

Section 11

Discussion

Introduction

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

There are very few studies that report the personal experience, expectations, and knowledge of people with triple negative breast cancer. A search of PubMed identified 12 studies conducted in the last 10 years that were focused on triple negative breast cancers. There was a single study that conducted interviews, this was focused on young African-American women with triple negative breast cancer¹. Five studies reported quality of life as an outcome of clinical trials²⁻⁶. Two studies focused on clinical trial participation^{7,8}, one study each on patient activation, health related quality of life⁹, lifestyle changes¹⁰, and coping¹¹.

This PEEK study in triple negative breast cancer includes 50 people diagnosed with triple negative breast cancer throughout Australia. About half were advanced breast cancer, and about half were diagnosed in the last two years. It is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations in a under-reported patient population.

Background

Triple negative breast cancers are defined by the lack of progesterone and oestrogen receptors, and HER2 proteins^{12,13}. 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^{14,15}.

In 2019, there were 19,371 new cases of breast cancer reported in Australia¹⁶. Approximately 12 to 17% of all breast cancers are triple negative¹⁴, that is an estimated 3000 new cases of triple negative breast cancer in Australia 2019.

Demographics

The demographic data we collect in the PEEK study helps us to understand how our PEEK participants compares to people in Australia, and with people that have breast cancer.

In this PEEK study, the proportion of participants that lived in major cities was all similar to that of Australia. There were more that lived in areas with a higher socioeconomic status, higher rates of paid employment, and lower rates of non-school qualifications (certificate, diploma or degree), compared to the Australian population¹⁷⁻¹⁹. In addition to being in paid employment, half of the participants in this PEEK study were carers to children. There were no participants from the Northern Territory, or Canberra, and there were a higher proportion of participants from Queensland and Western Australia, compared to the proportion that live in each state²⁰.

Table 12.1: Demographics

Demographic	Australia %	Lupus PEEK %
Live in major cities	71	60
Non-school qualification	65	52
Higher socioeconomic status (7 to 10 deciles)	40	34
Employment (aged 15 to 64)	74	56
New South Wales	32	26
Victoria	26	22
Queensland	20	20
South Australia	7	12
Western Australia	10	12
Tasmania	2	2
Northern Territory	1	0
Australian Capital Territory	2	6

Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36 questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with breast cancer participants.

Other health conditions

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition²¹. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%), asthma (11%), diabetes mellitus (5%), heart, stroke and vascular disease (5%), osteoporosis (4%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)²¹. The Australian Bureau of

statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition²¹.

In this PEEK study, participants had higher levels of anxiety (54% compared to 13%), depression (38% compared to 10%), and similar levels of arthritis (18% compared to 15%), and diabetes (6% compared to 5%) compared to the Australian population.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual²². 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 function²².

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the breast cancer community in this PEEK study compares with the Australian population²³. The triple negative positive breast cancer PEEK participants on average had considerably lower scores for all SF36 domains with the exception of emotional well-being, and role functioning/emotional.

Compared to a PEEK study of 100 participants with breast cancer that was conducted in 2018²⁴, participants in this Triple negative breast cancer study scored higher in the role functioning/physical, emotional well-being, and pain domains, and worse in the general health domain. The higher scores could in part be due to the younger participant population in the triple negative breast cancer study, and the lower general health due to half of the recent diagnosis for participants in the triple negative study. Another quality of life study comparing 85 African American people with triple negative breast cancer with 245 non- triple negative breast cancer reported worse quality of life in the triple negative groups, in particular with relation to health related anxiety and depression, emotional well-being and functional well-being⁹.

In this PEEK study, participants that had poor physical function had lower scores (worse health related quality of life) in the energy/fatigue, social functioning, pain and general health domains, and those that had been diagnosed in the past two years had lower scores for the physical function, pain, and general health domains. A study of 121 participants with triple negative breast

cancer in china reported that quality of life was positively associated with income, self-efficacy, and social support, and negatively associated with cancer stage²⁵, in contrast this PEEK study found no differences in health related quality of life by socio-economic status, or breast cancer stage.

Key points

- This is a population that are in paid employment and are carers to children
- Health related quality of life lower for most domains compared to Australian population

Risks and Symptoms

Early screening can help in reducing breast cancer related mortality and deaths.²⁶ Mammography is one such procedure which is commonly used and helps in evaluating local stage of disease and response to treatment^{26,27}. Ultrasonography can be used as an additional tool for diagnosis of breast cancer ^{26,28}. Magnetic resonance imaging (MRI) is another non-invasive procedure used for diagnosis of breast cancer to provide highly accurate imaging of the lesion; the disadvantage of MRI is that is an expensive and invasive procedure ^{26,28}. Breast self-examination is a cheap and easy procedure which woman can conduct at home ^{26,29,30} and helps woman to learn about basic structure of breast and detect atypical structures in mammary gland^{26,31}.

In this PEEK study the most common diagnostic pathway described was self-detecting a lump or other breast abnormality, seeking attention from a general practitioner and being referred to mammogram, ultrasound and biopsy. Very few participants were diagnosed as a result of population screening, as most of the participants are under the recommended age of breast screening in Australia.

Participants in this PEEK study did not feel that they had enough support at the time of diagnosis, in particular older participants. In terms of information given at diagnosis, most were given at least some information but almost half felt they did not have enough information, especially those with trade or high school education, and those that lived in regional areas or lower socioeconomic status areas.

Key points

- Most were diagnosed as a result of finding a lump after self-breast examination
- Emotional support and information needs are not being met at the time of diagnosis

Biomarkers or genetic markers

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course.

In Australia, immunohistochemical assays to determine oestrogen receptor (ER) and progesterone receptor (PR) status are routinely performed on invasive breast carcinomas and are often performed on ductal carcinoma in situ³². The receptor status provides prognosis information and prediction of response to endocrine therapy³³⁻³⁵. HER2 (human epidermal growth factor receptor 2) status is recommended for early invasive cancers and for metastatic or recurrent disease, it is a prognostic factor and also predicts response to biological therapies³⁶.

All participants in this study knew that they had triple negative breast cancer, however, about 30% did not relate this to biomarker status and did not have discussions about biomarkers with their doctor, and wanted to have this sort of testing. Additional information about the implications of breast cancer markers may be important at the time of diagnosis and to help with decision-making.

My breast surgeon explained to me that it wasn't responsive to hormones, and it didn't come back with a HER2. He was the one who explained a little bit more about what triple-negative was, but at no point did I actually grasp how scary triple-negative is. I remember our fertility specialist telling us, because it wasn't hormonally driven, he was happy for us to do another round of IVF with fertility preservation. My husband and I thought we'd got the good breast cancer. Not that there's any good or bad breast cancer, but we were like, "Cool, we get to still do something. We're lucky that we got this version and hadn't got a hormonally driven version. It wasn't until pretty much I'd finished chemotherapy that I actually fully understood what triple-negative meant, and the statistics around triple-negatives, the statistics around survival rate. I remember my surgeon saying to me at the beginning that we needed to make some decisions within the first four weeks because they'd like to do something within the first week, but it was never because it's triple-negative. As far as we were concerned, we've got some good breast cancer and that was what it was. Participant_025

Understanding and knowledge

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result

in misconceptions and misunderstandings^{37,38}. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis^{39,40} others, especially those who have symptoms for long periods before diagnosis, will gain information in terms of how to live with or adapt to symptoms they experience⁴¹. For some people, the first time they have heard of their chronic condition is when they are diagnosed⁴². At the time of diagnosis, it may be useful for the healthcare professional to talk about how much a patient knows about a condition so that appropriate information can be given, and correct misconceptions⁴².

Most participants in this PEEK study were aware of breast cancer, however, did not know much about triple negative breast cancer. Those that had a good understanding of triple negative breast at diagnosis had a level of understanding due to the explanations given by healthcare professionals, or because of research they had done themselves during the diagnostic process, or because they had a professional background.

Nothing. I thought breast cancer- I didn't know that there were different types of breast cancer. That was the first thing that I, had no idea. I thought breast cancer was breast cancer. I thought breast cancer, everybody lives, and it's really easy to cure. Because it's so common. I didn't know that obviously, there's Triple-negative, but it's high rate of people that don't survive., I learned so much, I knew nothing. Participant_019

Key point

- There was a lack of awareness of different types of breast cancer, in particular, a lack of knowledge about triple negative breast cancer at the time of diagnosis.

Decision making

The decision-making process in healthcare is an important component in care of chronic or serious illness⁴³. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare^{44,45}, highlighting the importance of healthcare professional communication. In addition, the role of family members in decision making is important, with many making decisions following consultation with family⁴⁶.

Confidence to take part in decision-making is increased by knowledge, being prepared with relevant questions for their consultation, and summaries of previous

consultations and results^{47,48}. Most participants were presented with different treatment options (surgery, chemotherapy, and radiotherapy), but when it came to decision making and taking part in treatment decision making, few participated. This could be due to the lack of targeted therapies for this patient group, and the aggressive nature of the disease.

Participants in this PEEK study considered multiple factors when it came to decision making. The most important were taking the advice of their doctor, side effects, efficacy, cost, and quality of life.

Decision making over time had changed for participants, as they become more informed, assertive, and proactive. This may indicate this information needs change over time – with more information needed as treatments progress, especially information about side effects, cost, efficacy, and quality of life.

It has changed, in the sense, I realized that I thought that the approach I was presented with initially, I felt it was a very tunnel-view, like just, "This is what your treatment should be," kind of thing. Whereas, over the course, I realized I have to be in charge of things a lot more. I think I was quite trusting, and I'm not saying I should doubt the health professionals, but I definitely feel like I have a right to ask questions and it's okay to have a more active role in my treatment rather than passive. Participant _016

Key point

- Participants became more assertive and proactive in decision making over time – information should reflect important factors for decision making: side effects, efficacy, cost, and quality of life

Treatment and healthcare provision

In this PEEK study, to get an insight healthcare access, information about access to healthcare professionals, health insurance, health system, and financial consequences from having breast cancer are collected.

Access to health professionals

The main provider of treatment for participants in this PEEK study were medical oncologists. The time to travel to the main provider for treatment was less than 30 minutes for most of the participants in this study. Every participant had access to a medical oncologist, and most had access to a breast cancer surgeon. Over 80% had access to oncology nurses, and access to breast care nurses.

Affordability of healthcare

Almost half of the Australian population have private health insurance with hospital cover⁴⁹. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private health care funded hospitalisations in public hospitals rose from about 8% to 14%⁴⁹. In this PEEK study, a higher proportion had private health insurance compared to the Australian population. Equal numbers of participants in this PEEK study were treated in the public and private hospital systems.

Most participants in this PEEK study had no problem paying for treatments, and healthcare appointments. However, there was more difficulty paying for essentials such as housing, food and power. Most participants spent under \$250 a month in out of pocket expenses, and about half had experienced a reduced household income due to their diagnosis.

Women with breast cancer have reported changing work tasks or changing jobs to manage in the workforce^{50,51}. In this PEEK study, approximately a third had either had to quit their job or reduce the number of hours worked, and family members took leave from work to support them. In another study, almost 80% of spouses reported absences from work due to their partners breast cancer, and had a mean salary loss of \$1820 Canadian⁵². In addition to changes in employment, cost burdens in this PEEK study were also from the cost of treatments, diagnostic tests and scans, and travel and accommodation costs from medical appointments.

Treatment

The aim of surgery is excision of tumour with adequate margins or greater than 1mm. If local excision of not achievable or the tumour is large, multifocal or at the choice of the patient, a mastectomy is performed⁵³. Neo-adjuvant therapies are used to reduce tumour size and breast conservation⁵⁴. Pathological staging of the axilla is dependent on clinical presentation, clinically negative sentinel lymph node biopsy is usually conducted at the time of surgery⁵⁴. Axillary lymph node dissection is used for clinically positive or if the sentinel lymph node is positive in clinically negative patients⁵⁴.

For early breast cancer, following local excision with clear margins, it is standard for five weeks treatment with whole breast radiotherapy, this may also be offered to women with DCIS⁵⁵. Following mastectomy, radiotherapy may be given to the chest wall for those with high risk of recurrence (four or more involved lymph nodes, involved

margins), or at intermediate risk of recurrence (one to three involved lymph nodes, grade 3 disease, oestrogen receptor negative and aged under 40)⁵⁵. For locally advanced breast cancer, treatment is mastectomy followed by radiation.

The aim of treatment in advanced breast cancer is disease control, symptom palliation and improvement in survival⁵⁴. Radiation is used in advanced breast cancer in patients with bone metastases and pain, and in patients with brain metastases whole brain radiotherapy with or without resection⁵⁶.

The majority of participants (80%) had at least one surgery for breast cancer, most commonly a lumpectomy or mastectomy. Over 90% had chemotherapy, the most common regimens were doxorubicin, cyclophosphamide, and paclitaxel, single agent paclitaxel (n=11, 25.00%), and capecitabine. More than half of the participants had radiotherapy, mostly to the primary cancer site.

About half of the participants in this PEEK had current symptoms to deal with; mostly anxiety, fatigue, depression, weight and muscle, sleep, sexual function, and bone problems, of these reported quality of life was lowest from weight changes. Pain and fatigue were ranked as the most important symptoms to control.

Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of breast cancer. Most participants (77%) used at least one type of allied health service, and on average used two services. The most common types of allied health were psychology and physiotherapy. In other breast cancer studies, people with breast cancer have reported that they had a lack of psychological support, physiotherapy, and counselling^{57,58}

Lifestyle changes

Diet and exercise needs of people with cancer change throughout the course of their treatment and survivorship⁵⁹, and lifestyle changes may be made by individuals to improve treatment outcomes, improve quality of life and reduce recurrence risk factors⁶⁰. People with breast cancer have described the need for education about physical activity during chemotherapy, especially impact of side effects, and described the importance of personalised programs and support from peers, friends and family⁶¹. In this PEEK study, 86% made at least one lifestyle change following their diagnosis with breast cancer, most commonly diet and exercise changes. A study that included 23 people with triple negative breast cancer

lifestyle intervention reported loss in body fat and improved quality of life following exercise and dietary counselling¹⁰.

Complementary therapies

The advancements in the treatment of breast cancer and improvements in survival come with ongoing side effects which need to be managed, and one area of practice that has the potential to alleviate symptoms and side effects is complementary therapies⁶². People with breast cancer have expressed a belief that complementary therapies plays role in delivering personalised and holistic treatment⁶³. Over 65% of participants in this PEEK study used at least one type of complementary therapy, most commonly mindfulness, massage therapy, and supplements. Similarly, a study of complementary therapy use in Canada, menopausal women with breast cancer, nearly 70% used complementary therapies including mindfulness, and supplements⁶⁴

Clinical Trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on 11 August 2021. The search included any study that specifically included triple negative positive breast cancer participants, was conducted in Australia, and was open to recruitment in the last five years. A total of 57 studies were identified that had a target recruitment of between 5 and 2300 participants (median n=178), there were 43 studies that were international, and 14 studies that were conducted exclusively with in Australia. There were 56 studies that were for drug treatments, and one education study. There were 18 studies that were specifically for triple negative breast cancer, and the remaining 39 studies included triple negative breast cancer among other breast cancer or cancer types.

There were 41 studies conducted in Victoria, 40 in New South Wales, 22 in Western Australia, 19 in Queensland, 12 in South Australia, and four in Canberra. There were no studies identified that were open to recruitment in Tasmania or the Northern Territory.

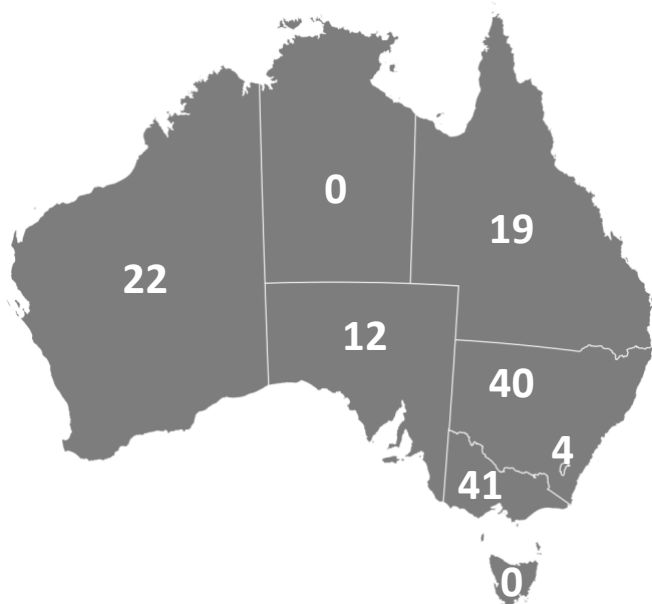


Figure 12.1: Distribution of clinical trials for triple negative breast cancer in Australia 2016-2021

In this PEEK study, 36% of participants had discussions about clinical trials with their doctors. Very few participants had taken part in a clinical trial, though more than 80% had either taken part or were willing to take part in a clinical trial if there was one suitable. One in five participants were not willing to take part in a clinical trial. Another study indicated that 60% of people with triple negative breast cancer would be willing to take part in a clinical trial evaluating different adjuvant treatments⁷. Another study of 15 participants with triple negative breast cancer indicated that people are motivated to take part in clinical trials to benefit both others and themselves⁸.

Patient treatment preferences

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance⁶⁵⁻⁶⁷. Patient preferences and priorities vary across different health issues, preferences are associated with health care service satisfaction, they refer to the perspectives, values or priorities related to health and health care, including opinions on risks and benefits, the impact on their health and lifestyle^{65,68}.

To help inform patient preferences in the triple negative breast cancer community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. Mild side effects were described as side effects that are self managed or do not interfere with life. Some participants used examples to describe mild side effects, such as nausea, feeling of discomfort, or headaches. In a similar way, participants describe severe

side effects, broadly as those that impact every day life, or using the examples of pain, emotional/mental struggle, neuropathy, fatigue, and nausea and vomiting. It is interesting to note that participants described, nausea and pain as both mild and severe side effects. Discussing both a list of side effects and the potential impact on daily life may be important for treatment decision making.

In the structured interviews, participants were asked about their treatment goals, what needs to happen to make them feel like the treatment is working, and what it would mean to them if treatments worked. A common theme for these questions was a return to day-to day functionality, and similar themes allowing participation in social and family life, return to work, ability to do domestic tasks, and live with independence.

Physical signs and symptoms was another reoccurring theme for treatment, seeing change in physical signs and symptoms was a signal that treatment is working, and treatment goals included managing side effects, physical improvements in their condition, and improvements in mental and emotional health.

Okay, so for example, with nausea, I would generally only take antiemetics if it was impacting on my diet, the ability of me being able to have a reasonable diet, and also, being able to allow me just to get up and do things. There were a couple of times, I guess, when the nausea was, I wouldn't say it was severe, but it was incapacitating, where you just really didn't feel like getting up and doing too much. Yes, taking antiemetics did relieve that, and allowed me to obviously continue to eat a reasonable diet, and be able to get up and do things. Same with pain, I don't think-- I had very minimal pain through any of my treatments, I really didn't-- I wasn't required--I didn't have to take any analgesia to improve my quality of life. Participant_013

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving⁶⁹. Components of self-management include information, activation and collaboration⁶⁹.

Information is a key component of health self-management^{70,71}. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about

how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management^{70,71}.

I was very confused actually at the start. The GP told me that I had what mum had. It turns out that was not the case. Hers was DCIS, whereas mine was invasive. I also didn't understand the meaning of triple negative. I actually took that to be a positive because I thought if hormones can't feed the cancer, then it can't grow, but I didn't understand that you can also target the hormones to treat the cancer and I didn't have that option. It took me a bit to understand that because I really thought it was a better diagnosis, but it was actually worse because it was more unknown. Participant 048

Participants in this PEEK study accessed information from a variety of sources including the internet, social media, healthcare providers, and pamphlets or books. They appreciated information from other people with triple negative breast cancer, information specific to triple negative breast cancer, and treatment options. They valued information from healthcare professionals and health charities. Information that is not helpful included information from non-credible sources, and also, a lack of new information was also unhelpful.

A preference for information found on the internet was because it is accessible, allows control and personal research, and because it is convenient. A preference for speaking to a healthcare professional was because of their knowledge, and the ability to ask questions,

Participants in this PEEK study were most often given information about treatment options, hereditary information, disease management and physical activity and least amount of information was given about complementary therapies, interpreting test results, and clinical trials. Of the topics given least by healthcare professionals, complementary therapies and how to interpret test results were the most often searched for topics.

Activation (skills and knowledge)

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and

psychological strategies such as problem solving and goal setting.

Patient activation is measured in the PEEK study using the Partners in Health questionnaire⁷². On average, participants in this PEEK study had very good scores for knowledge, recognition and management of symptoms, adherence to treatment, and good scores for coping with breast cancer.

Communication and collaboration

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support^{70,71} Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction⁷³⁻⁷⁶.

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making⁷⁷.

Building a relationship with patient, families and support networks is fundamental to establishing good communication⁷⁷. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding⁷⁷. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands⁷⁷. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources⁷⁷. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire⁷⁸. On average, the participants in this PEEK study had good communication and navigation of the healthcare system, and rated their quality of care as very good and care coordination as good.

In general, participants in this PEEK study had experienced good communication with healthcare professionals, and they felt they had been treated respectfully. Positive communication was holistic and helpful, while negative communication was described as limited, not forthcoming, and dismissive. Similarly, another study reported that patient understanding of their condition and ability to seek care when needed was improved when information was delivered in a two-way exchange.^{79,80}

I would say that on overall it's been very reasonable. Or however, I think the best information that I was given would have been from the McGrath Breast Care nurse that we have locally. She was excellent. She was very good at explaining, "Okay, about your type of breast cancer, what to expect in regards to treatment, what not to worry about. Don't, don't go looking for information that you don't need to know yet." She was very good at outlining all of that stuff and giving the information that I needed. The manner in which she approached it was very reassuring and settling. I found her the most useful. My breast surgeon was very good. He explained things in detail, and once again, easy to relate to, easy to communicate with. Probably the least helpful would have been my medical oncologist. He's very reserved, and I really had to drag information out of him. I think that, like I said, if I wasn't a health professional, I maybe wouldn't have got told a lot of things, informed a lot of things that I asked questions about. I don't know. I found that while the oncology nurses were great, they were just so busy that often I didn't have time to just stop and chat with you. Participant_013

Key points

- Returning to day-to-day functionality is a common treatment goal.
- Participants actively searched for information about interpreting test results and complementary therapies.

Anxiety associated with condition

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease⁸¹.

In this PEEK study, anxiety associated with breast cancer was measured by the fear of progression questionnaire⁸².

On average, participants had moderate levels of anxiety with relation to disease progression.

Quality of life

Symptoms from breast cancer and treatments, especially fatigue, nausea, cognitive problems, and physical limitations from loss of muscle strength and limitations on arm movement, impacted their day to day activities^{51,83,84}. In particular, it made household tasks, hobbies, work difficult, and had an impact on their ability to maintain their role in the family^{51,83,84}. On average, participants in this PEEK study rated their overall quality of life in the life is a little distressing range. Participants in this PEEK study commonly reported that breast cancer had an overall negative impact on their quality of life. This was because of the emotional strain on family, and symptoms and side effects. However, some reported a positive impact, and that was mostly due to changing perspectives on what is important in life.

Participants in this PEEK study commonly reported that breast cancer had an overall negative impact on their quality of life. This was because of the emotional strain on family, and symptoms and side effects. However, some reported a positive impact, and that was mostly due to changing perspectives on what is important in life. Another study that included six interviews with young African-American women with triple negative breast cancer that identified longer and more aggressive treatments with higher burden of care, and feeling out of place with peers had an impact on their quality of life¹.

Yes, yes. Yes. How much detail do you want to have? Because at the time it was there were all sorts of aspects for my children. There was the stress and the worry for my eldest child, who was sort of taking on more of the caring for my role. And then my younger daughter, she he even now she'll wake up and she'll have a nightmare about losing me. So, yeah, there was that sort of stress and anxiety on my children. There was the pressure on my husband to try and look after all the family and hold on to his job and keep up with that to do work after hours. And the worry, the stress for him about losing me and doing all the appointments, all these random appointments that you couldn't change. And he would just have to try and make it work fit into it. So, yes, at the time, the quality of life, it really affected it. And that's had the ongoing effect. It's just had all these knock on effects with our family life. Participant_001

Self-management and self-care can support patients with breast cancer to manage their own care and improve quality of life⁸⁵. Physical activity is considered as a universally accepted self-management technique and it has been demonstrated to have a positive effect on QoL⁸⁵. Physical activity has been observed to improve symptoms related to breast cancer such as fatigue^{86,87}, psychological problems and physical functioning^{87,88} and overall improvements on QOL.⁸⁵

Participants in this PEEK study reported ways they coped with the mental and emotional impact that breast cancer had. The most common ways to cope were remaining social, making lifestyle changes and hobbies, consulting a mental health professional, accepting condition and having a positive outlook, recognising the importance of family and friends, and physical exercise. Some of these coping mechanisms were used to maintain health, such as being physically active socialising with friends and/or family. In addition, health was maintained by diet, complying with treatment, and self care.

It definitely affects my mental and emotional health. The things that I do, I guess I have those self care strategies. So whether it's having a day in bed or a day of eating chocolate and takeaway food, whether it's booking in with a friend and going out to dinner and cocktails, or whether it's going for a massage or a run or a swim, whether it's just being out in the environment and absorbing some of the sun, whether it's going for a facial, I have access the counsellor who's a friend when need be, sometimes just, I guess, to check in and see how I'm going to talk about some things will come up with some strategies to implement, making sure that I sleep very well and that majority of time I am getting a balanced diet and exercise and looking after myself. I'm better at cancelling things. So whereas once upon a time I would be very much about what anyone in my life needed. Now I'm better about putting myself first and not seeing that is selfish, but just also looking after me. So I guess that's an important strategy, is thinking about what my body needs and giving it in that moment and not feeling guilty about that. Participant_010

Key points

- Physical activity was used to maintain both physical and mental health

Characterisation

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 from 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.

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