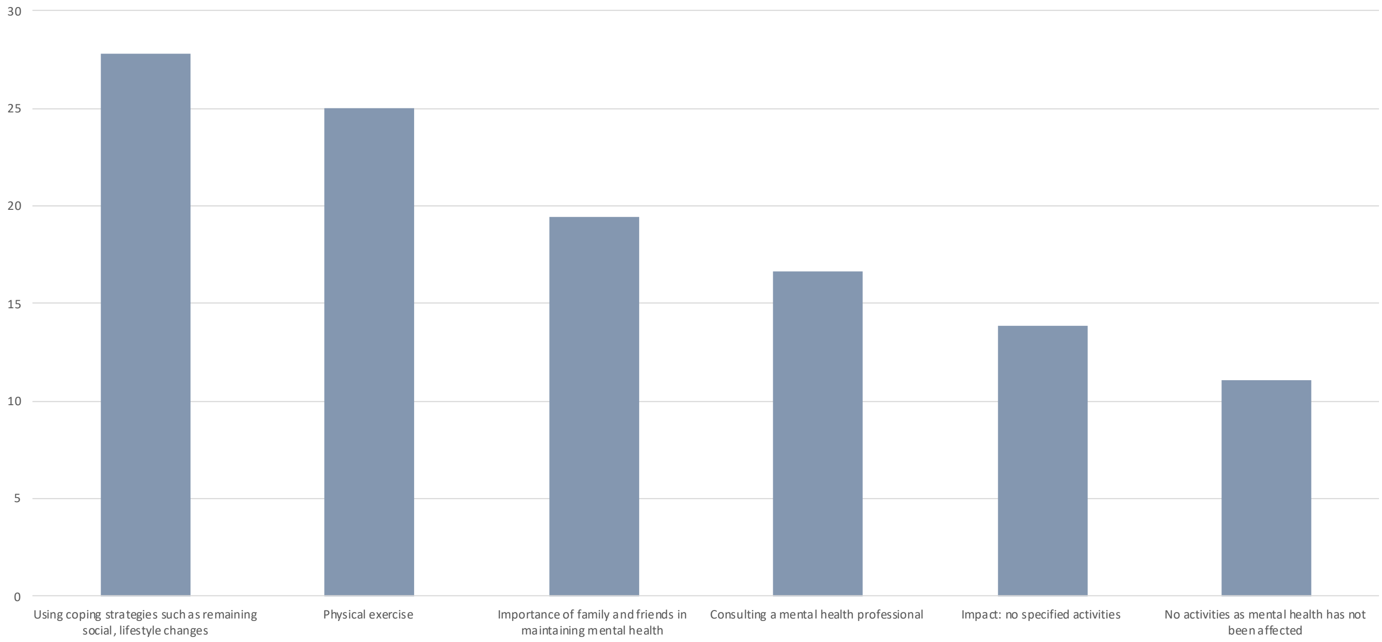


Figure 8.4: Regular activities to maintain mental health

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

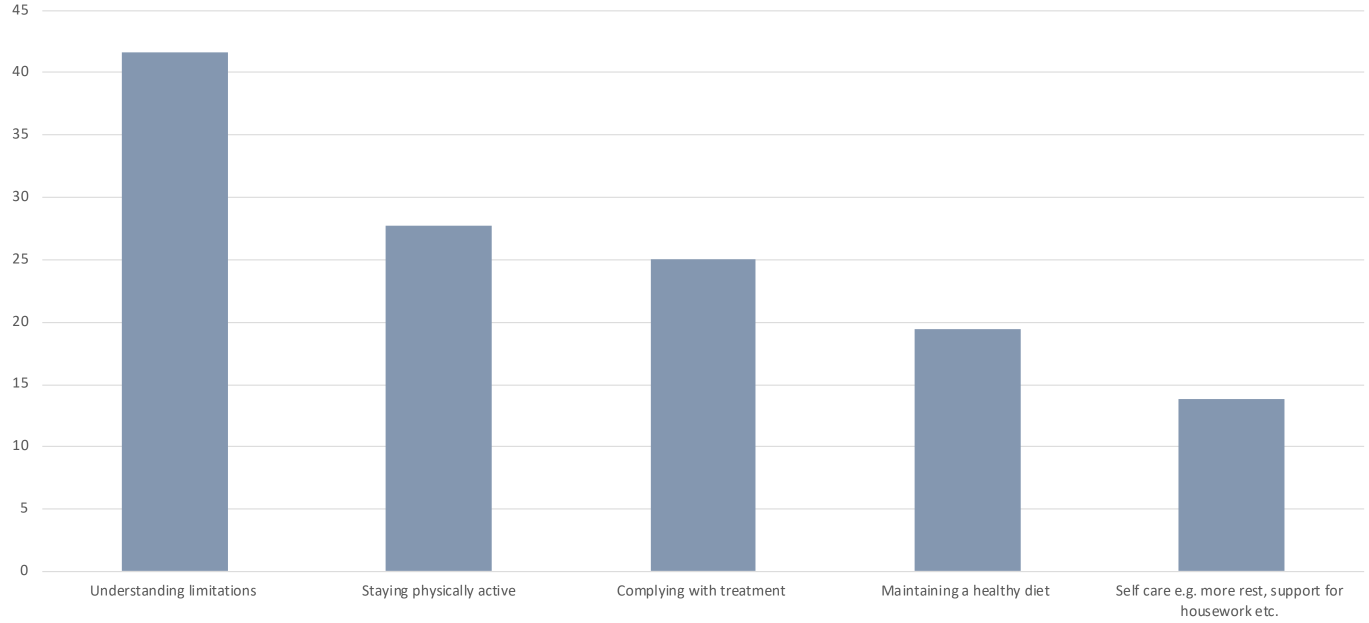


Figure 8.5: Regular activities to maintain health

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

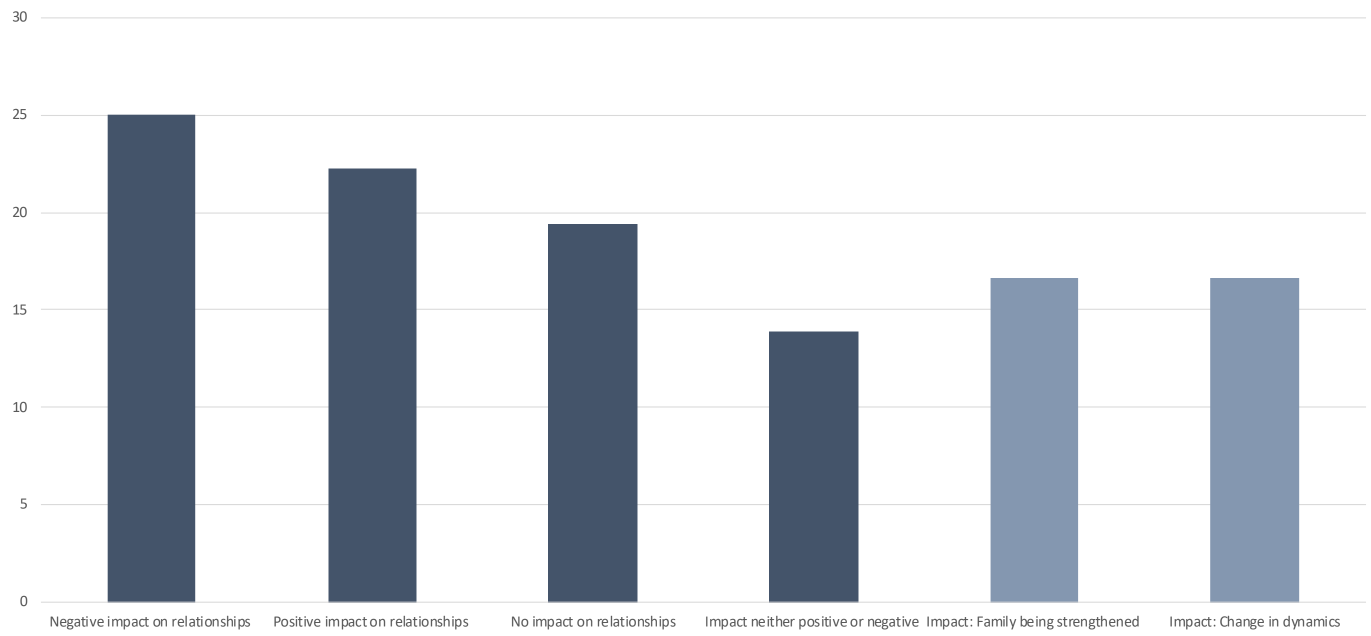


Figure 8.6: Impact on relationships

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

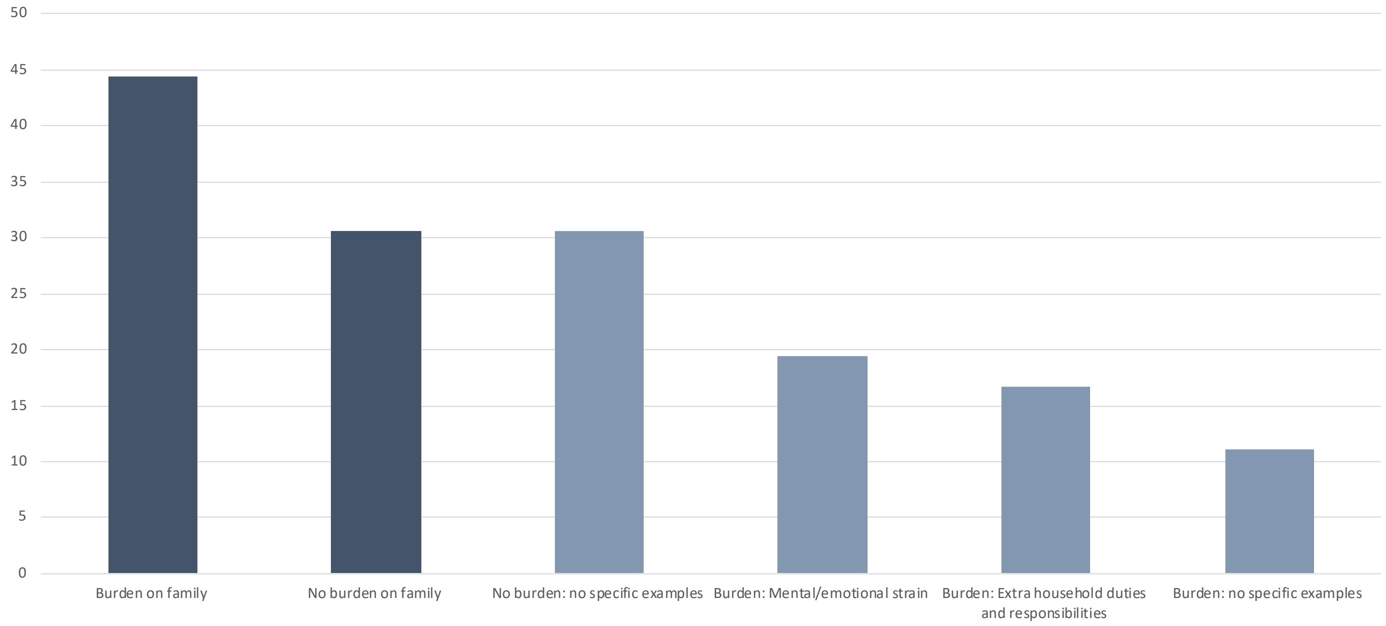
Yes. Probably a bit of extra burden on my wife. We've just accepted that's what it is and get on with life. Make the most of what's left. Participant 008ATR

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



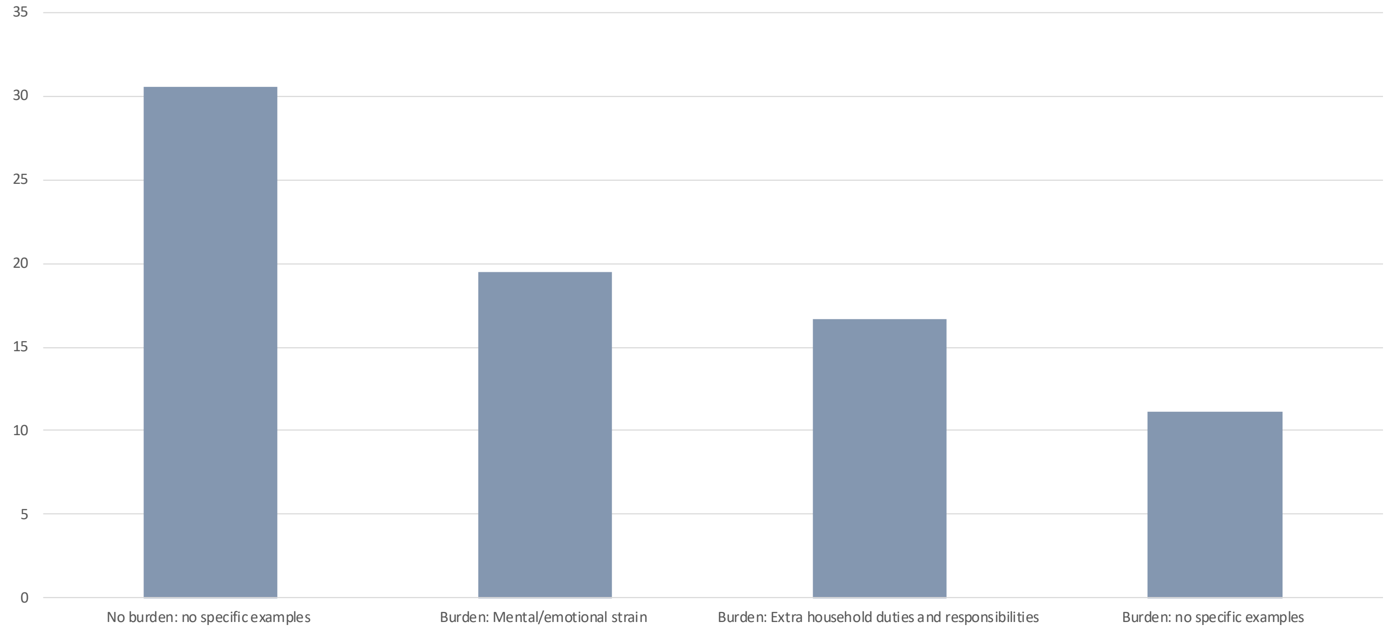


Figure 8.7: Burden on family

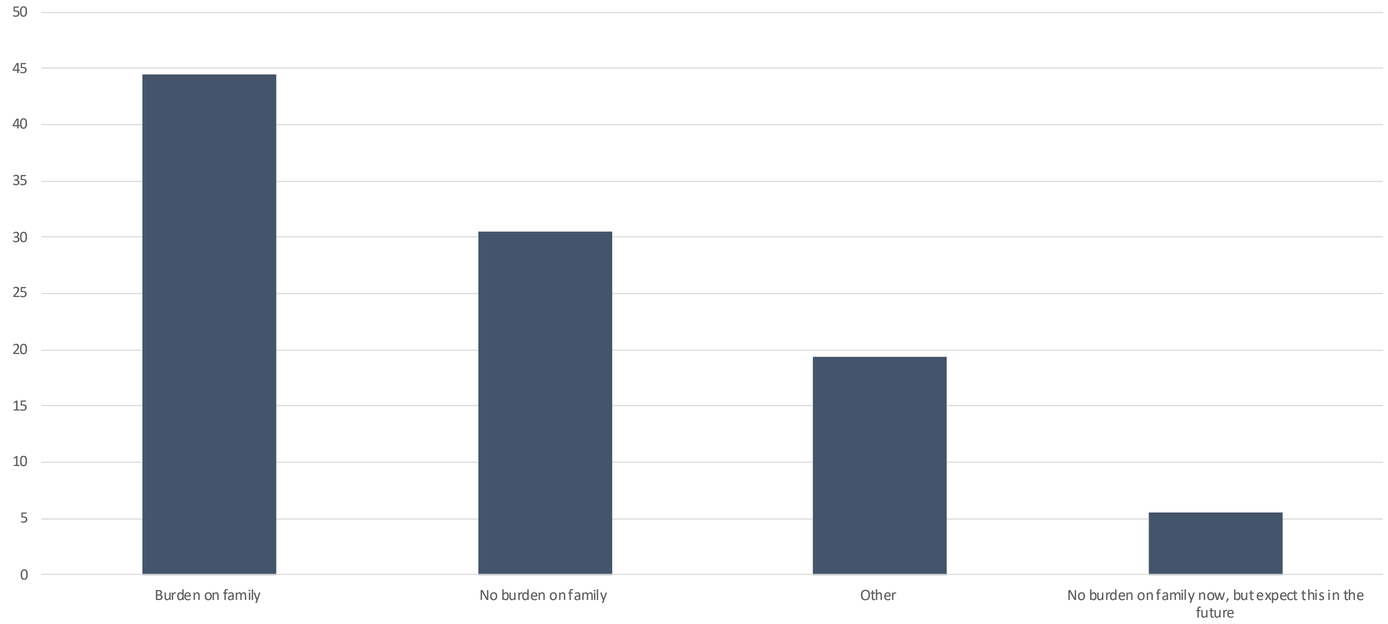


Figure 8.8: Burden on family (Additional burden/No additional burden/other)

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

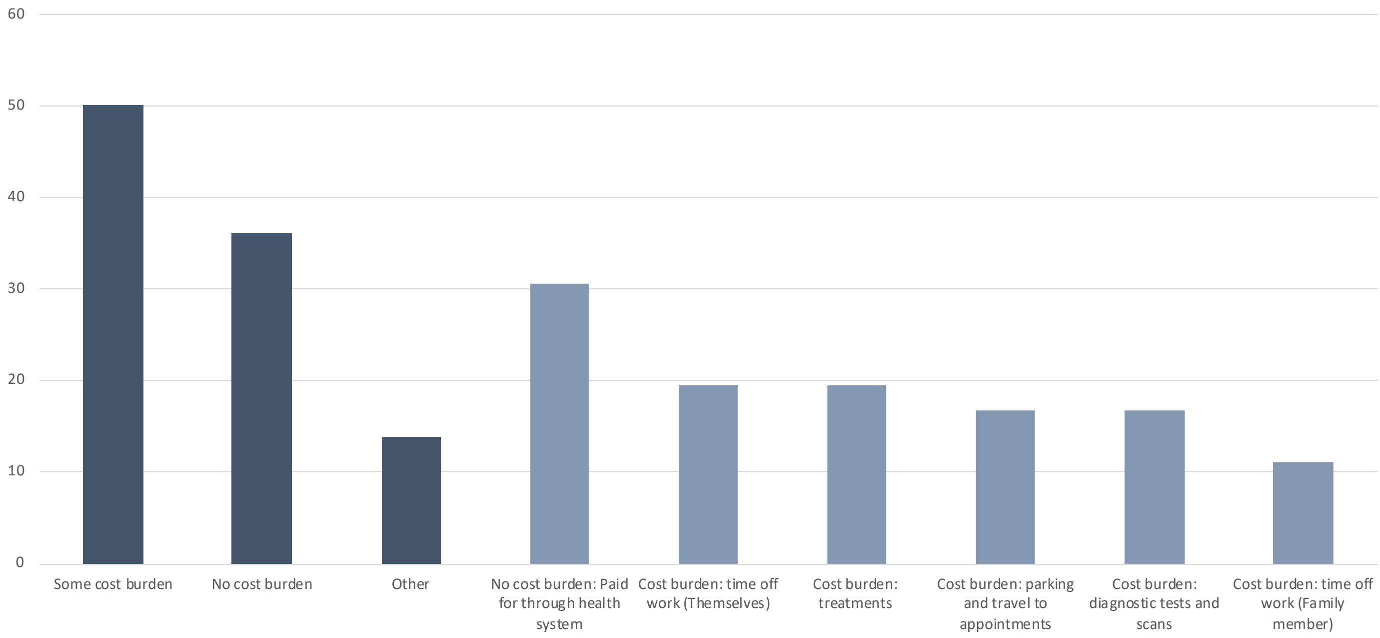


Figure 8.9: Cost considerations

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						

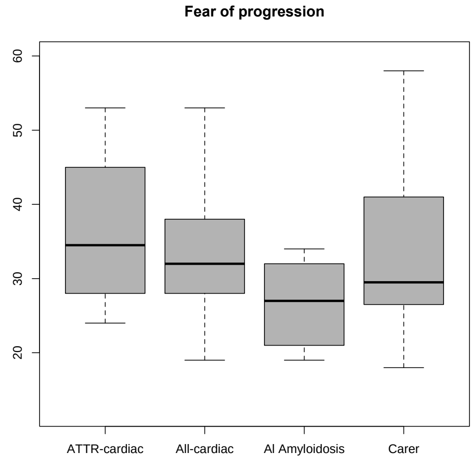


Figure 8.10: Boxplot of "Fear of progression total score" by participant type

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			

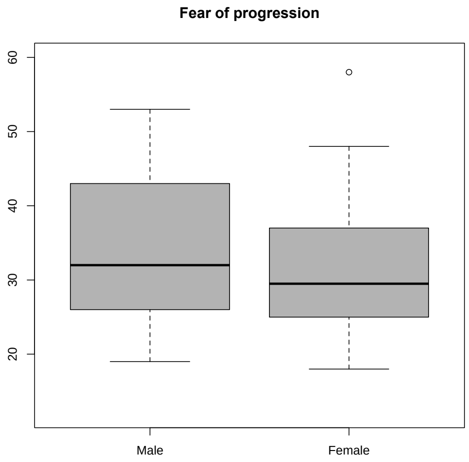


Figure 8.11: Boxplot of "Fear of progression total score" by gender

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			

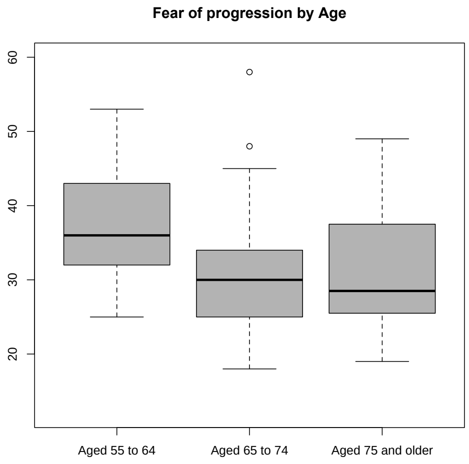


Figure 8.12: Boxplot of “Fear of progression total score” by age

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			

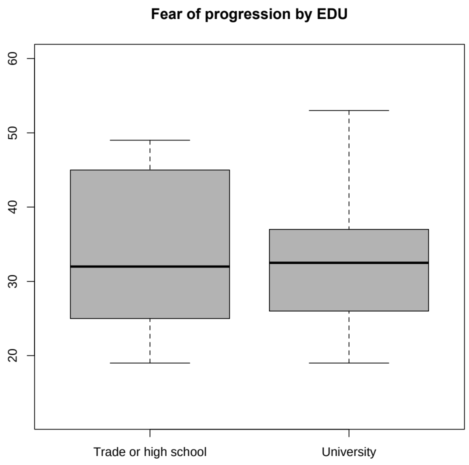


Figure 8.13: Boxplot of “Fear of progression total score” by education

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			

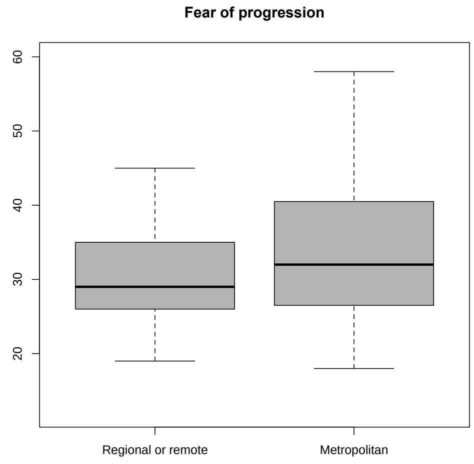


Figure 8.14: Boxplot of "Fear of progression total score" by location

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			

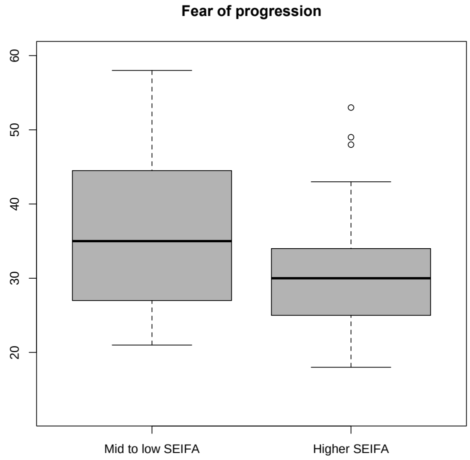


Figure 8.15: Boxplot of "Fear of progression total score" by SEIFA