Summary of results

Executive summary

There were 50 participants with triple negative breast cancer in the study from across Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the of participants identified as Caucasian/white, aged mostly between 35 and 54. About half of the participants had completed some university, and most were employed either full time or part time. Almost half of the participants were carers to family members or spouses.

About half of this group had ongoing breast cancer symptoms, commonly had thinking and memory problems, weight and muscle changes, and pain, which all contributed to their quality of life.

This is a group that had health conditions other than breast cancer to deal with, most often anxiety, sleep problems, and depression.

This is a patient population that experienced breast lumps which lead to their diagnosis. Most participants sought medical attention after noticing symptoms and were diagnosed after their general practitioner sent them for imaging studies. Very few participants were diagnosed through breast cancer screening.

On average, this group had three diagnostic tests for breast cancer, they were diagnosed by a general practitioner in a general practice. The cost of diagnosis was not a burden to them and their families. They were mostly diagnosed with invasive breast cancer, and stage II or III. This is a group that did not have enough emotional support at the time of diagnosis, but they did have enough information. This is a cohort that had conversations about biomarker/genomic/gene testing, and had knowledge of their biomarker status.

This is a study cohort that had little knowledge of triple negative breast cancer before they were diagnosed. This patient population described prognosis in terms of no evidence of disease or in remission, or in terms of statistics, particularly reaching five years.

This is a patient population that had discussions about multiple treatment options, with most being told what to do with little discussion.

This is a study cohort that took into account the advice of their clinician as part of many considerations when making decisions about treatment.

Within this patient population, most participants had changed decision making over time this was because they had become more informed and assertive.

When asked about their personal goals of treatment or care participants most commonly described wanting to treat the disease and get better.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a medical oncologist, and it usually took less than an 30 minutes to travel to medical appointments.

Three-quarters of this cohort had private health insurance, and equal numbers were treated as either private or public patients. They were equally treated in the private and public hospital systems. This is a group that did not have trouble paying for healthcare appointments, prescriptions. They had some trouble paying for basic essentials such as food, housing and power. Their monthly expenses due to breast cancer were slightly significant.

Participants in this study had to quit, reduce hours, or take leave from work. Carers and family did not have to change employment status. The loss of family income was somewhat a burden.

Participants had surgery, and drug treatments for breast cancer, and about half had radiotherapy. They on average used two allied health services, one complementary therapy and made two lifestyle changes.

More than third had conversations about clinical trials, and they would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects as those which can be self-managed and do not interfere with daily life.

This is a study cohort that described severe side effects as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population that would adhere to treatment according to the advice of their doctor, or as long as prescribed. This is a study cohort that needed to see a reduction in physical signs and symptoms to feel that treatment is working as well. If treatments worked, it would allow them to do everyday activities and return to a normal life.

Participants in this study had very good knowledge about their condition, were good at coping with their condition, were very good at recognizing and managing symptoms, and were very good at adhering to treatment.

Participants were given information about disease management, treatment options and hereditary considerations from health care professionals, and searched for interpreting test results, and complementary therapies most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, their treating clinician or social media.

This is a study cohort that found information about other people's experience, what to expect from the disease, and information specific to their type of breast cancer as being most helpful.

Participants commonly found information form sources that are no credible unhelpful.

This is a group that preferred online information, or talking to someone. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis, or during treatment.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication limited or not forthcoming.

The participants in this study experienced very good quality of care, and good coordination of care. They had a good ability to navigate the healthcare system, and experienced good communication from healthcare professionals.

This is a patient population that most found support through charities, and about a third had no support.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on family, and changes to relationships.

Life was a little distressing for this group, due to having breast cancer.

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they used coping strategies such as remaining social, lifestyle changes and hobbies, and consulted mental health professionals.

Within this patient population, participants described being physically active, and the importance of self-care, in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments, and when having sensitive discussion about their breast cancer. To manage vulnerability, they relied on support from their medical team.

This cohort most commonly felt there was a mix of positive and negative impacts on their relationships, with some relationships strengthened.

Participants felt they were a burden on their family, due to the extra household duties and responsibilities they had to take on.

Most participants felt there was some cost burden which was from the costs of treatments, tests and scans, and also from having to take time off work.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to have less side effects and be more effective.

This is a study cohort that would like more information about available services, treatments, and mental and emotional health support.

Participants in this study would like future communication to be more transparent and forthcoming. Many participants were happy with their communication with healthcare professionals.

Participants would like future care and support to include more access to support services..

This patient population was grateful for the timely access to treatment and they were grateful for healthcare staff.

It was important for this cohort to control fatigue, pain, and heart problems. Participants in this study would consider taking a treatment for more than ten years if quality of life is improved with no cure.

Participants' message to decision-makers was to improve access to care and support.

This is a patient population that wished they had known more about the pros and cons of treatment, what to expect from their condition especially the disease trajectory and disease biology and about the support services available to them.

The aspect of care or treatment that participants in this study would most like to change is to have changed or stopped the kind of treatment they had, however, many wouldn't change any aspect of their treatment or care.

Section 1

Introduction and methods

Section 1 Introduction and methodology

Triple negative breast cancers are defined by the lack of progesterone and oestrogen receptors, and HER2 proteins. Triple negative breast cancers are an aggressive form of breast cancer that typically affects younger women, has a poor prognosis, and lack of targeted therapies.

In 2019, there were 19,371 new cases of breast cancer reported in Australia[5]. Approximately 12 to 17% of all breast cancers are triple negative, that is an estimated 3000 new cases of triple negative breast cancer in Australia 2019.

A PubMed search was conducted in 2021 to identify studies reporting patient experience, patient reported outcomes, and quality of life studies in the triple negative breast cancer community. Studies conducted more than 10 years ago were excluded, and studies that included multiple types of breast cancers that did not report triple negative breast cancers separately (as a subgroup) were excluded. There were 12 studies identified of between six and 902 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on African Americans diagnosed with triple negative breast cancer.

This PEEK study appears to be among the largest cohorts of women diagnosed with triple negative breast cancer that includes a structured interview and it also covers the most domains.

Section 2

Demographics

Section 2 Demographics

There were 50 people with that took part in this study with triple negative breast cancer. Participants were aged from 25 to 74 years of age, most were aged between 45 to 54 years (n = 22 ,44.00%).

Participants were most commonly from New South Wales (n = 14, 28.00%), Queensland (n = 14, 28.00%), and Victoria (n = 11, 22.00%). Most participants were from major cities (n = 34, 68.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 30 participants (60.00%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 20 participants (40.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 26 participants that had completed university to at least an associate degree (54.00%). There were 27 participants who were employed either full time (54.00%), or part time (n =14, 28.00%).

Almost half of the participants were carers to family members or spouses (n = 26, 54.00%), most commonly carers to children (n = 25, 50%).

Breast cancer stage

There were 50 people with triple negative breast cancer who took part in this study. There were six participants (12.00%) with Stage I, 17 participants (34.00%) with, Stage II, 24 participants (6.00%) with Stage III, and three participants (6.00%) with Stage IV.

Other health conditions

The majority of participants had at least one other condition that they had to manage (n = 44, 88.00%), the maximum number reported was eight other conditions, with a median of three other conditions (IQR = 4.00). The most commonly reported health condition was anxiety either self or doctor diagnosed (n = 27, 54.00%), followed by sleep problems or insomnia (n = 22, 44.00%), chronic pain (n =13, 26.00%), and depression (Self or doctor diagnosed) (n = 19, 38.00%).

Baseline health

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

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health slightly interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems rarely interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were moderately fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average**,** participants had good emotional well-being.

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

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had a little pain.

The **SF36 General health** scale measures perception of health. On average, participants reported moderate health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their about the same as a year ago.

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms leading to diagnosis

In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was having a lump or lumps in breasts (n=39, 78.00%), this was followed by having no symptoms (n=5, 10.00%). Other symptoms (n=6, 12.00%) leading to breast cancer included pain and symptoms from metastases.

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 31 participants (62.00%) that described having symptoms and seeking medical attention relatively soon. There were six participants (12.00%) that described not having any symptoms before diagnosis, and six participants (12.00%) described having symptoms and not seeking medical attention initially.

Diagnostic pathway

Participants were most commonly diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=29, 58.00%). Other participants were referred directly to a specialist from their general practitioner which led to their diagnosis (n=11, 22.00%), and diagnosed through a population screening program (n=5, 10.00%)

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of triple negative breast cancer and the approximate date of diagnosis with triple negative breast cancer. Duration was calculated for 18 participants (23 participants had no symptoms before diagnosis), there were six participants (14.63%) that were diagnosed less than a month after noticing symptoms, four participants (9.76%) diagnosed between 3 and 10 months after noticing symptoms, and eight participants (19.51%) that were diagnosed more than 12 months after noticing symptoms (Table 3.7, Figure 3.4).

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis. Participants were most commonly diagnosed less than one week after diagnostic tests (n=27,57.45%). There were two participants (4.26%) diagnosed between 1 and 2 weeks, 12 participants (25.53%) diagnosed between 2 and 3 weeks, and three participants (6.38%) diagnosed between 3 and 4 weeks (Table 3.8, Figure 3.5).

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with triple negative breast cancer. Participants reported between 1 and 6 diagnostic tests (median = 3.00, IQR = 0.00) (Table 3.9, Figure 3.6). The most common tests were breast ultrasound (n = 42, 84.00%), core biopsy (n = 41, 82.00%), mammogram (n = 39, 78.00%), and fine needle aspiration (n = 34, 34.00%) (Table 3.10, Figure 3.7).

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis. More than half of the participants were given their diagnosis by a general practitioner (n = 28, 59.57%), and there were 13 participants (27.66%) given the diagnosis by a breast surgeon.

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common theme was that participants had no knowledge of their condition at diagnosis (n=22, 44.00%), followed by having had a good knowledge (n=15, 30.00%). There were 10 participants(20.00%) who had a limited knowledge about their condition at diagnosis.

The most common reasons for a good knowledge were being informed by a healthcare professional at the time of diagnosis (n=4, 8.00%), having a professional background (n=4, 8.00%), and researching the condition during the diagnostic process (n=4, 8.00%). The most common reason for having limited knowledge was because of general public awareness

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis. There were 11 participants (23.40%) who had enough support, nine participants (19.15%) that had some support but it wasn't enough, and 27 participants (57.45%) that had no support.

Information at diagnosis

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

There were 21 participants (44.68%) who had enough information, 20 participants (42.55%) that had some information but it wasn't enough, and six participants (12.76%) that had no information.

Costs at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests. There were 13 participants (27.66%) who had no out of pocket expenses, and nine participants (19.15%) who did not know or could not recall. There were 10 participants (21.28%) that spent Less than $500, 11 participants (23.40%) that spent between $500 to $1000, and four participants (8.51%) that spent more than $1000 (Table 3.21, Figure 3.15).

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses. In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

Genetic tests and biomarkers

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n = 13, 27.66%). There were 7 participants (14.89%) who brought up the topic with their doctor, and 27 participants (57.45%) whose doctor brought up the topic with them.

The majority of participants (n=32 68.09%) recalled having biomarker tests, and there were 14 participants (29.79%) that did not recall having biomarker tests but would like to have them (Table 3.24, Figure 3.18).

This question from the online questionnaire addresses the participants knowledge and understanding of having had biomarker tests. Despite all participants knowing that they had triple negative breast cancer, there were 70% that could relate this to biomarker status. The majority of participants knew the status for at least one biomarker (n = 42, 84.00%). Most commonly, participants knew their TNBC status (n = 35, 70.00%), followed by BRCA status (n = 19, 38.00%).

Current symptoms

More than half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 21, 44.68%). Participants had between 5 to 12 symptoms (median = 8.00, IQR = 3.00) (Table 3.26, Figure 3.20).

The most common current symptoms, and those where more than 35% of the participants experienced the symptom were; anxiety (n = 21, 44.68%), fatigue (n=21, 44.68%), thinking and memory problems (n = 20, 42.55%), depression (n = 19, 40.43%) weight and muscle changes (n = 18, 38.30%), and pain (n = 18, 38.30%).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. The median quality of life was between 2.5 and 4.5, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing to a little distressing” to “Life was average to good” range.

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. Participants most commonly described their prognosis in relation to no evidence of disease or that they are in remission (n=26, 54.00%), this was followed by prognosis described in relation to statistics such as five year survival rates (n=18, 36.00%). There were 14 participants (28.00%) who described prognosis in relation to probable recurrence/cycle of recurrence, 11 participants (22.00%) who described prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression, and seven participants (14.00%) who described prognosis in relation to it being positive that the condition will be cured in the future with treatment.

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple options/approaches, and this was described by 38 participants (76.00%). This was followed by being presented with one option/approach (n=8, 16.00%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, there were 28 participants (56.00%) who described feeling that they were told what to do with little or no discussion, and 29 participants (38.00%) who described that they participated in decision making or had informed discussions.

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 18 participants (36.00%). This was followed by taking side effects into account when making decisions about treatments (n = 11, 22.00%). There were seven participants (14.00%) who described taking efficacy into account, and the same number who described taking the survival benefit into account (n=7, 14.00%), and taking statistics/outcome of treatment into account (n=7, 14.00%). Other participants described taking cost into account (n=6, 12.00%), and taking quality of life into account when making decisions about treatment (n=6, 12.00%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (54.00%) that felt the way they made decisions about treatment had changed over time, and 18 participants (36.00%) that described decision making not changing.

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or assertive (n=13, 26.00%), becoming more proactive (n=6, 12.00%), and becoming more cautious and considered over time (n=5, 10.00%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was to treat the disease and get better (n=14, 28.00%), and this was followed by getting through medical treatment (n=12, 24.00%). Other themes included wanting to live independently, (n=7, 14.00%), wanting to see mental/neurological improvements (n=6, 12.00%), returning to work (n=5, 10.00%), physical improvements (n=5, 10%), and managing side effects (n=5, 10.00%).

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

The most common providers of treatment and care were medical oncologists (n = 23, 52.27 %), followed by general practitioners (n = 9, 20.45%).

There were 16 participants (37.21%) that travelled for less than 15 minutes, 15 participants (34.88%) that travelled between 15 and 30 minutes, eight participants (18.60%) that travelled between 30 and 60 minutes, three participants (6.98%) that travelled between 60 and 90 minutes, and one participant (2.33%) that travelled more than 90 minutes

Access to healthcare professionals

All participants had access to a medical oncologist (n = 44, 100%), and almost all had a specialist surgeon (n = 42, 95.45%) and a general practitioner (n = 41, 93.18%). There were 38 participants (86.36%) that had an oncology/chemotherapy nurse and 37 participants (84.09%) that had a breast care nurse.

Almost half of the participants had a pharmacist to care for their condition (n = 18, 40.91%). There were 21 participants (47.73%) treated by a physiotherapist and, 11 participants (25.00%) treated by a dietitian/nutritionist.

Respect shown

There were 34 participants (77.27%) that indicated that they had been treated with respect throughout their experience, and nine participants (20.45%) who were treated with respect with the exception of one or two occasions. .

Health care system

The majority of participants had private health insurance (n = 33, 75.00%). The majority of participants were asked if they wanted to be treated as a public or private patient (n = 28, 63.64%), and, they were asked if they had private health insurance (n = 39, 88.64%).

Throughout their treatment, there were 20 participants (45.45%) who were treated as a private patient, 20 participants (45.45%) were mostly treated as a public patient, and there were four participants (9.09%) who were equally treated as a private and public patient.

Affordability of healthcare

The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 39, 88.64%).

Almost all of the participants never or rarely were unable to fill prescriptions (n = 40, 90.91%).

There were 34 participants (79.28%) that never or rarely had trouble paying for essentials, such as such as food, housing and power, and six participants (13.64%) that sometimes found it difficult, and four participants (9.09%) often or very often found it difficult to pay for basic essentials.

There were four participants (9.09%) that paid for additional carers due to their condition.

Cost of condition

Participants spent between $50 and $10,000 per month, most commonly between $101 or less (n = 10, 22.73%), and $101 to $250 (n =10, 22.73%).

The amount spent was an extremely significant or moderately significant burden for 11 participants (25.00%), somewhat significant for nine participants (20.45%), and slightly or not at all significant for 24 participants (54.55%).

Changes to employment status

Work status for 12 participants (27.27%) had not changed since diagnosis, or were retired or did not have a job. There were four participants (9.09%) had to quit their job, 10 participants (22.73%) reduced the number of hours they worked, and four participants (9.09%) that accessed their superannuation early. There were 16 participants (36.36%) that took leave from work without pay, and 12 participants (27.27%) who took leave from work with pay.

There were 11 participants (25.00%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n = 22, 50.00%). There were four participants (9.09%) whose partners reduced the numbers of hours they worked, and no partners quit their job. The partners of five participants (11.36%) took leave without pay, and there were eight partners (18.18%) who took leave with pay.

Reduced income due to condition

Participants reported a reduced income from 500 to 10,000 per month, most commonly $1501 to 2500 (n = 6, 13.64%).

For eight of these participants (42.11%), the burden of this reduced income was slightly or not at all significant, for five participants (26.32%) the burden was somewhat significant, and for 6 participants (31.58%) the burden was extremely or moderately significant.

Summary of surgery

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). There were 15 participants (34.09%) that had one operation, 10 participants (22.73%) that had two operations, three participants (6.82%) that had three operations, and seven participants (15.91%) that had four or more operations.

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). The most common types of surgeries were mastectomies (n=19, 43.18%), and lumpectomies (n=19, 43.18%). There were 13 participants (29.55%) had breast reconstruction, and seven participants (2.27%) had surgery to remove ovaries

Summary of drug treatments

There were 40 participants (90.91%) that had used drug treatments to treat their breast cancer. The most common treatment regimen was doxorubicin, cyclophosphamide, and paclitaxel (n=17, 38.64%), followed by single agent paclitaxel (n=11, 25.00%), Capecitabine (n=10, 22.73%), Doxorubicin and cyclophosphamide (n=8, 18.18%), Carboplatin paclitaxel (n=6, 13.64%), and Doxorubicin (n=5, 11.35%)

Summary of radiotherapy

There were 25 participants (56.82%) that had radiotherapy to the primary cancer site, and three participants (6.82%) that had radiotherapy to the secondary cancer site .

Allied health

Most participants used at least one type of allied health service (n = 34, 77.27%), and on average used 2 services (median = 2.00, IQR = 1.00).

The most common allied health service used was psychology services (n = 21, 47.73%), followed by physiotherapy (n = 20, 45.45%), and Dietician (n = 10, 22.73%). There were six participants (13.64%) who saw an occupational therapist, five participants (11.36%) who saw a podiatrist, and four participants (9.09%) who saw a social worker.

Lifestyle changes

Most participants used at made at least one lifestyle change (n = 38, 86.36%), and on average made 2 changes (median = 2.00, IQR = 2.00).

The most common lifestyle change used was exercise (n = 28, 63.64%), followed by diet changes (n = 23, 52.27%), and reducing or stopping alcohol if applicable (n = 24, 54.55%).

Complementary therapies

Most participants used at made at least one complementary therapy (n = 29, 65.91%), and on average used one therapy (median = 1.00, IQR = 2.00).

The most common complementary therapy used was mindfulness or relaxation techniques (n = 20, 45.45 %), followed by massage therapy (n = 17, 38.64%), and taking supplements (n = 16, 36.36%) (Table 5.21, Figure 5.24).

Clinical trials

There was a total of 16 participants (36.36%) that had discussions about clinical trials, six participants (13.64%) had brought up the topic with their doctor, and the doctor of 10 participants (22.77%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 28, 63.64%).

There were four participants (9.09%) who had taken part in a clinical trial, 32 participants (72.73%) who would like to take part in a clinical trial if there was a suitable one, and eight participants, who have not participated in a clinical trial and do not want to (18.18%).

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 28 participants (56.00%) was the internet (including health charities). There were 18 participants (36.00%) that described Facebook and/or social media and 17 participants (34.00%) that described their treating clinician. Other types of information accessed included other patient's experience (n=16, 32.00%), books, pamphlets and newsletters (n=11, 22.00%), and nursing staff (n=10, 20.00%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 19 participants (38.00%) was other information from people's experiences (Peer-to-peer). There were 14 participants (28.00%) that described hearing what to expect (e.g. from disease, side effects, treatment) , and 13 participants (26.00%) that described condition-specific (including sub-types), as being useful. Other types of information described as being helpful included condition-specific information (including information about sub-types or stage) (n=13, 26.00%), talking to healthcare staff (n=9, 18.00%), treatment options (n=9, 18.00%), and information from charities (n=5, 10.00%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. There were 13 participants (26.00%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 17 participants (34.00%) were sources that are not credible (not evidence-based). There were 11 participants (22.00%) that described information from healthcare staff or hospital, and six participants (12.00%) that described lack of new information, as not helpful.

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common preference was online information (n=15, 30.00%) followed by talking to someone (n=12, 24.00%), talking to someone plus online information (n=11, 22.00%), and written information (n=11, 22.00%).

The main reasons for a preference for online information was accessibility (n=11, 22%), having control or personal research (n=7, 14%), convenience (n=6, 12%), and access to a lot of information (n=6, 12%). The main reason for talking to someone as a preference was it was valuable and knowledgeable (n=8, 16%), followed by having time for interaction and to ask questions (n=7, 14%). The main reason for written information as a preference was accessibility (n=7, 14%).

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was from the beginning when diagnosed (n=12, 24.00%), this was followed by participants describing being open to information during treatment (n=11, 22.00%), after the shock of diagnosis (n=8, 16.00%), and before starting treatment (n=8, 16.00%). There were five participants (10.00%) that were receptive to information a week after diagnosis, and the same number receptive three weeks after diagnosis (n=5, 10.00%).

Health professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience(n=26, 52.00%). There were 10 participants (20.00%) that described overall positive, with the exception of one or two occasions, and 8 participants (16.00%) that described a mix of positive and negative. There were four participants (8.00%) who described having an overall negative experience of health professional communication.

Participants that had positive communication, described the reason for this was because communication was holistic (two way, supportive and comprehensive conversations) (n=20, 40.00%), and helpful (n=5, 10.00%). The main reason for negative communication was communication that was not forthcoming, or generally lacking (n=11, 22.00%). This was followed by communication that was dismissive (one way conversations) (n=5, 10.00%), and that had limited understanding of the condition (n=4, 8.00%).

Partners in health

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

The overall scores for the cohort were in the highest quintile for the **Partners in health: knowledge** (mean = 25.98, SD = 3.51), **Partners in health: recognition and management of symptoms** (median = 20.00, IQR = 2.50), **Partners in health: adherence to treatment** (median = 15.00, IQR = 2.00), scales, indicating very good scores for managing their health.

The overall scores for the cohort were in the second highest quintile for the **Partners in health: coping** (mean = 16.18, SD = 4.26), **Partners in health: total score** (mean = 76.23, SD = 8.93), scales, indicating good scores for managing their health.

Ability to take medicines as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n = 23, 52.27%), and 18 participants (40.91%) responded that they took medicines as prescribed most of the time. There were 3 participants (6.82%) that sometimes took medicines as prescribed.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about Treatment options (n=41, 93.18%), Hereditary considerations (n=30, 68.18%), Disease management (n=26, 59.09%) and, Physical activity (n=20, 45.45%) were most frequently given to participants by healthcare professionals, and, information about Complementary therapies (n=6, 13.64%), Interpret test results (n=6, 13.64%) and, Clinical trials (n=6, 13.64%) were given least often.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were Interpret test results (n=28, 63.64%), Complementary therapies (n=23, 52.27%), Disease Cause (n=21, 47.73%) Disease management (n=21, 47.73%) and, Treatment options (n=21, 47.73%) were most frequently given to participants by healthcare professionals, and, information about Dietary (n=17, 38.64%), Psychological/ social support (n=13, 29.55%) and, Clinical trials (n=12, 27.27%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were Clinical trials (n = 27, 61.36%) and Dietary (n = 20, 45.45%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were Treatment options (n = 22, 50.00%) and Hereditary considerations (n = 18, 40.91%).

The topics that participants were given most information from both healthcare professionals and searching independently for were Sum of Complementary therapies (n = 20, 45.45%) and Treatment options (n = 19, 43.18%).

The topics that participants searched for independently after not receiving information from healthcare professionals were Disease management (n = 24, 54.55%) and Sum of Complementary therapies (n = 15, 34.09%) (Table 6.35, Figure 6.48).

Information accessed

Across all participants, information from non-profit, charity or patient organisations were most accessed followed by information from the government. Information from pharmaceutical companies and from medical journals were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 19 participants (43.18%) had accessed My Health Record, 21(47.73%) had not. Of those that had accessed My Health Record, there were 9 participants (47.37%) who found it to be poor or very poor, four participants (21.05%) who found it acceptable, and two participants (10.53%) who found it to be good or very good.

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

The overall scores for the cohort were in the highest quintile for the Care coordination: Quality of care global measure (median = 9.00, IQR = 1.00), scales, indicating very good scores for quality of care.

The overall scores for the cohort were in the second highest quintile for the Care coordination: Communication (mean = 44.64, SD = 7.85), Care coordination: Navigation (mean = 26.55, SD = 3.87), Care coordination: Total score (mean = 71.18, SD = 10.28), Care coordination: Care coordination global measure (median = 8, IQR = 2.25), scales, indicating good scores for care coordination, navigation, and communication.

There we no significant differences between sub-groups within the Care Coordination measure.

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common theme was that participant received support through charities (n=19, 38%). This was followed by receiving support from a hospital or clinical setting (n=11, 22%). There were 15 participants (30.00%) that described not receiving any support. There were five participants (10.00%) who described getting peer support, and the same number described getting support through a psychologist or counselling service (n=5, 10.00%).

Section 8

Quality of life

Section 8: Quality of life

Impact on 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 26 participants (52.00%) who described a negative impact on quality of life. There were seven participants (14.00%) who reported a mix of positive and negative impact on quality of life, and six participants (12.00%) who reported an overall positive impact on quality of life, and five participants. There were five participants (10.00%) who described no impact on quality of life, and three participants (6.00%) who described minimal impact.

The most common themes in relation to a negative impact on quality of life were the emotional strain on family/change in dynamics of relationships (n=25, 50.00%), the impact of symptoms/side effects (n=15, 30.00%), and the reduced capacity for physical activity (n=8, 16.00%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 45 participants (90.00%) who gave a description suggesting that overall there was some impact on their mental health and three participants (6.00%) who gave a description suggesting that overall there was no 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 ways that participants reported managing their mental and emotional health was maintaining social, lifestyle changes, and hobbies (n=18, 36.00%), consulting a mental health professional (n=17, 34.00%), and physical exercise (n=15, 30.00%). There were eight participants (16.00%) who described the importance of accepting their condition and having a positive outlook, and the same number who described the importance of family and friends (n=8, 16.00%). Other ways to maintain mental health included self-care (n=6, 12.00%), and mindfulness or meditation (n=5, 10.00%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common way that participants reported managing their health was by being physically active (n=26, 52.00%), followed by the importance of self-care (n=19, 38.00%). There 13 participants (26.00%) who described the importance of understanding their limitations, 12 participants (24.00%) who described maintaining a healthy diet and 11 participants (22.00%) who described the importance of treatment compliance. Other ways of maintaining health included keeping up with daily activities (n=7, 14.00%), and socialising with family and friends (n=5, 10.00%). There were five participants (10.00%) who described no regular activities to maintain their health.

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 43 participants (86.00%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and four participants (8.00%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common theme was feeling vulnerable during or after treatments (n=20, 40.00%), followed by feeling vulnerable when having negative thoughts (n=15, 30.00%). There were 14 participants (28.00%) who described feeling vulnerable when having sensitive discussions for example at diagnosis and treatment decisions, and nine participants (18.00%) described feeling vulnerable when feeling sick.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described support from their medical team to manage the feeling of vulnerability (n=9, 18.00%), and using self-help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=7, 14.00%). Other methods included adapting, for example being proactive. Assertive and understanding boundaries (n=6, 12.00%), and getting support from family and friends (n=5, 10.00%).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 19 participants (38.00%) who described a mix of positive and negative impacts on relationships. Other participants reported a negative impact on relationships (n=11, 22.00%), no impact on relationships (n=8, 16.00%), and a positive impact on relationships (n=7, 14.00%).

The most common theme in relation to having an impact on relationships was a mixed impact on relationships, some strengthened, others disappeared
(n=14, 28.00%). There were eight participants (16.00%) who described relationships suffering, because of people not knowing what to say or do and withdrawing from relationships, and the same number who described no impact on relationships with no specific reason (n=8, 16.00%). Other reasons included relationships with family being strengthened (n=7, 14.00%), and relationships suffering, due to emotional strain (n=6, 12.00%).

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Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 30 participants (60.00%) who felt there was an additional burden, and 18 participants (36.00%) who reported no additional burden.

Participants who described that they were no additional burden, mostly did this without giving any examples or explanations (n=13, 26.00%), followed by not being a burden because they manage their condition independently (n=5, 10.00%). For people that felt they were a burden on their family, most commonly did not give any specific reasons for this (n=12, 24.00%). The main reasons for burden on families were the extra household duties and responsibilities that their family must take on (n=10, 20.00%), and the mental/emotional strain placed on their family (n=6, 12.00%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 36 participants (72.00%) that described some cost burden and 11 participants (22.00%) who described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=25, 50.00%). Other cost burdens were in relation to diagnostic tests and scans (n=15, 30.00%), taking time off work (n=9, 18.00%), and the cost of private care (n=7, 14.00%). There were six participants (12.00%) who described the cost of specialist appointments, and the same number who described the cost of allied healthcare (n=6, 12.00%), and the cost of parking and travel to attend appointments, including accommodation (n=6, 12.00%). There were six participants (12.00%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. The average score was in the Life was a little distressing range (median = 3.00, IQR = 3.00) (Table 8.29, Figure 8.15).

Fear of 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 8.10. Overall the entire cohort had a mean total score of 35.89 (SD = 7.50), which corresponds to moderate levels of anxiety (Table 8.29)

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common themes reported were for future treatments to have fewer or less intense side effects (n= 12, 24.00%), followed by more effective future treatments (n = 11, 22%), and treatments that less cost (n = 11, 22.00%).There were eight participants (16.00%) who described wanting more research and more treatment advances, seven participants (14%) that described wanting more holistic treatments, and seven participants (14%) who described wanting a change in administration of the treatment. There were five participants (10%) that described wanting future treatment to be the same as it is now, and the same number who described wanting preventative measures (n=5, 10.00%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. There were eight participants (16%) who described that future information will provide more details about where to find available services and this was the most common theme. There were seven participants (14.00%) who described the expectation that future information will provide more details about treatments, and the same number described the expectation that future information will provide more details about mental health and emotional support (n = 7, 14.00%).

Other expectations included, how to manage personal and intimate problems (n = 6, 12.00%), general information about the condition (n = 6, 12.00%), symptom and side effect control (n = 5, 10.00%), and that information will be mores accessible and easy to find (n = 5, 10.00%). There were seven participants (14.00%) that had no recommendations and were satisfied with the information available.

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common themes were that participants had no recommendations and they had experienced good communication (n = 13, 26.00%), and that future communication should be more transparent and forthcoming (n = 13, 26.00%). There were 10 participants (20.00%) who described that future communication should be more accurate and detailed, 10 participants (20.00%) who described future communication should include listening to the patient, nine participants (18.00%) who described future communication should be more empathetic, and five participants (10.00%) who described future communication should include a care plan with follow-up.

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. There were 24 participants (48.00%) who described that future care and support should include access to support services and this was the most common theme. Other participants described that future care and support should include access to specialist clinics or services (n= 10, 20.00%), access to mental health and emotional support (n = 7, 14.00%), and access to peer support (n = 6, 12%). There were five participants (10.00%) as they were satisfied with the care and support available.

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common themes reported were that participants were grateful for timely access to treatment (n = 17, 34.00%), followed by grateful for healthcare staff (n = 16, 32.00%). There were 12 participants (24.00%) that described being grateful for low cost or free medical treatments , 10 participants (20.00%) that described being grateful for the entire health system, and 9 participants (18.00%) that described being grateful for low cost/free medical care.

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were fatigue pain, Heart problems and, memory loss and cognitive function. The least important were fertility, body image and sexual difficulties.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were “How safe the medication is and weighing up the risks and benefits”, and “How personalised the treatment is for me”. The least important were “Ability to follow and stick to a treatment regime” and “The financial costs to me and my family”.

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn’t offer a cure. The majority of participants (n = 28, 63.64%) would use a treatment for more than ten years for a good quality of life even if it didn’t offer a cure.

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. Participants they were equally effective (n = 15, 34.09%), followed by IV form (n = 16, 36.36%).

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?”. There were 22 participants (44.00%) with the message to improve access to support and care (including treatment) and this was the most common theme. Other participants had the message: to understand the financial implications (n = 16, 32.00%), to have a tailored care plan (n = 11, 22.00%), to invest in research (n = 7, 14.00%), and to invest in specialist health professionals, especially nurses (n = 7, 14.00%). There were five participants who were satisfied and thought that things should stay the same, and the same number who had the message that treatments need to be holistic (n= 5, 10.00%).

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. There were 11 participants (22.00%) that described that they wish they had known more about the pros and cons of treatment options, and this was the most common theme. Other participants wished they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology (n = 10, 20.00%), participants wished they had known more about what support was available to them (n = 10, 20.00%), and participants wished they had known more about side effects of treatments (n = 9, 18.00%). There were 10 participants (20.00%) who did not describe anything that they wish they had known earlier without giving a reason.

Aspect of care or treatment they would change

The most common themes reported were that participants would not change any aspect of their care or treatment/satisfied with care and treatment received (n = 12, 24.00%), followed by participants would not change any aspect of their care or treatment without giving a reason (n = 9, 18.00%). There were seven participants (14.00%) that described that they would change or stop the kind of treatment they received.