



Supportive care in breast cancer

Guest Editor: Phyllis Butow

MARCH 2017 | VOL 41 ISSUE NO 1

Cancer Forum March 2017

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Overview: Supportive care in breast cancer

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As survival after breast cancer increases, the focus of research and practice is increasingly turning to supportive care. This Forum is focussed on breast cancer in women.

Breast cancer is a traumatic diagnosis for any woman. Women have to engage in complex decision-making concerning multiple options for surgery, radiotherapy, chemotherapy and hormone therapy, taking into account genetic and fertility issues, as well as perceived benefits and risks.¹ They will face short and long-term side effects, potentially including hair loss, fatigue, cognitive decline, loss of fertility, menopausal symptoms and anxiety/depression. Despite ever-improving survival statistics, women experience fear of recurrence that can be ongoing even long after treatment and in the good prognostic context of early stage disease.² Women with advanced cancer face existential issues, ongoing treatment, as well as a range of symptoms and side effects.

Unsurprisingly, the need for information and support in this population is high.³ Thus this issue of *Cancer Forum*, very appropriately, focuses on the supportive care needs of women with breast cancer, complementing the medical/surgical focus in the previous issue, and mirroring one of the themes (breast cancer) of the Clinical Oncology Society of Australia meeting of 2016.

In the pages to follow, current models of supportive and decisional support are described, as well as the prevalence and severity of specific symptoms and side effects, and evidence-based interventions for these.

Claudia Rutherford and Nicholas Zdenkowski discuss the nature, benefits and challenges of shared decision-making (SDM), a model of decision making which is integral to patient centred care.⁴ While SDM is now strongly endorsed by most policy statements and frameworks, its implementation into routine care is variable. The authors identify the key decision-points in breast cancer, as well as resources that can be used to facilitate SDM. These include decision-aids, question prompt lists, patient navigators, decision coaches and online risk calculators, as well as training for clinicians in communication strategies that enhance SDM.

Janine Porter-Steele and colleagues provide an overview of models of supportive care in breast cancer, including shared care with GPs, specialist breast cancer nurses, peer support and e-health.⁵ They emphasise the importance of supportive care spanning the disease trajectory, including follow-up care and extending into survivorship.

Laura Kirsten and Kim Hobbs discuss models of supportive care specifically for women with advanced cancer.⁶ They highlight the multiple needs of this population, and the importance of screening for and managing distress through a stepped-care model. Information and general support will be required for all, but referral to specialist psycho-oncology services is needed to address more complex needs. A growing evidence base supports specialist interventions to reduce distress, address existential concerns and facilitate end-of-life adjustment and planning. These authors note the importance of maintaining an adequate workforce of psycho-oncology specialists to deliver these interventions.

Rebecca Tay and colleagues discuss sexual dysfunction after breast cancer arising from body image disturbances due to disfigurement or loss of the breast(s), menopausal symptoms and general fatigue.⁷ They provide guidance in taking a sexual history, using the PLISSIT (an acronym based on permission, limited information, specific suggestions and intensive therapy) model to guide sexual discussion and intervention, encouraging communication between women and their partners, and making referrals if necessary to specialist staff. Recent evidence on interventions to improve vaginal

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dryness or atrophy is presented, including fractional microablative CO₂ laser to improve microcirculation below the level of the mucosa.

Infertility after breast cancer is a major issue for women, discussed by Michelle Peate and colleagues.⁸ Issues covered include the risk of infertility, fertility measurement after cancer, the impact of future pregnancy on prognosis, birth outcome, contraception, the psychosocial impact of infertility and pregnancy and assisted reproduction after breast cancer. They emphasise the importance of discussing fertility issues with women before they make their treatment decisions, so that they can consider options that might decrease their risk of infertility.

Joanne Shaw and Fran Boyle discuss the sometimes under-rated chemotherapy side effect of alopecia.⁹ They discuss its impact on self-image, its role in marking women and men as cancer patients, and how it is a constant reminder of cancer. Pre-emptive shaving, wigs and head coverings can help women, but more recent attempts to limit hair loss through scalp cooling offer promise of at least reduced impact. Innovative Australian research on scalp-cooling is presented in this chapter.

Cognitive dysfunction after cancer, predominantly breast cancer, is explored by Victoria Bray and colleagues, including the growing evidence base that the so-called 'chemo-brain' is a real phenomenon, whether caused by cancer treatments or the cancer itself.¹⁰ Interventions to help women better manage or reduce cognitive dysfunction are described, though many interventions still under evaluation.

Lisa Beatty and David Kissane tackle the mental health outcomes after breast cancer, in particular anxiety and depression.¹¹ Levels of anxiety and depression are significantly higher in the cancer population than in the general population, and if left untreated, can add significantly to the burden of breast cancer, reduce adherence to medication and increase health costs. This article provides an overview of pharmacological and psychological treatments for anxiety and depression, including new and emerging therapies.

The special needs of patients in rural and regional areas, including indigenous patients, are discussed by William Fox and colleagues.¹² The tyranny of distance, as well as challenges in accessing expert care, can increase the burden of breast cancer on this population. The role of breast care nurses, aboriginal health workers, telemedicine and innovative IT solutions are presented.

Finally, Afaf Girgis and colleagues raise the banner for an often under-served group of people greatly affected by breast cancer – the caregivers.¹³ They note that distress can be as high or higher in this group as in the patients themselves. A number of individual, group and couple-based therapies have been shown to reduce distress and improve quality of life in caregivers, and by extension, in patients.

While this is not an exhaustive coverage of the supportive care needs of women with breast cancer, it is hoped that it will provide health care practitioners with an update on current knowledge and interventions to improve the supportive care of women with breast cancer, reducing suffering and improving quality of life.

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Strategies to support shared decision making in breast cancer

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Abstract

Shared decision making is a key component of patient-centred and evidence-based healthcare. Its integration into routine care is of interest to healthcare providers, consumers and policymakers who want to improve the quality of healthcare. The process of shared decision making enables healthcare providers and a patient with a condition that has more than one available clinically appropriate management strategy, to make a joint health decision. The decision takes into account the best available evidence, in conjunction with the patient's values and preferences and understanding of the benefits and harms of available options. There is unequivocal evidence that shared decision making improves the quality of healthcare decisions, reduces unwarranted variation in care, and improves patient outcomes. Despite these benefits, shared decision making has not been systematically adopted in clinical practice in Australia. Strategies exist that can help healthcare professionals who treat patients with breast cancer incorporate shared decision making into their practice. We review these strategies, including patient decision aids, patient navigators, decision coaches, and online risk calculators.

Patient-centred care is an important expectation of healthcare internationally. In 1988, the Picker/Commonwealth Program coined the term 'patient-centred care' to set an agenda for clinicians and healthcare systems to shift their attention from diseases back to the patient.¹ The patient's perspective is crucial to drive improvements in design and delivery of health services to enhance the quality of care by improved ability to meet patients' needs. The patient-centred care approach was further advocated by the Institute of Medicine, for improving the quality of US healthcare. They defined it as "care that is respectful of and responsive to individual patient preferences, needs, and values" and that ensures "that patient values guide all clinical decisions".² Breast cancer, with a wide array of both treatment options and patient preferences, is a key setting in which shared decision making can be applied.

Shared decision making (SDM), a process by which a healthcare choice is made jointly between the patient and one or more healthcare providers,³ is considered the crux of patient-centred care.^{4,5} SDM can facilitate patient-centred care, particularly given the increasing number of healthcare choices for treatment and disease management. Despite multiple benefits (box 1), SDM has not been systematically adopted in clinical practice in Australia.⁶ Studies report suboptimal levels of patient-involving behaviours in decision making, and a need for more healthcare providers to consistently facilitate patient involvement and adjust patient care to patient preferences.⁷

Box 1: Benefits of shared decision making of interest to healthcare providers and policy makers.

Shared decision making can:

- improve patient outcomes;⁸
- reduce overuse of options not clearly associated with benefits for all (e.g. breast cancer screening for some people);⁹
- enhance use of options clearly associated with benefits for the majority;¹⁰
- reduce unwarranted healthcare practice variations;¹¹ and
- promote the right of patients to be involved in decisions concerning their health.¹²

Involving patients in medical decision making can improve patients' quality of life, sense of control over illness, symptom relief and adherence to treatment, and decrease fatigue, depression and illness concerns.^{8,13} When patients are presented with multiple treatment options, they may experience uncertainty (known as decisional conflict) about which to choose. If patients are not supported to make these decisions, the consequence may be unresolved decisional conflict. Studies report patients with unresolved decisional conflict are more likely to change their mind, delay medical decisions, have regret after their treatment, depart from active treatment, and blame their treating clinicians for bad outcomes or sue their clinicians in cases of harms from treatment.^{14,15}

When decision support is needed

For decisions where a clear optimal treatment option is available, or there is a lack of equally beneficial alternatives, patient values and preferences may have little or no role. However, for most medical decisions where more than one treatment option is acceptable (e.g. treatment options for early-stage breast cancer), patient involvement in decision making is valuable for aligning decisions with individual values and preferences. For patients, some decisions are tougher than others. A decision between two or more options might involve a trade-off between associated risks versus the potential benefits, and the potential for regret if the intended outcome is not achieved. For example, patients might decide against post-operative chemotherapy for early-stage breast cancer due to concern about short and long-term toxicities, weighed against a modest incremental survival gain from that treatment. Patients will value benefits and harms of treatment differently and vary in how much risk, loss, regret or challenge to their personal life they prefer.

Through SDM, clinicians can help patients incorporate their values and preferences in making medical decisions that are best for them. When patients know they have options for the best treatment, screening test or diagnostic procedure, most prefer more active involvement in health decision making.¹ This interest is shared by patients worldwide, as demonstrated by the release of the Salzburg statement endorsing SDM by representatives from 18 countries.¹⁶

Major decision points in breast cancer

More than 16,000 Australians will be diagnosed with breast cancer in 2016.¹⁷ Due to improved treatment options, 89% will survive for more than five years.¹⁸ Treatment options for patients with breast cancer include surgery, radiotherapy, chemotherapy, endocrine therapy, biologic therapy and supportive care.¹⁹ Within each of these treatment modalities there can be a number of different options, each with benefits and harms that might be valued differently by individual patients.²⁰ Without involving patients in the decision, clinicians cannot confidently predict which option will be most suitable for that particular patient at that particular time.²¹

Major treatment decisions for breast cancer patients may include:

- *Surgical*: mastectomy or breast conserving surgery; axillary clearance or sentinel node biopsy; reconstruction surgery; contralateral prophylactic mastectomy.
- *Medical oncology*: chemotherapy; endocrine therapy; neoadjuvant chemotherapy.
- *Radiation oncology*: radiation to breast/chest wall, and/or nodal regions.

Many of these choices depend on decisions about other treatment modalities. For example, survival and recurrence rates are equivalent between breast conserving surgery and mastectomy, however this is only the case if breast irradiation follows breast conserving surgery.²² While most women with early stage breast cancer are cured of their cancer with one or more of these treatment modalities,¹⁸ receiving a diagnosis of a potentially life-threatening condition causes substantial distress for many patients and their support person(s).²³ This distress may impair their ability to be fully involved in their treatment decision-making.²⁴ However, women who were actively involved in treatment decisions for their breast cancer had higher physical and social functioning, and quality of life, and lower fatigue compared with those who took a passive role.²⁵ As such, strategies to support SDM in breast cancer patients are an important component of high quality multidisciplinary care. Box 2 presents a case study and highlights how decision support would benefit this patient.

Box 2: A case-based example of shared decision-making for breast cancer

Karen, a 39 year-old woman, is diagnosed with early-stage left breast cancer. She has an ultrasound and a core biopsy, showing a 30mm diameter, oestrogen, progesterone and HER2 negative (triple negative) tumour with at least one involved axillary lymph node. Her surgeon explains that with breast conserving surgery, the cosmetic outcome would not be optimal. Karen would like to retain her breast, but is also worried about the long-term effects of the radiotherapy that would be required after breast conserving surgery. Her mother was diagnosed with breast cancer at age 44, and she is concerned that she might carry a BRCA1/2 gene mutation that would predispose her to develop breast and/or ovarian cancer. Her surgeon refers her to a medical oncologist to consider pre-operative (neoadjuvant) chemotherapy, which would otherwise have been given after surgery, to shrink the tumour to facilitate breast conserving surgery. In addition, she could receive genetic testing prior to surgery, which if positive might cause her to have bilateral mastectomies and immediate reconstruction to reduce her risk of future new primary breast cancer. In order to prepare her for the discussion with the medical oncologist, the surgeon gives her a patient decision aid on neoadjuvant systemic therapy.

In this example, the patient has multiple decisions to make: decide between mastectomy and breast conserving surgery, whether to have radiotherapy and pre-operative chemotherapy, and whether to have genetic testing. The patient has preferences such as retaining her breast, but she also has worries about long-term treatment effects, so she would benefit from support to weigh up her values and preferences against possible treatment effects and her individual risk. There is also clinical information that she will need to understand to help her make an informed decision such as what her HER2 negative and involved axillary lymph node means for her individual risk. In addition, she has family history to consider.

Considering the likely suboptimal outcome with breast conserving surgery and that the patient has preferences but also evident decisional conflict around possible treatment effects versus risk reduction, this patient would definitely benefit from decision support. Decision coaching could help the patient consider her values and preferences and weigh up the harms and benefits of all possible treatment options. The patient decision aid will assist her in deciding whether to have pre-operative chemotherapy.

Strategies to facilitate SDM

Evidence summaries such as clinical practice guidelines and systematic reviews can be useful in supporting decision making, but these do not map well onto decision points in the consultation, nor do they promote patient interaction and discussion.²⁶ This is particularly apparent where the evidence is uncertain or where clinical equipoise exists and therefore benefits and harms need to be weighed up with patient preferences and clinical contexts to individualise decisions.²⁷ Strategies that facilitate adoption of SDM in clinical practice include: 1) patient-mediated interventions such as coaching patients and using patient decision aids, navigators, patient activation and printed educational materials;^{28,29} and 2) health professional-mediated interventions such as education, audit and feedback, and barriers assessment.³⁰ A systematic review of SDM interventions concluded that use of any one or multiple strategies was better than none at all, but no one intervention was clearly superior to the others.⁴

Decision support tools for breast cancer patients

Patient Decision Aids (PtDA)

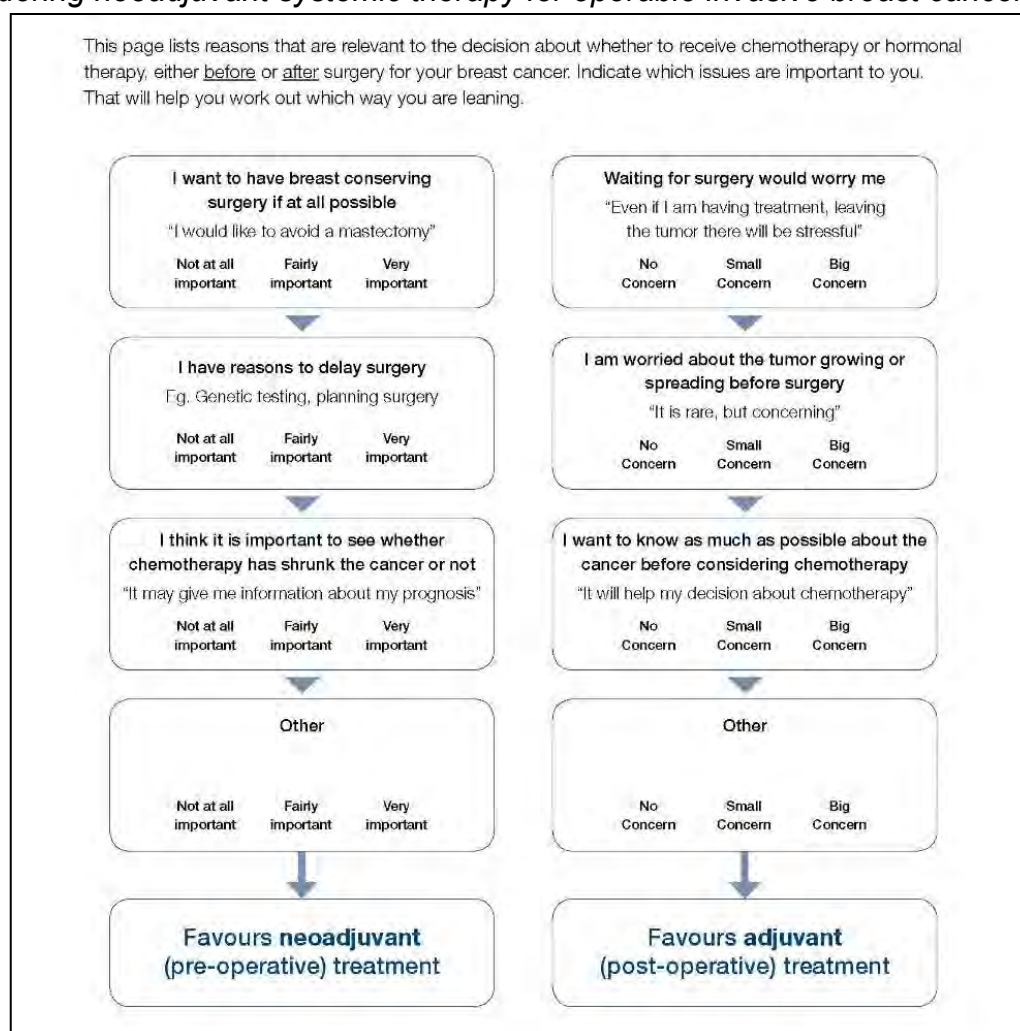
PtDAs are a proven method of implementing SDM principles into clinical practice. A PtDA is “a tool to help people participate in healthcare decisions with the goal of promoting deliberation between patients, healthcare providers and others about these options”.³¹ They are designed to raise patients’ awareness and understanding of treatment options, relevant clinical evidence and possible outcomes, and aid them in developing and communicating their preferences about these outcomes.¹³ They are not designed to convince a patient to choose a particular treatment, rather to clarify the decision for an individual.³²

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The core components that differentiate a PtDA from routine patient information are: presentation of two or more options; balanced, evidence-based content; inclusion of outcome probabilities for each option; and a values clarification exercise (figure 1).³³ A Cochrane review of PtDAs for treatment or screening decisions found PtDAs improve decision-related patient outcomes, including decisional conflict, knowledge, more accurate risk perceptions and expectations of possible benefits and harms; increase participation in decision-making; and help patients reach choices consistent with their values.¹³ Despite these benefits, PtDAs have had variable uptake, partly due to lack of widespread availability and physician awareness.

PtDAs have been developed for a wide variety of healthcare situations,¹³ including most major breast cancer decisions.³⁴ PtDAs have been found to improve breast cancer decision-related outcomes including: decreased decisional conflict, increased knowledge and decisional satisfaction. Notable gaps in the breast cancer PtDA literature include decisions about neoadjuvant systemic therapy and contralateral prophylactic mastectomy, however current studies are underway to fill these gaps.^{35, 36} A PtDA library is available at <https://decisionaid.ohri.ca/>, along with guidance for practitioners in the use and development of PtDAs.

Figure 1: Example of a values clarification exercise from a decision aid for women considering neoadjuvant systemic therapy for operable invasive breast cancer.³⁶



Patient navigators

A patient navigator is an appropriately trained former patient, consumer, volunteer or health professional whose role is to assist patients in receiving timely, quality care that is consistent with their values and preferences.³⁷ This practice has been widely adopted in cancer care. When cancer nurse coordinators have taken on navigator roles, their involvement was associated with better patient adherence to treatment and greater satisfaction with healthcare.^{38,39} However, not all studies have

shown improved decision-related outcomes as a result of patient navigators.⁴⁰ This approach appears particularly suited to patients considered vulnerable as a result of socioeconomic disadvantage, low health literacy, and/or belonging to a culturally or linguistically diverse group. Patient navigators have helped Latina and Black American breast cancer patients with decision-making and communication.^{41,42}

Decision coaches

A decision coach is a trained healthcare professional who is non-directive and provides support aimed to build patients' skills in: thinking about their options (deliberation); preparing for discussing the decision with their healthcare provider (communication); accessing support; and implementing the chosen option.^{4,28}

Decision coaching has application to breast care nursing practice. The role of a decision coach is to diagnose the problem and screen for decisional conflict, and provide options.²⁸ Specifically, a decision coach should: 1) assess and discuss individual patients' decisional needs and factors influencing decisional conflict; 2) provide decision support tailored to decisional needs and relevant information (e.g. options, benefits/harms); 3) assess understanding of the options and evidence, and clarify patients' values and preferred option; 4) monitor and facilitate progress in resolving needs and decision quality; and 5) screen for factors influencing implementation.⁴³

Coaching can be face-to-face or via the telephone, and used alone or in combination with a PtDA. Studies report when decision coaching was used alone or with a PtDA, patients were more knowledgeable, had higher perceived involvement and satisfaction in the decision making process, greater values-choice agreement, and reduced decisional conflict compared to usual care groups.²⁸ One study reported decision coaching, with and without use of a PtDA, reduced healthcare costs when compared with standard care.⁴⁴ Examples of healthcare professionals who have provided decision coaching are nurses, pharmacists, geneticists, health educators, psychologists, and social workers.

Online risk calculators

A key aspect of facilitating patient participation in decision making is availability of tailored information, presented in a comprehensible format, that describe outcome probabilities for available treatment options. Online risk calculators are available for predicting the benefit of adjuvant chemotherapy and/or endocrine therapy (Adjuvant!Online, Predict),^{45,46} sentinel/non-sentinel lymph node metastases,^{47,48} and the ductal carcinoma in situ recurrence (nomograms.mskcc.org).⁴⁹ These tools are designed for the clinician to use and interpret within the consultation, providing patients with details about individual risk. For example, [Predict](#) provides five and 10-year survival estimates based on clinical and pathological factors. It also shows the benefit of chemotherapy, endocrine therapy and trastuzumab, if indicated, as an absolute percentage point increment.⁴⁶ Once the patient understands the risks and benefits including survival outcomes, they can make a more informed decision in line with their own values and preferences.

Models for patient-engagement in decision making

SDM is an active process that begins with a decision to be made. Multiple models exist for patient engagement in SDM,^{27,30,50-52} however common features include: information exchange; decisional needs and decisional conflict assessment; empowering patients to process information and consider their values and preferences; and reaching agreement on the treatment to be implemented. In SDM, both parties exchange information: the clinician offers options and describes their risks and benefits, and the patient considers and shares their values and preferences. Through this process, both the patient and clinician have better understanding of the relevant factors and share responsibility in the decision made.²¹ In breast cancer, multiple health professionals must work together with the patient and each other to ensure that mutually satisfactory outcomes are achieved.³⁰

An important consideration is that patients will likely have different decision making styles. Preferences include leaving all control to the clinician, to full patient control, and anywhere in between. Preferred decision making style may change for different decisions and over the course of their illness.⁵³ This presents a challenge for clinicians for whom SDM is one of a number of competing

priorities for consultation time.²⁶ However, SDM can be effectively integrated into the clinical setting to enhance the quality of care.

Strategies for implementing SDM into practice

Strategies for advancing and implementing SDM into practice have been proposed, including: building SDM into existing healthcare delivery processes (e.g. clinical practice guidelines, clinical care pathways); engaging providers as partners throughout the SDM process and providing adequate training in SDM.⁵⁴ The Institute of Medicine made three recommendations for healthcare process redesign relating to SDM: 1) shared knowledge and free flow of information; 2) evidence-based decision making, whereby patients should “receive care based on the best available scientific knowledge” and that “care should not vary illogically from clinician to clinician;” and 3) the need for transparency, whereby information made available to patients allows them to make informed decisions when choosing among alternative healthcare choices.²

SDM is not dependent on the use of decision support tools, however tools exist to facilitate knowledge translation into practice. For example, PtDAs present knowledge in clear, concise, and user-friendly formats. A variety of approaches can be used concurrently and selected and tailored to individual healthcare settings. There are five steps for implementing PtDAs and decision support in health services from a systems perspective, based on the Knowledge to Action Framework:⁵⁵ 1) identify the decision; 2) find a PtDA or other decision support tool and consider their quality and relevance; 3) identify factors likely to influence their use (including policy) and explore ways to overcome these barriers;^{56,57} 4) select strategies to implement decision support (e.g. education and training in SDM, approaches to overcome barriers); and 5) monitor use of decision support tools, quality of decision support provided, and patient outcomes (e.g. informed values-based decisions, decisional conflict).⁵⁸

Conclusion

SDM is a process of interest to healthcare providers, consumers, and policymakers who want to integrate patient-centred concepts into standards of care to improve patient outcomes and evidence-based healthcare. This process is undertaken between healthcare providers and a patient with a condition with more than one clinically appropriate management strategy to help the patient decide among available options in accordance with their values and preferences. SDM is particularly relevant in breast cancer as there is unequivocal evidence that SDM improves the quality of healthcare decisions, reduces unwarranted variation in care, and improves patient outcomes. Despite these benefits, there remains room for improvement in the use of SDM in the Australian healthcare system. Healthcare providers and policy makers are supportive of SDM, but the challenge is how to effectively integrate and successfully implement SDM into existing healthcare processes. Although SDM can occur without decision support tools, tools now exist that effectively facilitate SDM in clinical practice.

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‘Not one size fits all’: A brief review of models of care for women with breast cancer in Australia

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Abstract

The impact of a breast cancer diagnosis goes beyond the early diagnosis and treatment phases. While survival has improved significantly over the last decade, women report ongoing quality of life (survivorship) concerns as a result of their diagnosis and treatment. There are many models of supportive care available in Australia, including those provided by specialist breast care nurses, general practitioners, peer support groups and cancer support agencies and councils, and more recently those provided through virtual platforms. Most models of care in Australia recognise the need to provide supportive care throughout the treatment trajectory and beyond, yet there remains an inconsistent pattern in providing coordinated supportive care post completion of acute treatment. This review provides a brief synopsis of some of the models of supportive care available within and outside of Australia.

Breast cancer remains the most commonly diagnosed cancer in women in Australia. In 2015, 15,050 women were diagnosed and by the end of 2020 it is estimated this number will increase to more than 17,000.¹ This equates to one in eight women diagnosed with breast cancer by the age of 85.² Despite the increasing numbers diagnosed, survival from breast cancer in Australia is improving. This is partly due to the wide range of treatments available, particularly the personalised therapies that have become available in the last decade.^{3,4} Alongside increased survival, has been the recognition there is more to survivorship than not dying, and quality of life throughout the treatment trajectory and beyond are paramount. Cancer affects both the physical and emotional wellbeing of individuals and their families. It also represents significant costs to the community in terms of the provision of healthcare, infrastructure, absence from work, and in some cases premature mortality,^{3,5} all significant factors when considering delivery of care to women during and following treatment. Supportive care is central to cancer care as it attempts to address the broad spectrum of issues that go beyond immediate treatment and encompass physical, social, psychological and spiritual domains for patients, their family and carers.⁶

Furthermore, the necessity of using a patient-centred, coordinated and multi-dimensional approach in caring for women and their families following a diagnosis of breast cancer has long been recognised by physicians, nurses, allied health teams and the women themselves.⁵⁻⁷ Certainly within many hospital settings there have been serious inroads to providing coordinated care for women following diagnosis and during treatment. This is often through a multi-disciplinary and in many sites an interdisciplinary approach, inclusive not only of the surgical and medical treatment teams but also of breast care nurses, physiotherapy, expert peer support, and counsellors or psychologists.

However, these contemporary models of care still focus on immediate diagnostic treatment and supportive needs with follow up frequently centred on detection of recurrent disease and are usually clinically or hospital-based.^{7,8} This is in direct contrast to other healthcare settings such as cardiovascular care or stroke care, where rehabilitation and prevention of recurrence are integral to the completion of an episode in acute care.⁹ The Institute of Medicine recommended recognising cancer survivorship as a separate phase of cancer care that warrants ongoing attention from all experts in the oncology arena.¹⁰⁻¹²

Research has also demonstrated that returning for specified appointments post-treatment can cause anxiety related to revisiting the cancer experience and because of the potential of the specialist finding a recurrence.⁸ This is despite it being widely acknowledged that the majority of recurrences are found by women themselves.^{8,13} Studies in the UK also found women tended to use their appointments for reassurance but were lacking sufficient information and support relating to day to day living with what for many had become a chronic disease as a result of treatment.^{8,14} They felt attendance at follow up clinics did not always acknowledge or provide strategies for living well after cancer.¹³ They provided a prescription for drugs but no 'prescription' for good health.

Many women would concur their supportive needs go beyond this type of follow up. When intense treatment and interaction with health professionals within the hospital is complete, they often feel isolated and alone, fearful of disease recurrence while struggling to manage side effects and societal attitudes that assume everything is now behind them.

The challenge is to provide cost-effective, well-coordinated, and holistic models of care that meet a variety of needs in a consistent manner throughout Australia. From this perspective, it certainly is not 'one size fits all' and clearly the implementation of assessment tools at commencement and completion of acute treatment may help identify appropriate and individualised supportive care needs.¹⁵

The majority of women diagnosed with breast cancer will survive their disease but will live with the numerous and varied side effects of ongoing treatment and the emotional consequences of their diagnosis. Clearly they can feel a loss of control and confidence and lack the resources and knowledge to empower themselves, especially in areas relating to quality of life, health and wellbeing for the future.^{16,17}

The role of the general practitioner in supportive care

A successful model helping to overcome this and in use in some regions of Australia is that of shared care with GPs. Emery suggests shared care is neither 'hospital' care nor 'primary health' care but a merging or blending of the two, a well-researched and practiced concept in the provision of obstetric care.⁸ Emery also notes systematic reviews of such alternative models have shown no significant difference in patient-related clinical, psychosocial, physical or emotional outcomes. It is also generally accepted after any cancer diagnosis and treatment there is a greater susceptibility to other chronic diseases as well as the risk of other cancers or recurrence.^{8,18,19} GPs have a broad knowledge of the management of multiple health issues and may be better placed to manage them than in the acute oncological clinic setting. GPs are also more likely to be able provide family-centred care which acknowledges the woman's diagnosis is not in isolation of other aspects of her life.^{20,21} However, GPs may have limited time for what can be lengthy conversations around practical and informational management of treatment side effects.

Specialist breast care model of supportive care

A model of supportive care provision that is autonomous yet complementary has evolved from specialist nursing. In both Europe and Australia, the role of the breast care nurse is widely recognised as the link between the woman and other interdisciplinary team members both within and outside the hospital environment.²² Unfortunately in Australia, while this role has been integrated into many tertiary hospitals and in the community primarily through the McGrath Foundation, and is an expectation of women with breast cancer, there are still inconsistencies across roles, competencies and training.²³ Some organisations profess to employ breast care nurses, yet they have not actually undertaken a specialised training breast care nurse course despite the existence of such courses through Australian Universities. Compounding this, qualifications are not necessarily a mandatory prerequisite to practice as a breast care nurse and despite attempts for the role to be accredited with regular competency approval, this still has not occurred. Lack of coordinated training in this arena and role ambiguity can lead to inconsistency in provision of supportive care,^{23,24} inappropriate patient assessment and lack of understanding of the complex nature of breast cancer treatment and side effects and therefore support for the women coping with these.

Supporting these comments, it is widely reported that where specialist breast care nurses are appropriately trained, there are many positive benefits of this role for both patients and other health professionals.²²⁻²⁴ In Australia essential to this role are the core domains of breast care nursing, supportive care, collaborative care, coordinated care, information provision and clinical leadership.²⁵ Each of those domains speak for themselves in describing the role of the specialist breast care nurse as being the link between the woman with her family and the treating team and all community resources. The expectation is the specialist breast care nurse is able to identify physical, informational, emotional, social, psychosocial, psychosexual and spiritual needs and provide flexible and evidence-based interventions around them in the context of collaboration and communication with a broader interdisciplinary framework.²⁶

In the UK, a supportive model of care called 'Moving Forward' was successfully trialled with specialist breast care nurses providing routine follow up for low to moderate risk patients rather than a specialist or shared care by the GP.¹³ In effect this model replaced routine follow up appointments with an education program and in doing so provided a more cost effective use of resources while continuing to address patient anxiety and provide support and reassurance around many aspects of after cancer treatment concerns. These include menopause issues, sexuality concerns, fear of recurrence and lymphedema to name but a few. Importantly this model also provided facilitated peer support through connection with other women undertaking the follow up program. In Victoria, a similar nurse-led follow up program was developed in conjunction with the multidisciplinary team and GPs, it focused on the delivery of a comprehensive screening and survivorship program for women with early or low risk cancer, that was coordinated with specialist or GP medical follow up and was successful in addressing many of the concerns previously discussed relating to the scope of follow up after breast cancer.²⁷

The value and success of the specialist breast care nurse role from the perspective of healthcare providers, community organisations and the women themselves has led to further development to include supportive care for women with metastatic disease. The supportive care needs of these women are notably different from those diagnosed with early breast cancer.²⁸ This group of women are no longer dealing with disease that is curable and for most, brings forth numerous different concerns around family management, ongoing treatment, potential job loss and significantly at this point in time living with a life threatening disease. The literature supports anecdotal information suggesting these women do not receive the same level of support as those diagnosed with early disease. In particular they are often not provided access to a specialist breast care nurse where one is normally available.^{28,29} This usually occurs where clinical pathways do not define identification and referral of this group of women.^{28,29} In Victoria, a model of care is emerging for training specialist breast care nurses at an advanced practice level to manage the diverse and unique needs of women diagnosed with metastatic disease. While similar to the model supporting women with early breast cancer it is a distinctly separate role and continues throughout the treatment trajectory and beyond. Importantly as women are living longer with metastatic disease, there is a clear focus on health promotion and wellness rather than simply disease management.^{28,29}

Peer support

Another equally valuable and often understated model of care is peer support. Peer support has many iterations in the context of cancer care and can be as simple as non-facilitated support where one woman connects with another in the hospital or clinic setting, or more complex support through trained peer support offering facilitated, coordinated and planned face-to-face visits or telephone contact. A number of national groups such as Breast Cancer Network, Dragons Abreast Australia and state Cancer Councils or local organisations such the Wesley Hospital Choices Cancer Care Centre, Chris O'Brien Life House, BreaCan, or the Olivia Newton John Cancer Centre provide this sort of supportive care model. Significantly expert peer support enhances both medical models of care and patient outcomes.³⁰ Indeed, sharing the 'lived experience' in an appropriate and expert manner has been shown to decrease patient anxiety and sense of isolation and contributes to a better quality of life.^{30,31} Additionally, those trained to provide expert peer support have much to offer in provision of educational programs particularly around strategies to enhance cancer survivorship, and managing day-to-day activities during and following treatment.³⁰ They bring with them a diversity of experience, information and perspective and can be excellent patient advocates when provided with appropriate training. They are well placed to support health professionals across both hospital and community domains to provide best possible and comprehensive care to patients.³⁰

As previously mentioned, breast cancer survivors have an increased risk for other health issues either as a direct result of the stage and grade of disease, or because of the treatment side effects which can engender or exacerbate pre-existing co-morbidities such as heart failure. However, at completion of treatment return to the workforce limits ability to attend conventional face-to-face support and survivorship groups. Women from rural and regional areas may also experience geographical isolation and inability to find face-to-face services locally.³² Emerging models of care supplement face-to-face consultations through virtual platforms. These flexible models are able to be offered in an evidenced-based, cost-effective manner, reducing not only costs to an overburdened healthcare system through no need for clinic space and set up but also the cost of time and traveling for the patient.³³

The role of eHealth in supportive care

Research focusing on models of care delivered through Internet, email, Skype, Smartphones and apps, suggest use of this technology to provide information and support can increase psychological and physical wellbeing in cancer patients.^{33,34} Immediate access to information through these mediums have led to greater opportunities for knowledge acquisition, social support and improved health-related quality of life both dependently and independently of health professionals.^{35,36} There are many good examples of evidence-based supportive care websites for women with breast cancer; a short list will be provided at the end of this article. However despite being demonstrated positively in the chronic disease setting,^{33,36,37} there are a paucity of interventions available through the internet that actually empower cancer survivors specifically in the area of physical activity, an important contributor to quality of life.^{33,34} An example of a model of supportive care, addressing physical activity, psychosocial, supportive and educational needs of patients after breast cancer through a virtual platform has been developed.³⁸ The Women's Wellness after Cancer Program and the Younger Women's Wellness after Cancer Program offer a 12 week e-health enabled lifestyle intervention that aims to reduce the risk of other chronic illnesses while addressing day to day concerns for women after cancer treatment and is underpinned by social cognitive theory.^{38,39} All women who register with the program receive health education materials including a hard copy book, an electronic interactive e-book/journal (iBook) and access to an interactive website with an online 'community'. The electronic solutions are integrated through a centralised cloud (internet-based) database to share common information and back up the data. In addition, users can use the online videoconference for personal consultations with a trained and experienced cancer care nurse. The step-wise approach focuses on goal setting around exercise, healthy eating and management of fatigue, sleep concerns, menopausal sexuality issues and cancer prevention and screening. The emphasis on self-efficacy enables women to empower themselves and take back control of their health and trials underway have shown promising results.

In conclusion, a brief overview of some supportive models of care for women with breast cancer has been discussed. This list is not exhaustive and it is important to acknowledge there are numerous models of supportive care and very many other healthcare partners involved in provision of supportive care to women after cancer. These people include social workers, psychologists, counsellors, complementary therapists, physiotherapists, occupational therapists and nurses from other disciplines, providing a range of choices and options for women. What is probably significant is the need for equitable, affordable and coordinated supportive care, and in Australia the most effective model is likely to be one using the trained specialist breast care nurse whose focus is entirely on the full trajectory of breast cancer. The specialist breast care nurse can then be the active link between all the supportive models of care to provide a seamless transition from hospital models of care to the community to obtain the best outcome for patients and their families, while recognising it isn't 'one size fits all.'

Australian supportive care web sites for women with breast cancer

Breast Cancer Network of Australia - (BCNA) bcna.org.au

BreaCan Support - breacan.org.au

Cancer Australia - canceraustralia.gov.au

Cancer Council Australia - cancer.org.au

Choices Cancer Support Centre - wesley.com.au/services/choices-cancer-support-centre

Chris O'Brien Lifehouse - mylifehouse.org.au

Dragon's Abreast Australia - dragonsabreast.com.au

Jean Hailes for Women's Health - jeanhailes.org.au/health-a-z/menopause

McGrath Foundation - mcgrathfoundation.com.au

National Breast Cancer Foundation - (NBCF) nbcf.org.au

Olivia Newton-John Cancer and Wellness Centre - austin.org.au

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Supportive care in advanced breast cancer

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Abstract

Improvements in outcomes for women diagnosed with advanced breast cancer make it imperative to address their wellbeing and medium to long-term supportive care needs. This paper highlights the need for specialised interventions directed towards the amelioration of psychological and social distress for this patient cohort and their caregivers. Screening to identify the supportive care needs of patients should occur at critical time points across the treatment trajectory. While many people respond well to support services to facilitate adjustment to a cancer diagnosis and treatment, as needs become more complex there is a requirement for specific referral to tailored interventions that aim to optimise psychosocial wellbeing. Referral to appropriately skilled psycho-oncology professionals should be the 'gold standard' to help people with advanced disease deal with the existential issues that arise. The lack of availability of skilled clinicians is one of the main barriers to the provision of high level psycho-oncology services. Health professionals and service providers need to consider new technologies and modalities to improve the reach of supportive care interventions for patients who are unable to access traditional face-to-face services. A challenge for psycho-oncology professionals is to undertake research to make psycho-oncology services more accessible and meaningful to the most vulnerable populations.

Major improvements in medical treatment of advanced breast cancer have resulted in improved survival, but with the potential for long-term psychosocial morbidity, characterised by persistent and elevated emotional distress. It has been estimated that around 7% of breast cancer diagnoses are advanced or metastatic.¹ The five year survival rate for women with advanced breast cancer was approximately 40% in 2012.² While the five year survival rate is relatively high, it is often associated with significant burden of disease and associated emotional distress,³ centring around uncertainty about the future and the impact of the illness on close family members.⁴ There are high supportive care needs in this patient cohort, as well as for their carers and family.⁵ A systematic review by Fiszer and colleagues of the supportive care needs of women with breast cancer found that predictors of higher level of needs included women with advanced disease stage, greater symptom burden, shorter time since diagnosis, higher levels of distress and younger age.⁴ Supportive care is defined as incorporating physical, psychological, social, spiritual and informational domains. However for the purposes of this review, the focus will be on psychological and social domains.

A number of guidelines exist to inform health care professionals about the supportive care needs of people with cancer; including the United Kingdom NICE guidelines,⁶ and from the United States the National Comprehensive Cancer Network,⁷ Institute of Medicine,⁸ and the American Cancer Society / American Society for Clinical Oncology *Breast Cancer Survivorship Care Guideline*.⁹ Australian guidelines for providing psychosocial care for people with cancer have been published by Cancer Australia, including the *Clinical practice guidelines for the psychosocial care of adults with cancer*¹⁰ and the *Clinical guidelines for responding to suffering in adults with cancer*.¹¹ Recently, guidelines and clinical pathways have been published for the management of anxiety and depression in adults with cancer both nationally and internationally.^{12,13} In addition to these guidelines which have been developed for use by health professionals, there are many resources developed for consumer use through government and non-government organisations.

Screening for distress

Given the high supportive care needs among this population, there is an imperative for treating health professionals to identify those at risk for persistent psychosocial distress and refer to the relevant member of the psycho-oncology team. Healthcare professionals need to monitor and reassess

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patients at multiple time points across the disease trajectory and make appropriate referrals, as supportive care needs often change over time. Referral, delivery of interventions and review of psychosocial outcomes need to be conducted in a timely manner to optimise psychosocial wellbeing.¹⁴

While there is general agreement among health professionals that all people with cancer should be offered basic resources to enhance their information and supportive care needs, there is no national consensus around the screening of cancer patients to determine their needs and to guide referral for those whose needs are higher. The process of undertaking screening is variable with divergent views about who should screen, at what time points and the screening tool. The Distress Thermometer is the most widely used instrument for screening distress in breast cancer patients.¹⁵ Other measures commonly used to assess distress in breast cancer patients include the Hospital Anxiety and Depression Scale,¹⁶ and the Edmonton Symptom Assessment Scale.¹⁷

Access to services

Even if screening is deemed appropriate and is conducted routinely, further questions arise as to the availability of suitably qualified and trained health professionals to respond in a timely manner to patients whose screening results indicate their need for referral to specialised psycho-oncology services. This problem is exacerbated for people living in regional, rural and remote locations, where the presence of dedicated psycho-oncology health professionals who can provide face-to-face interventions is varied at best, and likely to be missing or constricted in range of specialties available.

Optimal care pathways have been developed (for example, a report endorsed by Cancer Australia and Cancer Council Victoria¹⁸) to direct health care professionals towards timely and appropriate referrals for people with cancers of particular types (for example breast, ovarian, colorectal, melanoma). However, they are dependent upon the availability of service providers with specialist knowledge of psycho-oncology and often those specialised in psycho-oncology provide services across all disease sites. The manner and strategies for meeting the supportive care needs of people, particularly those in sub-groups at high risk of severe and ongoing distress, are left largely unaddressed. If there is no access to onsite psycho-oncology services at cancer treatment centres, other options for supportive care may be found through self-help or community-based support groups, psychologists, mental health specialists and other counsellors in private practice, through non-government organisations or breast cancer specific support organisations such as the Breast Cancer Network Australia. Cancer specialists and patients need to be mindful that the level of service provision in external agencies is highly variable. There is usually no mechanism for quality assessment or control; nor any minimum requirements for delivering such a service. The term counsellor is not protected.

Interventions

Fitch's model of supportive care recognises that most patients require screening for general support and information;¹⁹ however as the psychosocial needs become more complex, specific referral and intervention is required to ensure tailored supportive care is implemented. In response to this, increasingly psycho-oncology clinicians have developed specialised interventions to consider the unique needs of this population. Managing psychological morbidity in people with advanced breast cancer is often based on psychological therapies such as cognitive and behavioural therapies, mindfulness, acceptance and commitment therapy and supportive expressive therapy. In the current literature it is difficult to compare the relative effectiveness of therapies due to the variability in quality of the trials conducted.²⁰

People with advanced cancers are confronted with many existential challenges including those around death, loss, meaning and spirituality. People with advanced cancer are at increased risk of developing death anxiety with one study of 60 people with metastatic cancers reporting around 32% of participants having moderate levels of death anxiety, with the concern causing the greatest distress being the impact of their death on their loved ones.²¹ Low self-esteem, increasing age, having younger children and experiencing physical symptoms such as changes in physical appearance and pain were associated with death anxiety.²¹ In recognition of these existential challenges, specific

therapies have been developed for people with advanced cancer. These include dignity therapy, meaning and purpose therapy, supportive expressive group therapy and meaning-centred therapy.

Pharmacotherapies play an important role in the management of psychological morbidity in people with cancer especially for those with more severe psychiatric disorders and also for those who are unable or unwilling to engage in psychological therapies.²² Increasingly, there has been recognition of the role of pharmacotherapies in managing not only psychiatric conditions but also in assisting with physical symptoms such as nausea, hot flushes, disturbances in sleep and pain.²²

Similarly, the role of psychological interventions is being recognised in managing symptoms associated with the burden of disease such as managing cachexia, pain, breathlessness, fatigue and insomnia. Therapies such as cognitive behavioural therapy have also been used for the management of specific concerns such as pain,²³ fatigue,²⁴ and sleep disturbances²⁵ in a cancer cohort. Increasingly the role of lifestyle interventions, such as exercise programs, in symptom management in advanced cancer are being explored.²⁶

Furthermore, with improved technologies, there have been increasing alternatives to the traditional face-to-face method of delivery of therapies. Technologies such as telephone-based therapies, online interventions and computer-mediated videoconferencing technologies are being explored as possible mechanisms for psychotherapeutic interventions. Advantages of having a range of modalities for delivering therapy include improved accessibility for people unable to attend appointments due to illness or distance; these technologies may also be more acceptable to people who are reluctant to engage in traditional face-to-face therapy.

Further areas of investigation are warranted for some of the more complex cohort of the advanced breast cancer population. Many people diagnosed with advanced breast cancer will be concerned about issues of advance care planning and end of life care at the time it becomes clear to them that their cancer is progressive and incurable. In most instances this is a conversation which is best initiated by health care professionals. Most people have not thought about their choices and management options in end-stage disease,²⁷ and few people engage with their families in discussions about how to instigate strategies to maintain comfort and dignity at end of life. Issues around a will, ongoing care of dependent children, cognitive capacity for decision-making, funeral wishes and accessing financial and statutory entitlements, may become fraught for both patients and their caregivers in the context of the emotional distress inherent in facing end of life.

Facilitating these discussions in a timely manner can contribute immeasurably to the therapeutic acceptance of imminent death; and can serve as a cornerstone of anticipatory grief therapy for family members. Guidelines have been developed to assist health care professionals in delivering appropriate interventions at end of life; for example, The Australian Centre for Health Research (ACHR) 2016 report on *Conversation – Creating Choice in End of Life Care*²⁸ and Australian Commission on Safety and Quality in Health Care National Consensus Statement (2015): *Essential elements for safe high quality end of life care*.²⁹ In addition [Advance Care Planning Australia](#) provides comprehensive information and resources for health professionals and consumers on all aspects of end of life planning. Given the challenging nature of these conversations, continued support and input by health care professionals can enhance progress towards satisfactory completion of this process.

Vulnerable populations

There are a number of sub-populations of people with advanced breast cancer who are known to be at high risk for elevated distress. These include people of Aboriginal and Torres Strait Islander descent, people who are culturally and linguistically diverse, men, younger women, people with pre-existing mental illness, people who identify as lesbian, gay, bisexual, transgender, queer or intersex, people with familial cancers, older people and women with pregnancy-associated breast cancer. While most of these groups are referenced in general guidelines, additional specific resources have been developed for people who are Aboriginal and Torres Strait Islander,³⁰ older people³¹ and people who are culturally and linguistically diverse.³²

Health care professionals and administrators need to be aware of the health disparities that exist between people diagnosed with advanced breast cancer and should ensure delivery of supportive care services to these vulnerable populations.⁹ The psycho-oncology literature increasingly reinforces

the efficacy of psychological interventions to ameliorate distress in people with advanced cancer. However, the participants in most of the reported studies are largely women of younger age, usually English-speaking, with high educational levels and socio-economic status. Research evidence is lacking for people who fall within the groups whose supportive care needs are likely to be higher; including CALD, ATSI, regional, rural and remote, people with low health literacy and those with a history of mental health concerns.

Recommendations

With an increasing number of people living with advanced breast cancer there is a concomitant demand for supportive care services that is not matched by the limited specialised resources available to address psychosocial morbidity, especially for those at highest risk of significant morbidity. A requirement for patient-centred care is now well integrated into the health system across all levels of service delivery. Ideally, cancer patients should have access to a networked approach to healthcare, encompassing collaborative partnerships that transition seamlessly from primary care to community-based settings and through to tertiary cancer centres.

While the 'gold standard' comprehensive cancer centre service would embed a dedicated, specialised psycho-oncology team within it, this is rarely achieved in Australian settings especially in non-metropolitan areas. There is thus an impetus to consider alternate models of service delivery. Such models may include telehealth, e-interventions and cancer-specific training for generalist psychosocial service providers. Irrespective of the psycho-oncology service delivered, it is imperative that the focus of therapeutic interventions is on the needs of all people with advanced breast cancer and their families. Most current guidelines and evidence-based interventions have been developed for people whose socio-demographic characteristics place them in the category of those who often have better access to resources and psychosocial support than those who have been identified at highest risk of persistent psychosocial distress. The emphasis for the future needs to be on developing supportive care resources for those whose social and health inequalities are most apparent.

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Sexual dysfunction after breast cancer: A review of treatments and strategies

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Abstract

Background: Sexual dysfunction is an extremely common event affecting the wellbeing of women with breast cancer. It includes physical and psychological factors that may occur during early treatment and extend into the years following diagnosis. Without appropriate recognition and management, quality of life may be significantly reduced to a point where treatment compliance is impacted.

Aim: To assist healthcare workers to identify and manage sexual dysfunction in patients with breast cancer.

Methods: This article reviews both physical and psychological aspects of sexual dysfunction, together with the potential impact that breast cancer treatments will have on sexuality; additionally strategies for management are described.

Conclusion: Strategies to improve the recognition of sexuality issues together with approaches to management that are acceptable for the patient while not increasing breast cancer recurrence risk are vital.

Sexual dysfunction is one of the most prevalent issues among women with breast cancer, affecting women during their initial treatment and well into their survivorship years. It is categorised into three main domains; lack of sexual interest/arousal, inability to achieve orgasm and genito-pelvic pain.¹ The prevalence of sexual dysfunction in women with breast cancer was highlighted in a report on sexual wellbeing commissioned by the Breast Cancer Network Australia.² In this study, up to 89% of women surveyed reported significant changes in their sexual wellbeing. Failure to appropriately identify and manage these symptoms resulted in overall poor quality of life.² This review will focus on understanding the impact that breast cancer treatments have on sexual dysfunction and an approach to its management.

Screening and identifying sexual dysfunction

Screening and evaluating for sexual dysfunction should be part of routine care for breast cancer patients. Common barriers in doing so include limited time for patient assessment, perceived higher priority issues for the appointment and/or clinician or patient embarrassment or discomfort.³ It is estimated that less than 20% of breast cancer survivors seek medical help for sexual issues.⁴ The challenges to sexual functioning for women who have been treated for cancer are numerous. Women report reductions in multiple sexual domains including frequency of sex, arousal, interest, pleasure, satisfaction and intimacy. It is likely that these issues relate to multiple treatment effects including fatigue, pain, psychological distress, body image concerns and medically-induced menopausal changes (e.g. vaginal dryness, hot flushes and weight gain).⁵ Given the rapid and life-threatening nature of cancer, women have little time to adjust to symptoms such as reduced sexual desire, lack of sensation and difficulties with orgasm.⁶

Women undergoing surgery for breast cancer face the loss of a 'signifier of feminine sexuality' and a 'source of erotic pleasure' either in losing their breast or having it surgically altered.^{6,7} Feeling less feminine, and maimed and mutilated due to loss of the breast and scarring, are among the many body image concerns of breast cancer patients which challenge self-confidence, leading to worry about desirability and rejection.^{5,8} Studies comparing surgical interventions have produced inconsistent results. The greatest impact on sexual life appears to be with mastectomy alone, followed by breast conserving surgery, with the least impact occurring for women who underwent mastectomy with

delayed reconstruction.^{9,10} In a study comparing delayed implant breast reconstruction and deep inferior epigastric artery perforator flap, no difference was found on improvement to body image or on sexual satisfaction.¹¹

Radiotherapy brings its own challenges that are likely to impact on sexual functioning, albeit usually temporary, apart from chronic fibrotic changes which might impact on positioning during intercourse.¹² Women complain of pain or discomfort from skin toxicity, breast edema and sensory changes as well as changes to the appearance of the breast such as redness and peeling which can range from mild to severe.¹³ Women also report difficulties with sleeping, fatigue, worrying and drowsiness.¹⁴⁻¹⁶ Threats to body image and sexual functioning are well conveyed by women who express avoidance of being naked and being touched due to disfigurement arising from radiotherapy.¹³

Increasingly, based on improved cancer outcomes, aromatase inhibitors (AIs), are being recommended as adjuvant therapy for the management of breast cancer either as a single agent in post-menopausal women or in combination with GnRH agonists (goserelin) for premenopausal women.¹⁷⁻²⁰ In contrast to selective estrogen receptor modulators (e.g. tamoxifen), which acts as an estrogen agonist in some tissues (for example, bone or endometrium) and an antagonist in others (for example, breast), AIs produce profound suppression of estrogen in all tissues. Vaginal bleeding and discharge is more common with tamoxifen, however there is more reported vaginal dryness, painful intercourse (dyspareunia), and loss of sexual interest with AI use.^{21,22}

The most significant predictors of sexual difficulties include vaginal dryness and lower perceived sexual attractiveness.²³ Lubrication difficulties as well as problems with desire and arousal appear to be prevalent among young women treated for breast cancer.^{23,24} Sexual pain arising from vaginal dryness is commonly reported by women who have been treated for breast cancer.⁸ The changes arising from the sudden onset of menopause (either via surgical or medical induction) can be particularly traumatic for women who were not anticipating this alteration to their sexual self at this stage of their lives.⁶

Management of sexual dysfunction after breast cancer

The multifactorial nature of sexual dysfunction in the context of a breast cancer diagnosis generally defies a 'quick fix'; with each issue (psychologic, interpersonal, and physiologic) often requiring an individual approach to management. Available modalities range from education, counselling, and lifestyle interventions to mechanical devices, pelvic floor exercises, and pharmacotherapies. This section will focus on evidence-based strategies for sexual dysfunction in three domains; genito-pelvic pain, lack of sexual interest/arousal and inability to achieve orgasm.

An initial assessment of sexual complaints includes a history of active medical co-morbidities (including a detailed oncological, surgical, gynaecological history) together with sexual history. It is important to remember that sexuality encompasses more than genital functioning. The additional impact of a non-cancer-related chronic illness, fatigue, bladder and/or bowel dysfunction, changes to genital sensation, altered or decreased mobility, use of medications other than those for cancer together with sexual self-image and self-esteem all affect the sense of sexual self and sexual functioning

Clinicians are advised to enquire about vaginal dryness and sexual functioning at regular intervals during the patient's longer term follow up. Use of a sexual symptom checklist, such as the Female Sexual Function Index; a validated questionnaire designed to assess key domains of sexual function including desire/arousal, lubrication, orgasm, satisfaction and pain, is also advocated. While designed for use in clinical trials, the Female Sexual Function Index is brief and can be used as a bedside primary screening tool.²⁵

Psychosocial factors

Partner support is critical to sexual adjustment following treatment for breast cancer.²⁶ Women worry about the impact of sexual changes on their intimate relationship.⁷ One study identified lack of partner understanding feelings being associated with greater sexual problems.²⁷ Notably the quality of the partner relationship may have an even greater impact on sexual functioning than the chemical and physical damage arising from cancer treatment.²⁸ It would appear women's positive feelings about their relationship, about being cared for and understood, along with the capacity for communicating

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about concerns and working together toward solutions may reduce the likelihood of sexual dysfunction.²⁸ A partner's unconditional acceptance can be profoundly healing, restoring a woman's sense of femininity and desirability.²⁹

Partner communication is among the most common psychosocial concerns identified by women who have been diagnosed with cancer.³⁰ Sexuality concerns are also among the most avoided topics discussed between breast cancer-affected women and their partners and perceived avoidance of these topics is associated with poorer coping and mental health.^{31,32} Health professionals are ideally placed to model that it is healthy and normal to talk about sexual functioning and that sexual functioning is an important quality of life issue.

A useful model for discussing sexual concerns is the PLISSIT model which outlines four levels of increasing intervention depending on what the patient is seeking and their comfort in discussing sexual concerns.³³ Briefly, the first level Permission is about seeking and giving permission to voice sexual concerns. Statements such as; "It is not uncommon for women to experience challenges to sexual functioning when they undergo treatment for breast cancer; is it ok with you if we talk about how your cancer treatment may have impacted on your sex life?" might be an introduction for the patient to discuss issues. The second level Limited Information pertains to the provision of brief information and correction of any myths regarding the patient's sexual concern. The third level, Specific Suggestions, utilises a problem solving approach to each of the patient's specific sexual concerns after exploration of each issue, its meaning for the patient; how is it impacting on her relationship, sense of self, and quality of life; and what strategies she previously tried to resolve the issue. The fourth level Intensive Therapy is where we might refer our patient to another healthcare provider (e.g. psychologist, psychiatrist, sex therapist, physiotherapist, gynaecologist or other relevant medical specialist) for more specialised therapy.

Therapy for women experiencing sexual difficulties following breast cancer treatment can be sourced from a number of professional bodies. Medicare rebates are available for patients with sexual disorders to be treated by a psychologist under the Better Access initiative. The Australian Psychological Society referral service or their online 'Find a Psychologist' search engine can direct people to psychologists who indicate that they work with sexual difficulties. It is also possible to specify 'cancer support' to locate a [psychologist](#) who specifically works with these patient groups. The [Royal Australian & New Zealand College of Psychiatrists](#) also offers a search engine to locate psychiatrists who work with cancer patients and/or sexual disorders. The [Society of Australian Sexologists](#) represents health and allied health professionals working in the area of sexual health and can direct people to accredited psychosexual therapists in their state. The [Australian Society of Sex Educators Researchers and Therapists](#), is a further multi-disciplinary professional organisation that can direct people to accredited sex therapists. Some couples might also benefit from relationship counseling particularly if there were problems in the couple's relationship prior to, or in addition to the sexual dysfunction. Sex therapy is not likely to be helpful if a couple have lost the capacity to speak constructively to each other; couples need to feel safe in their communication with each other before they can begin to talk about sex (www.relationships.org.au).

Genito-pelvic pain (dyspareunia and vulvovaginal atrophy)

Reduced levels of oestrogen from menopause or endocrine therapy can result in vaginal atrophy and dryness. These changes to the vaginal epithelium can cause dyspareunia resulting in loss of sexual arousal and desire. Inflammation of the vaginal epithelium and changes in vaginal pH and vaginal flora may additionally contribute to urinary symptoms and recurrent infections.³⁵ Management of vulvovaginal atrophy and dyspareunia includes lifestyle measures, non-hormone and hormone treatments.

Signs of vaginal atrophy include dryness, pallor, and tissue fragility, erythematous change denotes inflammation. The Vaginal Health Index is a clinician assessment tool that evaluates the appearance of vaginal mucosa (elasticity, paleness, vaginal discharge, mucosal integrity, moisture) and vaginal pH. Each factor is scored on a scale of 1 to 5 and then summed up to provide the Vaginal Health Index score. A score of less than 14 indicates vaginal atrophy.³⁴

Lifestyle modifications

Irritants such as perfumed or dyed toilet paper; tight-fitting clothing; use of soaps, detergents, or fabric softeners; talcum powder; hygiene sprays; deodorant pads; rubber or latex products, including

diaphragms or condoms are increase the risk of dermatitis and inflammation. Simple lifestyle modifications include avoidance of soap and other irritants together with use of soap-free washes to reduce further vaginal dryness. Regular vaginal sexual activity increases the blood circulation to the pelvic organs and in itself may help to reduce the symptoms of vulvovaginal atrophy.³⁵ Unfortunately, these measures alone are usually insufficient to significantly improve symptoms in breast cancer survivors.³⁶

Vaginal lubricants and moisturisers

Topical non-hormonal therapies include vaginal lubricants and moisturisers. The effects of these products are temporary and do not reverse the underlying atrophic process. Repeat topical application is usually required. Vaginal lubricants and moisturisers are applied to the external genitalia, vaginal introitus, and vaginal mucosa during sexual activity to reduce irritation and friction. Vaginal lubricants are short-acting and have no effect on vaginal pH or underlying moisture content. Examples of vaginal lubricants include KY jelly© and Astroglide©.³⁶

One randomised controlled study compared the efficacy of water-based and silicone-based lubricant in reducing discomfort during sexual activity in postmenopausal breast cancer patients. There was no statistically significant difference in efficacy between the two types of lubricants (difference 0.7, 95% confidence interval (CI) 0–1.4, $p = 0.06$). Silicone-based lubricant did improve pain/discomfort during penetration compared to water-based lubricants in a post hoc analysis (odds ratio 5.4, 95% CI 1.3–22.1, $p = 0.02$). Patient preference was for silicone-based lubricants. However, despite these findings, 88% of patients continued to report clinically significant sexually-related distress with use of either lubricant.³⁷

Vaginal moisturisers such as Replens© contain polycarbophil, an acidic bioadhesive polymer that binds to the vaginal mucosa and releases water and electrolytes to induce vasodilation. This results in improved vaginal mucosal hydration and pH. Replens© was evaluated in a phase III study in women with breast cancer with four weeks of Replens© use, followed by a one week washout period followed by four weeks of placebo lubricating product, or the reverse order. Reduction in average vaginal dryness was similar between the two groups (64% Replens-placebo vs 62% placebo-Replens, $p=0.3$). Improved dyspareunia scores were detected in the Replens-placebo group compared to the reverse order (60% vs 41%, $p=0.05$). Symptom improvement occurred predominantly within the first two weeks regardless of type of lubricant and remained constant thereafter.³⁸

The use of a vaginal suppository containing vitamins A and E together with hyaluronic acid may also increase vaginal lubrication and alleviate irritation from atrophic and other forms of vaginitis. Patients reported a significant improvement in symptoms and in general compliance was high.³⁹

Fractional microablative CO₂ laser therapy

Fractional microablative CO₂ laser represents a novel, non-hormone based approach in treatment of vaginal atrophy. This intervention is advantageous over topical treatments with its potential for longer-term efficacy. Laser therapy applied to the vaginal mucosa aims to improve microcirculation below the level of the mucosa resulting in formation of new collagen on atrophic tissue.^{40,41} Use of fractional microablative CO₂ laser therapy in women with breast cancer has only been evaluated in a small pilot study involving 50 post-menopausal patients. Following three treatment sessions, there was significant improvement in dyspareunia evaluated using a visual analog scale. This pilot study indicated the intervention has a high rate of patient satisfaction with minimal adverse effects.⁴² More work is required to specially evaluate use of laser therapy in women on aromatase-inhibitors and assess degree of improvement compared to other interventions.

Topical oestrogens

In one observational study, women with recurrent breast cancer on endocrine therapy were evaluated for the risk of recurrence based on whether or not they had been additionally prescribed vaginal estrogen therapy. There was no association between recurrence risk and vaginal oestrogen use (RR 0.78, 95% CI, 0.48-1.25).⁴³ Another cohort study addressing a similar question involved 1472 patients with a history of breast cancer with use of topical oestrogen treatments occurring in only 69 of these women. Although the numbers were small, use of topical oestrogens was not associated with worse disease-free survival. However without randomised data, the safety of topical oestrogen remains unclear.

Hormone replacement therapy

Use of systemic hormone replacement therapy (HRT) in a general population of women may alleviate symptoms of vaginal atrophy. There is conflicting data with regards to the use of HRT in women with a history of hormone-positive breast cancer. With the end point of any new breast cancer event, the HABITS trial randomised women with previous breast cancer to HRT or best treatment without hormone replacement. The study closed early after 434 women and 2.1 years of follow up citing an unacceptable risk for women exposed to HRT after breast cancer. During this time, 26 women in the HRT group had a new breast cancer event compared to seven in the non-HRT group.⁴⁴ The Stockholm trial randomised 378 women to HRT or non-hormonal therapy. Despite no excess risk after four years of follow-up, this trial closed early when the HABITS trial reported increased breast cancer recurrence with HRT exposure. Results after 10.8 years of follow-up have been published with no difference found in new breast cancer events; 60 in the HRT group vs 48 among non-HRT group (hazard ratio 1.3, 90% CI 0.9-1.9). As the trial closed prematurely, the data does not allow well-founded conclusions regarding the safety of HRT. At present HRT is considered contraindicated in many consensus guidelines.⁴⁵

Androgen therapy

Testosterone has been hypothesised to induce vaginal epithelial proliferation as an alternative to oestrogen therapy. Use of topical testosterone has been evaluated in one small phase I/II study of postmenopausal breast cancer patients on AI therapy.⁴⁶ Daily application of topical testosterone at 300mcg (n=10) or 150mcg (n=10) was prescribed for 28 days. Estradiol levels, testosterone levels, symptoms of vaginal atrophy, vaginal pH and vaginal cytology were compared before and after therapy. At 28 days, topical testosterone at both doses was associated with improved symptoms of dyspareunia (=0.0014) and vaginal dryness (p<0.001) with raising estradiol levels. Only the 300mcg dose resulted in reduction in vaginal pH and improved the vaginal maturation index. Findings from this trial require reproducible results in controlled studies before clinical recommendations can be regarding testosterone.

Two studies using intravaginal dehydroepiandrosterone have evaluated the treatment of vaginal atrophy and dyspareunia including one with patients with a history of breast cancer.^{48,49} Use resulted in decreased pain from sexual activity (p=0.0002), reduction in vaginal dryness (p=0.004) and vaginal pH (p<0.0001).⁴⁷ In 441 postmenopausal women with a previous breast or gynecologic cancer, an improvement in the most 'bothersome' symptom was demonstrated with a statically significant improvement in sexual function at 12 weeks compared bioadhesive moisturiser alone.⁴⁸

Conclusion

The diagnosis and management of breast cancer result in sexual dysfunction in the majority of patients, both in the short and long term and as such, can impact on quality of life in breast cancer survivors. Symptoms of sexual dysfunction, include psychological and physiological factors and if left undocumented and untreated may lead to non-compliance or discontinuation of longer term therapies in particular. Optimising strategies to improve the recognition of sexuality issues together with approaches to management that are acceptable for the patient while not increasing breast cancer recurrence risk are vital.

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Fertility after breast cancer and strategies to help women achieve pregnancy

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Abstract

Around a quarter of breast cancer patients are premenopausal at diagnosis. As cancer treatment can increase premature menopause, fertility and pregnancy after breast cancer are important issues for many women. This review summarises the literature on fertility after breast cancer and strategies to help women achieve pregnancy – specifically, the risk of infertility, fertility measurement after cancer, the impact of future pregnancy on prognosis, birth outcome, contraception, the psychosocial impact of infertility and pregnancy and assisted reproduction after breast cancer. Pregnancy rates after breast cancer are low. Nonetheless, it is important that women are made aware of the potential impact on their fertility and given information regarding their options for fertility preservation before treatment and about their options after treatment to achieve a pregnancy. Decisions to conceive are challenging as women are weighing up their desire for children against fears of recurrence and potential inability to detect future cancers. Providing evidence-based information and psychosocial support to breast cancer survivors who wish to conceive is an important clinical issue in need of greater attention.

Approximately 25% of breast cancer patients are premenopausal at diagnosis.¹ Combined with the social trend of later childbearing,² there are growing numbers of women diagnosed with breast cancer before they have started or completed their families. Survival rates from early breast cancer are high but effective treatments commonly impair ovarian function and reduce fertility.^{3,4}

Clinical practice guidelines recommend discussion of the impact of cancer treatment on fertility and fertility preservation options *prior to* commencing gonadotoxic treatment.^{5,6} Although there is no guarantee of future parenthood, cryopreservation of embryos or oocytes gives women additional options for achieving a pregnancy if they become infertile. Ovarian tissue cryopreservation, although still considered experimental, may also be an option particularly if delays in treatment are not feasible. Ideally, fertility preservation should occur prior to commencing gonadotoxic therapy.⁵ In practice, when women are faced with a new cancer diagnosis, decisions relating to fertility presentation may seem overwhelming and often, these decisions are delayed until after adjuvant treatment.

Risk of infertility and predicting fertility after breast cancer treatment

Understanding the impact of breast cancer treatments on fertility is made more complex by the range of outcome measures used and the variation in baseline ovarian function in study participants. Post-chemotherapy amenorrhoea has been widely used as a marker of ovarian function, but definitions of amenorrhoea have varied between studies and age-groupings are inconsistent.⁷

It is well recognised, however, that the most commonly used adjuvant chemotherapy regimens are gonadotoxic and adversely affect fertility by reducing the primordial follicle pool.⁸ The classic cyclophosphamide-containing regimens are associated with rates of amenorrhoea ranging from 8%-98%.^{3,9,10} Taxane-containing regimens are associated with amenorrhoea in 15-85% of cases.^{11,12} The limited data on women under 35 show extremely low rates of chemotherapy-induced amenorrhoea, 0-10% in most studies,¹³ this circumstance becoming pronounced (and likely permanent) in patients over 40 years of age.¹⁴ Those who remain amenorrhoeaic for one year are likely to remain so

permanently.^{13,15} Although modern chemotherapies appear to be less toxic than older therapies, with many young women remaining pre-menopausal following treatment, they may still have varying degrees of ovarian dysfunction.¹⁶⁻¹⁸ It has also been suggested that the risk of ovarian failure after chemotherapy may be underestimated because of the use of amenorrhea as a proxy for fertility.¹⁹

Radiotherapy and endocrine treatment do not appear to reduce long-term fertility. With proper radiation technique and use of radiation shields there should be no adverse impact on fertility and birth outcomes.^{20,21} The impact of endocrine treatment is less clear. Although by definition endocrine treatment causes amenorrhea, most patients regain their menses after completion of therapy.¹⁰ The relative contribution of tamoxifen to treatment-induced amenorrhea is debated since most young patients have also received adjuvant chemotherapy. Some studies show an increased incidence with the addition of tamoxifen, others report no impact, with tamoxifen having apparently less effect on amenorrhea in younger women.^{7,17} Women need to consider that their ovarian reserve will naturally decrease when on endocrine treatment (5-10 years).¹⁷

Measuring fertility after breast cancer

Measuring fertility after cancer treatment is challenging and should reflect both the quantity and quality of gametes. Many published studies have used menstruation as a marker of ovulation, but it is not a reliable surrogate for this.

Indirect markers of fertility include age, endocrine markers such as follicle stimulating hormone (FSH), luteinising hormone, estradiol, inhibin B (InB), antimullerian hormone (AMH), and other measurements such as antral follicle count (AFC) and ovarian volume (ultrasound). Most information about these markers comes from the in vitro fertilisation context (i.e. women who are undergoing ovarian stimulation and/or have a history of infertility) and may not be directly applicable to spontaneous conception.

Growing information about the role of these indicators in the cancer population suggest that cytotoxic chemotherapy results in consistent measurable changes including lower AMH,^{17,22-24} AFC,^{17,23,24} InB,^{17,22,24} Ovarian volume,²⁴ and higher FSH^{17,23,24} and an increase in amenorrhea. Of these, AMH may be the most objective and consistently accurate as AMH reflects follicle numbers at early stages of development and does not vary substantially during the menstrual cycle.²³ However, it is still uncertain whether AMH reliably predicts ovarian recovery after chemotherapy.²³ Limitations of AMH include wide variations within age groups, lack of standardisation of assays and the possibility that women with breast cancer may have a lower AMH prior to chemotherapy compared to healthy age-matched controls.²⁵ Generally, none of these markers can reliably predict pregnancy or menopause.²⁶

In summary, current measures of fertility after cancer treatment have limitations. A combination of clinical information and measures of circulating AMH, AFC, FSH and InB will provide some insight into future reproductive potential and likely need for assisted reproductive intervention.

Prevalence of pregnancy after breast cancer

Few women become pregnant and give birth to a live infant after breast cancer. In Australia, a population-based descriptive study using the Western Australian data linkage system reported that only 4.8% of women with breast cancer (out of 2539) under the age of 45 had at least one subsequent pregnancy.²⁷ International studies report pregnancy rates of 4%-15%.^{16,27-29} This low pregnancy rate is surprising considering the importance of fertility reported by women with breast cancer. Factors contributing to this low rate may include treatment-induced infertility, fear of recurrence, poor understanding of the risks, insufficient counselling, and patient preference.^{16,27,29}

Impact of future pregnancy on prognosis

Pregnancy is associated with high circulating concentrations of sex steroids and this observation has led to concerns about the safety of pregnancy following hormone-sensitive breast cancer.³⁰ Existing evidence is reassuring that pregnancy after breast cancer does not increase morbidity or mortality, potentially due to a 'healthy mother effect' and may even confer a survival benefit.^{31,32} The mechanisms underlying this apparent survival benefit are not known, although they have been linked

with potential immunological changes associated with pregnancy.^{33,34} Overall, although the mechanisms are not fully understood, the clinical outcomes following pregnancy after breast cancer appear reassuring. However, in clinical practice, oncologists commonly advise against pregnancy for at least two to three years following diagnosis when the risk of recurrence is highest.³⁵⁻³⁷ However current best evidence suggests that a 6-12 month delay after diagnosis may be sufficient.^{31,38,39} Others have reported that because younger women have significantly lower survival rates and higher local and distant relapse rates than older women, those under 33 years of age might be better advised to delay pregnancy for at least three years, to reduce the risk of recurrence.³⁷ These same authors advise that patients with lymph node involvement should consider deferring pregnancy for at least five years after treatment and those with distant metastases should not consider conception at all because of treatment intensity and poor prognosis.³⁷ Ultimately, the decision as to when to attempt conception needs to take into account the evidence, its limitations and other factors like residual fertility and age at eventual conception.^{39,40}

Impact of a breast cancer diagnosis on future offspring

There are concerns about the impact of cancer treatment on future offspring.³⁹ These include concerns that treatment may cause genetic abnormalities (e.g. germ-line mutation, chromosomal aberrations), which could result in birth defects and/or cancer in offspring.³⁹ Existing evidence is limited but seems largely reassuring that birth abnormalities are not increased, although the induced abortion rate is high at 20-44% and the spontaneous miscarriage rate has been reported at up to 28%.^{8,39,41,42} Obstetric complications may also be increased after breast cancer, including caesarean section, very preterm birth (<32 weeks) and low birth weight (<1500g) in breast cancer survivors (compared to healthy controls).⁴³ Overall, it has been advised that women wait at least six months,⁴¹ if not 12 months,²¹ to minimise potential risk.

Contraception

Some women may opt not to have children after cancer treatment. They may have completed their families, fear the impact of a pregnancy on recurrence, fear a limited lifespan, or may be following a clinical recommendation to avoid pregnancy.^{35,36} Contraception is, therefore, likely to be necessary, but hormonal contraception (e.g. the contraceptive pill or implants) is contraindicated in hormone-receptive positive women. Therefore, it is recommended that women use non-hormonal forms of contraception such as barrier methods (e.g. condoms, diaphragms, intrauterine contraceptive devices), or male or female sterilisation.

Psychosocial impact of infertility and pregnancy

Concerns around quality of life, menstrual changes, potential infertility, desire for children, pregnancy, breastfeeding, contraception and support from partners and family may impact on decisions to have a child following breast cancer.^{44,45}

Over 50% of young women are concerned about future fertility and a major proportion (76%) wish to consider pregnancy following cancer treatment.^{8,46} Concerns about infertility appear to be greater in women who have yet to complete their families, those who have experienced prior difficulty in conceiving, and those younger than 40 years.⁴⁴ Unpartnered women report an additional concern of having to wait until they find a partner with whom they want to have a child before learning about their infertility.⁴⁷ Dealing with infertility has been associated with significant psychological distress, with levels of depression double that of the normal population and reduced quality of life in areas of emotional wellbeing, sexuality and relationships.⁴⁸ When this occurs in the context of cancer, the patient, partner and family may experience great distress and even if the patient is not planning to have children, the threat of infertility may result in anger and a sense of loss.^{48,49} Concerns about potential infertility and the inability to conceive in the future often result in psychological morbidity and worse physical wellbeing.^{44,50} Infertility may also impact a woman's role identity.⁴⁴ Clearly, issues related to fertility are very important in the short and long-term and should not be dismissed or trivialised.^{49,51-55}

Pregnancy-related issues have been identified as the second highest concern among women who had not yet completed their families.⁴⁹ A nested case-control study investigating physical and mental health correlates of pregnancy found that mental health was marginally better in women who had a child after breast cancer.⁵⁶ The main motivation for pursuing parenthood after cancer appears to be

that it gives women a sense of feeling normal by reclaiming their lives and achieving goals that they set prior to diagnosis.⁴⁸ More time since diagnosis appears to result in fewer pregnancy-related concerns.⁴⁹ Although not specifically a reason to avoid pregnancy, de-motivators include fears and concerns about the impact of pregnancy on recurrence,^{47,49,55} whether pregnancy and breastfeeding impacts on the detection of breast cancer,⁴⁷ and feelings that it would be selfish to have a child when lifespan is potentially compromised.⁴⁷ Other reasons given for decisions to avoid pregnancy include age or relationship status (29%) and clinician recommendation (19%).⁵⁵

Contraception is also a key concern among women with breast cancer.^{47,57} Failed contraception has been linked to anxiety and fear of recurrence.⁴⁷ Concerns about how to best avoid pregnancy have been reported, with hormonal contraception considered unsafe and male sterilisation thought undesirable.⁴⁷

When planning treatment for women with breast cancer, consideration needs to be given to the psychological implications of potential infertility, and fears associated with the impact of pregnancy on prognosis and recurrence. There are concerns that the desire for a child may impact on adherence to endocrine therapy.⁵⁸ American Society of Clinical Oncology recommends early discussions about fertility preservation and the management of psychosocial late effects of treatments.^{59,60} It has been suggested that fertility and pregnancy should be part of a survivorship care plan.⁶¹

Given the motivators and reasons for avoiding pregnancy, it is important that women are well informed about the risks and are well supported in the decision-making process. BRCA mutation carriers may be concerned about transmission to their offspring and so this may influence decisions regarding pregnancy. Several studies have identified unmet information needs about fertility, pregnancy and breastfeeding in this group.^{39,44} To address these needs, decision aids regarding fertility preservation prior to cancer treatment have been developed and found to be effective.^{54,62} However, there are no such tools for pregnancy after breast cancer.

Assisted reproduction after breast cancer treatment

Timing is a key challenge when considering pregnancy after breast cancer. Although the research suggests that women can safely pursue a pregnancy 12 months following cancer, many women with hormone receptor-positive breast cancer are advised to receive endocrine therapy for 5-10 years during which time they are advised to avoid pregnancy. The impact of a temporary treatment interruption to allow conception is currently being investigated. In the absence of data, women who wish to pause cancer treatment should only do so after seeking medical advice from both their oncologist and reproductive specialist.

Options to, and success in, achieving a pregnancy through assisted reproductive technologies will depend on a number of factors including access to preserved gametes. Ideally gametes should be preserved prior to chemotherapy. If this is not possible, it may be possible to pause endocrine therapy to try and achieve pregnancy or to preserve gametes for future conception. Infertility is defined as a 12-month period of unprotected intercourse that does not result in a pregnancy, after which it is recommended that women seek assistance.

Alternatively, women who have preserved oocytes, embryos or tissues can thaw and use these. Embryos can be transferred and oocytes fertilised and transferred into a prepared uterus. There are limited data on live birth rates from frozen embryos or oocytes following cancer. Live birth rates per frozen embryo transfer is approximately 44.1% in women <35 years and 35.8% in women aged 35-39 years,⁶³ with rates up to 75% reported.⁶⁴ Similar live birth per transfer rates of 50-55% in women <36 years and 18-37% in women >34 years have been reported.^{65,66} The use of exogenous sex steroids is avoided after hormone-positive breast cancers. Ovarian tissue cryopreservation is considered 'experimental', with only around 60 live births worldwide reported.⁶⁷ Although this procedure holds promise, there may be concerns about re-seeding the cancer. Should these options be unsuccessful or unfeasible, it may be worth considering using donor eggs or embryos. Donor eggs or embryos may also be a good option for women who are concerned about transmission of BRCA genes. The chance of success from these options is largely dependent on the age of the oocytes, with younger oocytes more likely to result in a successful live birth.⁶⁸

Alternative options for becoming a parent include surrogacy, adoption or foster care; however, these are not without challenges and can be difficult for cancer survivors to access.

Conclusion

Pregnancy after breast cancer is an important issue for many women. Pregnancy rates after breast cancer are relatively low. Nonetheless, it is important that women are made aware of the potential impact on their fertility and given information regarding their options for fertility preservation before treatment as well as about achieving a pregnancy after treatment. Decisions to conceive are challenging as women are weighing up their desire for children against fears of recurrence and potential inability to detect future cancers. Providing evidence-based information and psychosocial support to breast cancer survivors who wish to conceive is an important clinical issue in need of greater attention.

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Chemotherapy induced alopecia and strategies to manage its impact

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Abstract

Chemotherapy-induced hair loss is a common and distressing side effect of some chemotherapy agents, and is ranked as one of the top three most distressing side effects by patients. Hair loss (alopecia) is more prominent on the scalp but affects the eyebrows, eyelashes, beard, axillary and pubic hair and typically begins within the first three weeks of starting chemotherapy. Patients report lower quality of life, high levels of distress, negative body image and feelings of loss of control associated with their alopecia. For most patients regrowth occurs after treatment completion but the colour and structure of hair can be altered, prolonging the negative impact on patient sense of wellbeing. The impact of chemotherapy-induced alopecia on patients is underestimated by many health professionals. Management is typically to camouflage the loss by wearing a wig, head scarf, or hat/turban. Scalp cooling with coolant based devices to reduce chemotherapy-induced alopecia has been available in Europe for more than a decade, but has only recently been introduced in Australia. Scalp cooling works by reducing local concentration of chemotherapy agents and decreasing metabolic uptake by hair follicle cells. Given the significance of hair loss to patients, further research to ameliorate this common side effect of chemotherapy treatment is urgently required.

Chemotherapy induced alopecia

Hair loss (alopecia) is a common and visible side effect of chemotherapy.¹ The incidence and severity of chemotherapy-induced alopecia (CIA) depends on both the type and dose of chemotherapy agents. Alkylating agents (cyclophosphamide, ifosfamide), anthracyclines (doxorubicin, daunorubicin), antimicrotubule agents (docetaxel, paclitaxel), and topoisomerase inhibitors (etoposide) are known to cause the most severe CIA and hair loss is greater when chemotherapy agents are administered intravenously, particularly when they are administered in combination.^{1,2} Hair loss typically starts seven to 14 days after infusion and can be diffuse or patchy and may occur suddenly or gradually over time.^{3,4} Newer chemotherapy drugs can reduce the level of CIA however current protocols often involve administration in combination with traditional agents. Although hair loss is more prominent on the scalp because the scalp has greater proliferation of hair, CIA affects all parts of the body such as the eyebrows, eyelashes, beard, axillary and pubic hair.

Hair loss occurs because chemotherapy agents are designed to disrupt the mitotic and metabolic process of cancer cells. Unfortunately, rapidly dividing cells such as hair follicles are also affected. The rapid hair growth, as well as high blood flow around the hair bulb results in disturbances of normal hair-shaft production and hair-follicle cycling, causes breakage of the hair shaft and hair shedding.²⁻⁴ However the mechanism of action is still being identified and it is unclear whether the blood concentration or the exposure time of hair follicles to cytotoxics is more important for the toxic effect.¹

Generally, CIA is reversible, with regrowth typically occurring three to six months after the completion of chemotherapy.⁴ There is little research exploring the regrowth of hair on other parts of the body, however, reports suggest that for 60% of patients who lose scalp hair, regrowth results in changes to hair colour and structure.⁵ New hair is often grey or differs in colour due to distortion of the pigmentation process during chemotherapy, and is typically coarser, grows more slowly and is thinner.⁶ It may therefore take considerable time before patients' return to their pre-treatment

appearance, adding to patients' sense that cancer continues to impact them post treatment.⁴ Sadly, a small number of patients experience permanent hair loss.⁴ Permanent hair loss is most commonly observed in those patients receiving high dose chemotherapy prior to bone marrow transplantation possibly due to epithelial hair-follicle stem cell involvement.² however it has also been reported in a small number of patients with breast cancer receiving adjuvant anthracyclines and taxanes.⁷

Psychological impact of hair loss

Although CIA is not life-threatening, temporary for the majority of patients and is unlikely to lead to dose reduction, it causes significant distress to most patients.⁸ Of concern, is the influence on patient treatment decision-making, with approximately 8% of patients refusing chemotherapy due to the fear of hair loss.⁹ The importance of CIA to patients is underscored by its ranking as one of the top three most distressing chemotherapy side effects and although being aware of CIA as one of the side effects of treatment, patients report not being prepared emotionally for the impact hair loss.^{4,8,10} Despite the prevalence of CIA, there have been relatively few studies that have explored the impact of CIA on patients, with much of what we know based on small qualitative studies exploring chemotherapy side effects more generally. These studies confirm hair loss results in lower quality of life, high levels of distress, negative body image and feelings of loss of control.^{8,9,11} Even before commencing chemotherapy many patients experience anticipatory distress associated with hair loss,¹² with approximately one-third of patients mentioning hair loss during their first consultation with the oncologist.¹³

The impact of CIA for patients is underscored by a study by Jayde et al that qualitatively explored the experience of CIA in Australian women with ovarian cancer.¹⁰ This study found CIA to be the *most* distressing aspect of the ovarian cancer experience. Similarly, in a study with early breast cancer patients, hair loss was considered more distressing than losing a breast.¹⁴ In both of the studies, CIA represented a public confirmation of a cancer diagnosis and for women with ovarian cancer particularly, highlighted patient fears of mortality. Despite the high levels of patient distress reported across studies,^{4,8,9,15} surveys of oncology health professionals' attitudes to hair loss indicate that they frequently underestimate the impact on patient wellbeing.^{16,17} Furthermore, a recent study conducted in Australia (Shaw et al, in press) highlighted ambivalence among health professionals to intervene, even when recognising the negative impact of CIA on patients.

Body image

Hair loss has a significant negative impact on many women's self-confidence and body image resulting in lower social, physical, and total wellbeing than female patients without alopecia.¹⁸ In 28% of young women with breast cancer, low body image as a result of hair loss contributes in part to sexual problems experienced.¹¹ Additionally, Frith and colleagues found that body image to be poorer during treatment, but it did not return to pre-treatment levels when hair returned.¹² Negative body image is compounded with loss of eyebrows and lashes as hair loss challenges women's conceptualisation of femininity and attractiveness and men's sense of masculinity leading to poor post-treatment adjustment.^{9,19-21} Although much of research related to hair loss has focused on women, particularly those with breast cancer, there have been some studies that report CIA is also a distressing side effect for males and similar levels are reported across tumour groups.^{13,22} There is some suggestion that hair loss is more threatening to women's sense of self,²³ however Hilton and colleagues argue that while women are more distressed at losing hair above the eye line, men are more concerned at hair loss from other parts of the body such as face and limbs.²² Furthermore, the impact on body image is not age-related, with both younger (<50 years) and older patients reporting decreased body image related to CIA.²⁴ Patients with recurrent disease also report higher distress associated with hair loss.²⁵ Patients further report hair loss influences social confidence and role performance, with loss of facial hair impacting negatively on an individual's ability to express themselves.²⁰

Illness representation

Studies that focus on the meaning of CIA to patients highlight the link between hair loss and illness representation. CIA is perceived as a visual indication of illness. For some, the hair loss is a constant reminder of their cancer.^{4,20} However for others, CIA represents a public acknowledgement of cancer and patients report losing control over to whom they choose to disclose their diagnosis.^{22,25} Women with children report that hair loss causes distress to their children and was one of the most difficult side effects for partners to come to terms with.²⁴

Strategies to manage hair loss

Providing information on hair loss and teaching self-care strategies to minimise alopecia have been found to facilitate coping and adjustment to CIA, although health professionals rarely provide emotional support or counselling to patients.^{4,12} Typically both women and men take active steps to manage their hair loss as soon as it becomes noticeable.^{12,22} However some women find the act of cutting their hair or shaving their head as a traumatic blow and experience difficulties looking at themselves in the mirror.²⁶ Many women camouflage CIA by wearing a wig or head cover, particularly in public. Wearing a wig is a compensation for the changed appearance and is aimed at trying to look normal again for both self and others.^{19,20} Other patients choose to shave their head when CIA begins due to both practical and emotional considerations. Both men and women report shaving reduces the physical sensations such as itching and reduces the need to clear fallen hair from pillows and the shower. Shaving rather than waiting for hair to fall out is reportedly a strategy used by some to gain control over CIA.^{12,27} Pre-emptively purchasing wigs and head covering was also reported to be another means women sought to come to terms with their altered appearance and gain a sense of control over CIA.^{12,27} This is particularly important when some much of cancer treatment is out of the patient's control.²⁸ Strategies to manage non-scalp hair loss are limited, although pharmaceutical agents to reduce eyelash loss are being trialled (K. Morris, personal comm).

Some patients see CIA in a more favourable light, choosing to consider alopecia as reflective of "strong therapy" that will translate into better survival.^{19,27} Despite these patients being less concerned about hair loss, reports suggest that patients who do not hide their hair loss can experience stigma as they are perceived as breaking social norms by not covering up.²⁰ Male patients reported generally less pressure to hide their baldness although others perceived negative assumptions about them were made based on their bald status.^{19,22}

Scalp cooling

Scalp cooling is a supportive care intervention that is increasingly being utilised in many cancer centres as a strategy to reduce CIA. Scalp cooling has been available in cancer centres in Europe for more than a decade but it is a relatively new technology in Australia. Although application has evolved from frozen caps requiring frequent changes (e.g. Penguin™ Cold Caps) to continuous cooling of the scalp with super-cooled liquid gel caps (e.g. Paxman Orbis, Dignitana Dignicap) over recent years, the principles of scalp cooling involve concurrent cooling of the scalp during chemotherapy, as it is hypothesized the vasoconstriction reduces blood flow to hair follicles during peak plasma concentrations of chemotherapy agents, which in turn reduces its cellular uptake. Scalp cooling reduces biochemical activity making hair follicles less vulnerable to the damage of chemotherapeutic agents.¹ Efficacy may be related to the achievement of scalp skin temperatures below 18°C.²⁹

There is a growing body of literature confirming scalp cooling is an effective treatment to reduce chemotherapy-induced hair loss.³⁰⁻³² A recent meta-analysis summarising the available data confirmed scalp cooling significantly reduced CIA (RR 5 0.38, 95% CI 5 0.32–0.45).³³ Additionally, a large cohort study conducted through the Dutch Scalp Cooling Registry confirmed 50% of the patients with scalp cooling had good hair preservation, with a range of between 8% (TAC chemotherapy) to 94% (docetaxal) The study also reported that higher dose and shorter infusion time, older age, female gender and non-West-European type of hair significantly increased hair loss during scalp cooling.³¹ Despite the variability the technology is reported to be well-tolerated and there is high patient satisfaction.^{27,30,34,35} For example, Betticher and colleagues found that scalp cooling reduced the risk of hair loss by 78%, with adverse events experienced by 3.3% (n=8) of participants and only 30 of 199 patients (12.6%) receiving scalp cooling discontinuing due to tolerability issues such as headaches, sensation of cold or pain.³² Concern that protection of the scalp from chemotherapy might lead to an increased risk of scalp metastases has not been borne out in large breast cancer cohorts.^{36,37}

Current research

Although the technology has been available in Europe for more than a decade, scalp cooling has until recently been unavailable in Australia. Introduction of scalp cooling into cancer centres requires a significant change to current clinical practice. Uptake in Australia has been primarily driven by individual oncologists or cancer nurses and access has been largely limited to patients with breast cancer in a few metropolitan centres. Ongoing research to identify the barrier and facilitators to wider

implementation is currently underway. Internationally, there is research being conducted to build the evidence-base for scalp cooling, both in terms of greater understanding of treatment protocols and on investment in time and costs of scalp cooling from a health service perspective. Additionally, recent explorations of the scalp cooling and CIA literature have highlighted the need for a common objective measure for CIA. A consortium of Australian, Dutch and UK researchers is currently validating such a measure.³⁸ Randomised controlled trials will then be feasible to address issues such as determining optimal cooling times for different regimens. Pharmaceutical agents applied topically or as an injectable to prevent CIA and enhance regrowth are also being tested, although promising agents identified in animal models have failed to translate to effective treatments in humans.³⁹ Preliminary research to identify agents that may reduce the loss of eyelashes is also ongoing. (K. Morris, personal communication)

Chemotherapy-induced hair loss is a common side effect of chemotherapy. Hair loss is more prominent on the scalp but affects the eyebrows, eyelashes, beard, axillary and pubic hair and typically begins within the first three weeks of starting chemotherapy. Many patients experience psychological distress, report lower quality of life body image issues associated with this form of hair loss that are in addition to their cancer diagnosis. Management is typically to alter drug choice, or to camouflage the loss by wearing a wig, head scarf, or hat/turban. Scalp cooling is the most effective prevention strategy for chemotherapy-induced alopecia. Further research to optimise scalp cooling treatment protocols and identify pharmaceutical agents to prevent alopecia is urgently required.

Additional links:

COSA 2016 Conference breakfast session: [Scalp cooling: Why it's cool and how to keep you cool](#)
Mater Hospital – [Scalp cooling system](#) (information for patients and hairdressers)

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Cancer-related cognitive impairment in adult cancer survivors: A review of the literature

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Abstract

Cognitive symptoms are commonly reported by cancer patients. Qualitative research has shown that up to 70% of cancer patients experience symptoms of varying magnitude. Several studies have demonstrated only a weak association between self-reported cognitive symptoms and objective cognitive impairment on formal neuropsychological testing. Conversely, cognitive symptoms have been consistently shown to be associated with other patient reported outcomes, including anxiety/depression, fatigue and quality of life. Cognitive symptoms can have a major impact on individual's personal and professional lives. Initially, the terms 'chemo brain' or 'chemo fog' were used, as it was believed that cognitive changes were a direct result of chemotherapy treatment. It is now clear that the aetiology of cognitive change is more complex, with several studies showing presence of impairment in patients with a new cancer diagnosis, prior to commencement of systemic therapy. The exact aetiology of cognitive impairment is unknown, but it is likely multifactorial. There has been interest in the evaluation of pharmacological and cognitive training strategies for the management of cognitive impairment in cancer patients. Most recently, a large randomised study of a home-based, online cognitive rehabilitation program showed improvements in cognitive symptoms and patient reported outcomes. However, there remains no universally accepted treatment.

In the last two decades, there has been a growing body of research focused on the evaluation of cognitive symptoms in cancer patients. The incident rate varies, but studies in breast cancer patients suggest that up to 70% of patients receiving chemotherapy will self-report some cognitive impairment.¹ The cognitive domains most commonly affected are memory, concentration, information processing speed and executive function.^{2,3}

For some patients, their cognitive impairment may be transient, but for a subgroup, these symptoms can be long-standing and have a major impact on quality of life and function.^{4,5} Cognition has been recognised as an important component of cancer survivorship, particularly with the improvement in cancer treatments, leading to increased survival times.⁶ It is therefore imperative that we better understand these symptoms and how best to treat or prevent them, to ensure that cancer patients are not only living, but are 'living well' after their cancer diagnosis and treatment.

History of early research

Initial reports of cognitive changes associated with chemotherapy date back to 1980, in a small study of ten cancer patients.⁷ A study by Wieneke et al in 1995 in early stage breast cancer patients, <55 years of age, who had completed adjuvant chemotherapy, found that 75% of patients met the investigators' definition of moderate cognitive impairment on neuropsychological testing. The impairment was not associated with depression, type of chemotherapy, or time since treatment, but there was a positive association with the number of cycles of chemotherapy.⁸

In 1998, Van Dam et al published a cross-sectional study assessing the prevalence of cognitive deficits in high-risk breast cancer patients, <55 years of age, randomised to high (n=34) or standard-dose (n=36) adjuvant chemotherapy, followed by hormonal therapy. They included a

control group comprising patients with stage I breast cancer who had not received systemic therapy (n=34). Cognitive impairment on formal neuropsychological testing was seen in 32% undergoing high-dose treatment and 17% receiving standard-dose treatment compared to 9% of controls ($P=.043$). Patients receiving high-dose chemotherapy reported significantly more symptoms than controls ($P=.014$). However, no association was seen between cognitive symptoms and neuropsychological testing (Spearman correlation 0.03).⁹

A series of cross-sectional studies followed; the majority confirmed findings of early studies, although reassuringly the rates of cognitive impairment post-chemotherapy were lower than that first reported by Wieneke et al.¹⁰⁻¹³ However, there remains wide variability in the frequency of cognitive impairment across studies. There are multiple reasons for this including diverse patient populations and cancer treatments, time from treatment, instruments used to assess cognition, lack of a standardised definition of what constitutes cognitive impairment and methodological issues in earlier studies.¹⁴

The lack of association between self-reported cognitive symptoms and objective cognitive function on neuropsychological testing emerged during these early studies. It was noted that many participants reported cognitive symptoms, but were scoring within normal range on neuropsychological tests. Several factors may contribute including: 1) patients' functioning above the normal range of cognitive performance prior to their cancer diagnosis or systemic treatment, and while their cognition may have declined, it remained within normal range, albeit at a lower level; 2) lack of 'ecological validity' of the neuropsychological testing, i.e. the artificial conditions in which testing is performed is not representative of real life situations in which individuals are most likely to experience cognitive symptoms; 3) the neuropsychological tests are not sensitive enough to detect the subtle cognitive changes typically seen in cancer patients; and 4) self-reported and objective measures of cognitive function are measuring different constructs.

Recommendations for future research

There were a number of methodological limitations with earlier studies. Most used cross-sectional designs, with small sample sizes, and were restricted to young women with breast cancer. Little was known about cognitive function in men or in patients with tumour types other than breast cancer.

The International Cognition and Cancer Task Force made the following recommendations for future studies: 1) longitudinal study design; 2) inclusion of different primary tumour types with no gender restrictions; 3) incorporation of baseline assessment of cognition function prior to initiation of chemotherapy; 4) inclusion of a control group; 5) evaluation of potential underlying mechanisms e.g. imaging, blood parameters; 6) use of neuropsychological tests sensitive to the types of cognitive change reported in cancer studies; and 7) development and validation of self-reported questionnaires specific to cancer patients.¹⁵⁻¹⁷

Newer generation of studies

Longitudinal studies

A series of longitudinal studies have confirmed the findings of earlier cross-sectional studies demonstrating that a subgroup of patients experience cognitive issues following administration of chemotherapy.^{4,18,19} Hermelink et al completed a longitudinal study in 101 breast cancer patients reviewing cognitive function before and immediately prior to completion of neoadjuvant chemotherapy. At baseline, 31% of patients scored within the lower 5% range on neuropsychological testing. On follow-up, deterioration in performance was seen in 27%, with improvement in 28%. There was a significant increase in self-reported cognitive symptoms at the follow-up evaluation.¹⁹

Kopplemans et al performed a case-cohort study comparing cognitive performance of 196 breast cancers patients who had received chemotherapy (mean of 21 years following diagnosis), with 1509 healthy females. They found that women who had received chemotherapy performed worse on all neuropsychological tests compared to controls. Interestingly, patients experienced less symptoms of depression than controls ($P=.001$), but had more self-reported cognitive symptoms.⁴

Of note, there have been a small number of studies that have not found impairment associated with cancer treatment.²⁰⁻²³ Jenkins et al performed a prospective longitudinal study evaluating neuropsychological performance in 128 women diagnosed with early stage breast cancer (chemotherapy n=85; endocrine therapy +/- radiotherapy n=43) and healthy controls (n=49). There were no significant differences in cognition between the groups on assessments post-chemotherapy or 12 months later, with no associations between objective neuropsychological testing and self-reported cognitive function, quality of life and distress. However, the latter were significantly associated with one another.²⁰

Debess et al examined self-reported and objective cognitive function in 120 women who had received treatment for early breast cancer (chemotherapy n=75, hormone therapy n=26, no adjuvant treatment n=19) in comparison to 208 aged-matched women with no history of malignancy. There were no significant differences in neuropsychological testing between the three patient groups and the healthy controls at baseline or post-chemotherapy. All patients improved on most measures of self-reported cognitive function and psychological distress at six months and patients who did not receive adjuvant treatment, reached a level similar to controls at six months.²¹

Overall, the majority of cognitive studies in women with breast cancer show that approximately 30% have cognitive impairment on objective testing which is frequently sustained up to at least 10 years, with one study suggesting impairment still at 20 years.⁴ Most studies found a lack of association between neuropsychological test results and cognitive symptoms.

Studies conducted in non-breast cancer populations

More recent studies have evaluated cognitive function in non-breast cancer populations with a particular focus on colorectal, testicular and gynaecological malignancies.²⁴⁻³² These studies confirm that cognitive changes occur in a number of other tumour types, and in both men and women. This is important as it was initially postulated that the cognitive changes in women may be related to abrupt changes in the hormonal milieu induced by chemotherapy, leading to an early menopause.

The largest study reported by Vardy et al was a longitudinal study in 289 patients with localised colorectal cancer: 173 received adjuvant chemotherapy, and 116 did not. There were two additional groups: 72 patients with recurrent/metastatic colorectal cancer, and 73 healthy controls. The rates of cognitive impairment were significantly higher in localised colorectal patients than healthy controls at baseline, six and 12 months (43%, 39% and 46% compared to 15%, 6% and 13%). There was no significant effect from chemotherapy. Self-reported cognitive impairment was more common at six months in participants who received chemotherapy (32%) than those who did not (16%; $P=.007$) or in healthy controls (12.5%), with no significant differences between groups at 12 months.²⁹

There is a growing body of work highlighting the presence of cognitive changes in cancer patients before they have commenced systemic treatment.³³⁻³⁵ Ahles et al compared neuropsychological function of breast cancer patients (n=132) with invasive cancer and non-invasive cancer following surgery, but prior to any adjuvant treatment, with matched healthy controls (n=45). They found 22% of patients with breast cancer had lower than expected cognitive performance, compared to 4% of healthy controls ($P=.002$).³⁴ As described previously, Vardy et al's study in patients with localised colorectal cancer found more objective cognitive impairment in patients than healthy controls at baseline (45 vs 15%, $P<0.001$).³³

Potential explanations for the presence of cognitive changes prior to initiation of systemic treatment include the presence of a common risk factor for both the development of cancer and cognitive changes. Additionally, there may be some intrinsic property of the cancer driving cognitive changes.

Influence of age and comorbidities on cognition

Age is a known risk factor for cognitive decline in the general population. This is particularly relevant in today's oncological practice, with an ageing population and an increase in older patients receiving chemotherapy.

Hurria et al studied an older population in a longitudinal study enrolling 45 patients with early stage breast cancer with a mean age of 70 years. Half (51%) reported a decline in memory from baseline to six months post-chemotherapy. Patients who reported a below average memory prior to chemotherapy were more likely to report further memory deterioration after chemotherapy (63%) compared to those reporting their memory to be average or better prior to chemotherapy (27%).³⁶

Mandelblatt et al evaluated whether older patients with breast cancer have cognitive impairment prior to systemic therapy.³⁷ They recruited 164 newly diagnosed early stage breast cancer patients, ≥60 years, together with 182 community controls. The age range was 60-94 years. They found that the breast cancer patients and controls had similar neuropsychological scores. However, those patients with stage II-III cancers had lower executive function compared to those with stage 0-I disease ($P=.05$), with significantly higher impairment among older, non-white, less educated women and those with greater comorbidity.³⁷

Ahles et al evaluated age and baseline cognitive reserve in 132 patients diagnosed with early stage breast cancer prior to adjuvant therapy (chemotherapy $n=60$, no chemotherapy $n=72$), and 45 healthy controls. A three-way interaction among treatment group, age and baseline cognitive reserve ($P<.001$) revealed older patients with lower baseline cognitive reserve who received chemotherapy had significantly lower cognitive performance compared to the other two groups ($P<.003$).³⁸

These results highlight the need for collection of data relating to comorbidities and pre-morbid function in future cognitive studies. While these data may not be practice changing for the oncology community, it should be carefully considered when reviewing patients with multiple comorbidities and borderline functional status, prior to proceeding with adjuvant therapy that may confer minimal benefits.

There has been a consistent lack of association between self-reported cognitive symptoms and objective cognitive function measured by neuropsychological testing.^{9,10,20,39,40} A meta-analysis by Hutchinson et al of 24 studies, found eight reported a significant association between self-reported and objective cognitive function, and often the correlation was weak.⁴¹ This was more likely in studies of breast cancer patients and when the relationship between memory (rather than global cognitive function) and self-reported symptoms was explored. However, both self-reported cognitive symptoms and objective cognitive impairment are important to patients and where possible both measures should be incorporated in to trial designs. Finally, self-reported symptoms are frequently linked to fatigue, worse quality of life and symptoms of anxiety and depression.

Potential mechanisms

The aetiology of cognitive change in cancer patients is not known, but is likely to be multifactorial. Postulated mechanisms include: direct neurotoxic effects of therapy, genetic factors, oxidative stress and immune dysregulation.

Direct neurotoxicity

Traditionally chemotherapy agents, with the exception of methotrexate and 5-fluorouracil, were thought to have minimal penetration through the 'blood brain barrier.' However, a variety of neurotoxicities have been described with many chemotherapy agents.⁴²⁻⁴⁴ Imaging studies using positron emission tomography have shown that detectable levels of certain chemotherapeutic agents can be found in the brain following intravenous administration. While these levels are low, and are not at a level sufficient to cause an anti-cancer therapeutic response, there remains uncertainty whether they are sufficient to alter cognitive function.

Animal studies have suggested that neural progenitor cells and oligodendrocytes are the cell populations most vulnerable to multiple chemotherapeutic agents. Furthermore, repetitive drug exposure resulted in long-term suppression of cell division and prolonged cell death in the subventricular zone, the hippocampus, and major white matter tracts.⁴⁵⁻⁴⁷

Genetic factors

One potential candidate marker is the apolipoprotein (APO) Eε4 gene, a known risk factor for

Alzheimer's disease and other forms of cognitive impairment. Preliminary support for this came from Ahles et al who demonstrated that long term cancer survivors with at least one APOE ϵ 4 allele scored significantly lower in multiple neuropsychological domains ($P < .03-.05$).⁴⁸ By contrast, the larger colorectal study by Vardy et al found no association with APOE ϵ 4 and cognitive function.²⁹

There has been recent interest in the catechol-O-methyltransferase (COMT) genotype, which is associated with levels of dopamine in the prefrontal cortex of the brain. The COMT valine-158 methionine-158 single-nucleotide polymorphism is associated with increased enzymatic activity resulting in greater degradation of dopamine and less availability of dopamine at the synaptic receptor. Small et al studied breast cancer survivors treated with radiotherapy (n=58), chemotherapy (n=72) and healthy controls (n=204). The COMT valine carriers performed worse on neuropsychological tests ($P < .009-.033$) compared to those without the polymorphism, as did COMT valine carriers treated with chemotherapy compared to healthy control COMT valine carriers ($P < .001$).⁴⁹

Immune dysregulation

Cytokines have an important role in normal brain function, including the modulation of neuronal and glial cell functioning, neural repair and metabolism of a number of important neurotransmitters. Cancer and/or chemotherapy causes activation of the immune system with release of proinflammatory cytokines, many of which have been shown to cross the blood-brain barrier (e.g. interleukin(IL)-1, IL-6, tumour necrosis factor-alpha (TNF- α)) and have been associated with cognitive impairment in other diseases.

Some breast cancer studies have found an association between cognitive impairment and elevation of interleukin IL-6 and TNF.^{50,51} By comparison the much larger colorectal study, Vardy et al found no association between global cognitive function and cytokines in blood.²⁹

Neuroimaging findings

Recent developments in the field of cognition and cancer include the use of functional magnetic resonance imaging to determine which areas of the brain are activated both at rest and while doing a memory task. Cross-sectional studies in breast cancer survivors who received chemotherapy have found hypoactivation in prefrontal and parietal brain regions.⁵²⁻⁵⁶

Intervention studies

There are an increasing number of studies focusing on both pharmacological and non-pharmacological interventions for the management of cognitive symptoms in cancer patients. The majority are small and while some have shown promising results, no treatment has as yet been established in main stream practice.

Pharmacological interventions

A number of medications have been of interest in this area and the most commonly evaluated agents include erythropoietin, dexamethylphenidate and modafinil. Results from trials have largely been disappointing. Vardy et al are currently evaluating the Chinese herb, *Ginkgo biloba*, in a randomised controlled trial in breast cancer survivors. Its mechanisms of actions are reported to include anti-oxidant properties, increasing cerebral blood flow, improving glucose utilisation and stimulation of neurotransmitters.

Non-pharmacological intervention studies

Treanor et al recently published a Cochrane systematic review of non-pharmacological interventions for cognitive impairment related to systemic cancer treatment.⁵⁷ Their selection criteria included randomised controlled trial of non-pharmacological interventions in survivors of adult-onset cancers who had completed systemic cancer therapy. They identified five randomised controlled trials of six interventions (n=235) in breast cancer patients. Of these, two used computer-assisted cognitive training interventions (n=100); two compensatory strategy training interventions (n=95) and one each meditation (n=47) and physical activity (n=19).⁵⁸⁻⁶² They found that use of cognitive and compensatory strategy training had beneficial effects on objective cognitive function, self-reported cognitive function, well-being and spiritual quality of life. The evidence for the assessed studies was graded as low quality for physical and mental health outcomes and did not

permit firm recommendations to be made.

Our group recently reported the results of a large longitudinal randomised controlled trial of a web-based cognitive rehabilitation program in cancer patients reporting cognitive symptoms 6-60 months following completion of adjuvant chemotherapy. All participants received a 30-minute telephone consultation outlining cognitive training strategies and were then randomised to the 15-week, home-based intervention or standard care. The study met its primary outcome with improvements in self-reported cognitive function post intervention and these changes were sustained at six months. Importantly, symptoms of anxiety and depression, fatigue and stress were lower in the intervention group upon completion of the program and quality of life was improved at six months. There were no major differences found in objective neuropsychological test results between the groups.⁶³ Three other small intervention studies have also shown provisional efficacy of cognitive rehabilitation programs.⁶⁴⁻⁶⁶

There remain a number of unanswered questions with regards to cognitive interventions in the cancer population, including: the best method of delivering cognitive training; the optimal dose, frequency, and duration of training; how to improve adherence to training; whether benefits translate to real world situations; and, the long-term durability of cognitive training. Similarly, we need to better understand which patients are most at risk of persistent cognitive symptoms with the aim of selecting patients who may benefit from earlier implementation of an intervention.

Conclusion

Cancer-related cognitive symptoms are an issue for many cancer survivors and can have a significant impact on their daily life. As we make advances towards the implementation of effective management strategies for cancer patients reporting cognitive symptoms, it is vital that both health professionals and patients are educated about this important issue. Patients need to be informed about the potential risk of cognitive symptoms, in context of the benefits of treatment, to enable them to make informed choices about their treatment and recovery.

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Anxiety and depression in women with breast cancer

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Abstract

Anxiety and depression are the two most prevalent psychiatric presentations among women with breast cancer. If left untreated, anxiety and depression can have serious psychological, medical and health service utilisation consequences. These include reduced likelihood of accepting, tolerating and adhering to recommended treatments, and increased toxicities and severity of medical symptoms that, in turn, can increase healthcare costs and reduce quality of life. Risk factors for anxiety and depression in women with breast cancer include: a past history of anxiety or depressive disorder; younger age at diagnosis (<50 years); poor social support; burdensome somatic symptoms; currently undergoing active cancer treatment; specific drug treatments; and body image distress. Interventions for depression and anxiety in breast cancer have typically comprised a) pharmacological treatments, with citalopram, venlafaxine and mirtazapine being safe antidepressants to treat both anxiety and depression; and b) psychotherapy, with cognitive-behavioural therapy considered the current gold-standard treatment for primary breast cancer, and supportive-expressive approaches more appropriate to women with advanced disease. However, distress continues to be under-screened and under-treated. In order to increase the reach of our services, more tiered and systematic approaches to screening, and a stepped care approach to delivering treatments are required.

Despite improvements in early detection and medical treatment, a diagnosis of breast cancer continues to elicit greater distress for women than any other medical diagnosis, regardless of prognosis.¹ The nature of this distress can range from psychiatric morbidity, such as depression, anxiety, and post-traumatic stress symptoms;^{2,3} relationship and intimacy difficulties;^{4,5} to quality of life (QOL) impairments, including body image concerns.^{6,7} This review focusses on the two most common psychiatric presentations, depression and anxiety, and summarises the resulting impact on QOL. The current evidence base for psychological and pharmacological treatments will be summarised, and future directions highlighted.

Psychiatric morbidity

Although distress and worry in response to a stressful life event is normal (and experienced, to some degree, universally), depression and anxiety are considered problematic when they impair social, emotional, physical and/or occupational functioning.⁸

Prevalence of psychiatric disorder

Using the gold standard for establishing prevalence, a recent epidemiological study of 442 German women with breast cancer found a four week prevalence rate for any mental disorder of 41.6% (95% CI 36.8-46.4%), using the Computerised International Diagnostic Interview-Oncology (CIDI-O).³ Breaking this down by disorder type, the four week prevalence of (a) any mood disorder was 8.7% (95% CI 6.2 - 11.2); (b) any anxiety disorder, 16.8% (95% CI 13.6 - 20.6%); (c) adjustment disorder (with depressed or anxious mood), 14.4% (95% CI 11.0 - 17.7%); and (d) somatoform disorders (including somatisation disorder and hypochondriasis), 8.6% (95% CI 5.8 - 11.3%).³ Mixed

presentations of anxiety and depressive disorders also occurred – while approximately 30% of the German breast cancer sample presented with a single disorder, 8% had two disorders, and 2% had three or more mental disorders.³ This is consistent with the 10.8% mixed syndrome prevalence found in a sample of 1996 women with breast cancer at the Johns Hopkins Oncology Center, while 14.9% were pure anxiety and 2.8% pure depression symptoms.⁹

While advanced disease is often considered as a risk factor for increased vulnerability to depression and anxiety,^{10,11} when evaluated using a structured psychiatric interview (DSM-IV), in 303 Australian women with early stage and 227 with advanced breast cancer, rates of psychiatric morbidity were notably equivalent.¹² This suggests that the stress of the diagnosis was more relevant than stage of disease.¹² Early stage patients had an overall rate of DSM-IV mental disorder of 45%, compared to an overall prevalence of 42% for patients with advanced cancer.^{12,13} Women presented most commonly with either major depression, in 9.6% (95% CI 6.5 - 13.5%) of early breast cancer patients and 7.0% (95% CI 4.4 - 11.1%) of advanced;^{12,13} or adjustment disorder with anxious or depressed mood in 24.8% (95% CI 20.0 - 30.0%) of early stage and 24.2% (95% CI 19.1 - 30.2%) of advanced.^{12,13} Specific anxiety disorders (generalised anxiety disorder, post-traumatic stress disorder, simple phobias, and panic disorder) were less common (ranging from 0.9%-4.3%).^{12,13}

One of the single most prevalent types of anxiety for women is fear of breast cancer recurrence or progression, which is defined as the fear, worry or concern that cancer will come back or progress.¹⁴ While experienced by all women to a certain degree, this fear can escalate to clinical levels characterised by preoccupation, worry, rumination or intrusive thoughts; maladaptive coping; impairments to functioning; excessive distress; and difficulties making plans for the future.¹⁴ It shares many features of health anxiety (hypochondriasis), including misinterpretation of body sensations as signalling recurrence, reassurance-seeking including excessive health service-utilisation and screening, or cognitive and behavioural avoidance.¹⁵ Research further indicates that this worry about future health can have a direct effect on depression, independent of the illness intrusiveness.¹⁶

Who is most at risk for anxiety and depression?

A number of risk factors have been established for the diagnosis of mental illness in women with breast cancer, including: (a) personal vulnerability evidenced by a past history of anxiety or depressive disorder, with 30% of people with current depression and anxiety having a past history; (b) younger age (<50 years) at diagnosis; (c) poor social support, represented by relationship difficulties, isolation, alienation and family dysfunction; (d) burdensome somatic symptoms, ranging from breast pain, amputation syndrome, arm pain, difficulty raising the arm, and a variety of non-specific symptoms such as fatigue, insomnia, headache and nausea; (e) currently undergoing active cancer treatment; (f) certain drug treatments such as steroids; and (g) continuing distress at body image change and self-esteem.¹⁰⁻¹³ Not only is the existential threat associated with the diagnosis of breast cancer troublesome, but the consequences of anti-cancer treatment also contribute substantially to the psychological morbidity associated with this illness.

In addition to the psychological suffering caused, anxiety and depression can impact on health and medical treatment outcomes in numerous ways, including: reduced likelihood of accepting, tolerating and adhering to treatment, increased toxicities and severity of medical symptoms. This in turn can increase healthcare costs and reduce QOL. At the most extreme, untreated anxiety and depression can result in an 18% increased mortality from breast cancer;¹⁷ and higher suicide rates.¹⁸

Impact of breast cancer on quality of life

Assessment of QOL is seen as an essential component of therapeutic management of cancer patients.¹⁹ Research indicates that QOL is globally adversely affected immediately following breast cancer diagnosis and remains impaired over time if untreated.^{20,21} Prospective and longitudinal Australian data found that two years after diagnosis, women continued to experience significant reductions in general health, physical role, mental health and social functioning compared to women without breast cancer.²²

Body image changes are high and cause dissatisfaction and distress in women with breast cancer; these are reflected in perceived loss of femininity, decreased perceived attractiveness as a result of surgery, reluctance to look at oneself naked, feeling embarrassed by use of a prosthesis, and having reduced libido and sexual enjoyment.^{12,13} In terms of causes of poor body image, empirical evidence

clearly demonstrates that women who have breast conserving therapy have better body image than those who have a mastectomy;^{23,24} and those who have immediate breast reconstruction experience less distress and better psychosocial wellbeing than those who have delayed reconstructive surgery.²⁵ While the breast loss is a primary source of body image concern, other causes include weight gain or loss from chemotherapy, early menopause and hair loss – with hair loss causing more distress for women with early stage disease, and hot flushes being more prominent in those with advanced disease.¹² One specific body image concern for women with breast cancer is lymphoedema, with rates of arm lymphoedema rising from around 4% in early stage disease to 12% in advanced breast cancer, the latter still within four years of surgery.^{12,13}

Young women with breast cancer (defined as aged 50 or under) may be further impacted by concerns about infertility as a result of their treatment of the cancer. Up to 70% of young breast cancer survivors express a desire for children after treatment and are concerned about the possibility of not having biological children in the future as a result of cancer and its treatment.²⁶ Research indicates that women with cancer-related infertility may experience negative emotional reactions, enduring distress and strained relationships.²⁷ Furthermore, recent Australian qualitative data indicate that fertility represents more than child-bearing capacity; it was linked with identity and femininity. Therefore potential fertility loss is a source of considerable distress for patients, irrespective of their desire for future children.²⁸

Treating depression and anxiety in breast cancer

Interventions for depression and anxiety in breast cancer have typically comprised pharmacological treatments and/or psychotherapy.

Pharmacological treatment: traps and recommendations

Pharmacological treatments are a necessary component for the appropriate treatment of women with moderate to severe depression and anxiety.^{11,29} Drug interactions present the main hurdle for the unwary.¹¹ In particular, several antidepressants that use a metabolic pathway, mediated by cytochrome P450 2D6, in the liver will interfere with the metabolism of tamoxifen to endoxifen, its active metabolite.²⁹ Among the safe antidepressants to treat both anxiety and depression in women with breast cancer are citalopram, venlafaxine and mirtazapine; ones to avoid include paroxetine, sertraline and fluoxetine.²⁹

Psychotherapy

Several meta-analytic studies have confirmed irrefutably that anxiety and depression can be successfully treated in women with breast cancer.³⁰⁻³² The largest of these systematic reviews examined over 22,000 patients and recorded medium effect sizes for relief of anxiety and depression from both individual and group therapies, but not couple psychotherapy.³⁰ Within these modalities of delivering treatment, a wide range of psychotherapies have been trialled, including: cognitive-behavioural therapy (CBT) programs, psychoeducational treatments, relaxation training, problem-solving therapy, mindfulness-based interventions, interpersonal therapy, non-behavioural counselling or psychotherapy, and supportive-expressive therapy.^{11,30-32} Of these, CBT is considered the current gold-standard treatment for primary breast cancer, while supportive-expressive approaches are more appropriate to women with advanced disease.¹¹

CBT is structured in nature, usually comprised of between six and 10 weekly sessions of 60-90 minutes duration, and generally consists of three major components: 1) psycho-education about depression/anxiety in the cancer context, developing a conceptual framework that validates the range of personal symptoms experienced, and outlining responses that typically maintain the disorder; 2) cognitive strategies including cognitive restructuring, distraction, problem solving, and behavioural experiments to test key cognitions, coping skills training and communication; and 3) behavioural procedures, including behaviour activation, exposure, guided imagery/relaxation, and goal setting. For the treatment of major depression, behavioural procedures are typically implemented first; indeed behaviour therapy alone was recently found to yield equivalent benefits to the full cognitive behaviour therapy in a primary care setting, and can be administered by more junior therapists.³³

In contrast to CBT, supportive expressive therapy was developed specifically for metastatic breast cancer patients as an intensive and comprehensive group program of weekly 90 minute sessions for a 12 month (minimum) period.³⁴ Unstructured in nature, it was developed within an existential

framework during the 1970s, and was designed to facilitate social support, encourage emotional expression, enhance communication skills, symptom control and deal with existential concerns. Rather than having set weekly topics or strategies, therapists are trained to track emotions that lead to relevant themes and foster group discussion in those areas.³⁵ An early study controversially found that group supportive-expressive therapy improved the quantity, as well as quality, of life.³⁴ None of the subsequent supportive-expressive therapy trials replicated this survival benefit,³⁶⁻³⁸ and it has since been noted that most participants were married, which is as protective as chemotherapy in cancer care.³⁹ While demonstrably beneficial for women with metastatic disease, a brief nurse-led 12 session version of the program was trialled in women with primary breast cancer, but its use was unsupported as no effect on distress was found, even among women with high baseline distress.³⁵

The benefits of these two therapeutic frameworks for women with breast cancer have also been demonstrated in Australian settings. In a series of group therapy trials, cognitive-existential psychotherapy for women with primary breast cancer demonstrated reduced anxiety and fear of recurrence;⁴⁰ cognitive therapy for women with advanced breast cancer reduced depression and improved self-esteem;⁴¹ and supportive-expressive therapy for women with advanced breast cancer reduced depression and improved social functioning.³⁸ A small effectiveness trial demonstrated that an empirically supported cognitive behaviour group program can be successfully implemented in an applied clinical setting, yielding clinical improvements in cancer-related distress and social support in women with primary breast cancer.⁴²

Overall, the evidence base is strong that our psycho-oncologic interventions can ameliorate anxiety and depression; however, not everyone is universally benefitted, and several moderating variables have been identified. These include: 1) the timing and duration of the intervention, with higher effect sizes obtained when offered directly after diagnosis or surgery,^{43,44} and longer interventions producing more sustained benefits;³⁰ 2) the expertise of the therapist, with greater benefits being reported when interventions are delivered by psychologists;⁴⁴ and 3) baseline level of distress; when participants in trials of individual and group therapy are selected for distress, effect sizes increase to large.³⁰

Under recognition and under-treatment of patients in need

Despite this evidence for the efficacy of interventions, many patients in need fail to be recognised by our clinical programs.⁴⁵ Distress is normalised as comprehensible and existentially triggered. Clinicians can remain reluctant to probe, for fear of opening a Pandora's Box; patients may mask what remains a stigmatising problem for many. Efforts have been made to routinise distress screening as one way to redress this challenge, however a tiered approach is further required such that a second level of more specific screening and triage of anxiety and depression, to fully overcome this problem of under recognition.

Even in patients who are screened as distressed, a recent Australian clinical audit indicated only 29% were willing to accept psychological assistance.⁴⁶ Barriers to uptake include geography, particularly for those in regional or rural areas, and personal and illness-related barriers, including stigma associated with accessing mental health services. This has led to a recent surge in interest in online psychological interventions, given that 86% of Australians have access to the internet. A number of randomised trials have been recently published in this area, with promising findings across the treatment trajectory for early stage breast cancer.⁴⁷⁻⁵¹ More specifically, the online CBT-based psychological interventions were efficacious in improving: (a) global and physical QOL, cancer-related distress, and anxious preoccupation in Australian women currently going through medical treatment;⁴⁸ (b) distress, fear of recurrence, fatigue and self-efficacy during the immediate survivorship period (two to four months after completion of active cancer treatments);⁵¹ and (c) perceived health, coping self-efficacy, emotion regulation, and post-traumatic stress in extended breast cancer survivors.^{49,50} Furthermore, the effect sizes obtained were comparable to those often obtained in face-to-face interventions.^{49,51} While online interventions do not replace traditional therapist-administered options (and non-inferiority studies have not been conducted), they are a useful first step in a stepped care framework, and as a treatment option for women where the alternative is no treatment (such as in rural or remote areas).

New directions in the treatment of anxiety and depression in breast cancer

While supportive-expressive therapy and CBT remain the gold-standard treatments of choice, more emphasis in recent times has been placed on the role of perseverative thinking (worry and

rumination), attentional biases, and metacognitive processes as maintenance factors for psychological morbidity.⁵² Interventions that specifically target these factors, such as the 'third-wave' psychological intervention strategies (metacognitive or mindfulness-based therapies), are starting to be trialled, with promising evidence emerging for these new intervention types in non-metastatic breast cancer populations,⁵³ including for fear of cancer recurrence.⁵⁴ Given a recent Breast Cancer Gap Analysis flagged this as a priority for research,⁵⁵ this will be an exciting area to track.

Conclusion

Anxiety and depression in women with breast cancer are highly prevalent, but very treatable. If left untreated, there are serious medical and health consequences, which impact on quality of life and healthcare costs. A range of evidence-based pharmacological and psychotherapeutic treatments exist, and new interventions are currently being trialled to reduce the suffering of this population. However, in order to increase the reach of our services, more systematic approaches to screening, and a range of options for delivering treatments (such as through a stepped-care approach) are warranted.

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Supportive care for women with breast cancer living in rural Australia

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Abstract

Breast cancer is the most common cancer diagnosis among women in Australia. The incidence in rural/remote areas is lower compared to metropolitan areas however management in non-metropolitan regions is complicated by reduced access to support services, screening and diagnostic tools, as well as cultural factors and the tyranny of distance. Despite improvements in technology, reducing the disparity of care between rural and metropolitan patients, further investment in known solutions and supportive care research is required to assist with managing the individual psychosocial needs of women as they go through their breast cancer journey, in order to improve rural patients' poorer outcomes.

Breast cancer in the rural setting

In Australia there are more than 15,000 women diagnosed with breast cancer annually. Approximately 30% of the Australian population, or five million people live in rural or remote areas, with 20% of these five million people living in rural or remote communities with less than 5000 residents.¹ It is predicted that there will be over 200,000 women in Australia living with breast cancer by 2017.² The incidence of breast cancer decreases with increasing remoteness from 114 per 100,000 in major cities to 94 per 100,000 in very remote areas. This may in part be due to uptake of screening mammography in very remote areas being 47% and as low as 36% in Aboriginal and Torres Strait Islander women.

Breast cancer mortality rates are higher in inner and outer regional areas (25 per 100,000) compared to major cities (23 per 100,000) despite lower incidence. Five year relative survival was also lower at 84% versus 89.5% for rural/very remote and major cities respectively.³ The biggest determinants of survival in the rural setting are neighbourhood socioeconomic status, being employed in blue collar occupations, having advanced disease and indigenous status.⁴

One per cent of women in Australia diagnosed with breast cancer identify as indigenous. While incidence is lower than in non-indigenous Australians, indigenous women are more likely to present with advanced disease and less likely to receive surgical treatment compared to non-aboriginal women. Risk of death from breast cancer is 39% higher in Aboriginal women compared to non-aboriginal women.⁵ The inequality in survival between indigenous and non-indigenous women with breast cancer has closed over the last 20 years, however this disadvantage must continue to be addressed.⁶

Studies have demonstrated the difficulties in providing optimal breast cancer management in non-metropolitan settings. Delays in commencement of adjuvant chemotherapy for early breast cancer are associated with increased mortality. In one large rural centre, the median time from primary surgery to chemotherapy was 53 days compared to 33 days in an inner metropolitan centre. Patients studied in another large rural centre with a fly-in medical oncologist were more likely to experience delays in receiving adjuvant chemotherapy than their city peers.⁷⁻⁸

Primary treatment support

Australia has clinical practice guidelines for the management of breast cancer however geography, access to specialist services and socioeconomic levels are significant factors that impact patient treatment decisions in the rural setting. The majority of breast cancer patient's first specialist contact

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will be with the surgeon. A cross sectional survey of 70 women in rural Victoria reported that in 60% of cases it was the surgeon who confirmed the cancer diagnosis with the patient. The general practitioner told 22% of patients and in 13% of cases it was the radiologist. Surgeons will refer most women to breast care nurses but only 2% of women in this cohort were referred to a psychologist.⁹

Supportive care needs are highest around the time of diagnosis for women in the rural setting.¹⁰ In general, 20% of women will suffer from anxiety after they are told that they have breast cancer and 40% of women will report depression.¹¹ Oncology counsellors are available at some rural centres' but resources are limited (see table 1 – the Dubbo experience). Counselling services can be accessed through GP management plans, but access is not equitable across the country.¹² There are also breast cancer support groups that may be available to some rural patients. For patients who are more rurally isolated, the Cancer Council has a one-on-one telephone support line with a professional counsellor. Further, websites hosted by Cancer Council Australia, Breast Cancer Network Australia, McGrath Foundation and Cancer Australia provide information on what breast cancer is, treatment options and what to expect, members of the treating team, how to have discussions with family, how to access support services, complementary medicine, and general health and wellbeing information.

Box 1: The Dubbo Experience: Summary of support services available at the Alan Coates Cancer Centre

<p>The Alan Coates Cancer Centre (ACCC) is located in Dubbo, NSW. Dubbo sits on the Macquarie River, a town of 42,000 situated 400km north west of Sydney. It is the referral centre for 130,000 people, from Mudgee in the south east to the Queensland border. Hungerford, the town in the catchment furthest away from ACCC, is 590km away by road, the first 200km on unsealed roads. There is an eight chair chemotherapy suite in Dubbo, as well as a satellite four chair chemotherapy unit in Mudgee. Treatments are supervised by one resident medical oncologist and one resident haematologist, with support from visiting colleagues from Sydney one day per fortnight. Face-to-face consultations are provided at Mudgee (120km east of ACCC), Walgett (270km north) and Cobar (300km north west), with video consultations to most of the 23 hospitals in the catchment. The nearest linear accelerator is 160km to the south east of Dubbo, in Orange.</p>	
Support	Services
<i>Psychological/ Emotional</i>	Breast care nurses - Survivorship programs - Secondary telephone counselling Oncology counsellor Counselling services (through GP management plan) Cancer Council peer support programme/telephone counselling Breast cancer support groups (one monthly held in the day, second one every second month in the evening) Genetic counselling service Telemedicine
<i>Physical</i>	ENCORE program Wig library Look Good Feel Better programme Lymphoedema specialist Physiotherapy Aqua therapy programme
<i>Financial/Social</i>	Pink Angels - provide practical support i.e. meals, cleaning, yard maintenance, fuel vouchers Canassist - accommodation expenses Social welfare officer Isolated Patients Travel and Accommodation Assistance Scheme (A New South Wales government initiative for patients who live more than 100km from the nearest treating specialist) Angel Flight
<i>Indigenous Health</i>	Aboriginal Health Worker Indigenous cancer support group

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<i>Complementary Medicine</i>	Reflexology (off site) Remedial massage (off site) Acupuncture (off site)
<i>Other</i>	BreastScreen Services Community Dietitian

An Australian qualitative study has demonstrated that non-metropolitan cancer patients identify travel as the biggest disadvantage associated with treatment, leading to social isolation, financial distress and family disruption.¹³ At least half of women with breast cancer living in regional or remote areas will require financial assistance for travel with 13% having difficulty organising or claiming back these expenses.¹⁴ Women will make decisions based on reduced need to travel, a woman with early breast cancer is more likely to undergo mastectomy and less likely to have breast conserving surgery if she lives more than two hours from a radiation facility or comes from a socioeconomically disadvantaged area.¹⁵

Bridging the gap

Breast care nurses were introduced in the 1990s to improve continuity of care and provide increased psychosocial support to women with breast cancer. The role of the breast care nurse is not clearly defined and may vary depending on geographic location. These roles include coordination of patient care and provision of information and support to cater to the individual needs of the patient.¹⁶

Difficulty in navigating the complex system of cancer care and misunderstanding about communication and information needs are commonly cited as reasons for lack of engagement of Aboriginal Australians in screening, surveillance and treatment for all cancers.¹⁷ Additionally, suspicion of dominant social structures such as healthcare from a common perception of marginalisation discourages some Aboriginal Australians to enter the system. Aboriginal Health Workers can help with personalising, accessing and explaining the system in a culturally appropriate manner.¹⁸

In Australia, Queensland Health has been active in adopting the telehealth model to help bridge the divide of lack of specialist medical oncology services in rural and remote communities. The majority of patients preferred the initial consultation to be done in person but attitudes towards subsequent telemedicine consultations resulted in positive feedback from the patients and healthcare workers.¹⁹ Telehealth also benefits clinicians by reducing travel time, enhanced education, peer review and better support for isolated practitioners.²⁰

The Patient Remote Intervention and Management System is being trialed in haematology patients. The aim of the intervention is to improve patient outcomes using telemedicine with real time assessment of treatment side effects.²¹ In rural Western Australia, The Improving Rural Cancer Outcomes Trial is a general practice level factorial cluster-randomised controlled trial of a complex intervention to reduce time to diagnosis in rural patients with cancer.²²

The road to recovery

The needs and supports of women with breast cancer change as they progress through their treatment journey. Following the completion of primary treatment, many women report apprehension at the sudden change in frequency of appointments with their specialist. This sense of isolation is compounded by limited availability of specialists and support programs in rural setting.²³ Common concerns include physical sequelae of treatment, intimacy issues, fear of recurrence and the stigma of death associated with breast cancer. Despite these concerns, women identify personal growth as a positive result of the treatment.²⁴

A breast cancer diagnosis may have a lasting impact for years, particularly on sexual well-being and as many as half of women continue to feel unattractive. Ongoing symptoms include tiredness, vaginal dryness, and hot flushes.²⁵ The Look Good Feel Better program teaches cancer patients how to manage the appearance related side effects caused by cancer treatment. The ENCORE program is an eight week course for women who have undergone surgery for breast cancer. The aim is to

improve fitness and quality of life and reduce the treatment related side effects as well as improve body image and self-esteem.

Lymphoedema will affect 20% women even four years after primary treatment.²⁶ Patients living in the country were 37% more likely to develop lymphoedema than city patients.²⁷ Lymphoedema therapists provide a key management service, but are only available in some rural areas, with limited capacity.

Breast cancer patients develop a strong and trusting relationship with their cancer specialists and are reluctant to transfer their care to a general practitioner-led model. This ongoing specialist contact assists with the transition to the surveillance pathway. Due to the lack of specialist services, a shared care arrangement between specialists and general practitioners may be more feasible.²⁸ In the absence of specialist led follow-up, women would prefer to have routine surveillance conducted by a breast physician or breast care nurse as opposed to a regular GP.²⁹ In terms of screening, despite poorer access to mammography services, women in rural areas had similar screening mammography rates as their metropolitan counterparts. Women in rural areas were less likely to have a clinical breast exam but more likely to conduct breast self-examination.²⁹

Summary

The management of breast cancer patients in the rural setting remains challenging due to the heterogeneous nature of the disease, geography and patients' own needs. A one-size fits all model will likely fail in this setting and therefore care of women should be individualised to the patient and support services based on geography. While there has been progress in bridging the divide between rural and non-rural access to healthcare, there is still room to improve equity of access to medical services for rural patients through investment in innovative rural-based supportive care research, and increasing funding to rural cancer centres to increase access to proven medical, nursing and allied health led interventions.

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The role and supportive care needs of the partners and carers of women with breast cancer

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Abstract

More than 15,000 women are expected to be diagnosed with breast cancer in Australia in 2016. The shift towards delivering cancer care through ambulatory treatment centres means that partners, relatives, children, siblings and friends of women diagnosed with breast cancer are commonly required to provide much-needed care and support for these women post-treatment. The role of 'carer' can take many different forms and for some, it can be equivalent to a full-time job, with many carers reporting having more things to do than they can handle. Being a carer can be a positive experience, for example some husbands of breast cancer patients undergoing active treatment reported both interpersonal and intrapersonal benefits of caring, such as feeling closer to their partner and growing as a person. However, there is ample evidence that taking on the role of carer has significant impacts on carers' physical and mental health and many carers feel ill-prepared for that role, especially if the care requires them to address complex medical needs while also supporting their loved one with the psychological challenges experienced following a cancer diagnosis. The inter-relationship between patients' and carers' wellbeing is well-documented, with evidence suggesting that carers' physical and mental wellbeing may influence patient status. Hence, offering informal carers interventions that are structured, goal-oriented and time-limited is recommended to support them in their roles, and many argue that family carers should be considered a 'co-user', or 'co-client' of cancer services.

It is projected that over 15,000 women will be diagnosed with breast cancer in Australia in 2016.¹ Over the past 20 years, there has been a shift towards providing cancer care through ambulatory treatment centres. This has resulted in a considerable expansion of both family carer numbers and the variety and complexity of tasks they perform.² Caring for a loved one with cancer has the potential to impact on both the physical and mental health of carers, and many feel ill-prepared for being a carer.³ This paper provides an overview of the roles undertaken by carers, including of women with breast cancer, the impact of being a carer, carers' supportive care needs and interventions which may support carers in that important role.

Carers of women with breast cancer include their partners, relatives, children, siblings, or friends. In 2015, one in eight (2.8 million) Australians reported being an unpaid carer, 770,000 (29%) of whom identified as a primary carer. In Australia, females represent the majority of primary carers (70%) and carers generally (56%),⁴ and are likely to be a close relative (e.g. parent, partner or child). Cancer is one of the top 10 health conditions requiring a carer, and the demand for carers will continue to increase as cancer incidence and survival continue to rise.⁵

Carer roles and responsibilities

Often, carers are a patient's decision maker, communicator and advocate. The support carers provide to women with breast cancer varies widely and includes instrumental support, such as driving patients to medical appointments, coordinating their healthcare, financial management, assistance with housework;^{4,6} information support, such as helping patients find information about their cancer and treatment; assistance with decision making;^{6,7} and emotional support.^{8,9}

Many primary carers are balancing paid work and caring for their loved one. In an Australian study approximately half of carers reported having more things to do than they could handle, and for many, their caring continued even when the patient was admitted to a residential care facility.⁹ Many carers report becoming the primary carer due to a sense of family responsibility and emotional obligation, with little choice and nobody else available to undertake the role.⁴ Stepping into a carer role can be a difficult transition, involving negotiations with the patient, their families and healthcare team. However, often carers assume their novel roles and responsibilities without being fully aware of the burden these might cause, regardless of their readiness to do so and with little to no formal training.¹⁰

The caring needs of people with cancer vary. Carers are estimated to provide about 70–80% of patients' cancer care,¹¹ and for some carers the role can extend over several years and be akin to a full-time job.¹² Yabroff and Kim reported that informal carers of breast cancer patients provided 6.4 hours of care per day for 13.6 months in the two years post-diagnosis, which translated to an average of \$38,334 per patient in carer time costs.¹³ In Australia, it is estimated that informal carers save the Federal budget \$60.3 billion annually (equivalent to 60% of the health and social work industry), highlighting the economic value of their roles.¹⁴

Worryingly, with the increasing shift from inpatient to outpatient healthcare provision and changes in population demographics, forecasts show that the demand for informal caring will outstrip supply within the next 10 years.¹⁴ This widening healthcare gap presents significant challenges in cancer care that will lead to poorer patient outcomes and greater pressure on informal carers if left unmet.

The impact of caring for someone with cancer

Providing care for a partner with cancer has the potential to affect the physical and mental health of carers, who often feel ill-prepared to take on such a role, especially if they are required to address complex medical needs while simultaneously supporting their loved one with the psychological challenges associated with cancer.

Carers report high levels of anxiety and depression,¹⁵ burden and unmet needs,^{16,17} and declining physical wellbeing;¹⁸ and some carers do not 'bounce back' after a period of initial adjustment, creating an at-risk group of carers.^{15,17} Across the first year post-diagnosis, psychosocial adjustment levels in breast cancer patients' husbands were reported to be worse than husbands of women with benign breast disease and no different to that of the breast cancer patients themselves.¹⁹ Psychosocial adjustment difficulties are reflected in poorer carer quality of life (QOL) in domains including general health, vitality, role-emotional, and mental health.²⁰ Importantly, the strongest predictor of husbands' psychosocial adjustment one year post-diagnosis was adjustment levels immediately post-diagnosis,²¹ indicating that initial difficulties persist over time, and also highlighting the importance of early intervention to support carers.

The physical and psychosocial impact of caring can vary significantly depending on the patient's functional status. For example, carers of breast cancer patients with more comorbidities report significantly higher levels of fear of cancer recurrence.²² Caring for women with advanced breast cancer can exact a particularly high toll. Grov et al found that male primary carers of advanced breast cancer patients experienced greater anxiety and lower mental QOL compared with age-adjusted norms.²³ Further, Grunfeld et al reported that significantly more carers of women with advanced breast cancer were depressed (30% vs 9%) and perceived a greater burden at the start of the terminal period (i.e. closer to death) versus the start of the palliative period; and that burden was the strongest predictor of anxiety/depression.²⁴

Sleep quality has been explored in breast cancer patients and their carers, given its established correlation with psychological mood and interpersonal relationship quality.²⁵ The prevalence of sleep problems in carers of women with breast cancer is high (up to 88-95%).²⁶ Importantly, in one study, sleep problems predicted 63% of variance in carer depression.²⁶ While non-pharmacological interventions have been shown to improve patients' sleep quality and immune function,²⁷ reduce sleep medication use and mood disturbance,²⁸ and reduce fatigue and enhance daily activities,²⁹

there is a dearth of interventions targeting carer sleep quality. This is clearly an area that requires attention.

The impact of the relationship between the carer and patient on carer outcomes has been explored in several studies. In a qualitative study of bereaved carers of women with advanced breast cancer, Coristine et al found that spousal and non-spousal carers perceived their roles quite differently, with spousal carers considering themselves decision makers and non-spousal carers seeing themselves more as patient advocates.³⁰ Non-spousal carers also perceived they had more roles to juggle, as they managed separate residences, jobs and/or their own family. Many studies of breast cancer carers have included only heterosexual male partners. While gender may influence carer outcomes - for instance Lopez et al found adherence to masculine norms of stoicism meant male carers were less supported³¹ - carer sexual orientation does not appear to be significant, although more research is needed in this area.²²

Carers' affective states and personality traits may colour their perceptions of the impact of caring. Kurtz et al found that carers (25% of sample was caring for breast cancer patients) with higher optimism levels reported a lesser impact on their schedule and health and lower levels of depression.³² Male spouses of breast cancer patients who felt more hopeful, less guilty, and had greater self-efficacy reported better QOL.³³ This research highlights the need to explore a wide range of variables to better understand carers' preparedness to cope with the known stresses of a carer role, particularly as impairments in carers' wellbeing can limit their ability to provide care.

Despite cancer carers facing many challenges they also experience positive outcomes. In one Australian study, 42-98% of carers identified at least one positive element in their cancer caring experience.³⁴ Another study found husbands of breast cancer patients reported both interpersonal and intrapersonal benefits of caring, such as feeling closer to their partner and growing as a person.³⁵ More research is needed to understand the complex interrelationships between caring benefits and burdens, with mixed associations found to date.^{35,36}

Carers' unmet needs

Carers report significant unmet needs, particularly relating to comprehensive cancer care, information, emotional and psychological, daily activities, social and relationship, and spiritual issues. A recent systematic review identified that carers of cancer patients report an average of 1.3-16 unmet needs (range 17-67), suggesting that 5-47% of carers' needs remain unmet.³⁷ Studies have also reported carers' needs exceeding those of patients,³⁷ including within the breast cancer context,^{38,39} and persisting well beyond the cancer diagnosis.¹⁷ Predictors of unmet needs include: being female, distress, anxiety, interpersonal conflict, having lower social support, caring for someone other than a partner/spouse, and having other caring responsibilities (e.g. for children).^{37,40}

Information needs are frequently cited by carers of breast cancer patients. A study of information needs of informal carers of women treated for breast cancer found that information regarding prognosis and treatment options were priority areas for carers.⁴¹ Furthermore, carers wanted honest information so they knew what to expect in the future. Similarly, Schmid-Buchi et al reported that unmet information needs, particularly regarding medication, side effects, treatment plans and knowing what to expect, were the primary unmet need for relatives of breast cancer patients.³⁸ Additionally, family carers needed greater access to, and opportunity to communicate with, medical staff. Obtaining information from medical professionals is important, with Nikoletti et al finding that family carers of post-surgery breast cancer patients who received information from a breast care nurse and medical staff reported significantly fewer unmet needs compared with carers who used other information sources.⁴² Spouses of women with breast cancer have expressed a preference for information from physicians and nurses rather than family, friends, books and the internet.⁴³ Carers are more likely to be distressed, anxious or depressed if they are not adequately informed,⁴⁰ highlighting the importance of addressing carers' information needs.

Within the context of breast cancer, informal carers report unmet needs in other domains, including emotional/psychological,^{18,44} navigating the health care system,⁴⁵ social and practical support,¹⁸ and sexuality.⁴⁴⁻⁴⁶ For example, Hilton et al found that spouses of breast cancer patients report difficulties navigating the health care system and a sense of marginalisation through health care professionals' failure to adequately acknowledge their role.⁴⁵ Regarding sexuality, male carers frequently indicate negative changes to sexual relationships,⁴⁶ although few seek assistance.⁴⁴ The inter-relationship between patients' and carers' wellbeing is now well-documented, with evidence suggesting that carers' physical and mental wellbeing may influence patient status. For example, a meta-analysis by Hodges et al found a positive correlation between patient and carer psychological distress.⁴⁷ Importantly, there is also the potential for carer outcomes to positively impact on patients, with Keefe et al finding that high self-efficacy for pain management tasks in carers was linked to increased patient energy and time out of bed, and reduced patients' sense of feeling ill.⁴⁸ Other studies have shown beneficial outcomes for patients where their carers have received support, with improvements in patient depression⁴⁹ and hopelessness,⁵⁰ enhanced symptom management⁵¹ and reduced symptom severity/intensity.⁵² Therefore, by supporting carers and improving their wellbeing and self-efficacy, there is the potential to enhance cancer patients' QOL.

Interventions to address carer needs

While support groups can assist some carers, there is a paucity of groups specifically for male carers of women with breast cancer and carers may not attend due to time constraints. Research has consistently found that cancer carers have insufficient knowledge and skills regarding caring tasks (e.g. symptom management) and experience communication barriers and inadequate emotional support.^{16,53} Most carers report needing some level of support,⁵³ and identify psycho-educational programs as an avenue to address their needs.^{53,54} A meta-analysis of cancer carer training interventions showed carer training significantly improves carer burden, QOL and self-efficacy;¹⁰ has the potential to improve anxiety and depression;^{55,56} and improves carer preparedness and competence.⁵⁷ A review by Applebaum and Breitbart concluded that interventions for informal carers that are structured, goal-oriented and time-limited are most effective and feasible.⁵⁸

There is a developing literature examining the effectiveness of interventions specifically developed to address the needs of carers for women with breast cancer. A review by Lally and Brooks found six interventions designed for supporters of women with early breast cancer, and while results were mixed, all studies found positive change in at least one outcome.⁵⁹ Similarly, a review of couple-based interventions in breast cancer found that both women and their partners reported improvements in QOL and relationship functioning, with reductions in distress and physical symptoms.⁶⁰ Results from several pilot studies suggest that supportive care interventions targeting carers or patient-carer dyads dealing with breast cancer can positively impact cancer-related stress and mental health,⁶¹ carer burden,⁶² sexual dysfunction,⁶³ partner anxiety,^{56,63} depression, caring skills, self-confidence and self-care.⁵⁶

Larger randomised controlled trials are also beginning to emerge examining the efficacy of interventions for patient-carer dyads in both early-stage and advanced-stage breast cancer.^{64,65} Manne et al compared a couple-based support group to an eight-week structured skills group intervention for couples dealing with early-stage breast cancer ($n=302$), finding improvements in anxiety, depression, distress and positive wellbeing over time in both groups.⁶⁴ A moderating effect was observed for baseline distress, with supportive group therapy most effective for highly distressed patients and structured skills-based therapy most beneficial for less distressed patients. Another trial conducted by Northouse et al with a mixed sample of advanced cancer patients and supporters ($n=157$; 32% breast cancer patients and carers) compared a three or six-week information and support intervention to a usual care control group.⁶⁵ Overall, findings suggested that both intervention groups benefitted, with short-term improvements in coping, self-efficacy and QOL (social and emotional). Both interventions reduced avoidant coping and maintained social QOL, the three-week intervention was particularly effective in improving patient and carer health behaviours, while the six-

week intervention had a greater effect on self-efficacy. While intervention effects were not sustained over time, this is understandable given the advanced disease facing couples in this trial.

In light of the evidence presented in this paper, some argue that family carers should be considered a 'co-user', or 'co-client' of cancer services.⁶⁶ However, in reality, most carers are not the recipient of care in relation to their caring role and are often considered by health care providers as being outside their scope of responsibility, despite growing recognition of their unmet needs.⁶⁷⁻⁶⁹ New models of care are needed to both acknowledge carers' inclusion in the broader care team and also to support them in the critical role they play in caring for women with breast cancer.

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2016 Tom Reeve Award for Outstanding Contributions to Cancer Care

Fran Boyle

It was a great honour to be presented with the Tom Reeve award at COSA this year, and to have the opportunity to reflect on Tom's many contributions to leadership in the Australian oncology scene, and to my own career development.

I first met Tom when I was an advanced trainee at Royal North Shore Hospital in 1990. The legendary 'Prof' of the thyroid cancer world was seen striding the corridors in a white coat, trailed by minions, and when we called him in to consult, everyone on the team knew they needed to be all over the case, including knowing all about the patient's personal circumstance, in preparation for a grilling. What was not so clear to us was the extent to which he was regarded worldwide as a clinical expert and organisational leader. We just knew we had to get it right.

Tom and I developed a closer relationship during my time as a PhD student, when we found ourselves sharing a desk and consulting room in Bob Ravich's nearby private practice for our weekly clinical sessions. I had made some design modifications when I began work, turning the desk around so that I could consult across the corner, and installing a crystal ball, that essential tool for prognostication for a medical oncologist*. Prof, superior in height and gravitas, said he thought the desk worked perfectly well the other way, and his data base could answer any necessary patient question about prognosis. This polite battle of generations continued for some time, until our attendance at the National Breast Cancer Centre (NBCC) communication training courses run by UK expert Lesley Fallowfield in 1997 reinforced my desk fung shui choices.

Tom became involved in the work of the NBCC to lead the development of the first Early Breast Cancer Guidelines, and introduced me to the Director Sally Redman to assist with a review of Breast Cancer Research in Australia. This was a "crucible" event in many ways.¹ My own experience with Breast Cancer had not been a happy one, having observed at close quarters the distressing journey of the mother of one of my close friends at medical school in the 1980's: a late diagnosis, radical surgery, lymphoedema, relapse with few treatment options, poor communication and fragmentation of care, and little support in managing the emotional impact on the patient or the family. It was everything that the NBCC sought to change, in partnership with consumers such as Lyn Swinburne and Sally Crossing, and communication experts such as Lesley and our own Stewart Dunn.

The chance to get involved in this change was irresistible, and my involvement with that initial project not only got me out of the animal house isolation and into a role with the NBCC, it also introduced me to the ANZ Breast Cancer Trials Group. They were the one research group who had been successful in attracting National Health and Medical Research Council funding since their inception in 1978, and clearly had leaders with international reputations and networks. Prof Coates and Prof Forbes were out of the Tom mould – if you did your homework and got it right, they were very supportive of young investigators getting involved.

Over the years since then it has been a privilege to observe at close quarters the work of these diverse leaders. Not only have they transformed the Breast Cancer landscape, they have innovated in ways that have flowed on to improvements in the management of other cancers and other health issues. During 2016 I enjoyed participating in a leadership course for women in the tertiary sector through the Australian School of Applied Management (asam.edu.au – highly recommended) and it gave me further insight into what it was that they were doing that worked to facilitate progress in the complex adaptive challenges we face in health.

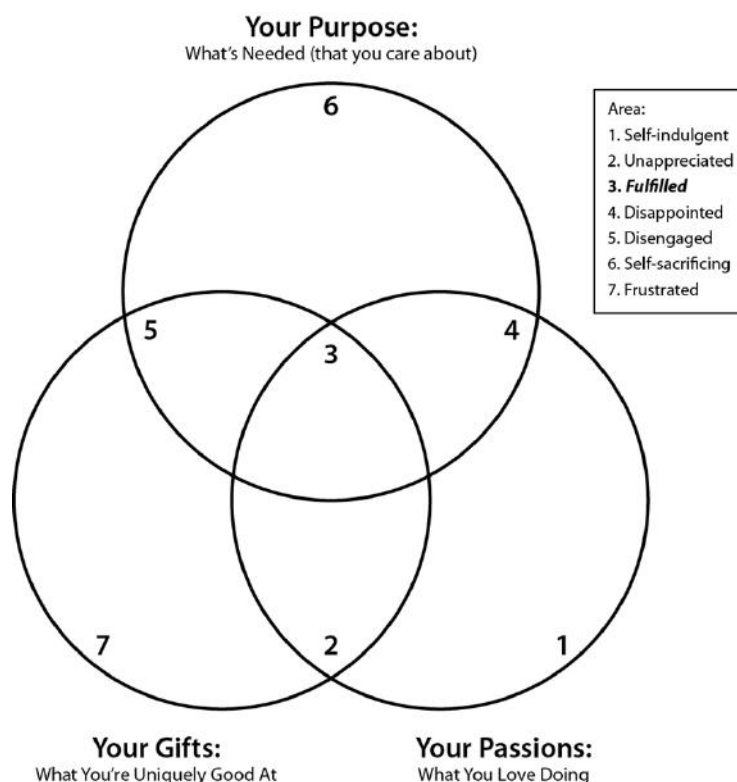
Ronald Heifetz has identified key factors in effective leadership when change requires attention to values, beliefs, roles, relationships and approaches to work, rather than just technical fixes.² It is clear to me now that Tom and the others involved in transforming Breast Cancer into a 'team game' instinctively knew these principles of adaptive leadership.

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1. 'Get up on the balcony', away from your own discipline's constraints, and try to see the big picture and the long-term outcomes.
2. Identify the adaptive challenge and the values and relationships that will be at stake.
3. Regulate distress – keep things hot enough to progress, but not so hot that there is a melt down.
4. Maintain disciplined attention and ensure outputs are carefully documented.
5. Give the work back to the people by ensuring delegation to those with an interest in making progress.
6. Protect the voices of leadership emerging in those who are young, until they have a chance to stand on their own feet.

It is these last principles that benefited me, and those like Nicholas Wilcken, Martin Stockler, Jane Turner, Afaf Girgis, Helen Zorbas, Phyllis Butow and others who developed their careers under the protection of the NBCC. Pollard describes a career 'sweet spot' as the intersection of your unique abilities, your passions and your purpose and opportunities (figure 1).³ For those passionate about improving care of breast cancer patients, the NBCC under Tom and Sally's leadership brought together our various abilities, and gave us opportunities to make a difference.

Figure 1: Finding your career 'Sweet Spot'



When I asked my children as part of this course what my unique ability was they pondered for a second and then said "You talk to strangers", recalling the many times I had embarrassed them in public. This ability to make connections is critical to the network of relationships, including those with consumers, that is required to bring about that 'Tipping Point' for social change.⁴ From design of a clinical trial, to the eventual PBS approval of a new agent and its introduction into guidelines, a multitude of national and international relationships need to be maintained. That connectivity, with its demands for midnight teleconferences and long haul flying when playing for Australia, and the ability to sustain effort over a long time, are hallmarks of our leaders who have dedicated their working lives to better outcomes for our patients and their families.

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In closing, I would also like to thank my family for their support over the past 30 years. When I was an intern in the now infamous Bundaberg Hospital, my surgical supervisor, poised over my term report, advised me that “You will never make a surgeon, the best you can hope for is to sleep with one”. Although I politely declined his offer, it turned out to be excellent career advice. My husband Michael Hennessy, an Ophthalmic Surgeon, has been 'technically brilliant' in keeping my life focused. Our twins Clare and Leo are also to be thanked for improving my efficiency, and for turning into really nice people, who understand that 'the sick people' sometimes need to come first, and that we all need to work as a creative team to achieve progress.



* I do have a Crystal Ball

During my training at RNSH, I was on a ward round with one of my consultants when a young woman with breast cancer and spinal cord compression asked him “Do you think I will ever walk again?” He answered “I don’t have a crystal ball” and moved on to the next patient. Sensing that this did not really answer her question, I returned after the ward round to find her in tears. “You think these questions are hard to answer” she sobbed, “but you don’t realise how hard they are to ask!”

I decided that when I grew up, I wanted to be able to listen and respond better, and so visited the local crystal shop in search of a ball for my desk. Naturally drawn to the cheapest ones (being a PhD student), I was approached by the shop assistant. “What are you planning to use it for?” she asked. I explained I was the new oncologist on the block and wanted to be able to help people better with prognostication. She went pale and sweaty, and said “It doesn’t work that way!”

I enquired whether I should be buying a more expensive quartz version, but she shook her head. “The symbolism of the crystal ball is frequently misunderstood. It’s not about foretelling the future, it’s about helping people to ask questions that reveal what is important to them.”

“Ah well, that’s exactly what a young oncologist needs then” I replied, and have kept a crystal ball on my desk ever since. Not a week passes but a patient says “Well I know you don’t have a crystal ball...” and I point to it “But I do, what would you like to talk about?” and the most surprising priorities and values can emerge in the ensuing discussion. If you would like to improve your communication skills, and get to know your patients better, it’s a relatively inexpensive addition to your desktop that I would recommend. And the glass one works just as well as the expensive quartz model.

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Behavioural Research and Evaluation (BREU), Cancer Council SA

Practical support program: Evaluation of the first 12 months of operation

The practical support program provides short-term practical relief where treatment for a cancer diagnosis is having a significant effect on a person's ability to remain independent. It is intended for people who do not qualify for government-funded services and are unable to access support from family or friends. Support that may be accessed through the program includes cleaning, light housekeeping and meal preparation, short-term care of children and basic gardening. Clients, referrers (including nurses on Cancer Council's 13 11 20 information and support line) and service providers were surveyed to provide feedback on the program. Data from record keeping systems were also examined to provide process measures on the number of referrals, referrals granted/declined, and average spend on services.

Referrals were higher than expected in the first year and were generated both from Cancer Council SA staff and health professionals working in cancer treatment centres. The results indicated satisfaction from the perspective of clients, referrers and service providers in a number of domains including information provision, referral and booking processes, speed and quality of service provision, and communication. Areas for improvement were identified through feedback, about the service not meeting a small number of client's needs. Service providers indicated they would value further information or training to support their understanding of clients' having cancer treatment. The impact of the program was reflected in clients' reports of improvements in stress, general coping, energy/fatigue and ability to focus on treatment. Overall, the program is operating as intended. The evaluation has identified some areas where improvements could be made, particularly to support service providers to ensure the needs of clients are understood and addressed.

Challenges to the uptake of cancer education resources by rural Aboriginal health workers

The burden and expenses associated with transport and accommodation have been identified as barriers to accessing medical treatment for Aboriginal and Torres Strait Islander people affected by cancer, who may additionally experience cultural and linguistic barriers. In response to a lack of culturally appropriate resources to explain cancer and the cancer journey to Aboriginal and Torres Strait Islander cancer patients, Cancer Council SA lead the development of the Cancer Healing Messages flipchart and patient flyer to assist health professionals, particularly those working in regional and remote areas of South Australia.

The evaluation examined the usage, acceptability and perceived usefulness of the resources, barriers to uptake, and strategies to improve their utilisation and sustainability. This was accomplished through the participation of Aboriginal Health Workers and other health professionals working with Aboriginal clients in South Australia in a survey.

The resources were considered valuable, useful and culturally appropriate. However, despite the collaborative development with key stakeholders and reported high levels of acceptability, the uptake and usage of the resources was low. Barriers to usage were identified including access to the resources when needed. A long-term strategy and clear implementation plan involving education, training and promotion of the materials, is required to achieve broad reach and sustainable utilisation of the Cancer Healing Messages flipchart and patient flyer. The results will be presented in Melbourne at the Behavioural Research in Cancer Control conference, May 2017.

Centre for Behavioural Research in Cancer (CBRC), Victoria

Prevalence of drinking behaviours among Australian secondary students in 2014

The Australian Secondary Students' Alcohol and Drug (ASSAD) survey, conducted triennially since 1984, is a collaboration between Cancer Councils in Victoria, Queensland, Tasmania and South Australia as well as Commonwealth and state and territory health departments. Led by A/Prof Vicki White, around 23,000 students aged 12 to 17 years from 352 schools participated in the study in 2014. Two of every three Australian secondary students aged between 12 and 17 years had tried alcohol at some time in their lives (68%) and just under half had consumed alcohol in the past year (45%). Drinking became more common as students progressed through secondary school, with 36% of 17 year-olds drinking in the past seven days (current drinkers) compared to four percent of 12 year-olds. Nine percent of 16 year-olds and 17% of 17 year-olds reported drinking five or more drinks on at least one of the past seven days. Students who drank in the past seven days most commonly accessed alcohol from their parents (38%), drank alcohol at a party (35%) or at home (31%) and most commonly consumed premixed spirits (35%). In the past year, 61% of current drinkers experienced at least one negative outcome from drinking (e.g. vomiting, arguing, trying drugs). In 2014, the proportion of students ever drinking (68%) was significantly lower than in 2011 (74%) and 2008 (82%). The proportion of current drinkers decreased between 2008 (23%) and 2014 (15%) and between 2011 (17%) and 2014. The full ASSAD report is available [online](#).

Can systematically developed alcohol health warning labels reduce drinking intentions and behaviours?

Alcohol use ranks among the top five contributors to global disease burden, yet the public has relatively poor awareness of the wide range and seriousness of alcohol-related harms. Health warning labels on alcohol containers have the potential to address knowledge deficits and reduce drinking intentions and behaviours. Despite strong public support for warning labels and WHO and government reports recommending them, a lack of robust evidence has hindered policy implementation. Professor Melanie Wakefield and colleagues have been awarded a National Health and Medical Research Council Project Grant to assess the content and design of alcohol warning labels with the greatest potential to encourage drinkers to reduce their alcohol-related risk. The project will use health communication principles and a pre-testing approach adapted from developing effective tobacco warning labels. A population survey will determine the 16 alcohol harms linked to lower-risk drinking intentions and behaviours which have the greatest potential for improving awareness. The second study will pre-test the 16 selected harm topics to determine the strongest eight and identify which image options and linguistic devices (personal agency, hedging) improve persuasive potential. The final study uses an experimental approach to compare effects on drinking intentions and behaviours of repeated point-of-sale exposure to alcohol containers with a) text only or b) text and image warning labels against two control groups representing the usual situation c) no label and d) alcohol-industry funded DrinkWise warning labels. The findings will greatly strengthen the evidence base available for policy deliberations.



Mock-up of a text only health warning label on a wine bottle.

Newcastle Cancer Control Collaborative (New-3C), NSW

Improving self-management of health risks among general practice patients

Background

Preventative health guidelines highlight the important role of general practitioners in identifying and managing cancer risk factors. However, general practitioners have reported several barriers to implementing such guidelines into practice, including lack of time and competing demands within the consultation. Patient self-management may offer a solution to overcome such barriers, by empowering the patient to manage their own healthcare via lifestyle changes and encouraging them to seek support from their doctor when needed.

Aims

Members of New-3C are undertaking a study to test the impact of a low intensity intervention to increase patient self-management of cancer risk factors and screening needs. The study examines whether providing general practice patients with brief information about their health risk factors and cancer screening tests that may be appropriate for them, has an impact on the self-management strategies used to manage their health. For the purpose of this study we have focussed on selected cancer risk factors – smoking, and risky alcohol consumption – as well as screening for breast, bowel and cervical cancer. We are also assessing depressive symptoms, and for those with elevated depression scores, providing brief information on self-management and sources of professional help. While depression is not a cancer risk factor; it may co-occur with risk factors such as smoking and risky alcohol intake. Where depression co-occurs it may impede self-management efforts to reduce preventable risk factors, and therefore, it is important that information on depression is obtained and addressed.

Methods

Eligible general practice patients are asked to complete a brief touchscreen computer survey in the waiting room prior to their appointment. The survey includes questions about their cancer health risk factors (e.g. smoking) and their participation in cancer screening. Upon survey completion, participants in the intervention condition receive tailored printed feedback about their health risk factors and recommended cancer screening tests. All participants are followed up with a 15 minute telephone interview one month after their initial survey. The telephone interview asks about any self-management steps and cancer screening tests which they may have undertaken since the initial survey. This allows us to test whether providing this brief feedback to patients at their primary care appointment results in actions to improve health. (Protocol paper is published here: Carey C, Sanson-Fisher R, Oldmeadow C, Mansfield M and Walsh J. (2016). Improving self-management of cancer risk factors, underscreening for cancer and depression among general practice patients: study protocol of a randomised controlled trial. *BMJ Open*, 6: e014782).

Progress

Data collection is underway at two general practices in the Hunter region, with plans to expand recruitment to a third general practice in 2017. To date 130 participants have been recruited across two practices and follow-up interviews have been completed with 80% of participants.

Western Australian Cancer Prevention Research Unit (WACPRU), Curtin University

How does the new Health Star Rating system for packaged foods stack up?

Packaged foods form a major part of the average Australian's diet. As different products within the same food category can vary widely in healthiness, it can be difficult to make the healthy choice. Poor diet is a substantial contributor to cancer risk, which makes it important for individuals to be able to identify healthy foods. Nutrition labels on the front of pre-packaged foods can facilitate healthier choices by providing prominent, simplified information. These labels come in a wide range of formats, but the two that will be most familiar to Australians are the Daily Intake Guide (in use since 2006) and the Health Star Rating (in use since 2015). The Daily Intake Guide emphasises product healthiness through specific nutrients (e.g. sugar, salt, fat) while the Star Rating does so through a formula that weights the levels of various nutrients to form a composite score. Currently both labels coexist in Australian supermarkets with the Health Star Rating set to replace the Daily Intake Guide over the next few years. Until now there has been no research directly comparing which of these labels is more effective at guiding consumers to healthier choices.

Researchers at Curtin University's WACPRU surveyed a large, diverse sample of Australians (over 1900 males and females, aged 10 to 85, of low and high socioeconomic status) on their impressions of fictional cookie, cornflake, pizza and yoghurt products. The product pack images featured either no front-of-pack nutrition label or either the Daily Intake Guide or Health Star Rating and were designed to be unhealthy. Unhealthy variants of these foods were the focus of this study since they should be consumed most sparingly and since people tend to consume more of a product when they perceive it to be healthier.

The survey results showed that overall impressions of the products were more positive when the Daily Intake Guide was present on the pack than when the Health Star Rating or no label was present. People also thought the products were healthier and were more willing to buy them with a Daily Intake Guide compared to a Health Star Rating.

One explanation for these findings is that the Health Star provided information in a format that was easy for respondents to understand, thus allowing them to more accurately gauge product healthiness compared to the Daily Intake Guide. The fact that the Daily Intake Guide led to more favourable impressions than *no label at all* suggests that the label's mere presence leads them to think more highly of the product it is on.

These findings are highly relevant to policy makers who need to consider which front of pack labels should be applied to foods. It is also important for the general public to be aware of the cognitive biases they may be susceptible to and how to counter these.

The findings of this study have been recently published in *Nutrients*.

Cancer Council Australia

Australians encouraged to get active on World Cancer Day

On Saturday 4 February, Cancer Council Australia joined organisations around the world to mark World Cancer Day and encourage Australians to get physically active to reduce their cancer risk.

Only around one in two Australians aged 18-64 meet the Australian physical activity guidelines of more than 150 minutes of moderate physical activity or more than 75 minutes of vigorous physical activity, or an equivalent combination of both, including walking, per week.

Research shows that 1800 preventable cancer cases in Australia each year were attributed to inactivity and a further 3900 cases were caused by high body mass, a risk factor that cancer also be reduced by being more active.

Australian Institute of Health and Welfare's *Cancer in Australia 2017*

National cancer data released on the eve of World Cancer Day (4 Feb) highlights lost opportunities in bowel cancer screening and an alarming increase in liver cancer deaths, indicating the benefits of cancer prevention and early detection.

The report shows that Australia continues to have some of the best cancer outcomes in the world. Cancer incidence rates and the cancer death rate continue to fall – the report shows that 68 per cent of people diagnosed with cancer survive at least five years, a 20 per cent increase from the 1980s.

However cancer continues to be the biggest cause of disease burden in Australia – largely because of its contribution to the number of premature deaths. Over 134,000 Australians will be diagnosed with cancer in 2017, but sadly there is low participation rates in the three cancer screening programs from bowel, breast and cervical cancer.

The report also showed that liver cancer was the only common cancer where mortality had increased, likely due to increases in Hepatitis B and C infection and risk factors such as high body mass and excess alcohol consumption.

National Skin Cancer Action Week

Cancer Council research released in November showed fewer Australians are using hats to protect themselves from the sun and, as a result, are getting sunburnt on their face, head, nose or ears.

The data from Cancer Council's National Sun Protection Survey revealed that just 44 per cent of Australian adults wear a hat when exposed to UV on summer weekends, down from 48 per cent in 2003.

Australian adults' use of clothing to protect their skin also decreased and their tendency to seek shade during peak UV times showed no improvement. However, the survey did show that Australian's use of sunscreen had increased.

Cancer Council and the Australasian College of Dermatologists used the findings to remind Australians about the importance of protecting themselves in five ways for National Skin Cancer Action Week.

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Cancer Council and Australian Cancer Survivorship Centre – On the Road to Recovery CALD Project

On the road to recovery is a collaboration designed to produce translated booklets to assist cancer patients and survivors from cultural and linguistically diverse communities.

Developed by Cancer Council in conjunction with the Peter MacCallum Cancer Centre, the project has been supported with funding from Cancer Australia.

Stage one developed booklets on cancer survivorship in Cantonese, Mandarin and Greek. Stage two produced bilingual booklets and fact sheets in Arabic, Vietnamese and Italian.

Stage three is now underway with a view to developing resources on survivorship in Hindi and Tagalog. This project is again being supported by Cancer Australia.

For details, contact Jane Roy on 02 8063 4100 or email jane.roy@cancer.org.au

Supporting people with cancer

Cancer Council Australia has received funding support from Cancer Australia for the development of psychosocial and information resources, focusing on a supportive care framework for patients in Australia, with rare or less common cancers with less common cancers. In addition, the project aims to develop web-based content on 10 less common cancers.

Clinical Guidelines Network

Cancer Council Australia aims to produce concise, clinically relevant and up-to-date electronic clinical practice guidelines for health professionals, accessible on its wiki platform at wiki.cancer.org.au

For more information or to be added to the mailing list for notification of guidelines open for public consultation or guidelines launches, please email guidelines@cancer.org.au.

Guidelines in development

Guideline	Status
National Cervical Screening Program: Guidelines for the management of screen detected abnormalities, screening in specific populations and investigation of abnormal vaginal bleeding	Will be launched in 2017, in support of the Renewal of the National Cervical Screening Program.
Clinical practice guidelines for the prevention, diagnosis and management of lung cancer	Systematic reviews and content development in progress for second set of content. The first set of questions were published in November 2016.
Clinical practice guidelines for the diagnosis and management of melanoma	Second set of draft content went to public consultation Jan/Feb 2017 and post public consultation in progress. Email guidelines@cancer.org.au to be notified when the final content will be published. Further systematic reviews in progress.

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Clinical practice guidelines for the prevention, early detection and management of colorectal cancer	These guidelines will be open for public consultation from 10 March to 8 April 2017. Please see http://wiki.cancer.org.au/australia/Guidelines:Colorectal_cancer to submit feedback.
Clinical practice guidelines for the management of sarcoma in AYA	Systematic reviews in progress.
Clinical practice guidelines for Surveillance Colonoscopy	Guidelines revision commissioned by Department of Health and systematic review updates are underway.

Cancer Council Australia guidelines

Guideline	Last updated
Clinical practice guidelines for PSA testing and management of test-detected prostate cancer	August 2015
Clinical practice guidelines for the diagnosis and management of Barrett's oesophagus and early oesophageal adenocarcinoma	September 2014
Clinical practice guidelines for the treatment of lung cancer	December 2012 (update in progress)
Management of apparent early stage endometrial cancer	March 2012
Clinical practice guidelines for surveillance colonoscopy	December 2011 (update in progress)
Clinical practice guidelines for the management of adult onset sarcoma	February 2015
Clinical practice guidelines for the management of locally advanced and metastatic prostate cancer	April 2010

Clinical Oncology Society of Australia guidelines

Guideline	Last updated
Clinical practice guidelines for teleoncology	December 2015
Diagnosis and management of gastroenteropancreatic neuroendocrine tumours guidance	August 2012
Evidence-based practice guidelines for the nutritional management of adult patients with head and neck cancer	August 2013
Early detection of cancer in AYAs	May 2012
AYA cancer fertility preservation	September 2012
Psychosocial management of AYA cancer patients	June 2012

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Other guidelines

Guideline	Last updated
Cancer pain management	August 2013

Clinical Oncology Society of Australia, COSA

COSA Annual Scientific Meeting (ASM)

The 2016 COSA ASM was another highly successful conference. Our partnership with the Australia and New Zealand Breast Cancer Trials Group helped ensure the program covered all aspects of breast cancer research and treatment. As always, COSA's emphasis on multidisciplinary care was soundly embodied in the presentations.

The common overarching themes from all presenters in the opening plenary "Global advances in breast cancer" set the scene for three full days of conferencing, recognising the heterogeneous nature of breast cancer, and the importance of tailoring patient management to their tumour biology and individual risks of recurrence.

Our Exercise and Cancer Group was keen to highlight the importance of this emerging area at the ASM by hosting a booth in the exhibition hall and featuring the topic in the program. The interactive booth allowed delegates to participate in exercise challenges, gain insight into what patients referred to an exercise program experience and learn about exercise. We were pleased to include a session on "Exercise and breast cancer" featuring one of the international invited speakers, Melinda Irwin from Yale. This is clearly a very important topic for COSA delegates, as it was standing room only. The impact of exercise on some of the troublesome and difficult to manage side effects of breast cancer and its treatment were discussed in this session. All the speakers endorsed exercise as an important adjunct therapy for patients, even those with high symptomology.

We included a stimulating session on another topic not often presented at cancer conferences: "Male breast cancer". One of the key challenges faced by men is lack of awareness of male breast cancer, which leads to delayed diagnosis by both patients and doctors. Treatment can impact on self-esteem, sexuality and physical appearance. There is less support for men with breast cancer, but groups such as the Breast Cancer Network Australia are developing male-targeted resources. Survivorship issues are often less well addressed in men, with treatments causing hot flushing, joint pains, lymphoedema and weight gain. The conference heard that treatments that work well in females with breast cancer are less effective in men. Tamoxifen is often the best adjuvant treatment as most male breast cancers are ER-positive. Some studies have found that men are under-treated and chemotherapy should be given to patients with larger or node-positive cancers.

We closed the ASM with the COSA Presidential Lecture and the Hot Topic Debate. Dr Ranjana Srivastava, a medical oncologist in Melbourne and accomplished writer gave a Lecture titled "The Good Doctor – The oncologist as advocate: Making a difference beyond the bedside". Ranjana spoke of her work with refugees and asylum seekers who struggle to find appropriate healthcare in Australia. She challenged delegates to use their talents to advocate for better care for our patients and those who will need healthcare in the future.

Planning is well underway for the 2017 COSA ASM, to be held at the new International Convention Centre Sydney. We have changed our schedule slightly and will run from Monday 13 to Wednesday 15 November, with pre-conference workshops on Sunday 12 November 2017. The program for COSA's 44th ASM will focus on immunotherapy with a subtheme of implementing quality and safety in cancer care. These are hot topics in oncology at the moment, so we are confident we can deliver a program with something for everyone.

New immunotherapy treatments have shown great success in melanoma, and more recently in many other difficult to treat cancers. We plan to feature as many as possible in the ASM program. The inclusion of quality and safety will complement the strong molecular and therapeutic theme of

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immunotherapy. In this subtheme we will focus on the cost and value of cancer care and treatments; the implementation and de-implementation of evidence into practice; preventing errors in cancer care; why quality improvement matters; and discuss tips for choosing wisely.

Working with Cancer Council Australia

In COSA's role as medical and scientific advisors to Cancer Council Australia, we often collaborate on submissions to government. Since the last report we have submitted the following joint submissions from Cancer Council Australia and COSA:

1. Therapeutic Goods Administration Consultation: Orphan drug Program (November 2016)
2. Therapeutic Goods Administration consultation: Expedited pathways for prescription medicines (December 2016)
3. Therapeutic Goods Administration consultation: Criteria for comparable overseas regulators, Enhanced international collaboration in the regulation or prescription medicines (December 2016)

For more information about COSA activities please visit www.cosa.org.au

Marie Malica

Executive Officer, COSA

Faculty of Radiation Oncology

Funding of Radiation Therapy

The priority area for the Faculty in 2016 was to engage with the Department of Health on the reviews of Medicare Benefits Schedule (MBS) and the Radiation Oncology Health Program Grants (ROHPG) Scheme. Through the Faculty's MBS Review Working Group, we have provided advice to the Oncology Clinical Committee of the MBS Review Taskforce.

We are yet to see the final report from the Oncology Clinical Committee and the proposed changes to the radiation oncology schedule. There is also uncertainty about the implementation of any proposed MBS changes and its impact on the sector. The Faculty will continue to advocate for the best possible funding model for the sector.

The ROHPG Scheme has been instrumental in providing patient access to modern, up-to-date radiation oncology equipment. The Department of Health conducted a review of the ROHPG scheme in 2016, and provided a report to the Faculty, which was positive in general. However, the proposed changes to ROHPG scheme announced in the most recent Mid-Year Economic and Fiscal Outlook were disappointing and could adversely affect patient access to modern radiation therapy in the long term. They represent a significant withdrawal by the Commonwealth from funding vital radiation therapy equipment such as brachytherapy units, treatment planning systems and CT simulators. The Faculty has prepared a submission to the Health Minister to raise our concerns regarding the proposed changes and its implications for the radiation oncology sector and patient care.

Faculty of Radiation Oncology 2016 Industry Roundtable

The Faculty convenes an annual Industry Roundtable, which provides an opportunity for industry stakeholders to meet and discuss new and evolving technologies and techniques in the radiation therapy sector. On 2 December 2016, the Industry Roundtable was held in the College, and attracted more than 20 participants.

A number of issues were discussed at the Roundtable, including the review of the MBS and ROHPG Scheme, proton therapy in Australia, raising the profile of radiation oncology, as well as radiation oncology in developing countries. Feedback received indicates that most of the industry representatives perceive the Faculty as important to their organisations and regard the Industry Roundtable a very useful forum. The Faculty will continue to engage with industry stakeholders to share information and seek their input where needed.

Targeting Cancer Campaign

Raising the profile of radiation oncology is one of the Faculty's key strategic priorities. We continue to reach many cancer patients and their families, as well as health professionals, in particular GPs through the [Radiation Oncology Targeting Cancer](#) campaign, to increase awareness of radiation therapy as an effective, safe and sophisticated treatment for cancer.

Recent evidence from the Prostate Testing for Cancer and Treatment Trial (ProtecT) shows that modern radiation therapy is as effective as surgery to cure prostate cancer. There is also no difference in overall quality of life between radiation therapy and surgery, but less urinary incontinence and fewer sexual problems after radiation therapy. In light of this, the Faculty will focus our awareness raising efforts in 2017 on advocating for prostate cancer patients to receive adequate information on all available options before making a final decision on their treatment.

Please like [Targeting Cancer](#) on Facebook, or follow [@targetingcancer](#) on Twitter, and help us promote radiation therapy as a safe and cost-effective cancer treatment option.

Vale Ms Sally Crossing AM

It is with great sadness that we acknowledge the recent passing of Sally Crossing AM (1946-2016) on 28 December 2016, after a long and brave battle with breast cancer.

Sally has been a strong consumer advocate for people affected by cancer over many years following her own diagnosis with breast cancer in 1995. One of her countless contributions was as the consumer member of the Faculty of Radiation Oncology Council in 2015 and 2016. The College is indebted to Sally for her active involvement, keen interest and contribution in support of our work and our patients – including advocating for the continuation of the Australian Clinical Dosimetry Service,

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the implementation of the Radiation Oncology Practice Standards, and appropriate funding to ensure patient access to radiation therapy.

Sally will be sadly missed; however her legacy will live on and continue to influence consumer engagement. Our thoughts and best wishes are with Sally's family and loved ones.

Dr Dion Forstner
Dean, Faculty of Radiation Oncology

Medical Oncology Group of Australia

The Medical Oncology Group of Australia (MOGA), the peak professional organisation for medical oncologists and the profession in Australia plays a leading role in the national oncology sector. MOGA is the key point of reference on all matters relating to medical oncology education and clinical practice, and is committed to supporting the development of our members and our profession in today's rapidly-evolving professional environment.

Education in medical oncology

MOGA works closely with the Royal Australasian College of Physicians on training and education for medical oncology trainees. This process is managed by a group of our members who compose the College's Advanced Training Committee-Medical Oncology. The Group is chaired by Dr Weng Ng, who took over this demanding role late in 2016 when Associate Professor Phillip Parente stepped down.

Dr Rachel Wong, Deputy Director of Oncology, Eastern Health and an Advanced Training Committee-Medical Oncology Member is the Project Lead for a new educational initiative, ASCO Education Essentials that is being piloted in 2017. This self-directed learning program is open to trainees who are registered in the medical oncology training program and provides access to a range of valuable learning resources including, unlimited access to over 100 e-learning courses; access to the ASCO Essentials Program 2017 for Australian Medical Oncology Trainees is supported by an educational grant from MSD Australia.

Our members, our workforce

As a medical speciality with a growing and evolving membership, working with rapidly changing workplace environments and practices, the importance of medical oncology workforce planning and development is paramount. The Association is pleased to be participating in a major international study covering twenty-four international societies and countries that is being conducted by Professor Chris Booth, a Canadian medical oncologist and focuses on the global medical oncology workload.

Research and advocacy

MOGA is committed to taking a leading role in research and advocacy focussed on cancer, oncology drugs, treatments as well as patient care. MOGA congratulates Dr Ganessan Kichenadasse, from the Flinders Medical Centre on the recent publications of his study on, The current practice, preparedness and educational preparation of oncology professionals to provide spiritual Care, *Asia-Pacific Journal of Clinical Oncology* 2016 doi: 10.1111/ajco.12654.

MOGA is engaged in various research activities through the development of policy and position statements, drug submissions and independent clinical advice. MOGA has provided the Financial Services Council with important clinical advice on the new minimum standards medical definitions detailed in the new national Life Insurance Code of Practice, which sets out mandatory obligations on life insurers. The Association is also currently developing position statements on biosimilars and chemotherapy dosing.

Oncology drugs and treatments

The Association welcomed the recent opportunity to contribute to the Therapeutic Goods Administration's consultations on new expedited pathways aimed at streamlining the registration processes and improving access to new medicines and medical devices including expedited pathways for the registration of new medicines and devices that addressed unmet clinical needs in specific circumstances; with pathways entry to be based on transparent eligibility criteria consistent with those adopted by comparable overseas regulators.