



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

personal experience, expectations & knowledge

DECISION-MAKER BRIEF

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triple negative breast cancer

Brief for decision-makers considering treatments and services for people diagnosed with triple negative breast cancer

Purpose: When making decisions about the type of treatment and services people diagnosed with triple negative breast cancer can access, decision-makers need to understand the context in which their decisions are being made, what characterises the patient population, and ensure assumptions are not being made on behalf of this patient population.

This brief provides this context and information about the experience and expectations of people diagnosed with triple negative breast cancer, based on their knowledges as experts with lived experience.

Key points

- This is a population that are often in paid employment and are carers to children
- Health related quality of life lower for most domains compared to Australian population
- Emotional support and information needs are not being met at the time of diagnosis
- Cost burden was noted by this patient population with about half experiencing a reduced household income
- Triple negative cancer is different to other types of breast cancer and there is a lack of tailored information and support for triple negative breast cancer patients
- Returning to day-to-day functionality is a common treatment goal for this patient population
- Decision-makers are asked to consider as a priority the impact that this condition has on quality of life

Introduction: Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). PEEK studies give us a clear picture of what it is like to be a patient at a given point in time. 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. The data presented from the PEEK study in triple negative breast cancer represents the most comprehensive study covering all aspects of disease experience and represents the largest cohort of structured interviews conducted with this patient population reported in a focused, single study. [Access at www.cc-dr.org]

Background: Triple negative breast cancers are defined by the lack of progesterone and oestrogen receptors, and HER2 proteins^{1,2}. 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^{3,4}. In 2019, there were 19,371 new cases of breast cancer reported in Australia⁵. Approximately 12 to 17% of all breast cancers are triple negative³, that is an estimated 3000 new cases of triple negative breast cancer in Australia 2019.

Health status: 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 function.

When compared with population norms, 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. 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.

Support at diagnosis: Participants in this PEEK study did not feel that they had enough support at the time of diagnosis. 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.

Biomarkers or genetic markers: 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.

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: 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

Affordability of healthcare: Most participants in this PEEK study were able to access currently available and subsidised treatments, and healthcare appointments. However, there was more difficulty paying for essentials such as housing, food and power.

Women with breast cancer have reported changing work tasks or changing jobs to manage in the workforce^{6,7}. In this PEEK study, approximately a third had either had to quit their job or reduce the number of hours worked, and in addition family members took leave from work to support them. Overall, about half had experienced a reduced household income due to their diagnosis. 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.

Goals of treatment: To help inform patient preferences in the triple negative breast cancer community, participants in this PEEK study 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. It is important to note that half of the participants in this PEEK study had children under their care.

Anxiety associated with condition: In this PEEK study, anxiety associated with breast cancer was measured by the fear of progression questionnaire⁸. On average, participants had moderate levels of anxiety with relation to their condition.

Quality of life: Participants in this PEEK study commonly reported that triple negative 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.

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

Decision-making: Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. This patient population urges decision-makers to consider as a priority quality of life for patients, and that all patients are able to access all available treatments and services.

References

1. Hammond ME, Hayes DF, Dowsett M, et al. American Society of Clinical Oncology/College Of American Pathologists guideline recommendations for immunohistochemical testing of estrogen and progesterone receptors in breast cancer. *J Clin Oncol* 2010; 28(16): 2784-95.
2. Wolff AC, Hammond MEH, Allison KH, et al. Human Epidermal Growth Factor Receptor 2 Testing in Breast Cancer: American Society of Clinical Oncology/College of American Pathologists Clinical Practice Guideline Focused Update. *J Clin Oncol* 2018; 36(20): 2105-22.
3. Foulkes WD, Smith IE, Reis-Filho JS. Triple-negative breast cancer. *N Engl J Med* 2010; 363(20): 1938-48.
4. Malorni L, Shetty PB, De Angelis C, et al. Clinical and biologic features of triple-negative breast cancers in a large cohort of patients with long-term follow-up. *Breast Cancer Res Treat* 2012; 136(3): 795-804.
5. Australian Institute of Health and Welfare 2019. Cancer in Australia 2019. Cancer series no.119. Cat. no. CAN 123. Canberra: AIHW.
6. Kalfa S, Koelmeyer L, Taksa L, et al. Work experiences of Australian cancer survivors with lymphoedema: A qualitative study. *Health Soc Care Community* 2019; 27(4): 848-55.
7. Jakobsen K, Magnus E, Lundgren S, Reidunsdatter RJ. Everyday life in breast cancer survivors experiencing challenges: A qualitative study. *Scand J Occup Ther* 2018; 25(4): 298-307.
8. Hinz A, Mehnert A, Ernst J, Herschbach P, Schulte T. Fear of progression in patients 6 months after cancer rehabilitation-a- validation study of the fear of progression questionnaire FoP-Q-12. *Support Care Cancer* 2015; 23(6): 1579-87.