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Report



CEP 2020 S1 – Project 19 – Organisation: So Brave

So Brave

Social Impact Study of Breast Cancer in Young Women

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Executive Summary

So Brave provides a voice for young women with breast cancer through its advocacy to the government and the wider community.

In support of So Brave's advocacy, this project provides an analysis of the social impacts of breast cancer in young women reported in the literature, with a focus on quantified impacts. A selection of six prominent social impacts were explored, namely quality of life and psychological impacts, body image, employment and career, fertility, sexuality and intimate relationships, and children and family. A statistically significant association has been found between aspects of each of these social impacts and breast cancer, often with far-reaching consequences for the wider community. Results of data studied also reveal that several of the social impacts studied are interrelated, suggesting that these should be addressed together.

The wide range of results studied shed light on the sheer scale of the social impacts of breast cancer. The key lesson to be learned from the literature is that these social impacts, though often not as tangible and measurable as the financial impacts of breast cancer, cannot be overlooked.

1. Introduction

Although young women account for 5% of all women diagnosed with breast cancer each year BreastScreen programs that operate across Australia only provide free breast screening to women from age 40.¹ Women who are diagnosed before they are 40 can face unique challenges, such as having young families and being financially insecure. For the purpose of this report, “young women” is predominately defined as women under the age of 40, unless stated otherwise. It should be noted that various academic articles have defined “young women” as women aged under 45 or under 50.

So Brave’s vision is to raise awareness that young women do get breast cancer, empower survivors through creative expression, and fund research to change future outcomes. This project provides So Brave with an overview of research into the social impacts of breast cancer among young women and forms a base for future research efforts. Clear quantifiable measures and data are provided to aid So Brave’s mission to be the voice and support of young women with breast cancer through advocacy of their unique needs to government and health agencies, the community, and health professionals.

Section 6 of the report provides a discussion of the project findings for each social impact explored. Discussion of each social impact first addresses the current quantitative and qualitative research, then provides an overview of the support available in Australia as well as recommendations for improvements. The conclusion of the report summarises the key findings and recommendations of each social impact explored.

¹ National Breast Cancer Foundation (2020). Viewed 1 May 2020. Available at: <https://nbcf.org.au/about-breast-cancer/further-information-on-breast-cancer/breast-cancer-in-young-women/>.

2. Purpose of Project

Breast cancer survivors represent the largest proportion of cancer survivors, and the rate of young breast cancer survivors who are diagnosed before the age of 40 is increasing². This project summarises useful research conducted on these often under-explored social impacts of breast cancer.

In Australia, younger women previously treated for cancer represent a growing population in Australia³. Around 23% of all new breast cancer diagnoses each year involve adults aged between 25 and 49 years⁴. Women in this age group comprise the highest proportion of cancer survivors, making the study of this group a priority⁵.

Women's development up to the age of 40 years represents a period of life in which women start to become independent, build their own networks of social support, set off down a career path, develop new friendships and romantic relationships, and make important decisions about their identities, and relationships⁶. Having breast cancer during such an important developmental period can impede a young woman's ability to adapt to critical life events⁷ and have significant implications for the rest of their life path⁸.

Young survivors have a poorer prognosis than do older survivors, including a higher risk for cancer recurrence and death⁹, greater reductions in cognitive functioning¹⁰, greater reproductive health and financial concerns¹¹, and greater disruption to their social relationships¹². Their return-to-work rate was higher than that of older women, which was reported as closer to 60%¹³, as the change from full-time worker to early retiree was not an option for the group¹⁴.

² Arneil, M. (2018). *Investigating physical activity and cognitive alterations in younger women after breast cancer treatment*. Queensland University of Technology.

³ Arneil, M. (2018).

⁴ Arneil, M. (2018).

⁵ Arneil, M. (2018).

⁶ Boyd, D. R., & Bee, H. L. (2008). *Lifespan development* (5th ed.): Boston: Allyn & Bacon/Pearson.

⁷ Shaha, M., & Bauer-Wu, S. (2009). Early adulthood uprooted: Transitoriness in young women with breast cancer. *Cancer Nursing*, 32(3), 246-255.

⁸ Boyd, D. R., & Bee, H. L. (2008).

⁹ Han, W., Kim, S. W., Park, I. A., Kang, D., Kim, S.-W., Youn, Y.-K., . . . Noh, D.-Y. (2004). Young age: an independent risk factor for disease-free survival in women with operable breast cancer. *BMC cancer*, 4(1), 82.

¹⁰ Arndt, V., Merx, H., Stürmer, T., Stegmaier, C., Ziegler, H., & Brenner, H. (2004). Age-specific detriments to quality of life among breast cancer patients one year after diagnosis. *European Journal of Cancer*, 40(5), 673-680.

¹¹ Avis, N. E., Crawford, S., & Manuel, J. (2004). Psychosocial problems among younger women with breast cancer. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 13(5), 295-308.

¹² Alex Matthews, B., Baker, F., Hann, D. M., Denniston, M., & Smith, T. G. (2002). Health status and life satisfaction among breast cancer survivor peer support volunteers. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 11(3), 199-211.

¹³ Fantoni, S. Q., Peugniez, C., Duhamel, A., Skrzypczak, J., Frimat, P., & Leroyer, A. (2010). Factors related to return to work by women with breast cancer in northern France. *Journal of occupational rehabilitation*, 20(1), 49-58.

¹⁴ Hassett, M. J., O'Malley, A. J., & Keating, N. L. (2009). Factors influencing changes in employment among women with newly diagnosed breast cancer. *Cancer*, 115(12), 2775-2782.

3. Scope of Project

In line with the purpose of the project outlined above, this project explored the social impacts women have to face from the time of diagnosis to recovery, in addition to the negative effects endured by other members of the community during these periods. Our findings can pave ways and build a foundation for more large-scale research in the future.

3.1 Original scope

The original scope consists of finding quantitative evidence on women with breast cancer in Australia with the following central impacts: quality of life and psychological impacts, body image, employment and career, fertility, sexuality and intimate relationships, and children and family. We have chosen these topics as they are prominent in numerous studies and we hypothesised that they are significantly connected to a certain degree. We set out to compile an in-depth report by the end of May 2020 and present our findings to So Brave and Stakeholders.

3.2 Process of refining the project scope

We encountered some research constraints in finding the information initially requested by So Brave, especially geographical differences and statistical studies on young Australian women. The project team weighed the risks and the time needed in searching for these topics and, in consulting with So Brave, decided to analyse both international and available Australian data.

First stage of refining (February - March 2020)

Objective: Send various potential Project Scopes to So Brave to start our research and do a background research on So Brave.

Deliverables: Project Scopes, an Outline for Related Social Impacts, and some quantitative/qualitative data.

Milestones: Final Project Scope was approved and we began researching breast cancer in Australia.

Limits and Exclusions: Conflicting ideas with the Financial Team (P18) and initial uncertainties as to the specifics of the data needed by So Brave.

Reviewed By: Project Advisor, Eloise Gilbert and So Brave Founder & Managing Director, Rachele Panitz.

Second stage of refining (March - April 2020)

Objective: Complete Task Brief Draft and reach out to professionals in the field.

Deliverables: Submission of Task Brief to Carlene.

Milestones: Attended team training workshops, Continued with weekly meetings, Reached out to professionals, and Submitted Task Brief.

Limits and Exclusions: Insufficient data on some of our social impacts, Many of the experts in the field who we contacted were unreachable or unavailable.

Reviewed By: Project Advisor, Eloise Gilbert and So Brave Founder & Managing Director, Rachele Panitz

Third stage of refining (April - May 2020)

Objective: Present our findings to So Brave and related Stakeholders and then submit our Final Report.

Deliverables: Final Presentation and Report.

Milestones: Presented our findings to So Brave and completed our Final Report.

Limits and Exclusions: Not all statistical data were available during the presentation, So Brave wanted more quantitative evidence on certain topics which have limited resources and provided recommendations as to what to add in the Final Report.

Reviewed By: Project Advisor, Eloise Gilbert, So Brave Founder & Managing Director, Rachele Panitz, So Brave Board Chair, Arthur Alexander, BELCEP Coordinator, Carlene Kirvan, and BELSET Employability Specialist, Ashil Ranpara.

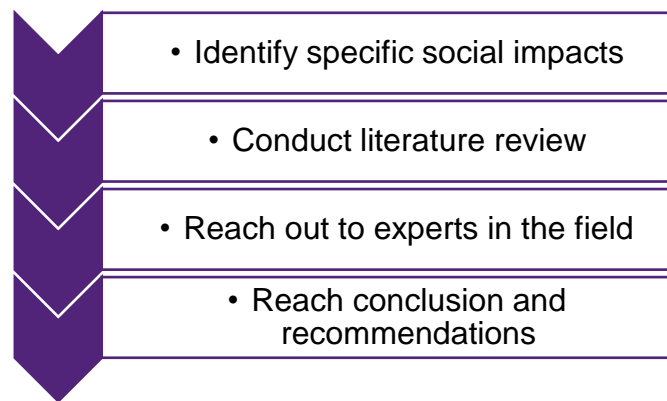
4. Objectives

Our objectives were:

1. Develop a project scope and conduct comprehensive research on women with breast cancer in Australia for future social impact studies.
2. Investigate current health policies, screening programs, and research in the potential social impacts that can negatively affect the wider community.
3. Investigate quantitative data and previous research into this area.
4. Identify quantifiable measurement indicators.
5. Investigate and analyse areas of social impact - fertility, psychological, health, relationships, career, family etc.
6. Engage with key stakeholders, the general public, and professionals from the field.
7. Find interviews and surveys conducted on young breast cancer survivor communities and the general public.
8. Report findings to the So Brave Board and key stakeholders.
9. Submit a final report on all our findings at the end of the project.

5. Methodology

Prominent social impacts that warranted further investigation were identified first. This was done by determining the most commonly reported social impacts in the academic literature and other sources of information such as surveys and blogs. We then conducted an in-depth literature review to unpack the latest research on selected social impacts, before reaching out to professionals in the field to acquire additional information or clarification on existing data. Where possible, we focused on the research carried out in Australia to draw conclusions and make recommendations.



6. Social Impacts of Breast Cancer

6.1 Quality of life

Quality of life evaluation has increasingly been an essential factor when considering the overall treatment of breast cancer patients. Provided with critical insights into quality of life through self-reported questionnaires, doctors will be better able to make decisions relating to therapy.¹⁵ This section will present some popular quality of life assessment tools and discuss five parts which are commonly concerned with qualifying life differences for breast cancer patients.¹⁶

6.1.1 Quality of life assessment

No single assessment is able to comprehensively and sensitively report a meaningful outcome due to the complexity of breast cancer and the diverse nature of its patient population. Nevertheless, quality of life assessments still provide clinical experts significant influences in advance treatment. A number of instruments commonly applied in clinical research on quality of life exist.¹⁷

Table 1. Assessments of Quality of Life (Self-made)

Quality of life (QoL) assessment	Summary
Quality of Life Instrument - Breast Cancer Patient Version (QOL-BC) ¹⁸	A 46-items questionnaire to measure the quality of life of breast cancer patients and it can be used for either clinical or research objectives.
Quality of Life Patient/Cancer Survivor Version (QOL-CSV) ¹⁹	An ordinal questionnaire to measure the quality of life in cancer patients over 42 items rated on 10 point Likert-type scale.
The Breast Cancer Chemotherapy Questionnaire (BCQ) ²⁰	A measurement based on the problems and experiences felt to women undergoing adjuvant chemotherapy.
Functional Assessment of Cancer Therapy – Breast Symptom Index (FACT-B – FBSI) ²¹	An assessment used to measure health-related quality of life in clinical research and practice.

¹⁵ Reed, E., Kössler, I., & Hawthorn, J. (2012). Quality of life assessments in advanced breast cancer: should there be more consistency?. *European journal of cancer care*, 21(5), 565-580.

¹⁶ Muldoon, M. F., Barger, S. D., Flory, J. D., & Manuck, S. B. (1998). What are quality of life measurements measuring?. *Bmj*, 316(7130), 542.

¹⁷ Perry, S., Kowalski, T. L., & Chang, C. H. (2007). Quality of life assessment in women with breast cancer: benefits, acceptability and utilization. *Health and Quality of life Outcomes*, 5(1), 24.

¹⁸ Tomich, P. L., & Helgeson, V. S. (2004). Is finding something good in the bad always good? Benefit finding among women with breast cancer. *Health Psychology*, 23(1), 16.

¹⁹ Ferrell, B. R., Dow, K. H., & Grant, M. (1995). Measurement of the quality of life in cancer survivors. *Quality of life Research*, 4(6), 523-531.

²⁰ Levine, M. N., Guyatt, G. H., Gent, M., De Pauw, S., Goodyear, M. D., Hryniuk, W. M., ... & Bramwell, V. H. (1988). Quality of life in stage II breast cancer: an instrument for clinical trials. *Journal of Clinical Oncology*, 6(12), 1798-1810.

²¹ Yost, K. J., Yount, S. E., Eton, D. T., Silberman, C., Broughton-Heyes, A., & Cella, D. (2005). Validation of the functional assessment of cancer therapy-breast symptom index (FBSI). *Breast cancer research and treatment*, 90(3), 295-298.

SF-36 Questionnaire ²²	A 36 questions assessment grouped into several domains within physical, social functioning, emotional, psychological aspect.
EuroQoL-5D (EQ-5D) ²³	An assessment which evaluates the health-related quality of life developed in Europe and widely used.
Quality of Life in Adult Cancer Survivors (QLA-CS) ²⁴	A health-related quality of life assessment specifically for use with persons who are 5 or more years past their cancer diagnosis.
Health-related quality of life (HRQoL)-WHO ²⁵²⁶	A multi-dimensional assessment that includes domains related to physical, mental, emotional, and social functioning.
Long-Term Quality of Life (LTQL) Instrument ²⁷	A 34-item assessment to measure quality of life in physical, psychological, social, and spiritual domains for women cancer survivors.

The common areas for assessing quality of life are: physical and social wellbeing, mental health, emotional reactions, and social functioning.²⁸ This result refers to the survey which be addressed in the Table1. In the following context, the research will look for how the assessments results of quality of life be conducted in different dimensions which include stage difference, chemotherapy, breast reconstruction surgery, rural and urban differences, and life-long survivor.

6.1.2 How do we look for quality of life

Stage differences

Breast cancer patients need to adapt to different stages which will cause a dramatic change in their quality of life. Breast cancer patients can be assigned to early-stage and severe stage groups.²⁹ Research shows perceiving benefits has some negative results for quality of life, but these adverse links were often confined to women with more severe stages.³⁰ Moreover, women in the more severe stage were most likely to ignore the benefits of life. Compared with those who are in the early stages of the cancer, women may acquire benefits from traumatic experiences as a way to cope with distress.³¹ The women in the severe stage are easier to deteriorate the quality of life. In mental and physical functioning studies identify that some patients' psychological state with greater physical pain cannot even complete the survey.³²

²² Brazier, J. E., Harper, R., Jones, N. M., O'cathain, A., Thomas, K. J., Usherwood, T., & Westlake, L. (1992). Validating the SF-36 health survey questionnaire: new outcome measure for primary care. *Bmj*, 305(6846), 160-164.

²³ Balestroni, G., & Bertolotti, G. (2012). EuroQoL-5D (EQ-5D): an instrument for measuring quality of life. *Monaldi Archives for Chest Disease*, 78(3).

²⁴ Stiggelbout, A. M., Jansen, S. J. T., Nooy, M. A., & Kievit, J. (1999). Response Shift in Quality of Life Assessment in Breast Cancer. *Quality of Life Research*, 627-627.

²⁵ Yin, S., Njai, R., Barker, L., Siegel, P. Z., & Liao, Y. (2016). Summarizing health-related quality of life (HRQOL): development and testing of a one-factor model. *Population health metrics*, 14(1), 22.

²⁶ World Health Organization. (1993). Rehabilitation after cardiovascular diseases, with special emphasis on developing countries: report of a WHO expert committee [meeting held in Geneva from 21 to 18 October 1991]. World Health Organization.

²⁷ Wyatt, G., Kurtz, M. E., Friedman, L. L., Given, B., & Given, C. W. (1996). Preliminary testing of the Long-Term Quality of Life (LTQL) instrument for female cancer survivors. *Journal of Nursing Measurement*, 4(2), 153-170.

²⁸ Shafaie, F. S., Mirghafourvand, M., & Amirzehni, J. (2019). Predictors of quality of life in patients with breast cancer. *Indian journal of palliative care*, 25(1), 73.

²⁹ Stiggelbout, A. M., Jansen, S. J. T., Nooy, M. A., & Kievit, J. (1999). Response Shift in Quality of Life Assessment in Breast Cancer. *Quality of Life Research*, 627-627.

³⁰ Craft, M. A., Davis, G. C., & Paulson, R. M. (2013). Expressive writing in early breast cancer survivors. *Journal of advanced nursing*, 69(2), 305-315.

³¹ Shafaie, F. S., Mirghafourvand, M., Harischi, S., Esfahani, A., & Amirzehni, J. (2018). Self-confidence and quality of life in women undergoing treatment for breast cancer. *Asian Pacific journal of cancer prevention: APJCP*, 19(3), 733.

³² Glanz, K., & Lerman, C. (1992). Psychosocial impact of breast cancer: A critical review. *Annals of behavioral medicine*, 14(3), 204-212.

Early-stage patients indicated that the expressive writing process about breast cancer trauma and facts related to breast cancer significantly improved the quality-of-life outcome and effectively coped with their depression.³³ For severe stage patients, intensive psychological intervention and mental support will be the first step to help them to cope with the fear of death.³⁴ Future research should consider the differential effects derived at different stages of the process.

Chemotherapy

Breast cancer chemotherapy options are influenced by personal preferences and other information about cancer. Fatigue has a significant level of differences between "improved" and "worsened" patients. Also, physical functioning will get worse for nausea and vomiting symptoms.³⁵ It is worse for the role and social functioning which will be discussed in other impacts. The outcome of chemotherapy effects is unpredictable since it is caused by individual body functioning reactions. However, some of the research showed that the tested group scored significantly higher on global quality of life and physical functioning after chemotherapy reacted to positive results.³⁶

The present outcomes must be tested in the context of the population of patients studied, most of whom had already received chemotherapy for breast cancer. The treatment may not be administered at an earlier stage of patients until each patient has a maximum response.³⁷ However, those who are concerned about the toxicity of chemotherapy will find reassurance that continuous treatment was perceived by the patients as providing a better quality of life during chemotherapy for breast cancer.³⁸

Breast reconstruction surgery

In previous means of cancer care has indicated underuse of breast reconstruction as well as racial and socioeconomic differences in its delivery.³⁹ These findings prompted breast reconstruction to broaden use at the turn of this century. Breast reconstructions are principally conducted to improve patients' quality of life. Breast represents a significant body image for women. The most typical reason for immediate reconstruction was the desire to avoid broken images and to improve well-being and quality of life for women undergoing breast cancer.⁴⁰

We examined the patients' quality of life differences after breast reconstruction which provides a perspective that has shown that women have both positive and negative body-related experiences with the

³³ Helgeson, V. S., Cohen, S., Schulz, R., & Yasko, J. (1999). Education and peer discussion group interventions and adjustment to breast cancer. *Archives of General Psychiatry*, 56(4), 340-347.

³⁴ Ververs, J. M. M. A., Roumen, R. M. H., Vingerhoets, A. J. J. M., Vreugdenhil, G., Coebergh, J. W. W., Crommelin, M. A., ... & Voogd, A. C. (2001). Risk, severity and predictors of physical and psychological morbidity after axillary lymph node dissection for breast cancer. *European journal of cancer*, 37(8), 991-999.

³⁵ Joensuu, H., Holli, K., Heikkinen, M., Suonio, E., Aro, A. R., Hietanen, P., & Huovinen, R. (1998). Combination chemotherapy versus single-agent therapy as first-and second-line treatment in metastatic breast cancer: a prospective randomized trial. *Journal of Clinical Oncology*, 16(12), 3720-3730.

³⁶ Nabholz, J. M., Senn, H. J., Bezwoda, W. R., Melnychuk, D., Deschenes, L., Douma, J., ... & Drbal, J. (1999). Prospective randomized trial of docetaxel versus mitomycin plus vinblastine in patients with metastatic breast cancer progressing despite previous anthracycline-containing chemotherapy. *Journal of Clinical Oncology*, 17(5), 1413-1413.

³⁷ Coates, A., Gebiski, V., Bishop, J. F., Jeal, P. N., Woods, R. L., Snyder, R., ... & Simpson, J. (1987). Improving the quality of life during chemotherapy for advanced breast cancer. *New England Journal of Medicine*, 317(24), 1490-1495.

³⁸ Svensson, H., Einbeigi, Z., Johansson, H., Hatschek, T., & Brandberg, Y. (2010). Quality of life in women with metastatic breast cancer during 9 months after randomization in the TEX trial (epirubicin and paclitaxel w/o capecitabine). *Breast cancer research and treatment*, 123(3), 785-793.

³⁹ Edsander-Nord, A., Brandberg, Y., & Wickman, M. (2001). Quality of life, patients' satisfaction, and aesthetic outcome after pedicled or free TRAM flap breast surgery. *Plastic and reconstructive surgery*, 107(5), 1142-53.

⁴⁰ Devulapalli, C., Bello, R. J., Moin, E., Alsobrooks, J., Fallas, P. B., Ohkuma, R., ... & Rosson, G. D. (2018). The effect of radiation on quality of life throughout the breast reconstruction process: a prospective, longitudinal pilot study of 200 patients with long-term follow-up. *Plastic and reconstructive surgery*, 141(3), 579-589.

treatment.⁴¹ Compared with the population, some breast-reconstructed patients felt more tired, stressful, unhappy, and restless. However, other groups scored all domains in the reference that they were satisfied with breast reconstruction. The major determinant of body aesthetic satisfaction was the completion of the procedure which will discuss in body image impacts.⁴²

The use of breast reconstruction surgery was statistically increased from 13% to 26% from 1998 to 2007.⁴³ There are many factors associated with breast reconstruction including younger ages, higher incomes, private or managed care insurance, and treatment in an academic hospital setting.

Rural and urban differences

Dr Tracey from the University of Queensland conducted research indicating that for the quality of life of breast cancer survivors living in rural and urban areas was similar.⁴⁴ However, the cancer-related concerns being more dominant in women from rural locations since the treatment delivery gaps within the urban and non-urban community. Therefore, additional support and cancer care enhancements in rural areas are essential. Also, the patient could benefit from regular interventions.⁴⁵

The reasons for non-urban survivors remain a far worse quality of life caused by the differences of the patients who experienced complications following surgery, reported body problems, has higher perceived stress levels and/or poor perception of handling stress. The most important detriment to the quality of life was among non-urban breast cancer survivors who reported statistically and clinically poorer following cancer care or support in the process. It is believable that non-urban survivors suffer in terms of their breast cancer-specific quality of life, more so than urban survivors, as a result of inequalities in accessing specialised services.⁴⁶

The results suggested that the organisation or government should be used to identify rural area women at risk of the low quality of life and to notify components of tailored recovery interventions to optimize the quality of life for these women following cancer treatments.⁴⁷

Long-term survivor

It can be concluded that long-term survivors with a high quality of life by steadily fixing physical functions.⁴⁸ They are probably those who did not need more chemotherapy; who received sufficient emotional support from family and friends; and who had employment or no children under 18 living at home. The better treatment outcomes lead them to enjoy a feeling of good health; experiences little life stress; believes that life is controllable; seeks the purpose for the rest of life.⁴⁹

⁴¹ Sisco, M., Du, H., Warner, J. P., Howard, M. A., Winchester, D. P., & Yao, K. (2012). Have we expanded the equitable delivery of postmastectomy breast reconstruction in the new millennium? Evidence from the national cancer data base. *Journal of the American College of Surgeons*, 215(5), 658-666

⁴² Devulapalli, C., Bello, R. J., Moin, E., Alsobrooks, J., Fallas, P. B., Ohkuma, R., ... & Rosson, G. D. (2018). The effect of radiation on quality of life throughout the breast reconstruction process: a prospective, longitudinal pilot study of 200 patients with long-term follow-up. *Plastic and reconstructive surgery*, 141(3), 579-589.

⁴³ Brunet, J., Sabiston, C. M., & Burke, S. (2013). Surviving breast cancer: women's experiences with their changed bodies. *Body image*, 10(3), 344-351.

⁴⁴ DiSipio, T., Hayes, S. C., Newman, B., Aitken, J., & Janda, M. (2010). Does quality of life among breast cancer survivors one year after diagnosis differ depending on urban and non-urban residence? A comparative study. *Health and quality of life outcomes*, 8(1), 3.

⁴⁵ Rural, M. (2006). Regional Oncology Services in Australia. *Clinical Oncological Society of Australia*.

⁴⁶ Hegney, D., Pearce, S., ROGERS-CLARK, C., MARTIN-MCDONALD, K., & Buikstra, E. (2005). Close, but still too far. The experience of Australian people with cancer commuting from a regional to a capital city for radiotherapy treatment. *European Journal of Cancer Care*, 14(1), 75-82.

⁴⁷ Lyons, P., & Shelton, M. M. (2012). Psychosocial impact of cancer in low-income rural/urban women: Phase II. *Online Journal of Rural Nursing and Health Care*, 4(2), 6-24.

⁴⁸ Ganz, P. A., Coscarelli, A., Fred, C., Kahn, B., Polinsky, M. L., & Petersen, L. (1996). Breast cancer survivors: psychosocial concerns and quality of life. *Breast cancer research and treatment*, 38(2), 183-199.

⁴⁹ Dow, K. H., Ferrell, B. R., Leigh, S., Ly, J., & Gulasekaram, P. (1996). An evaluation of the quality of life among long-term survivors of breast cancer. *Breast cancer research and treatment*, 39(3), 261-273.

Even though the quality of life for long-term survivors is mostly positive, there is no doubt that many survivors still suffer substantial complaints as a result of cancer or its treatment. Most commonly noticed are sexual functioning problems and a painful or swollen arm.⁵⁰ These complaints can be caused by many factors, some of which are known, others are not yet uncovered or are based on weak evidence. Those research outlined in this review were partially uncertain, even though most of the studies concluded in a higher quality of life.

The study also combined the spiritual domain of the quality of life and to existential interests of surviving a life-threatening sickness. The current clinical treatments conducted to the particular medical and psychosocial needs of survivors are needed to be able to create additional intervention studies.⁵¹ By the implementation of further qualitative studies, more clarity concerning the quality of life of long-term breast cancer survivors could be achieved.

⁵⁰ Mols, F., Vingerhoets, A. J., Coebergh, J. W., & van de Poll-Franse, L. V. (2005). Quality of life among long-term breast cancer survivors: a systematic review. *European journal of cancer*, 41(17), 2613-2619.

⁵¹ Holzner, B., Kemmler, G., Kopp, M., Moschen, R., Schweigkofler, H. R., Du Nser, M., ... & Sperner-Unterweger, B. (2001). Quality of life in breast cancer patients—not enough attention for long-term survivors?. *Psychosomatics*, 42(2), 117-123.

6.2 Psychological impacts

Psychological impacts are the significantly essential domain of breast cancer health care. The fact is the depression is highly possible caused by the process so the mental health problems of cancer patients need to be addressed not only during ongoing treatment but also throughout the continuum of survivorship care, especially the women who have been diagnosed in the younger ages in the early stage⁵² Additionally, conditions such as cardiotoxicity and accompanying illness might happen after treatment, showing the need for long-term monitoring of and specialized care for cancer survivors.⁵³

Psychosocial oncology is a multidisciplinary field that specializes in the psychological, social, and behavioural dimensions of cancer. The research indicated that it can be well applied in breast cancer treatment.⁵⁴ It has identified the specific importance for mental issues among cancer patients from diagnosis in early-stage through survivorship care, and it is able to exceedingly assist in improving the general health status of survivors.⁵⁵

The studies reported that numbers of breast cancer patients were usually diagnosed with light to severe mental distress. The overall frequency of mental disorders peaked within one month after the cancer diagnosis. Further, depression was relatively high in the young age group (38.6%), and anxiety was high in the elderly group (32.5%).⁵⁶ The result showed different patterns of predominance according to time, and age. In current clinical practice, early intervention with validated psychological screening tools for relative mental health problems and referral systems are essential for managing mental distress.⁵⁷ In general, the screening tools are recommended across the continuum of cancer care. The common screening assessments include the 9-item Personal Health Questionnaire, the Hospital Anxiety and Depression Scale, the Geriatric Depression Scale, the Beck Depression Inventory, the Center for Epidemiological Studies–Depression Scale, the Spielberger State-Trait Anxiety Inventory, and the Beck Anxiety Inventory.⁵⁸

6.2.1 Impacts on patients

The research indicated that early intervention could be effective in controlling symptoms of mental illness and could greatly improve the depression symptoms throughout different stages of breast cancer.⁵⁹ Stage differences lead to distinctive psychological impacts and cause extra factors to influence patients themselves. For example, newly diagnosed groups experience fewer role limitations in the mental screening survey.⁶⁰ Also, emotional control is more obvious among women with deteriorated condition than in women

⁵² Fernandes-Taylor, S., Adesoye, T., & Bloom, J. R. (2015). Managing psychosocial issues faced by young women with breast cancer at the time of diagnosis and during active treatment. *Current opinion in supportive and palliative care*, 9(3), 279.

⁵³ Andersen, B. L., DeRubeis, R. J., Berman, B. S., Gruman, J., Champion, V. L., Massie, M. J., ... & Rowland, J. H. (2014). Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. *Journal of Clinical Oncology*, 32(15), 1605.

⁵⁴ Watson, M., Dunn, J., & Holland, J. C. (2014). Review of the history and development in the field of psychosocial oncology. *International review of psychiatry*, 26(1), 128-135.

⁵⁵ Hanson Frost, M., Suman, V. J., Rummans, T. A., Dose, A. M., Taylor, M., Novotny, P., ... & Evans, R. E. (2000). Physical, psychological and social well-being of women with breast cancer: the influence of disease phase. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 9(3), 221-231.

⁵⁶ Heo, J., Chun, M., Oh, Y. T., Noh, O. K., & Kim, L. (2017). Psychiatric comorbidities among breast cancer survivors in South Korea: a nationwide population-based study. *Breast cancer research and treatment*, 162(1), 151-158.

⁵⁷ Pirl, W. F., Fann, J. R., Greer, J. A., Braun, I., Deshields, T., Fulcher, C., ... & Wagner, L. (2014). Recommendations for the implementation of distress screening programs in cancer centers: report from the American Psychosocial Oncology Society (APOS), Association of Oncology Social Work (AOSW), and Oncology Nursing Society (ONS) joint task force. *Cancer*, 120(19), 2946-2954.

⁵⁸ Naughton, M. J., & Weaver, K. E. (2014). Physical and mental health among cancer survivors considerations for long-term care and quality of life. *North Carolina medical journal*, 75(4), 283-286.

⁵⁹ Glanz, K., & Lerman, C. (1992). Psychosocial impact of breast cancer: A critical review. *Annals of behavioral medicine*, 14(3), 204-212.

⁶⁰ Watson, M., Greer, S., Rowden, L., Gorman, C., Robertson, B., Bliss, J. M., & Tunmore, R. (1991). Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. *Psychological medicine*, 21(1), 51-57.

with a benign tumour, that a helpless attitude towards the disease is related to a poor prognosis.⁶¹ Fatalism, helplessness, and psychological morbidity are followed by the conditions in different levels of breast cancer stage.⁶² The outcomes indicated a highly significant association between the tendency to control mental distress and a fatalistic attitude toward breast cancer.⁶³

Psychosocial interventions indicated positive effects of social support, cognitive therapy, and supportive information.⁶⁴ The experts recommend a combination of group therapy and individual therapy for breast cancer patients. The intervention allows women to share social support, further, improve their physical and psychological well being. Also, it helps women gain problem-solving skills and alter patterns of negative thinking.⁶⁵ The studies supported that effective communication and patient involvement in care may be most beneficial for their mental health.⁶⁶ Therapists can cope with different degrees of mental disorder with appropriate intervention therapy. Patients who were treated by optimize mental health services have shown a positive condition on their psychosocial as well as physical outcomes.⁶⁷

These findings also recorded plenty of hypotheses that could be examined in clinical trials research. Problem-solving therapy programme help cancer patients to transform impertinent thoughts that improve patients' use of problem-focused engagement coping (cognitive restructuring and planned problem-solving), and that decrease patients' reliance on emotion-focused disengagement coping (self-criticism and social withdrawal) and problem-focused disengagement coping (avoidance and wishful thinking) could be evaluated for their impact on emotional distress.^{68,69} These data further recommend that it may be necessary to complete the interventions early as the effects of proximal responses on emotional distress are obvious at this early point in the process.⁷⁰ The early interventions might promote a rapid recovery to psychological health and, consequently, lessen the emotional burden of breast cancer.⁷¹

6.2.2 Impacts on patients' families

Open communication is particularly critical for the family setting since the family is usually the primary source of support. Many studies determined the association between open family communication about cancer and breast cancer patients' mental health.⁷² It has shown a negative consequence for both patients and their family if they do not have enough mental support from external resources during the process.⁷³ Moreover, increased emotional support and more open communication have a significant association with better

⁶¹ Burgess, C., Cornelius, V., Love, S., Graham, J., Richards, M., & Ramirez, A. (2005). Depression and anxiety in women with early breast cancer: five year observational cohort study. *Bmj*, 330(7493), 702.

⁶² Jacobs, J. R., & Bovasso, G. B. (2000). Early and chronic stress and their relation to breast cancer. *Psychological medicine*, 30(3), 669-678.

⁶³ Mystakidou, K., Tsilika, E., Parpa, E., Kyriakopoulos, D., Malamos, N., & Damigos, D. (2008). Personal growth and psychological distress in advanced breast cancer. *The Breast*, 17(4), 382-386.

⁶⁴ Andersen, B. L., Farrar, W. B., Golden-Kreutz, D., Emery, C. F., Glaser, R., Crespin, T., & Carson III, W. E. (2007). Distress reduction from a psychological intervention contributes to improved health for cancer patients. *Brain, behavior, and immunity*, 21(7), 953-961.

⁶⁵ Maeda, T., Kurihara, H., Morishima, I., & Munakata, T. (2008). The effect of psychological intervention on personality change, coping, and psychological distress of Japanese primary breast cancer patients. *Cancer Nursing*, 31(4), E27-E35.

⁶⁶ Jassim, G. A., Whitford, D. L., Hickey, A., & Carter, B. (2015). Psychological interventions for women with non-metastatic breast cancer. *Cochrane Database of Systematic Reviews*, (5).

⁶⁷ Helgeson, V. S., Cohen, S., Schulz, R., & Yasko, J. (2000). Group support interventions for women with breast cancer: who benefits from what?. *Health psychology*, 19(2), 107.

⁶⁸ Epping-Jordan, J. E., Compas, B. E., Osowiecki, D. M., Oppedisano, G., Gerhardt, C., Primo, K., & Krag, D. N. (1999). Psychological adjustment in breast cancer: processes of emotional distress. *Health Psychology*, 18(4), 315.

⁶⁹ Hirai, K., Motooka, H., Ito, N., Wada, N., Yoshizaki, A., Shiozaki, M., ... & Akechi, T. (2012). Problem-solving therapy for psychological distress in Japanese early-stage breast cancer patients. *Japanese journal of clinical oncology*, 42(12), 1168-1174.

⁷⁰ Mynors-Wallis, L. (2005). Problem-solving treatment for anxiety and depression: A practical guide. OUP Oxford.

⁷¹ Casellas-Grau, A., Font, A., & Vives, J. (2014). Positive psychology interventions in breast cancer. A systematic review. *Psycho-Oncology*, 23(1), 9-19.

⁷² Mallinger, J. B., Griggs, J. J., & Shields, C. G. (2006). Family communication and mental health after breast cancer. *European Journal of Cancer Care*, 15(4), 355-361.

⁷³ Naaman, S., Radwan, K., & Johnson, S. (2009). Coping with early breast cancer: Couple adjustment processes and couple-based intervention. *Psychiatry: Interpersonal and Biological Processes*, 72(4), 321-345.

psychological results. It is possible to experience mental health disturbance if the patients perceive greater family avoidance.

In the findings, we realised the efficacy and the utility of psychological interventions for patients' family coping with breast cancer. Although, it still needs to identify and to understand the differential responses to treatment and the change process involved in the interventions.⁷⁴ The assessment of patients' family well-being should be more routine and general. Family members should be incorporated into psycho-social care in order to recognise their needs, preserve their well-being, and to facilitate their essential roles as providers of support for breast cancer patients.⁷⁵ It is possible to relieve family members' stress if the psycho-education, treatment information, and psycho-social impacts can be included in survivorship care.⁷⁶ The overall systematic reviews contribute to raising awareness of the value of including family members with breast cancer in psychological interventions.

6.2.3 Support in Australia

People often feel overwhelmed, scared, anxious and upset after a diagnosis of cancer. Therefore, having practical and emotional support during and after breast cancer diagnosis and treatment is very crucial. Healthcare experts must realize that they serve as essential gatekeepers to assist patients and their friends and families. It is useful to refer to families who are having difficulties with a specialist who is more experienced in family's therapy techniques. Healthcare providers may be able to counter these concerns through multiple family counselling and support.⁷⁷

The support is available from the Australian government on- or off-line breast cancer support service.⁷⁸ Not only Australian authorities sector but numerous private organisations deliver a comprehensive range of support services for breast cancer patients across every state and territory.⁷⁹ More information about group supports or physical supports can be found in the dedicated website online with cancer section. Most of the organisations around Australia provide information deals with some of the challenges experienced by people affected by cancer. It includes information about managing some of the long term side effects of treatment, how people close to you might feel after a diagnosis of cancer, and where to find practical and emotional support.

⁷⁴ Baucom, D. H., Porter, L. S., Kirby, J. S., Gremore, T. M., Wiesenthal, N., Aldridge, W., ... & Keefe, F. J. (2009). A couple-based intervention for female breast cancer. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 18(3), 276-283.

⁷⁵ LeRoy, A. S., Shields, A., Chen, M. A., Brown, R. L., & Fagundes, C. P. (2018). Improving Breast Cancer Survivors' Psychological Outcomes and Quality of Life: Alternatives to Traditional Psychotherapy. *Current Breast Cancer Reports*, 10(1), 28-34.

⁷⁶ Brandão, T., Schulz, M. S., & Matos, P. M. (2014). Psychological intervention with couples coping with breast cancer: a systematic review. *Psychology & health*, 29(5), 491-516.

⁷⁷ Cancer Australia - <https://www.australiancancertrials.gov.au/>

⁷⁸ Cancer Council Australia - <https://www.cancer.org.au/about-cancer/patient-support/>

⁷⁹ Breast Cancer Network Australia - <https://www.bcna.org.au/>

6.3 Body image

6.3.1 Body image change

As body image incorporates an individual's cognitions, feelings, behaviours and evaluations toward one's own body, the negative body image change such as hair loss, breast loss, skin discoloration, and weight fluctuations could bring severe impacts on breast cancer survivors' overall psychological well-being after cancer treatment.⁸⁰ About one in three women with breast cancer suffer from body image-related distress and over 50% of breast cancer survivors experience concerns regarding their body appearance and function.⁸¹ Research also shows that younger women who aged especially value body image as key concerns and the number of women expressing body image disturbance is likely to increase over time.⁸² This is concerning given the average age of breast cancer patients has been declining, with women being diagnosed at an earlier age.⁸³ In several studies, body image disturbance or dissatisfaction is significantly linked to women's psychological distress and identity recognition difficulties, emphasising the importance of body image to breast cancer survivors' overall psychological well-being.^{84,85,86,87}

6.3.2 Body image and psychological distress

Anxiety, stress, and depression are indicated to be the most common aspects of psychological distress resulting from body image disturbance. Other feelings such as social pressure and self-avoidance are demonstrated as negative outcomes of changes in body image as well. A report shows that breast cancer survivors who develop lymphedema and have a high level of appearance investment, typically experience greater distress than those who do not.⁸⁸ Moreover, in Sherman et al.'s study, about 25% of women develop long-lasting anxiety and depression.⁸⁹ In Przedziecki et al.'s research, 279 women patients were asked to do an online survey in the aspect of body image scale, self-compassion scale, depression, anxiety and stress scale and items measuring perceived normative pressure and comfort with one's weight.⁹⁰ The results showed that body image disturbance was associated with increased psychological distress among these breast cancer survivors. Similarly, 105 female breast cancer survivors completed an initial background questionnaire and a writing activity regarding depression, anxiety and stress Scale, body image scale, body appreciation scale and self-compassion scale in Przedziecki, & Sherman's study.⁹¹ The outcomes indicated that negative effects

⁸⁰ Przedziecki, A., Sherman, K. A., Baillie, A., Taylor, A., Foley, E., & Stalgis-Bilinski, K. (2013). My changed body: breast cancer, body image, distress and self-compassion. *Psycho-oncology*, 22(8), 1872-1879.

⁸¹ Sherman, K. A., Przedziecki, A., Alcorso, J., Kilby, C. J., Elder, E., Boyages, J., ... & Mackie, H. (2018). Reducing body image-related distress in women with breast cancer using a structured online writing exercise: Results from the my changed body randomized controlled trial. *Journal of Clinical Oncology*, 36(19), 1930-1940.

⁸² Przedziecki, A., & Sherman, K. A. (2016). Modifying affective and cognitive responses regarding body image difficulties in breast cancer survivors using a self-compassion-based writing intervention. *Mindfulness*, 7(5), 1142-1155.

⁸³ National Breast and Ovarian Cancer Centre. Addressing the needs of younger women with breast cancer: Evidence from the literature and recommended steps, 2007. National Breast and Ovarian Cancer Centre, Surry Hills, NSW.

⁸⁴ King, M. T., Kenny, P., Shiell, A., Hall, J., & Boyages, J. (2000). Quality of life three months and one year after first treatment for early stage breast cancer: influence of treatment and patient characteristics. *Quality of Life Research*, 9(7), 789-800.

⁸⁵ Przedziecki, A., Sherman, K. A., Baillie, A., Taylor, A., Foley, E., & Stalgis-Bilinski, K. (2013). My changed body: breast cancer, body image, distress and self-compassion. *Psycho-oncology*, 22(8), 1872-1879.

⁸⁶ Sherman, K. A., Woon, S., French, J., & Elder, E. (2017). Body image and psychological distress in nipple-sparing mastectomy: the roles of self-compassion and appearance investment. *Psycho-oncology*, 26(3), 337-345.

⁸⁷ Todorov, N., Sherman, K. A., Kilby, C. J., & Breast Cancer Network Australia. (2019). Self-compassion and hope in the context of body image disturbance and distress in breast cancer survivors. *Psycho-Oncology*, 28(10), 2025-2032.

⁸⁸ Sherman et al., 2018

⁸⁹ Sherman et al., 2018

⁹⁰ Przedziecki et al., 2013

⁹¹ Przedziecki & Sherman, 2016

were positively correlated with psychological distress and body image disturbance. In another similar research conducted by Sherman et al, 81 women from Australia were asked to answer several cancer-specific body image questions associated with the impact of surgery on their body image.⁹²For example, one of the question is like “Have you felt less physically attractive as a result of your disease or treatment?”. They rated each answer from 0 to 3, depending on their perceptions (0=Not at all, 3=Very much). Results from these studies were same as the outcomes in previous two studies, indicating that there was a significant effect of depression and stress on body image.

The results of the three quantitative studies mentioned above all found that negative feelings such as anxiety, stress and depression are significantly correlated with body image disturbance, which means that the more women suffer from negative body image, the more they experience these psychological feelings. A summary of the statistics that comprise these results is provided in Table 1.

Table 1. Summary of statistics regarding the relationship between psychological feelings and body image disturbance

Independent Variable	Anxiety	Stress	Depression
Correlation Coefficient	0.26**	0.30**	0.39**
	0.281**	0.349**	0.385**
	0.08	0.23**	0.34**
Dependent Variable	Body image disturbance		

** Correlation significant at the 0.01 level (two-tailed)

Source: *Przedziecki et. al., 2013; Przedziecki, & Sherman, 2016; Sherman et al., 2017*

6.3.3 Impacts on identity recognition difficulties

In the aspect of identity recognition, many women demonstrate a loss of self-identity, femininity, sexuality, attractiveness and self-acceptance while facing changes to their body, particularly the removal of the breast.^{93,94} In some cases, women see their breasts as a key feature of femininity - what it means to be a whole or complete woman - such that losing the breast is not merely the removal of the diseased part but also part of their identity.⁹⁵ In particular, younger women who have had a mastectomy are reported to have higher identity recognition problems compared with older women who have had a mastectomy.⁹⁶ The body image change in women with breast cancer can also be explained in the aspect of sociocultural context when it influences the core aspects of women’s identity, femininity and sexuality.⁹⁷ Especially the feminist theory argues that a woman’s breast typically represents a woman’s core identity in the society. It leads to the outcome that women doubt whether their body image after the surgery match the society standards with their sense of self-worth or not, and is also a response to pathological societal pressures.

⁹² Sherman et al., 2017

⁹³ Lalithambigai Rajagopal, P. P., & McBride, K. A. (2019). The lived experience of Australian women living with breast cancer: A meta-synthesis. *Asian Pacific journal of cancer prevention: APJCP*, 20(11), 3233.

⁹⁴ Beatty, L., & Kissane, D. (2017, March). Anxiety and depression in women with breast cancer. In *Cancer Forum* (Vol. 41, No. 1, p. 55). The Cancer Council Australia.

⁹⁵ Sun, L., Ang, E., Ang, W. H. D., & Lopez, V. (2018). Losing the breast: A meta-synthesis of the impact in women breast cancer survivors. *Psycho-oncology*, 27(2), 376-385.

⁹⁶ King et al., 2000

⁹⁷ Sun et al., 2018

6.3.4. Support in Australia

The support services such as consultations provided from not-for-profit organizations for young women with breast cancer are provided in Australia, however, there are not many methods addressed especially in the aspect of body image change. The following studies are conducted to identify the influences of several factors on body image change in order to reduce the impacts from the body image disturbance. The studies are not all Australian based, instead some of the interventions used are from overseas, representing insufficient approaches and more research need to be conducted in Australia in future studies.

Self-compassion and Hope

Research indicates that breast cancer survivors who have poor body image may be more likely to be depressed, anxious or stressed because of their lower levels of self-compassion and hope.^{98, 99} Self-compassion is a cognitive construct that addresses present emotions and thoughts, whereas hope is one regarding how the future is perceived. Przewdziecki's research demonstrated that the expressive writing activity which focuses on self-compassion could be a useful way to manage the body image disturbance caused by breast treatment. It proved to help decrease negative experiences including body image difficulties. Similarly, an intervention called My Change Body (MyCB) was also implemented to investigate whether it could still reduce the body image disturbance and improve body appreciation through a self-compassion-focused online writing activity, compared with the expressive writing. The study results showed that there was statistically significantly lower body image disturbance and greater body appreciation and self-compassion in participants who received MyCB than those who received expressive writing. MyCB also assists in overcoming current clinician-patient barriers, allowing patients to access the intervention in a more private way.

In the aspect of hope, Todorov argued that patients who have a higher level of hope see physical changes to their body in a more positive light than those who have a lower level of hope.

Breast reconstruction/prostheses

Several studies show that prostheses and breast reconstruction provide better body images which make women feel more attractive and experience less stress and anxiety. Breast reconstruction and prostheses are also presented as options that can empower women, promoting freedom, a sense of femininity, and boosting self-esteem in patients.^{100,101,102,103,104,105}

⁹⁸ Todorov et al., 2019

⁹⁹ Przewdziecki et al., 2013

¹⁰⁰ Jabłoński, M. J., Streb, J., Mirucka, B., Słowik, A. J., & Jach, R. (2018). The relationship between surgical treatment (mastectomy vs. breast conserving treatment) and body acceptance, manifesting femininity and experiencing an intimate relation with a partner in breast cancer patients. *Psychiatr. Pol.*, 52(5), 859-872.

¹⁰¹ Archer, S., Holland, F., & Montague, J. (2014). 'Do you mean I'm not whole?': An interpretative phenomenological analysis of younger women's experiences of electing to not undergo breast reconstruction after mastectomy following breast cancer. *Psycho-oncology*, 23.

¹⁰² Crabb, S., & LeCouteur, A. (2006). 'Fiona Farewells Her Breasts': A popular magazine account of breast cancer prevention. *Critical public health*, 16(1), 5-18.

¹⁰³ Crompvoets, S. (2012). Prosthetic fantasies: Loss, recovery, and the marketing of wholeness after breast cancer. *Social Semiotics*, 22(1), 107-120.

¹⁰⁴ McGannon, K. R., Berry, T. R., Rodgers, W. M., & Spence, J. C. (2016). Breast cancer representations in Canadian news media: A critical discourse analysis of meanings and the implications for identity. *Qualitative Research in Psychology*, 13(2), 188-207.

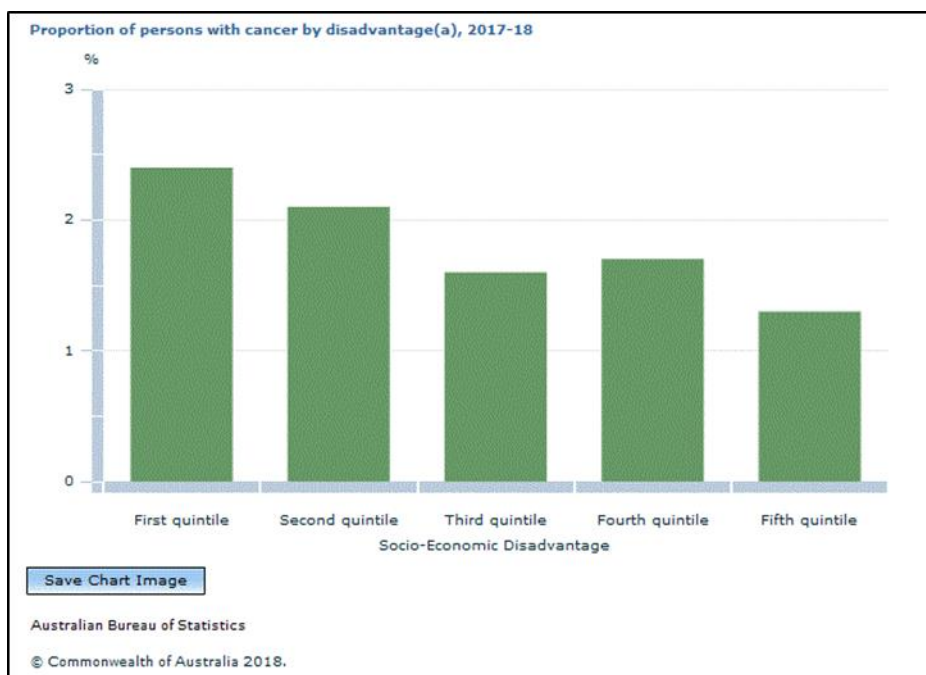
¹⁰⁵ Fanakidou, I., Zyga, S., Alikari, V., Tsironi, M., Stathoulis, J., & Theofilou, P. (2018). Mental health, loneliness, and illness perception outcomes in quality of life among young breast cancer patients after mastectomy: the role of breast reconstruction. *Quality of Life Research*, 27(2), 539-543.

6.4 Fertility

In 2016-2017, more than 1.8 million women aged 50-74 participated in BreastScreen Australia¹⁰⁶, representing an age standardised participation rate of 55%, with Northern Queensland having the highest participation rate of 61%¹⁰⁷. Breast cancer is the most common cancer in Queensland women; it accounts for 30% of all cancers in women and the free mammograms under BreastScreen Queensland only target the age group 50-74¹⁰⁸. Awareness around breast cancer in younger women is close to non-existent, unless it is either too late or someone, they know suffered from breast cancer. The effects of breast cancer on younger women differ to those of older women; younger women may have difficulty coming to terms with loss of fertility, sexuality, and the probability of experiencing body image disfigurement. Younger women may face these struggles as a result of the treatment and surgery they have received to contain breast cancer and attempt to improve their chances of survival. It has been noted that there can be a delay in diagnosis in younger women, and this is attributed to a misconception that they are too young to be diagnosed with breast cancer.

While the risk of developing breast cancer is statistically low, with 1% occurring before 30, it is estimated at least 70% aged between 20-29 and 80% aged 30-39 will live five years after their diagnosis¹⁰⁹. All things considered (see Figure 1), the rate of cancer was higher for people living in the most disadvantaged areas (first quintile) across Australia compared with those living in the least disadvantaged areas (fifth quintile) (2.4% and 1.3% respectively).

Figure 1. Proportion of persons with cancer disadvantage, 2017-2018



Source: ABS National Health Survey: First Results, 2017-18

¹⁰⁶ The national breast cancer screening program, BreastScreen Australia began in 1991. It aims to reduce illness and death from breast cancer using screening mammography for early detection of unsuspected breast cancer in women. Women aged 40 and over are eligible for free mammograms every 2 years, and women aged 50–74 are actively targeted to participate in the program.

¹⁰⁷ Australian Institute of Health and Welfare. (2019). *National cancer screening programs participation*. Retrieved from <https://www.aihw.gov.au/reports/cancer-screening/national-cancer-screening-programs-participation/contents/breastscreen-australia>

¹⁰⁸ Queensland Government. (2020). *Why can't I get a free mammogram if I'm under 40?* Retrieved From: <https://www.health.qld.gov.au/news-events/news/mammogram-breast-aware-women-under-forty>

¹⁰⁹ Australian Institute of Health and Welfare. (2005). *Breast health: evidence based information for women and their families*. Retrieved from <https://www.aihw.gov.au/reports/men-women/female-health/contents/how-healthy/burden-of-disease>

That being said, breast cancer is the most common complication in childbearing women. In the last few decades, considerable improvement in breast cancer-related issues have been achieved with various kinds of therapies (chemotherapy, radiotherapy, hormone therapy, and targeted therapies); however, some treatments may induce premature menopause and lead to infertility¹¹⁰. This can impact on a woman's opportunity to bear children in the future. Yet, despite the abundance of research and literature regarding the impact of breast cancer and loss on women, fewer studies have been carried particularly on women younger than 50 focusing on recovery and surgery¹¹¹.

6.4.1 Geological Differences and disadvantages for breast cancer treatments

Table 1. Breast Cancer Report on Women in Queensland 2012-2016

	Incidence			Excess deaths			Mortality		
	Count	Rate	SIR [95% CI]	5-year (%)	EHR [95% CI]		Count	Rate	SMR [95% CI]
Total Queensland	3,327	127.9		9.6			557	20.5	
By remoteness	Overall significance ¹ , p<0.001			Overall significance ¹ , p =0.340			Overall significance ¹ , p =0.541		
Major city	2,090	130.8	1	8.8	1		320	19.0	1
Inner regional	719	122.7	0.94 [0.91, 0.98] *	8.4	0.96	[0.79, 1.15]	123	19.5	1.04 [0.95, 1.14]
Outer regional	454	125.6	0.96 [0.92, 1.01]	9.1	1.02	[0.82, 1.27]	71	19.6	1.02 [0.91, 1.15]
Remote/Very remote	51	92.0	0.68 [0.58, 0.80] *	12.2	1.46	[0.94, 2.27]	9	17.5	0.80 [0.54, 1.19]
By area disadvantage	Overall significance ¹ , p=0.0003			Overall significance ¹ , p =0.003			Overall significance ¹ , p =0.818		
Least disadvantaged	639	136.8	1	10.8	1		85	18.2	1
Less disadvantaged	678	124.4	0.91 [0.87, 0.96] *	9.1	1.09	[0.84, 1.40]	104	18.9	1.04 [0.91, 1.18]
Middle 20%	707	129.4	0.94 [0.90, 0.99] *	9.2	1.39	[1.09, 1.76] *	113	19.5	1.05 [0.93, 1.20]
More disadvantaged	663	125.2	0.92 [0.87, 0.96] *	8.2	1.36	[1.07, 1.74] *	113	20.2	1.08 [0.95, 1.23]
Most disadvantaged	626	121.9	0.90 [0.86, 0.95] *	6.9	1.51	[1.18, 1.93] *	106	19.2	1.05 [0.93, 1.20]
By accessibility	Overall significance ¹ , p=0.004			Overall significance ¹ , p =0.600			Overall significance ¹ , p=0.669		
<1 hour	2,666	129.1	1	8.7	1		419	19.4	1
1-<2 hours	174	123.9	0.96 [0.89, 1.02]	8.7	0.84	[0.57, 1.23]	26	17.8	0.90 [0.75, 1.07]
2-<4 hours	233	123.9	0.97 [0.91, 1.03]	9.7	1.09	[0.82, 1.44]	38	19.1	0.99 [0.85, 1.14]
4-<6 hours	185	118.7	0.92 [0.86, 0.98] *	9.1	1.11	[0.82, 1.49]	29	18.0	0.93 [0.79, 1.10]
6+ hours	56	110.0	0.85 [0.75, 0.95] *	10.9	1.30	[0.81, 2.09]	10	22.2	1.08 [0.81, 1.43]

Source: Cancer Queensland Cancer Report 2012-2016

Another critical aspect is the geological differences in Queensland of being diagnosed with cancer, surviving with cancer, and dying from cancer. Cancer Queensland has covered where people lived according to remoteness, disadvantage, and accessibility to treatment facilities from 2012-2016. Incidence = number of new breast cancers diagnosed; Standardised Incidence Ratio = compares the diagnosis rate between regions; Excess Hazard Ratio = survival-based ratio; Mortality = number of deaths; and Standardised Mortality Ratio = compares cancer mortality rates between regions.

According to Table 1, the number of new breast cancers in Queensland has increased every year. There has been a total of 3,327 women who have been diagnosed with breast cancer and a rate of 127.9 increase annually. Women typically live over a period of 5-years after being susceptible to breast cancer and have a 9.6% of excess deaths with a mortality count of 557. Note that, a ratio of 1.0 indicates no difference from the Queensland average, while a ratio above 1.0 indicates an increase in incidence (SIR), excess death

¹¹⁰ Christinat, A. and Pagani, O. (2012). "Fertility after breast cancer", *Maturitas*. 73(3), 191-196.

¹¹¹ Beale, B., Elmira, R., Jackson, D., and Schmied, V. (2010). "Against all odds: Australian women's experiences of recovery from breast cancer", *Journal of Clinical Nursing*. 19(17-18).

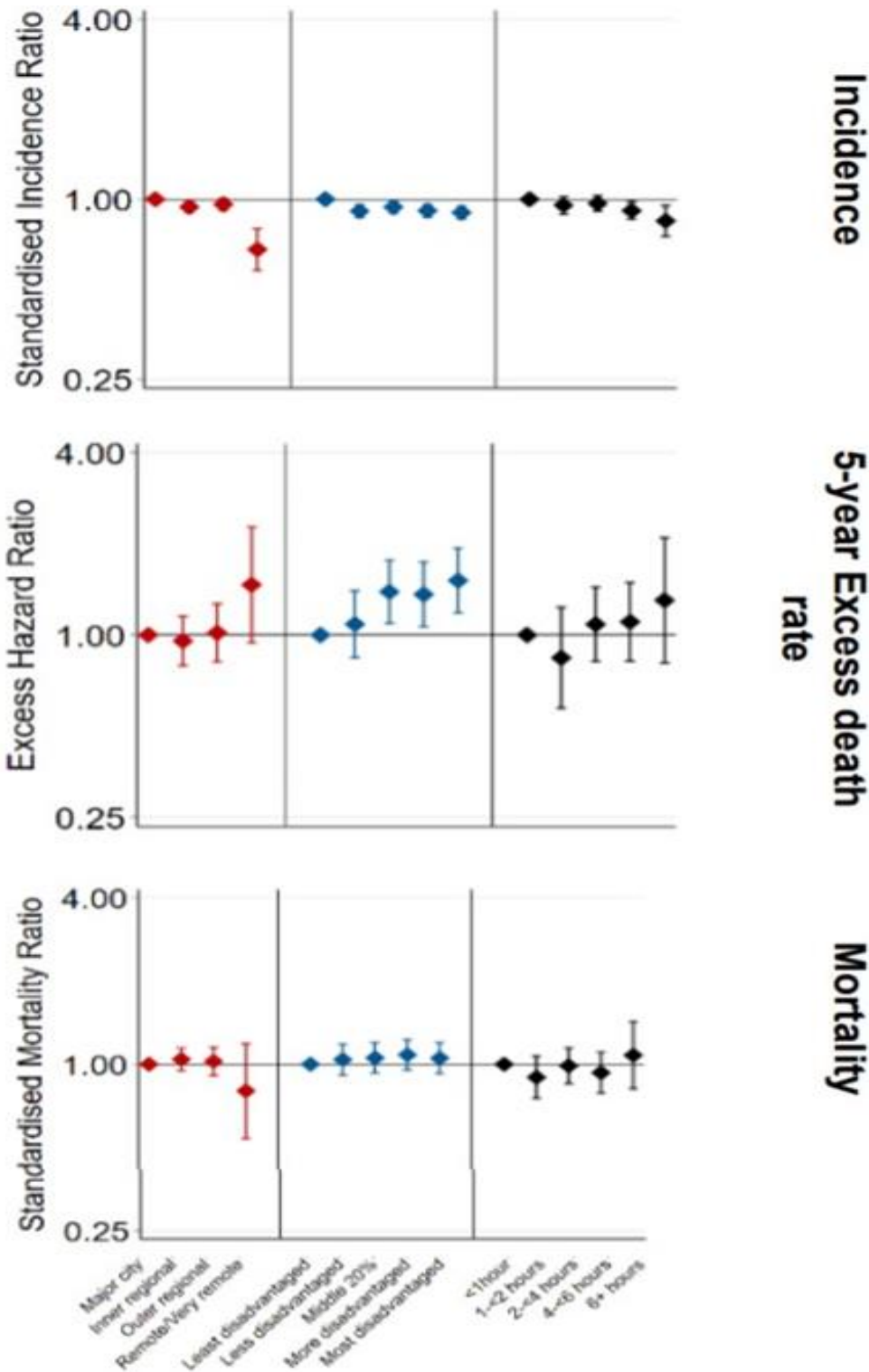
rate (EHR) and mortality (SMR), compared to the Queensland average. Note that a higher excess death rate (HER) is equivalent to a lower relative survival (examples are highlighted in red boxes in Table 1).

For example, an SIR of 0.68 for all breast cancers among females who live in remote/very remote areas compared to those who live in major cities (see Table 1) indicates that people living in remote/very remote areas have an 32 percent lower rate of cancer diagnosis compared to those who live in major cities. The 95 percent confidence interval for this SIR is [0.58-0.80]. Since this does not include 1, this is considered to be significantly lower.

An EHR of 1.30 among females who live 6+ hours away from the closest treatment facility compared to those who live <1 hour away (see Table 1) indicates that people who live 6+ hours away have a 30% higher excess death rate (or lower survival) due to breast cancer compared to those who live <1 hour away. The 95 percent confidence interval for this EHR is [0.81-2.09]. Since this does include 1, this is considered to be significantly higher.

An SMR of 1.05 among females living in the more disadvantaged areas compared to the least disadvantaged areas (see Table 1) indicates that people living in the most disadvantaged areas have an 8% higher mortality rate due to breast cancer compared to those who live in the least disadvantaged areas. The 95 percent confidence interval for this SMR is [0.93-1.20]. Since this does include 1, this is considered to be significantly higher.

Table 2. Overview of differences in cancer incidence, 5-year excess deaths by **Remoteness**, **Area Disadvantage** and **Accessibility**, 2012-2016



Source: Cancer Queensland Cancer Report 2012-2016

Table 2 shows the visual illustration of Table 1 and we can conclude that remote areas have lower incidence of breast cancer; however, as females in those areas have reduced accessibility to treatments, excess deaths and mortality rates are significantly higher compared to major cities.

6.4.2 Treatments and risks that may cause infertility

Matters of the reproductive system are of great importance to younger women, especially those who are planning to have a family before the breast cancer diagnosis. Research has shown that approximately 800 Australian women between the ages of 20 to 39 have been diagnosed with breast cancer, accounting for 5% of all who are diagnosed every year¹¹². Cancer Australia states that it is appropriate for health professionals to discuss and consider fertility treatments with premenopausal women before they undergo breast cancer treatment. A number of young women do not realise the implications for what will happen to their fertility after the treatments¹¹³.

Chemotherapy

Chemotherapy adopts drugs intravenously or orally to either kill the cancer cells or slow their growth. Adverse effects can range from mild to severe, depending on the type and extent of the treatment and other individual factors including family history. Chemotherapy can lead to alopecia (hair loss) and to an extent, ovarian failure¹¹⁴. There are different types of drug agents and depending on the drugs used, side effects will be different on each individual. Some women find that their periods become irregular or stop during the treatment. Periods may return to normal after the treatment, but the risk of experiencing early menopause is high, causing infertility¹¹⁵. Other side effects include mouth ulcers, tiredness, nausea, and vomiting. Chemotherapy can also lower the immune system, increasing the risk of infection.

Age is also a main factor that contributes to the success rate of the treatment. Most adolescent girls develop amenorrhea (absence of menstruation) during the treatment, but ovarian failure is rarely seen unless they receive a combination of both chemotherapy and radiotherapy. Compared to patients over 30 years old, 50% suffer from ovarian failure due to smaller stores of ovarian follicles¹¹⁶. As a result, these women have higher rates of permanent infertility.

Radiation therapy

As one of the other main treatments for cancer, radiotherapy uses X-rays to destroy or injure the cancer cells to prevent them from multiplying. This treatment can be used for primary and advanced cancer. It can also be used to reduce the size of the cancer, relieve pain, and discomfort. As stated above, radiation therapy may be used to assist another treatment. Adjuvant radiation therapy may be used to shrink the cancer before, during, and after surgery. However, this also significantly increases the risks of damaging targeted organs¹¹⁷. The location of the ovaries and breasts in relation to the radiotherapy fields can affect fertility temporarily or permanently. Ovarian follicles are more radiosensitive, thus also affecting the menstrual cycle

¹¹² Breast Cancer Network Australia. *Cancer Australia recommendations highlight importance of fertility discussions before breast cancer treatment*. (2017). Retrieved from BCNA News website: <https://www.bcna.org.au/news/2017/01/cancer-australia-recommendations-highlight-importance-of-fertility-discussions-before-breast-cancer-treatment/>

¹¹³ Cancer Australia The Statement. (2016). Retrieved from: <https://thestatement.canceraustralia.gov.au/the-practices/practice-3>

¹¹⁴ Meirov, D. and Nugent, D. (2001). "The effects of radiotherapy and chemotherapy on female reproduction", *Hum Reprod Update*. 7, 535–43.

¹¹⁵ Cancer Council. (2018). *Chemotherapy*. Retrieved from: <https://www.cancercouncil.com.au/breast-cancer/cancer-treatment/chemotherapy/>

¹¹⁶ A. Demiroglu, C. Salman, and T. Gurgan (2008). "Pregnancy and Assisted Reproduction Techniques in Men and Women after Cancer Treatment", *Placenta*. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/18790328>

¹¹⁷ Cancer Council (2019). *About Cancer*. Retrieved from:

https://www.cancer.org.au/aboutcancer/treatment/radiotherapy.html?gclid=Cj0KCQjwLT1BRD9ARIsAMH3BtX-6ST65XboU3OpFgl_AQ2qdW8e_MDHDd7wgqvvg1uMDDjtnUEqbJ8aAhuoEALw_wcB

of young women. The estimated ionising radiation dosage enough to damage half the human body was reported to be 2 Gy (Gray)¹¹⁸. A single dose of radiotherapy is lethal and the more dosages, the higher the percentage of causing ovarian failure.

Hormonal therapy

Hormonal therapy or endocrine therapy is a treatment that add, removes, and blocks hormones to slow or stop the growth of cancer cells that require hormones to develop¹¹⁹. Most estrogen in women's bodies is made by the ovaries and it makes hormone-receptor-positive breast cancers grow. In some cases, taking drugs or undergoing surgery is part of the treatment as a preventative measure for women with very high risk of breast cancer. This treatment is completely different from Hormone Replacement Therapy (HRT), which women take during menopause¹²⁰.

Treatment with hormonal therapies does not cause infertility. However, a woman's fertility may naturally fall while taking it after a few years as they grow older. It may reduce fertility temporarily or permanently, but it does not mean it is impossible to become pregnant after the treatment¹²¹.

Surgery

One of the major operations women take with breast cancer is a mastectomy – a surgery to remove all breast tissue from the breast. Some women opt to have a mastectomy to avoid radiotherapy or harsher treatments to lower the risks of the cancer. The procedure does not affect a woman's fertility, but it may affect her ability to breastfed or lactate¹²². The breasts involved may not be able to produce milk, depending on how much breast tissue was removed. This type of loss is proven to have greater effect on younger women who are considering having children and unmarried women who are with or seeking partners¹²³. The *External Breast Prosthesis Reimbursement Program* provides for both new and replacement external breast prosthesis as a result of breast cancer as it is not considered as a cosmetic surgery. The government also assists with some costs for women who are in need of treatment away from their local area with travel and accommodation¹²⁴.

6.4.3 Fertility treatments and alternatives in Queensland

It is highly recommended that health professionals discuss the treatments breast cancer patients have to undertake before making a decision concerning their lives post-treatment. This includes the risks of becoming infertile during and after the treatment. Women who are planning to have children before their breast cancer diagnosis should seek professional help and fertility specialists to discuss available options.

Recent studies show that young women prefer to bear a child of their own than to adopt as it greatly impacts the emotional well-being of both parents. They will look for donors first, surrogacy is the second choice, and then adoption.

¹¹⁸ K. Misha (2013). Explainer: How much radiation is harmful to health? *The Conversation*. Retrieved from: <https://theconversation.com/explainer-how-much-radiation-is-harmful-to-health-17906>

¹¹⁹ Canadian Cancer Society. *Diagnosis and Treatment for Cancer*. Retrieved from: <https://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/chemotherapy-and-other-drug-therapies/hormonal-therapy/?region=on>

¹²⁰ Breast Cancer Org. (2020). Hormonal Therapy. Retrieved from: <https://www.breastcancer.org/treatment/hormonal>

¹²¹ Australian Government: Cancer Government. (2017). *Effects of breast cancer treatments on fertility*. Retrieved from: <https://breast-cancer.canceraustralia.gov.au/living/physical-changes/fertility>

¹²² Australian Government: Cancer Australia. (2017). *Mastectomy*. Retrieved from: <https://breast-cancer.canceraustralia.gov.au/treatment/surgery/mastectomy>

¹²³ Australian Breastfeeding Association. (2015). *Breastfeeding after breast surgery*. Retrieved from: <https://www.breastfeeding.asn.au/bfinfo/breastfeeding-after-breast-surgery>

¹²⁴ Health Direct. (2018). *Breast cancer and financial support*. Retrieved from: <https://www.healthdirect.gov.au/breast-cancer-and-financial-support>

Policies

In Vitro Fertilization (IVF)

In Australia, there are strict guidelines before women may be considered fertility treatments. In Vitro Fertilization (IVF) is the process of extracting eggs from the female, retrieving a sperm sample from the male, and then manually combining the egg and sperm in a laboratory dish. The embryo is then transferred to the uterus.

A typical IVF treatment cycle in Queensland involves the following steps:

1. A woman's ovaries are stimulated by injection of fertility drugs (ovarian hyperstimulation).
2. Oocytes (eggs) are then collected from the woman in a day surgery procedure (under local or general anaesthetic). This is referred to as either oocyte pick up (OPU) or egg collection.
3. The eggs are then fertilised - this may involve intracytoplasmic sperm injection (ICSI) where a single sperm is injected into each egg to assist fertilisation.
4. After maturation one or more fresh embryos may be transferred to the woman's uterus, this is known as a "fresh embryo transfer").
5. If there are other embryos they can be frozen and may be transferred at a later date. This procedure is known as a "frozen embryo transfer" or FET. After all the fresh and frozen embryos from the initial stimulated cycle have been used the IVF treatment cycle is considered complete

Source: Queensland Fertility Group – IVF Statistics

There is currently no Commonwealth legislation that directly regulates Assisted Reproductive Treatment (ART) or IVF in Australia, but a woman's age is the single most important factor affecting a couple's chances of conceiving. That is why it is strongly recommended women seek assistance after 6 months of trying for ages above 35, and after 12 months of trying for ages under 35¹²⁵. Furthermore, Queensland, Western Australia, Tasmania, Australian Capital Territory, and New South Wales have not passed laws that set our criteria for people who wish to access ART. There is also no national legislation imposing a maximum age for IVF in Australia, but medical practitioners recommend that ages below 40 for a higher success rate. Medical practitioners in these states would be guided by their own professional judgement, general medical practice, and ethical guidelines¹²⁶.

The procedures of artificial insemination or in vitro fertilization (IVF) in Queensland and the premise of parentage follows the 'Status of Children Act 1978 (QLD). These regulations only apply to married couples, a man and a woman living in a genuine domestic relationship and female same-sex de facto couples. Complexities surround the use of IVF in same-sex relationships, surrogacy agreements or for people whose relationships may not meet the definition of "de facto". Heterosexual couples who cannot conceive after attempting to do so for 12 months might be eligible for Medicare rebates for IVF treatment on the basis they are "medically infertile". Additionally, fertility clinics that provide assisted reproductive technology services may refuse to provide their services to LGBTIQ+ couples and single people. This makes the Anti-Discrimination Act relevant, but it does not apply to Queensland and Northern Territory with regards to ART services.

Another strict regulation is that both parents must have consented to the IVF procedure. When either married couples, a man and a woman living in a genuine domestic relationship or a female same-sex de facto couple, consent to artificial insemination, both partners are presumed to be the parents of children born as a

¹²⁵ IVF Australia. What is infertility? Retrieved from: <https://www.ivf.com.au/planning-for-pregnancy/what-is-infertility>

¹²⁶ Barrett, A. and Barrett, J. (2018). IVF clinics can still refuse same-sex couples in Queensland. *Brisbane Times*. Retrieved from: <https://www.brisbanetimes.com.au/national/queensland/ivf-clinics-can-still-refuse-same-sex-couples-in-queensland-20181012-p5098w.html>

result of those procedures, regardless of the source of the ovum or semen that created the embryo. If the woman gives birth without the consent of the partner, the donor of the sperm has no right or liabilities in relation to the child born¹²⁷.

Surrogacy and adoption

A surrogacy is an arrangement between the birth mother and another person or couple (intended parents) where the birth mother agrees to become pregnant with a child for the intended parents. There are two types of surrogacy arrangements:

1. Altruistic (Non-commercial)
2. Commercial

Only the Altruistic surrogacy arrangement is legal in Queensland. Commercial surrogacy, where there is payment, reward, or any material benefit given to the birth mother is illegal. Any person, regardless of relationship status can enter into a non-commercial arrangement. According to the Surrogacy Act 2010, there are laws including transferring the parentage of a child born through a surrogacy arrangement. To enter a surrogacy agreement and transfer parentage, you must complete all of the following steps:

1. Seek independent legal advice
2. Get counselling
3. Put the agreement in writing
4. Conception and pregnancy
5. Register the birth
6. Get surrogacy guidance report
7. Apply for parentage order
8. Court decision

Source: Queensland Government – Surrogacy Process

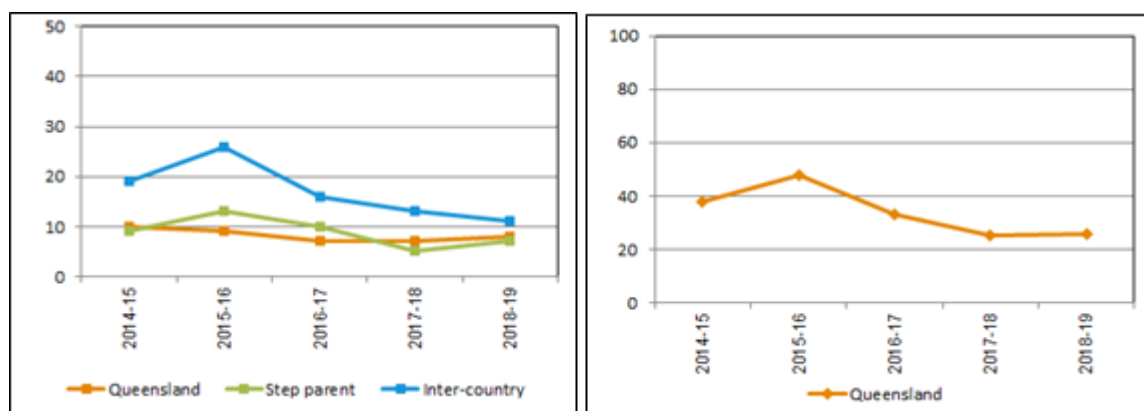
The process of adopting is quite similar with surrogacy. Queensland practices Open Local and Intercountry Adoption, which means adopted children are raised with an understanding of their past whether inside or outside the state. The female should not be pregnant and both partners should be of Australian citizenships¹²⁸. However, there are only a few children put up for adoption in Queensland each year, 50 being the most (See Table 3). It takes on average five years; from application fees to health and background checks, interviews, and once approved, wait to be matched with the right child. Even if the couples pass the eligibility criteria, there are no guarantees they will be match with a child¹²⁹.

¹²⁷ The Queensland Law Handbook: Family Law. (2019). *In Vitro Fertilisation – Liabilities and Rights of Parents*. Retrieved from: <https://queenslandlawhandbook.org.au/the-queensland-law-handbook/family-law/surrogacy-and-in-vitro-fertilisation/in-vitro-fertilisation-liabilities-and-rights-of-parents/>

¹²⁸ Queensland Government. (2020). How to adopt a child in Queensland. Retrieved from: <https://www.qld.gov.au/community/caring-child/adoption/adopting-child-queensland/how-to-adopt-a-child-from-queensland>

¹²⁹ Clun, R. (2017). 'There are no guarantees': What it is like to adopt in Queensland. *Brisbane Times*. Retrieved from: <https://www.brisbanetimes.com.au/national/queensland/there-are-no-guarantees-what-it-is-like-to-adopt-in-queensland-20170303-guqjck.html>

Table 3. Adoption Performance in Queensland 2014-2019



Source: Queensland Government – Adoption Performance

Local adoption in Australia has been in decline since the 1970s, partly because of the availability of contraception and the different attitudes towards forming a family beyond traditional marriages.¹³⁰ The process of putting a child up for adoption is equivalently complicated. Both parents must consent to put up the child for adoption and the grandparents also have a say if they want the child removed from the family¹³¹. Adoption is a service for the children. It is not a service to make families – this is a subtle but important difference. The adoption in Australia is small because not all children separated from their families need adoption, therefore panic claims about the welfare of children should be resisted¹³². The long process makes sure that adoptions are legal and ethical for everyone involved, especially for the children.

6.4.4 Support in Australia

A great step to raise awareness on breast cancer for young women in both remote and major areas is to directly teach schools about the risks and the safety precautions to take to prevent it. This does not limit it to only breast cancer, but also to major illnesses and diseases that may accumulate overtime. The free mammogram is not available to younger women, because young breasts tend to have denser tissue, which makes it difficult to see breast cancer on a mammogram. The concerns about the effects of radiation is higher on young breasts and there is no evidence that mammograms are effective in detecting early stage breast cancer in women younger than 40. Therefore, being familiar with one's breast to check for any irregularities and lumpiness is the best way for now. Furthermore, women who have already had breast cancer have an increased risk of developing a second breast cancer¹³³. It is important to see a health professional for any unusual changes and practice prevention.

Another major recommendation is for Queensland to safely regulate the legislation for IVF treatments and treat all patients equally. When it comes to accessing IVF services, same-sex couples and single women can still legally be refused treatment in some states. They are also denied the same government rebates afforded to heterosexual couples. With the legalisation of same-sex marriage there are calls for changes in laws surrounding IVF to keep pace with a changing society. Secondly, there is no central registry or body in Australia that women can turn to if they are seeking an egg or an embryo to become pregnant. Instead, women

¹³⁰ Fronek, P. (2018). Explainer: HOW HARD IS IT TO ADOPT IN AUSTRALIA? *SBS News*. Retrieved from:

<https://www.sbs.com.au/news/the-feed/explainer-how-hard-is-it-to-adopt-in-australia>

¹³¹ Queensland Government.(2020). *Child and family Report*. Retrieved from: <https://www.csyw.qld.gov.au/child-family/our-performance/adoptions>

¹³² Claption, G., Cree, V., and Smith, M. (2013). "Moral Panics, Claims-Making and Child Protection in the UK", *The British Journal of Social Work*. 43(4), 802-812. Retrieved from: <https://academic.oup.com/bjsw/article-abstract/43/4/803/1645615>

¹³³ Cancer Council. (2019). *Breast Cancer*. Retrieved from: <https://www.cancer.org.au/about-cancer/types-of-cancer/breast-cancer/>

are left to recruit their own donor through advertising or are directed to private organisations which help connect donors and potential recipients. Which means, women have more chances in getting pregnant outside of Australia¹³⁴.

Not only that, there is a social stigma in Australia attached to infertility and fertility clinics are treated more as a money-making industry. Even then, the majority of the issues were called out regarding the treatments given to patients include missed infertility diagnosis, poor communication, lack of individualised care and heavy costs¹³⁵. There is no transparency within the industry and they only give out the basic requirement as the law suggests. Couples feel emotionally devastated by the services they are given and realistic information about their personal chance of success, potential risks, and cost of treatment should be discussed before the process begins. One could argue that changes must be made to the policies regarding the treatments families have to go through just to have a child.

¹³⁴ Wylie, B. (2019). Australian women travel overseas for donor eggs amid calls for regulation. *ABC News*. Retrieved from: <https://www.abc.net.au/news/2019-07-03/egg-donation-women-in-australia-forced-overseas/11055992?nw=0>

¹³⁵ McCormack, A. and Scott, S. (2020). IVF is big business in Australia — but these people are calling the industry out. *ABC News*. Retrieved from: <https://www.abc.net.au/news/2020-01-21/fertility-ivf-parents-analysis-issues-with-industry/11876280>

6.5 Employment and Career

6.5.1 Trends in employment

Rosenberg et al.¹³⁶ conducted a survey on 911 young women diagnosed with breast cancer in the US to identify any trends in employment by comparing their employment status prior to diagnosis and one year after. The result, summarised in table 1, indicated a drop in employment. Further research, as part of this project, was conducted to analyse the root cause of this trend in employment.

Table 1. Employment Trend

	Employment prior to diagnosis	Employment 1 year after diagnosis
Full time	578 (63%)	729 (80%)
Part time	148 (16%)	
Self-employed	36 (4%)	
Unemployed for health or for other reasons	30 (3%)	182 (20%)
Full-time home-makers	119 (13%)	

6.5.2 Cognition

Employment status is directly related to deterioration in cognitive function, commonly referred to as “chemobrain” or “chemofog”, which leads to limited ability to manage certain responsibilities or get around¹³⁷. Therefore, the deleterious impact of chemotherapy on cognitive function is an area of concern. Although cognitive impacts as one of many side effects of breast cancer treatment was not acknowledged by the medical community before, it has recently been more accepted and researched. There is a substantial amount of research suggesting cognitive alterations affect anywhere between 19-78% of breast cancer patients, depending on a multitude of factors such as the type of regimen received¹³⁸. Respondents reported decreased efficiency and speed at work, thus reducing their chances of being promoted or assigned to projects, as they and their employers realise that they are no longer able to handle the level of work they were accustomed to pre-cancer treatment. Memory problems also often increased stress, with more severe symptoms being

¹³⁶ Rosenberg, S. M., Vaz-Luis, I., Gong, J., Rajagopal, P. S., Ruddy, K. J., Tamimi, R. M., . . . de Moor, J. S. (2019). Employment trends in young women following a breast cancer diagnosis. *Breast cancer research and treatment*, 177(1), 207-214.

¹³⁷ Boykoff, N., Moieni, M., & Subramanian, S. K. (2009). Confronting chemobrain: an in-depth look at survivors’ reports of impact on work, social networks, and health care response. *Journal of Cancer Survivorship*, 3(4), 223.

¹³⁸ Cheung, Y., & Chan, A. (2013). Linguistic validation of Functional Assessment of Cancer Therapy-Cognitive Function (FACT-Cog): methodological concerns. *Supportive Care in Cancer*, 21(3), 655.

reported by those who were job hunting and experiencing stressful situations. In addition, setbacks in writing and reading were also reported.

In a quantitative study of 122 breast cancer survivors and 113 non-cancer control women, distress, fatigue, and job stress were higher in the breast cancer survivor group who were on average three years post-treatment. Survivors reported higher levels of cognitive limitations than non-cancer control women, which in turn, predicted work output¹³⁹. Changes in work output were more responsive to changes in job stress and fatigue in the breast cancer survivor group. More specifically, cognitive impacts after diagnosis and treatment for breast cancer are categorised into 6 domains¹⁴⁰ and summarised in Table 2. Similarly, a piece of research evaluated 21 women receiving adjuvant chemotherapy through a combination of self-reported questionnaire, High Sensitivity Cognitive Screen and a semi-structured interview to explore the nature of different symptoms and impacts on daily function. Patients reported changes in short-term memory (20 of 21), concentration (contributed by emotional factors), language (word finding ability and articulation), mental fluency, processing speed and, to a lesser degree, planning and visual–spatial abilities (10% reported poorer sense of direction or poorer coordination and distance judgment)¹⁴¹.

Table 2. Cognition Impacts

Cognitive domains	Number of participants
Short-term memory	22 (100%)
Long-term memory	20 (91%)
Speed of processing	16 (73%)
Attention and concentration	12 (55%)
Language	8 (36%)
Executive function	5 (22%)

In order to identify cognitive impacts of different breast cancer treatments, a one-year longitudinal study was performed on a group of women who had received adjuvant chemotherapy (CT-RT group) and a group of women who had not received adjuvant chemo-therapy but who were treated with RT during the same period of inclusion (RT group)¹⁴². RT (34%) patients and CT-RT (24%) patients had initial mild cognitive impairments, which were exhibited one year after treatment by 19% and 13% respectively. Although fatigue was the main symptom in patients with localised breast cancer treated with radiotherapy, this did not impact cognitive functions, anxiety or depression.

¹³⁹ Calvio, L., Peugeot, M., Bruns, G. L., Todd, B. L., & Feuerstein, M. (2010). Measures of cognitive function and work in occupationally active breast cancer survivors. *Journal of Occupational and Environmental Medicine*, 52(2), 219-227.

¹⁴⁰ Von Ah, D., Habermann, B., Carpenter, J. S., & Schneider, B. L. (2013). Impact of perceived cognitive impairment in breast cancer survivors. *European Journal of Oncology Nursing*, 17(2), 236-241.

¹⁴¹ Downie, F. P., Mar Fan, H. G., Houédé-Tchen, N., Yi, Q., & Tannock, I. F. (2006). Cognitive function, fatigue, and menopausal symptoms in breast cancer patients receiving adjuvant chemotherapy: evaluation with patient interview after formal assessment. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 15(10), 921-930.

¹⁴² Noal, S., Levy, C., Hardouin, A., Rieux, C., Heutte, N., Ségura, C., . . . Delcambre, C. (2011). One-year longitudinal study of fatigue, cognitive functions, and quality of life after adjuvant radiotherapy for breast cancer. *International Journal of Radiation Oncology* Biology* Physics*, 81(3), 795-803.

6.5.3 Career development

The impairments above directly affect breast cancer survivors' social relationships and interfere with productivity and career development. Women have developed different compensatory strategies at work, which were perceived to be essential. For example, since work was perceived to be harder and took more effort, some people reported that they worked harder than before to make sure their performance was up to standard, while others coped by informing colleagues of their limits¹⁴³. There were also signs of increasing reliance upon external aids such as calendars, lists, and notes⁵. However, not everyone was strong-minded. It was reported that some left their employment due to concerns regarding their cognitive ability.

There are four typical responses from reappraisal of career development after cancer: "increased desire to have more work-life balance", "increased desire to be passionate or enjoy work more", "slowed down, blocked, or forced a change in career path" and "career ambitions and priority placed on career decreased", which make sense due to either ability limits or discovery of new focus in life.

6.5.4 Support in Australia

The support system in Australia for young women with breast cancer in terms of career development is not mature nor dedicated.

Firstly, from the perspective of health care provider support, the research on cognitive impairments is lagging. 64% of women reported that their healthcare provider did not assess or inquire about cognitive concerns after treatment and they could not receive substantial help even if they raised their concerns. Also, they became even more frustrated when their disclosure of related concerns was not recognised or attributed to other symptoms. In Australia, there are few formalised after-treatment programs offered by public and private hospital outpatient settings due to already-stretched healthcare resources. Depending on hospital policy and resourcing, former breast cancer patients tend to be reviewed sporadically by the treating consultant or their aftercare is assigned to their general practitioner, who frequently knows little about the longer-term outcomes of breast cancer treatment. An innovative model of care was recently implemented in five Australian hospitals, which provides women who have completed treatment for early breast cancer with shared follow-up care between their GP and their specialist, while these five hospitals are currently working with Cancer Australia to evaluate the delivery of this program.

Secondly, support from colleagues/ employers and human resources/ management were typically portrayed as positive. Thirdly, a few government departments and non-profit organisations provide general support. For example, Fair Work Ombudsman assists in discrimination in workplace. Cancer Council in each state has a program providing free legal, financial and workplace advice to people affected by cancer who cannot afford to pay for advice. Most non-profit organisations offer consulting and advice services. For instance, Think Pink organised "Plan the Next Steps for your Career" workshop¹⁴⁴. However, it is hard to find professional and customised support related to employment and dedicated for young breast cancer survivors.

Based on the above findings, the following changes are proposed:

¹⁴³ Downie, F. P., Mar Fan, H. G., Houédé-Tchen, N., Yi, Q., & Tannock, I. F. (2006). Cognitive function, fatigue, and menopausal symptoms in breast cancer patients receiving adjuvant chemotherapy: evaluation with patient interview after formal assessment. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 15(10), 921-930.

¹⁴⁴ Foundation, T. P. (2019). Returning to Work After Breast Cancer. Retrieved from <https://www.thinkpink.org.au/returning-to-work-after-breast-cancer/>

Medical community

It is recommended that the cognitive impacts of breast cancer on young women be given more recognition. Oncologists or other healthcare providers should provide information about cognitive impairment as a potential symptom prior to treatment, so that women would at least be mentally prepared and understand the risks of cognitive changes after treatment.

Also, there are currently no specific diagnostic criteria for chemotherapy-related cognitive alteration¹⁴⁵. Clinical practice is encouraged to provide reliable and standardised patient-reported measures of cognitive function in daily practice, which would contribute greatly to both patient treatment and future study in the field.

Employers

A formal return-to-work program contributes to a supportive workplace environment¹⁴⁶. Any reports of cognitive problems at work should be carefully followed up. There is evidence of an adverse relationship between effects of cancer-related fatigue and workplace support, including work adjustment policies, adjustment to working hours and alternative working arrangements, return-to-work meetings, and regular consultations about managing workload.

Family and friends

Those close to women with breast cancer should take complaints about cognitive changes seriously and provide care and support since ignorance contributes to survivors' psychometric distress. Participants generally described social support from outside of their work environment as being important to coping with breast-cancer-related work challenges¹⁴⁷.

Researchers

Little is known about the unique career and work experiences of breast cancer survivors under the age of 40. Further study about cognition and employment status would be desirable especially in an Australian context. Additionally, there is a gap in research exploring different situations faced by women living in rural and urban areas.

¹⁴⁵ Arneil, M. (2018). Investigating physical activity and cognitive alterations in younger women after breast cancer treatment. Queensland University of Technology,

¹⁴⁶ CancerCouncil. Cancer Impacts in the Workplace [Press release]

¹⁴⁷ Raque-Bogdan, T. L., Hoffman, M. A., Ginter, A. C., Piontkowski, S., Schexnayder, K., & White, R. (2015). The work life and career development of young breast cancer survivors. *Journal of counseling psychology*, 62(4), 655.

6.6 Sexuality and Relationships

6.6.1 Sexual dysfunction

Sexual dysfunction afflicts many young women with breast cancer. One study found that among 360 young women aged 50 or under, approximately half (52%) reported having some degree of sexual dysfunction¹⁴⁸. This often leads to women engaging in less sexual activity after breast cancer treatment. In fact, 77.9% of 1956 Australian women with a mean age of 54 years were found to be less sexually active after a breast cancer diagnosis or treatment¹⁴⁹.

Physical changes brought about by breast cancer treatment are a major contributor to sexual dysfunction. Various types of treatment can have an effect, including chemotherapy, endocrine therapy and breast surgery. The effects of these treatments are comprehensively explored in Rosenberg et al.'s study, which was conducted on 461 young women aged 40 or under¹⁵⁰.

With regards to chemotherapy and endocrine therapy, Rosenberg et al. (2014) found that treatment-induced amenorrhea (i.e. absence of menstruation), was statistically significantly associated with reduced sexual interest and sexual dysfunction in young women. This is consistent with the findings of other studies relating to the effect of chemotherapy on sexual functioning^{151, 152, 153}. It is worth noting, though, that in Rosenberg et al.'s study, the association between chemotherapy and sexual dysfunction was not statistically independent of vaginal pain symptoms, body image and fatigue. This is shown in Table 1 below.

Table 1. Multivariable Analysis of Factors Associated with Sexual Interest and Sexual Dysfunction^a

Variable	CARES Sexual Interest		CARES Sexual Dysfunction	
	$\beta \pm SE$	P^b	$\beta \pm SE$	P^b
Treatment-associated amenorrhea				
No amenorrhea/no chemotherapy	Reference		Reference	
Amenorrhea	0.37 ± 0.12	.003	0.20 ± 0.16	.21
No amenorrhea/chemotherapy	0.30 ± 0.12	.02	0.20 ± 0.16	.23
Symptoms				
Vaginal pain ^c	0.11 v0.04	.002	0.62 ± 0.05	<.0001
Hot flashes	-0.02 ± 0.04	.52	-0.05 ± 0.05	.28
Weight problems	0.32 ± 0.05	<.0001	0.05 ± 0.06	0.47
CARES body image	0.36 ± 0.04	<.0001	0.17 ± 0.05	.002
Fatigue	0.14 ± 0.09	.12	0.35 ± 0.11	.003
Musculoskeletal pain	0.07 ± 0.04	.10	0.04 ± 0.05	.43

Abbreviations: CARES, Cancer Rehabilitation Evaluation System; SE, standard error.

^a The analyses were adjusted for stage, age, race/ethnicity, treatment, partner status, time from diagnosis, and all variables included in the table.

^b Positive coefficients with a P value $\leq .05$ are associated with higher CARES scores, which indicate significantly more sexual functioning concerns.

^c In nonsexually active women, "vaginal pain" includes the single item measuring vaginal dryness severity. In sexually active women, "vaginal pain" includes items measuring both vaginal dryness and dyspareunia severity.

Source: Rosenberg et al., 2014

¹⁴⁸ Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., & Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology*, 15(7), 579-594. <https://doi.org/10.1002/pon.991>

¹⁴⁹ Ussher, J.M., Perz, J., & Gilbert, E. (2012). Changes to Sexual Well-being and Intimacy After Breast Cancer. *Cancer Nursing*, 35(6), 456-465. <https://doi.org/10.1097/NCC.0b013e3182395401>

¹⁵⁰ Rosenberg, S.M., Tamimi, R.M., Gelber, S., Ruddy, K.J., Bober, S.L., Kerekoglow, S., Borges, V.F., Come, S.E., Schapira, L., Patridge, A.H. (2014). Treatment-related amenorrhea and sexual functioning in young breast cancer survivors. *Cancer*, 120(15), 2264-2271. <https://doi.org/10.1002/cncr.28738>

¹⁵¹ Boswell, E. N., & Dizon, D. S. (2015). Breast cancer and sexual function. *Translational Andrology and Urology*, 4(2), 160-168. <https://doi.org/10.3978/j.issn.2223-4683.2014.12.04>

¹⁵² Biglia, N., Moggio, G., Peano, E., Sgandurra, P., Ponzone, R., Nappi, R. E., & Sismondi, P. (2010). Effects of surgical and adjuvant therapies for breast cancer on sexuality, cognitive functions, and body weight. *The Journal of Sexual Medicine*, 7(5), 1891-1900. <https://doi.org/10.1111/j.1743-6109.2010.01725>

¹⁵³ Avis, N.E., Crawford, S., & Manuel, J. (2004). Psychosocial Problems Among Younger Women with Breast Cancer. *Psych-Oncology*, 13(5), 295-308. <https://doi.org/10.1002/pon.744>

As for breast surgery, undertaking a mastectomy is associated with decreased interest in sex. This is also the case for breast conserving therapy, albeit to a lesser extent¹⁵⁴.

The effects of radiation therapy are less clear-cut, as they are often used in conjunction with other treatment methods. Nevertheless, there is evidence that radiation therapy plays a role in reducing sexual functioning and well-being¹⁵⁵.

Sexual dysfunction may persist even after treatment^{156,157}. In fact, one study found that issues relating to sexual functioning lingered for at least five years after treatment¹⁵⁸. Worse still, Arora et al. found that women who had undergone surgery or chemotherapy experienced declining sexual functioning over a period of five months. This was despite improvements in other aspects of health such as physical functioning, psychological well-being and body image¹⁵⁹.

Treatment effects aside, the changes in a woman's sexual well-being can be explained by various bodily symptoms. Fatigue and vaginal pain, for instance, were statistically significantly associated with sexual dysfunction in Rosenberg et al.'s study¹⁶⁰. Fatigue was also identified by Ussher et al. as being the biggest factor of sexual well-being¹⁶¹. Psychological factors also played a role when it came to sexual dysfunction. Body image concerns were a factor for 77% of respondents in Ussher et al.'s study¹⁶², in line with Rosenberg's study¹⁶³.

6.6.2 Relationships

In connection with the issue of sexual dysfunction, breast cancer can stifle sexual relationships. In Ussher et al.'s study¹⁶⁴, only 15% reported no effect on their sexual relationship. This was attributed to various physical factors such as tiredness (71%). Psychological reasons for changes in sexual relationships included the woman's fear of her partner causing harm during sex (52%) and lack of interest in sex (37%). Importantly, the pattern of the percentages in all of the above items did not depend on age, meaning the same trend would apply to young women with breast cancer. Table 2 (below) illustrates the above responses, among others.

¹⁵⁴ Aerts, L., Christiaens, M. R., Enzlin, P., Neven, P., & Amant, F. (2014). Sexual functioning in women after mastectomy versus breast conserving therapy for early-stage breast cancer: a prospective controlled study. *Breast (Edinburgh, Scotland)*, 23(5), 629–636. <https://doi.org/10.1016/j.breast.2014.06.012>

¹⁵⁵ Boswell, E. N., & Dizon, D. S. (2015). Breast cancer and sexual function. *Translational Andrology and Urology*, 4(2), 160–168. <https://doi.org/10.3978/j.issn.2223-4683.2014.12.04>

¹⁵⁶ Kedde, H., van de Wiel, H.B.M., Weijmar Schultz, W.C.M., Wijsen, C. (2013). Sexual dysfunction in young women with breast cancer. *Support Care Cancer* 21(1), 271–280. <https://doi.org/10.1007/s00520-012-1521-9>

¹⁵⁷ Fobair, P., Stewart, S. L., Chang, S., D'Onofrio, C., Banks, P. J., & Bloom, J. R. (2006). Body image and sexual problems in young women with breast cancer. *Psycho-Oncology*, 15(7), 579-594. <https://doi.org/10.1002/pon.991>

¹⁵⁸ Engel, J., Kerr, J., Schlesinger-Raab, A., Sauer, H., & Hölzel, D. (2004). Quality of life following breast-conserving therapy or mastectomy: results of a 5-year prospective study. *The Breast Journal*, 10(3), 223–231. <https://doi.org/10.1111/j.1075-122X.2004.21323>

¹⁵⁹ Arora, N.K., Gustafson D.H., Hawkins R.P., McTavish F., Cella D.F., Pingree, S., Mendenhall, J.H., & Mahvi, D.M. (2001). Impact of surgery and chemotherapy on the quality of life of younger women with breast carcinoma: a prospective study. *Cancer*, 92(5), 1288–1298. [https://doi.org/10.1002/1097-0142\(20010901\)92:5<1288::AID-CNCR1450>3.0.CO;2-E](https://doi.org/10.1002/1097-0142(20010901)92:5<1288::AID-CNCR1450>3.0.CO;2-E)

¹⁶⁰ Rosenberg et al., 2014.

¹⁶¹ Ussher et al., 2012.

¹⁶² Ussher et al., 2012.

¹⁶³ Rosenberg et al., 2014.

¹⁶⁴ Ussher et al., 2012.

Table 2. Aspects of Breast Cancer or Breast Cancer Treatment That Have Affected Sexual Well-Being (N = 1956)

Item	% (n)
Tiredness	71.0 (1387)
Vaginal dryness	63.3 (1237)
Hot flushes	51.2 (1000)
Feeling unattractive	50.8 (993)
Weight gain	48.8 (953)
Difficulty being aroused	45.8 (894)
Feeling uncomfortable exposing my body	44.0 (860)
Medication adverse effects	39.0 (762)
Loss of confidence in myself	38.4 (751)
Depression/anxiety	37.8 (738)
Change in size or shape of breast	37.6 (734)
Difficulty reaching orgasm	35.9 (701)
Loss of sensation	35.8 (700)
Reduced nipple sensation	35.4 (692)
Pain during intercourse	33.4 (653)
Anxiety about sex	28.6 (558)
Early menopause	28.1 (550)
Appearance changes (eg, hair loss)	27.0 (527)
Pain in upper body	26.9 (525)
Relationship changes	22.8 (446)
Fear	21.4 (418)
Loss of identity	17.0 (332)
Anger	16.3 (319)
Lymphedema	16.3 (318)
Guilt	12.6 (246)
Feelings of shame	10.2 (200)
Other ^a	36.9 (722)
Erectile difficulties (for men with breast cancer)	100.0 (5)

^aEach less than 10%: increased sensitivity (9.9%, n = 193), thrush (8.4%, n = 164), vaginal discharge (8.0%, n = 157), irregular menstruation (6.1%, n = 120), weight loss (3.9%, n = 76), and more energy (0.6%, n = 12).

Source: Ussher et al., 2012

Breast cancer can also change the dynamics of a couple's emotional relationship, for better or worse. Communication problems are commonly cited as a pressing issue for couples¹⁶⁵. They were found to be an issue for 34% of respondents in Ussher et al's study¹⁶⁶. Nevertheless, cases exist where women and their partners grew closer as a result of breast cancer. This was found in Avis et al.'s study¹⁶⁷.

6.6.3 Impact on the intimate partner

Intimate partners represent a major source of support for women with breast cancer, and so it is important to understand their side of the story¹⁶⁸. Social support generally is associated with lower psychological distress in women with breast cancer¹⁶⁹. However, partners may struggle to provide this crucial support due to their own distress¹⁷⁰.

The emotional burden of breast cancer on partners is evident¹⁷¹. For example, Bigatti et al.¹⁷² found that husbands of breast cancer patients were statistically significantly more depressed than husbands of non-patients. This was also the case in a recent study, which also discovered that compared to partners of healthy women, the partners of young women aged 50 or under with breast cancer experienced statistically significantly lower quality of life and marital satisfaction¹⁷³.

¹⁶⁵ Avis et al., 2004.

¹⁶⁶ Ussher et al., 2012.

¹⁶⁷ Avis et al., 2004.

¹⁶⁸ Pitceathly, C. and Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: A review. *European Journal of Cancer*, 39(11), 1517–1524. [https://doi.org/10.1016/S0959-8049\(03\)00309-5](https://doi.org/10.1016/S0959-8049(03)00309-5)

¹⁶⁹ Baider, L., Andritsch, E., Goldzweig, G., Ever-Hadani, P., Hofman, G., Krenn, G., & Samonigg, H. (2004). Changes in psychological distress of women with breast cancer in long-term remission and their husbands. *Psychosomatics*, 45(1), 58–68. <https://doi.org/10.1176/appi.psy.45.1.58>

¹⁷⁰ Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C.C., Willan, A., Viola, R., Coristine, M., Janz, T., Glossop, R. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170(12), 1795–1801. <https://doi.org/10.1503/cmaj.1031205>

¹⁷¹ Pitceathly et al., 2003.

¹⁷² Bigatti, S. M., Wagner, C. D., Lydon-Lam, J. R., Steiner, J. L. and Miller, K. D. 2011. Depression in husbands of breast cancer patients: Relationships to coping and social support. *Supportive Care in Cancer*, 19, 455–466. <https://doi.org/10.1007/s00520-010-0835-8>

¹⁷³ Cohee, A., Storey, S., Winger, J.G., Cella, D., Stump, T., Monahan, P.O., & Champion, V. (2020). A cohort study of quality of life in partners of young breast cancer survivors compared to partners of healthy controls. *Journal of Patient-Reported Outcomes*, 4(1), 19. <https://doi.org/10.1186/s41687-020-0184-4>

The health outcomes of the partners can also be influenced by the woman's own health¹⁷⁴. Some studies found that a woman's stress and depression were associated with reduced physical health in her partner^{175, 176}. It is therefore crucial that the needs of intimate partners are also addressed.

6.6.4 Support in Australia

The impact of breast cancer on women's sexual wellbeing and intimate relationships is an issue that often takes a back seat¹⁷⁷.

Partner support is one of the most effective ways of alleviating issues concerning sexuality and relationships. Indeed, this was found to be the case in a large-scale Australian survey¹⁷⁸. The 1999 participants involved in the survey most commonly spoke to their partners when it came to matters concerning sexuality and relationships, with 48% reporting being satisfied with the discussion. This reinforces the important role of partners in a woman's recovery from breast cancer, as discussed above. In fact, an Australian study found that a couple's return to intimacy post-cancer was associated with good communication and positive relationship context¹⁷⁹.

Women with breast cancer also make other efforts to seek help. Respondents in the aforementioned survey reached out to support groups and a breast care nurse – the two support options that were deemed most satisfactory. Furthermore, over two-thirds of respondents wished to receive information about breast cancer and sexual wellbeing. Key issues that respondents particularly wished to be informed on included vaginal dryness, relationship changes, lack of arousal, hot flushes, pain during intercourse, information for partners and relationship communication. All of these topics were, in fact, discussed above as being major determinants of sexual well-being.

¹⁷⁴ Bergelt, C., Koch, U. and Petersen, C. (2008). Quality of life in partners of patients with cancer. *Quality of Life Research*, 17(5), 653–663. <https://doi.org/10.1007/s11136-008-9349-y>

¹⁷⁵ Dorros, S. M., Card, N. A., Segrin, C., & Badger, T. A. (2010). Interdependence in women with breast cancer and their partners: An interindividual model of distress. *Journal of Consulting and Clinical Psychology*, 78(1), 121-125. <https://doi.org/10.1037/a0017724>

¹⁷⁶ Kim, Y., Kashy, D.A., Wellisch, D.K., Spillers, R.L., Kwei Kaw, C., Tenbroeck, S.G. (2008). Quality of Life of Couples Dealing with Cancer: Dyadic and Individual Adjustment among Breast and Prostate Cancer Survivors and Their Spousal Caregivers. *Annals of Behavioral Medicine*, 35(2), 230-238. <https://doi.org/10.1007/s12160-008-9026-y>

¹⁷⁷ Ussher, J.M., Perz, J., & Gilbert, E. (2011). Sexual wellbeing and breast cancer in Australia: Experiences of people with breast cancer and health professionals.

¹⁷⁸ Ussher et al., 2011.

¹⁷⁹ Hawkins, Y., Ussher, J., Gilbert, E., Perz, J., Sandoval, M., & Sundquist, K. (2009). Changes in sexuality and intimacy after the diagnosis and treatment of cancer: the experience of partners in a sexual relationship with a person with cancer. *Cancer Nursing*, 32(4), 271–280. <https://doi.org/10.1097/NCC.0b013e31819b5a93>

6.7 Children and Family

6.7.1 Quantitative Studies

Women under 40 often have younger children still at home, and face issues that their counterparts without children do not face. One third of women in a study of 816 Canadian and American women, reported that they experienced heightened stress specifically linked to their younger age, especially related to having children still at home.¹⁸⁰ Successive studies have found younger mothers with breast cancer have higher levels of depressive symptoms,¹⁸¹ increased psychological distress¹⁸² and higher fear of recurrence and illness intrusiveness.¹⁸³

Figure 1 illustrates the effect of children in the home on depressive symptoms, drawn from a study of 225 American women.¹⁸⁴ This particular study included women between the ages of 27-91, with the mean age at 57. Of the participants 84 (34.1%) had children in the home and 156 (63.4%) did not, with no distinction made about the age of the women who still had children in the home.¹⁸⁵

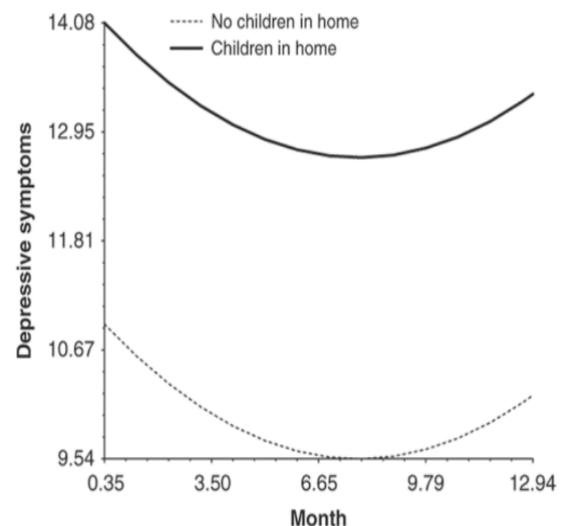


Figure 1. Depressive symptoms (Source: Shlegel et al., 2012)

One survey of 816 Canadian and American young breast cancer survivors (YBCS), found there was a stronger relationship between psychological adjustment and illness intrusiveness for young breast cancer survivors (YBCS) with children (with children $r = -0.779$, 95% CI: $-0.711, -0.848$ vs without children $r = -0.525$, 95% CI: $-0.423, -0.627$).¹⁸⁶ Furthermore, in addition to the link between higher fear of recurrence and children, having younger children has also been linked to higher fear of recurrence than having older children.¹⁸⁷ Thewes' study was drawn from a sample of 218 breast cancer survivors between the ages of 18-45, and assessed fear of recurrence using the 42-item fear of cancer recurrence inventory.¹⁸⁸ This method of assessment was developed by Simard and Savard and is noted in this report due to its high level of internal consistency and temporal stability (Cronbach's $\alpha = 0.95$, test retest = 0.89).¹⁸⁹

¹⁸⁰ Wan, C., Arès, I., Gareau, A., Collins, K.A., Lebel, S., & Bielajew C. (2018). Motherhood and well-being in young breast cancer survivors. *Breast Cancer Management* 7(1).

¹⁸¹ Schlegel, R.J., Mark A. Manning, Lisa A. Molix, Amelia E. Talley & Bettencourt, A.B. (2012). Predictors of depressive symptoms among breast cancer patients during the first year post diagnosis. *Psychology & Health* 27(3), 277-293. DOI: 10.1080/08870446.2011.559232

¹⁸² Wan et al., 2018.

¹⁸³ Arès I., Lebel, S. & Bielajew C. (2014). The impact of motherhood on perceived stress, illness intrusiveness and fear of cancer recurrence in young breast cancer survivors over time. *Psychology & Health* 29(6), 651-670. DOI: 10.1080/08870446.2014.881998, 2014; Lebel, S., Beattie, S., Arès, I., & Bielajew, C. (2013). Young and worried: Age and fear of recurrence in breast cancer survivors. *Health Psychology* 32(6), 695-705. <http://dx.doi.org.ezproxy.library.uq.edu.au/10.1037/a00301862013>; Thewes, B., Bell, M.L., Butow, P., Beith, J., Boyle, F., Friedlander, M., & McLachlan, S.A. (2013). Psychological morbidity and stress but not social factors influence level of fear of cancer recurrence in young women with early breast cancer: results of a cross-sectional study. *Psycho-Oncology* 22(1) 2797-2806. doi:10.1002/pon.3348

¹⁸⁴ Schlegel et al., 2012

¹⁸⁵ Ibid.

¹⁸⁶ Wan et al., 2018

¹⁸⁷ Thewes et al., 2013

¹⁸⁸ Ibid.

¹⁸⁹ Ibid.; Simard S, & Savard J. (2009). Fear of cancer recurrence inventory: development and initial validation of a multidimensional measure of fear of cancer recurrence. *Support Care Cancer* 17(3), 241-251.

Overall, quantitative studies demonstrate that YBCS with children have greater rates of multiple psychosocial issues.

6.7.2 Qualitative studies

Second to fear of recurrence and future uncertainty, children and family were the most commonly reported concern of YBCS, with 20% of one study referring to it as their major concern, and 31.5% specifically mentioning their children.¹⁹⁰ This study was drawn from a sample of 35 Australian women with breast cancer, diagnosed at 40 years of age or younger.¹⁹¹ 27 (77.14%) had children, with the majority of these children under 18 (only four of the total of 39 children were over 18).¹⁹²

YBCS survivors with children often have very specific concerns relating to their status as parents. These include worries about being a good parent and telling children, including difficulties with knowing how to best talk with kids.¹⁹³ One third of survivors in one study were somewhat to highly concerned about the emotional and practical impact of their cancer on their children.¹⁹⁴ It is important to note that this study was conducted on cancer survivors in general, not just breast cancer survivors. Parents reported the physical and emotional strain of cancer exacerbating parenting challenges,¹⁹⁵ and leading to sadness and guilt if they were not able to be fully and consistently available.¹⁹⁶ Worry about personal financial situation was the factor most closely associated with worry about children, followed by still having children at home, then fear of dying.¹⁹⁷

However, some women reported their cancer bringing about a positive role shift in their family, in which their partners took on more responsibility and became closer with their children.¹⁹⁸

¹⁹⁰ Connell, S., Patterson, C. & Newman, B. (2006). Issues and concerns of young Australian women with breast cancer. *Support Care Cancer* 14, 419–426. <https://doi-org.ezproxy.library.uq.edu.au/10.1007/s00520-005-0003-8>

¹⁹¹ Ibid.

¹⁹² Ibid.

¹⁹³ Semple, C.J. & McCance, T., Parents' Experience of Cancer Who Have Young Children, *Cancer Nursing: March 2010 - Volume 33 - Issue 2* - p 110-118 doi: 10.1097/NCC.0b013e3181c024bb; Walsh, S. R., Manuel, J. C., & Avis, N. E. (2005). The Impact of Breast Cancer on Younger Women's Relationships With Their Partner and Children. *Families, Systems, & Health*, 23(1), 80-93. doi:10.1037/1091-7527.23.1.80

¹⁹⁴ Inhestern, L., Bultmann, J. C., Beierlein, V., Möller, B., Romer, G., Muriel, A. C., Moore, C. W., Koch, U., and Bergelt, C. (2016) Psychometric properties of the Parenting Concerns Questionnaire in cancer survivors with minor and young adult children. *Psycho-Oncology*, 25: 1092–1098. doi: 10.1002/pon.4049.

¹⁹⁵ Schlegal et al., 2012

¹⁹⁶ Stiffler D, Haase J, Hosei B, Barada B. (2008). Parenting experiences with adolescent daughters when mothers have breast cancer. *Oncology Nurse Forum* 35(1), 113–120.

¹⁹⁷ Welsh, Manuel & Avis, 2005

¹⁹⁸ Ibid.

6.7.3 Support in Australia

Support for YBCS with children in Australia is not sufficient, leading many studies to conclude there is a need for early interventions to provide more support. Although the majority of YBCS agreed that their informational needs were adequately met¹⁹⁹ the greatest unmet need in Australia was support.²⁰⁰ Half of the women in a study of 260 of Australian women, reported that 40% of their overall needs were unmet.²⁰¹

Particular areas of concern identified were insufficient material support for parents,²⁰² need for early intervention and screening for depressive symptoms and illness intrusiveness,²⁰³ and support and resources for speaking to children about their cancer.²⁰⁴ One study flags this need for early inclusion as an area for development in both social and oncological programs.²⁰⁵ With regards to telling children about cancer, this is seen as particularly important as telling children is one of the most common triggers of distress for young women with breast cancer.²⁰⁶ One study noted that children's books are often used to provide information to younger children which can provide some support for women in telling their children.²⁰⁷ However, this does not account for talking to older children, and there are gaps within children's books that do not address topics such as financial concerns and impacts on school.²⁰⁸ Much of this research is also focused on interventions used in the US, with less information to be found about interventions used in Australia. This therefore represents an area for further research in Australia in order to identify effective methods for these proposed interventions.

¹⁹⁹ Rana, P., Ratcliffe, J., Sussman, J., Forbes, M., Levine, M. & Hodgson, N. | Udo Schumacher (Reviewing Editor) (2017). Young women with breast cancer: Needs and experiences. *Cogent Medicine* 4(1). DOI: 10.1080/2331205X.2017.1278836

²⁰⁰ Connell, Patterson & Newman, 2006; Fernandes-Taylor, S., Adesoye, T. & Bloom, J.R. (2015). Managing psychosocial issues faced by young women with breast cancer at the time of diagnosis and during active treatment. *Current Opinion Support Palliative Care*. 9(3), 279–284. doi: 10.1097/SPC.0000000000000161; Semple & McCance, 2005

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²⁰⁵ Wan et al., 2018

²⁰⁶ Rana et al., 2017

²⁰⁷ Fernandes-Taylor, S., Adesoye, T. & Bloom, J.R., 2015

²⁰⁸ Huang X, Lee S, Hu Y, Gao H, & O'Connor M. (2015). Talking About Maternal Breast Cancer With Young Children: A Content Analysis of Text in Children's Books. *Journal of Paediatric Psychology* 40(6), 609-21.

7. Conclusion

This project has led to the clear conclusion that breast cancer has significant impacts on young women in the form of physical, psychological, and social problems. These impacts of breast cancer are manifested in issues concerning quality of life and psychological wellbeing, body image, fertility, employment and career, sexuality and relationships, and children and family.

To summarise the project findings on the social impacts of breast cancer:

1. The assessments of quality of life can present an overall situation in the process of breast cancer from different dimensions. The reviews suggested that the psychosocial interventions for young women help to reduce symptoms and emotional distress during treatments. The implementation of quality of life assessments in breast cancer clinical practice is discussed, with evidence detailing how such tools would benefit treatments provided. Although the psychological intervention cannot guarantee a low frequency of distress recurrence, the research still recommended that to involve or develop a regular mental care intervention in the treatments is necessary for the process.
2. Body image change resulting from cancer related treatments is studied to have significant impacts on breast cancer survivors' overall wellbeing, especially in the aspect of psychological distress (e.g. anxiety, stress, and depression), and identity recognition difficulties where losses of self-identity, femininity, self-acceptance, sexuality, and attractiveness are identified. Supported by studies, increasing patients' perception of self-compassion and hope, as well as having breast reconstruction and prostheses if circumstances permit, are indicated to help reduce the impacts from body image disturbance.
3. Fertility is one of the most important aspects a woman can ever have. The possibility of not having children in the future due to breast cancer and treatments can affect not only their lives, but also the people around them. In addition, the inequality regarding the treatment for IVF should not be overlooked and the government should safely regulate the related policies with proper guidelines. Children in schools can be taught at an early age about the risks and prevention of different illnesses from breast cancer to mental health. When more people are made aware of the dangers of such diseases as they grow older, more lives can be saved and more families can be made.
4. Breast cancer significantly influences a woman's career even after recovery. Mainly concerned with Radiation therapy, the cognitive impacts, especially in short-term, long-term memory and speed of process, force young breast cancer survivors to come up with coping strategies to finish their work while they might still face less career progression. The support system in Australia is not mature nor dedicated. It is recommended that the medical community provides reliable and standardised patient-reported measures and employers set up a formal return-to-work program. Besides care and support from families and friends, further research in the domain of cognition and employment status is desired.

5. A woman's sexual wellbeing can be significantly compromised by diagnosis and treatment of breast cancer. Studies show that challenges around sexuality can in turn feed into relationship complications, as breast cancer can also take a toll on the health of young women's partners. Couple-based interventions can serve as an antidote to this. For example, evidence suggests one effective solution is to have couples discuss concerns around sexuality together. Social support is, after all, the key to a healthy recovery from breast cancer.

6. Young breast cancer survivors with children often experience a greater severity of depressive symptoms, illness intrusiveness, and psychological adjustment, in addition to unique problems that are not experienced by those without children. Studies have concluded that the best method to address these problems are providing early interventions and screening for these negative effects, although future research would need to address gaps in the application of this in an Australian context.

Support mechanisms exist for breast cancer survivors; however, our literature review reveals that there are still gaps in the level of support provided. Examples of how these can be addressed have been included in the report, and can inform future health practices concerning breast cancer, especially for young women.

Ultimately, the results of this project suggest that effective support groups and appropriate psychological interventions for patients and their family and friends play an essential role in the recovery of a young woman with breast cancer.

8. Limitations

The limitations in our research derive from issues in the availability of data, and the quality of data available, indicating gaps in the literature.

- Firstly, some of the project findings could only be obtained through data that was not specific to young women (defined in this report as women aged under 40, unless stated otherwise). In addition, the definition of 'young women' tended to vary depending on the study. This may mean that some of the project findings may not be as insightful as they would otherwise have been had data on young women been available.
- Secondly, the lack of Australian data available generally may detract from the persuasiveness of the project findings in the eyes of Australian stakeholders. This is especially the case when it comes to the impacts of breast cancer on career and employment. Little research has been conducted to identify this issue and the data available on this issue is quite limited.
- Thirdly, again due to shortage of data, there is a lost opportunity to explore urban and rural differences in the social impacts studied (hence our need to refine our original scope, as explained in Section 3).
- Fourthly, the research measurements used were not always consistent across the studies exploring each social impact. This made the findings of different studies less comparable within each topic in Section 6.
- Finally, throughout our research, we have often found that the social impacts discussed are interrelated. Notwithstanding, some of the linkages established in some studies are not necessarily backed by data, leading to doubts in the reliability and validity of the results.

Future projects should collect new data that specifically relate to young women in Australia, that identify any differences in outcomes between urban and rural areas, that use consistent research measures, and that statistically validate any relationships among the social impacts.

When collecting data, using a vector autoregression model is highly recommended in analysing the significance of the social impacts of breast cancer and their interrelationships.

Despite their limitations, the studies that are referred to in this report provide valuable insights into how breast cancer impacts on the social lives of young breast cancer survivors, and what potential recommendations could be implemented to assist in their recovery from what would be a difficult time for them and those around them.

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