



**NATIONAL BREAST
AND OVARIAN
CANCER CENTRE**

COMMUNICATION SKILLS TRAINING INITIATIVE

ADDRESSING THE NEEDS OF YOUNGER WOMEN WITH BREAST CANCER

**EVIDENCE FROM THE LITERATURE
AND RECOMMENDED STEPS**

This literature review forms part of a communication skills training module presented in a professionally facilitated and interactive workshop

**PREPARED BY THE NATIONAL BREAST AND OVARIAN
CANCER CENTRE**

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Addressing the needs of younger women with breast cancer: Evidence from the literature and recommended steps was developed by the Centre for Health Research & Psycho-oncology on behalf of the National Breast Cancer Centre:

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NATIONAL BREAST AND OVARIAN CANCER CENTRE

COMMUNICATION SKILLS TRAINING INITIATIVE

Benefits of effective communication between treatment team members and people with cancer include improvements in the patient's psychosocial adjustment, decision making, treatment compliance and satisfaction with care.[#] Since 1997 the National Breast and Ovarian Cancer Centre (NBOCC) has sought to improve the communication skills of oncology health professionals in Australia through the provision of the Communication Skills Training Initiative.

The NBOCC Communication Skills Training Initiative is implemented through:

- the development and provision of standardised communication skills training modules and recommendations for best practice
- building capacity to implement communication skills training through conducting workshops for communication skills trainers
- development and maintenance of a website to support and promote communication skills training for health professionals
- supporting the implementation of local training workshops that use a best practice approach.

The Communication Skills Training Initiative supports the implementation of the NBCC* and National Cancer Control Initiative's *Clinical practice guidelines for the psychosocial care of adults with cancer.*[#]

For further information on the NBOCC's Communication Skills Training Initiative:

www.nbocc.org.au/commskills

[#] National Breast Cancer Centre and the National Cancer Control Initiative. *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, NSW: 2003.

^{*} In 2008, National Breast Cancer Centre Incorporating the Ovarian Cancer Program (NBCC) changed its name to National Breast and Ovarian Cancer Centre (NBOCC)

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INTRODUCTION

A breast cancer diagnosis can be devastating for many women and their families, irrespective of the age of the woman at diagnosis. However, there are a number of issues that may be particularly pertinent to younger women who are diagnosed with breast cancer, including having to decide on treatments that may precipitate premature menopause and infertility, or change their body image and sexuality; the challenges of caring for young children whilst having treatment; the potential impact of the diagnosis and treatment on their employment status and on their relationships with partners. This module addresses the issues that need to be considered when communicating with younger women with breast cancer.

Method

The NBOCC *Clinical practice guidelines for the management and support of younger women with breast cancer*¹ were reviewed to identify all evidence pertaining to communication to address the needs of this group. Furthermore, an extensive literature search was undertaken to identify research published after the development of these guidelines. The following databases were searched - MEDLINE, PSYCHINFO and CINAHL – using the following search terms and limited to articles in English: cancer, oncology, young women, communication, breaking bad news, doctor-patient communication and palliative care. The resulting articles were screened for duplicates and irrelevant references (eg those pertaining to more clinical issues). Further manual searches were undertaken of articles cited in publications.

After considering the range of possible definitions of 'younger', a functional definition (rather than chronological) of 'young' was adapted from Dunn and Steginga's research.² In this module, a 'young' woman is defined as any one of the following:

1. a woman who has young children who are not yet in secondary school,
2. a woman who has not reached menopause,
3. a woman who is of childbearing age.²

This definition ensures that the communication issues identified are applied to the potentially broad range of women who fit this category.

All retrieved articles were reviewed using the following NHMRC Levels of Evidence.³

Level I	Evidence is obtained from a systematic review of all relevant randomised controlled trials, usually found in meta-analysis.
Level II	Evidence is obtained from at least one properly designed randomised controlled trial.
Level III	Evidence is obtained from well-designed controlled trials without randomisation; or from well designed cohort or case control analytic

studies, preferably from more than one centre of research; or from multiple time series, with or without the intervention.

Level IVa Evidence is obtained from descriptive studies of provider practices, patient behaviours, knowledge, or attitudes or a systematic review of the descriptive studies.

Level IVb Represents the opinions of respected authorities based on clinical experience or reports of expert committees.

Level QS Evidence from qualitative studies. [NB: this level has been added to the standard NHMRC levels of evidence given the significant amount of qualitative research.]

This module includes the literature reported in the NBCC *Clinical practice guidelines for the management and support of younger women with breast cancer*¹ as well as new literature found since those guidelines were published. When reading the literature review, readers should be mindful that much of the evidence reported relates to the incidence or prevalence of physical and psychosocial morbidity and of various practices. In such descriptive studies, Level IV evidence is the highest level of evidence that can be collected and is therefore considered the gold standard.

LITERATURE REVIEW

GENERAL INFORMATION NEEDS AND PREFERENCES FOR HOW THESE NEEDS SHOULD BE ADDRESSED

The studies specific to younger women and their information and support needs during and after breast cancer were primarily qualitative.⁴⁻⁶ The studies suggest that:

- Younger women request more information than older women.⁴
- Information needs continue over time, and also change over time (Australian studies).^{4,5}
- The support that younger women request is not only for themselves but for their family members as well.⁶

Australian and Canadian research offers some guidance on young women's preferences for how they would like to receive information:

- The majority of the 24 young women with breast cancer in an Australian qualitative study reported that they only received information verbally and that they would find it beneficial to receive 'take home' information, which they could review at a later time (Level QS).⁵
- A Canadian study of 276 women, the majority of whom had cancer when they were young, suggests that there is a reliance on information from clinicians (Level QS);⁶ with Australian qualitative research suggesting a preference for individual consultations with specialists, as well as information videos and decision aid tools (Level QS).⁵
- Canadian research suggests that doctors should be encouraged 'to make standardised information package[s] available to women at the point of diagnosis', which include 'media resources, contact information about breast cancer survivors, support group information, information about professional psychosocial support personnel, books, websites and information on treatment and treatment side effects', in various formats (Level QS).⁶
- Australian research suggests that information regarding the impact of treatment on long-term health, including menopausal status, is particularly important to younger women at the time of their diagnosis and during follow up (Level QS).^{4,5}
- In an Australian study of 18 women with breast cancer (8 pre-menopausal), brief information sessions were identified as potentially helpful in educating 'survivors about potential physical and emotional consequences after treatment ends'.⁴

One Australian study (Level QS) of 24 young women with breast cancer found that the Internet was one of the most common sources of information gathering.⁵ A Level III

longitudinal study of 217 women with breast cancer found that 16 months after diagnosis, the Internet was the most frequently cited source of information.⁷ The types of information sought at eight months after diagnosis included treatment information and specific breast cancer information, whilst at 16 months after diagnosis women sought information regarding specific breast cancer information and medications.⁷ Studies indicate that one of the main predictors of women with breast cancer using the internet is age, with young women far more likely than older women to use the internet as a source of information.^{5,7,8}

DECISION MAKING

In a study of 996 women with breast cancer (not specific to young women) in the United States (Level III),⁹ Caplan *et al* found that younger women with breast cancer were more prone than older women to incur delays in referrals to specialists. They suggest that interventions such as a tailored approach to screening and other early detection programs may help to minimise these delays, specifically among younger women who present without a classic painless lump.⁹ Qualitative research with Canadian women with breast cancer (n=276, primarily young) concurred with these findings and also reported that women felt rushed into making decisions after having to incur delays in diagnosis.⁶

PSYCHOLOGICAL WELLBEING

A Level III study of 817 women of all ages who had previously had breast cancer found that breast cancer positively affected their lives because they made changes in their diets, lifestyle, exercise habits and religious beliefs.¹⁰ However, the majority of the published literature points to less positive outcomes.

Younger women with breast cancer are reported as having a higher risk for significant psychological distress, including mood disturbance,¹¹ anxiety,¹² depression^{12,13} and other psychological problems requiring intervention (Level III).¹⁴ Age has also been reported as a predictor of overall fear of recurrence, death worries, health worries, role worries and womanhood worries (Level IVa),¹⁵ and higher levels of helplessness/hopelessness (Level IVa).¹⁶

In an Australian study of 731 young women with breast cancer, 23% of the sample had 'probable' psychological morbidity due to anxiety, but only 3% had 'probable' psychological morbidity due to depression (Level IVa).¹⁷ However, a study of 577 young women in the USA who had cancer 2 – 10 years previously found no evidence of age-related differences in global quality of life (QoL) (Level IVa).¹⁸

Mental health at diagnosis

A study of breast cancer survivors across the age spectrum in the USA (diagnosed 1 – 7 years previously) found that the experience of distress in younger women is highest in proximity to diagnosis (Level III).¹⁹ Health related QoL was also reported to be poorest in recently diagnosed young women compared to middle and older aged women, in a study

of 1082 women with breast cancer (Level III).²⁰ However, other research (n=80) suggests that distress does appear to diminish over time (Level III).²¹

Mental health during treatment

Studies of primarily Level III evidence have shown that younger women not only suffer physical side effects from treatment but also psychological side effects.²²⁻²⁸

Surgical procedures for breast cancer have been linked to psychological distress, body image, and functional, emotional and physical wellbeing, though the evidence is inconsistent.²⁴⁻²⁹ Age at diagnosis appears to be an important variable. One study of 124 breast cancer survivors reported that for women aged 50 years or less (n=50), those who received a partial mastectomy were less psychologically distressed than those who underwent a total mastectomy (Level III).²⁴

Although not specific to young women, a study of 103 women aged younger than 60 years found that shortly after a mastectomy (n=54), women reported significantly poorer physical wellbeing and body image compared to women who underwent breast conserving surgery (n=49). Although those women who underwent the breast conserving surgery had significantly lower emotional wellbeing, six months post-operation all women reported similar quality of life (Level III).²⁷

Studies suggest that chemotherapy also has an influence on women's psychological wellbeing. An American study of 61 women of all ages who were 3 to 36 months post-chemotherapy treatment found that younger women compared to older women were more at risk than older women of having poorer mental wellbeing and increased symptoms of depression (Level III); the symptoms were present throughout the entire post-treatment period.²² A longitudinal study of 2687 women (1475 pre or peri-menopausal) also found that chemotherapy had an adverse effect on quality of life, however this was only brief (Level III).²³

Long-term mental health

A study of 90 women with breast cancer in the UK found that young women (younger than 50 years) had significantly higher levels of clinical depression, anxiety and irritability two years post-surgery than older women and matched control subjects.¹³ However, in another longitudinal study of 185 young women with breast cancer, mental wellbeing was found to increase over a five-year time frame (Level III).³⁰ In a third study, at 5 – 10 years post-diagnosis, women with breast cancer (n=216) had a QoL similar to that of women who did not have cancer (Level IVa).³¹

Predictors of psychological adjustment

A number of studies have identified factors that can affect young women's psychological adjustment to breast cancer and its treatment.

A longitudinal study of 185 young women with breast cancer in the USA suggests the factors that predict *better* adjustment include being employed (full or part-time); and having no minor children (Level III);³⁰ with Australian research (n=731) identifying a

higher education as an additional predictor of better psychological adjustment (Level IVa).¹⁷

A number of studies using different methodologies have identified a range of significant predictors of *poorer* adjustment to breast cancer, including:

- the severity and recency of the breast cancer (case-control study of 349 women; Level III)¹⁹
- significant anxiety and depression scores at baseline (longitudinal study of 91 women; Level III)¹²
- being born outside of Australia (study of 731 women in Australia; Level IVa)¹⁷
- relationship status, specifically being single (study of 291 women with breast cancer in Australia; Level III).³²

In younger women, physical symptoms and treatment side effects are reported to impact on intrusiveness of the illness, according to a study involving 307 young women with breast cancer (Level III).³³

Evidence regarding emotional distress/stress of lesbian versus heterosexual women with breast cancer is contradictory, with a small study comparing 13 lesbian and 28 heterosexual women reporting lesbian women to have significantly higher stress levels when initially diagnosed and throughout treatment (Level III).³⁴ A larger study comparing 29 lesbian and 246 heterosexual women reported no significant differences between the groups in emotional distress levels, anxiety or depression (Level III).³⁵ However, within one year of diagnosis, lesbians were more likely to express anger and less likely to demonstrate fighting spirit, fatalism and cognitive avoidance compared to heterosexual women with breast cancer (Level III).³⁵

FERTILITY, SEXUALITY AND BODY IMAGE

The majority of studies relating to the needs of younger women regarding treatment and its psychological and physical effects were conducted in the USA (primarily Level IVa evidence). In summary, these studies indicate that most young women are concerned about treatment effects such as infertility, premature menopause, sexual difficulties and other physical burdens.^{4,5,18,20,25,28,30,31,36-38} Studies also suggest that different types of treatment invoke particular psychological and physical stressors for young women (majority of studies are Level III).^{22,24,25,27,28,32,39,40} Young women also seem to express concerns about recurrence and future pregnancies.^{15,25,38,41-43}

Infertility and menopause

Treatment-induced infertility and menopause are a concern for many young women diagnosed with breast cancer.^{4,5,25,38} A descriptive study of 204 young women post-diagnosis reported that their highest concern was premature menopause and that some were shocked to enter premature menopause (Level IVa).²⁵ In a second study, 73% of 657 participants (of whom 40% underwent breast-conserving surgery) were concerned

about becoming infertile as a result of treatment to some degree, with a significant correlation between concerns about menopause and infertility (Level IVa).³⁸

With respect to when such concerns are most prevalent, the only evidence available is qualitative. Results from one study of 24 young women with breast cancer in Australia suggests that women are concerned about their fertility and menopause status prior to treatment and that concern over the impact of treatment on fertility and menopause status increase over time. These women reported that they wanted to be given information regarding the impact of treatment on their long-term health including menopausal status, and that this information was seen as particularly important prior to adjuvant treatment (Level QS).⁵

Importantly, a substantial proportion (56%) of participants in a study of 657 young women with breast cancer (40% of whom underwent breast-conserving surgery) overestimated their risk of becoming post-menopausal as a result of treatment, reinforcing the need for information about the real risk, presented as accurately as possible (Level IVa).³⁸

Pregnancy

Level III evidence, including one study of 562 young women (91 women who previously had a cancer diagnosis with subsequent deliveries and 471 women matched for stage, age, and year of diagnosis)⁴³ and another study of 108 young women⁴² who had become pregnant after their diagnosis,⁴² suggests that pregnancy after a breast cancer diagnosis does not increase the risk of recurrence or affect overall survival.^{42,43} However, in two large studies from the USA (220 and 657 participants) younger women reported concerns about the impact of future pregnancies on their prognosis, as well as other pregnancy-related issues, including the effect of cancer on a child (Level IVa).^{25,38} Australian research has identified a need for information on appropriate forms of contraception and the impact a pregnancy may have on women's long-term prognosis and overall wellbeing (Level QS).^{4,5}

There is minimal evidence regarding the needs of young women who develop breast cancer during pregnancy. However, one Level IVa study suggests that 'physicians should aggressively pursue work-up in women with a palpable breast mass because early diagnosis may improve the prognosis of breast cancer during pregnancy'.⁴⁴

Sexuality and body image

Evidence from a study of 216 young breast cancer survivors suggests that younger women report more sexual difficulties than the general population (Level IVa),³¹ with difficulties including lack of sexual interest, problems with general sexual functioning and vaginal dryness.^{10,20,25,28,30,31,36,37,39}

A heightened lack of sexual interest has been reported in a number of studies. In an Australian study of women who had undergone breast-conserving surgery or mastectomy, almost one third of the 303 participants reported a lack of sexual interest three months after surgery (Level IVa).³⁶ A smaller study of 103 young breast cancer survivors concurred with this finding, and also reported that sexual interest was perceived to be less of a problem than sexual dysfunction (Level IVa).²⁵ Sexual dysfunction

appears to be more prevalent in younger women than in older women with breast cancer, according to study of 1082 women with breast cancer (Level III).²⁰

Vaginal dryness during sex is reported as a common problem among young women with breast cancer compared with the general population, and was reported by 41% of the 103 survivors in one study, with 42% also reporting lack of sexual interest (Level IVa).²⁵ Another study of 691 young women with breast cancer found that vaginal dryness was a predictor of sexual activity problems (Level IVa).²⁸

There is limited evidence regarding which sub-groups of women are most likely to experience sexual difficulties. A longitudinal study found that more than two-thirds (69%) of 185 partnered young women with breast cancer reported no change over time in their sexual activity levels. However, although sexual activity did not change over time, women in this study still reported many problems, including lack of sexual interest (56%) and difficulties with arousal (46%), enjoyment (35%) and orgasm (38%) (Level III).³⁰ A study of 691 young women with breast cancer found that being partnered but not married positively affected sexual activity, and that those most likely to incur sexual problems were married. Furthermore, the study reported that the women most likely to be sexually active had regular menstrual periods and increased vitality (Level IVa).²⁸ Lesbians (n=29) with breast cancer were more likely than heterosexuals (n=246) to say that they were not interested in sex, but there were no reported differences in sexual satisfaction between the groups, or in the number of women in an intimate relationship and their sexual activity (Level III).³⁵

Evidence indicates that women receiving chemotherapy suffer sexual difficulties. One randomised controlled trial (Level II) of 294 pre-menopausal women found that chemotherapy was associated with sexual problems continuing up to three years post-treatment.³⁹ Another study of 103 young breast cancer survivors concurred with the above findings that chemotherapy was associated with greater sexual dysfunction (Level IVa).²⁵

A number of studies have examined the impact of type of surgery on body image and found that:

- younger women who have had a mastectomy report having a lower body image compared with older women who have had a mastectomy (study of 291 women with breast cancer [Level III])³²
- mastectomies are associated with more body image problems for younger women with breast cancer compared with breast-conserving surgery, as reported in three studies (Level IVa) of 220 women;²⁵ 577 women;²⁹ and 691 women²⁸
- breast reconstruction increased positive attitudes from partners, although this effect was not specific to younger women (study of 22 women with post-mastectomy breast-reconstruction;⁴⁵ study of 196 women post mastectomy;⁴⁶ both Level III).

RELATIONSHIPS AND EMPLOYMENT ISSUES

Relationship with partners

Younger women are likely to experience more concerns about relationships than older women following a diagnosis of breast cancer, including perceptions of the breast cancer causing strain on their relationships (Level IVa)^{47,48} and feelings of guilt about the impact of their illness (Level IVa).⁴⁹ Furthermore, young single women appear to report different issues from their married counterparts, including concerns about dating (Level IVa),²⁵ pessimism regarding future relationships and fears of disclosing their illness to partners (Level QS)⁵⁰ and perceptions that they would be a liability to potential partners due to the possibility of recurrence (Level QS).⁴

A survey of 220 young women with breast cancer found 'overall, relationships with partners were not a problem, though communication was.' The women also felt that the breast cancer experience strengthened good relationships, and had negative effects on bad relationships (Level IVa).²⁵

Some relationship differences have been reported between lesbian and heterosexual women with breast cancer, though these are not specifically related to the age of the women. In a study comparing lesbian and heterosexual women's response to newly diagnosed breast cancer, lesbian women more than heterosexual women felt 'that their partners made them feel loved and cared for, that their partners were willing to listen' and to help out with daily tasks during the time when they had cancer. Heterosexual more than the lesbian women reported that their partners made 'too many demands on them'. However, no differences were reported regarding the ability to express feelings or deal with conflict, or in cohesiveness within the relationship (Level III).³⁵

Children

As many young women with breast cancer have children in secondary school or younger, concerns regarding children are prominent, with two qualitative studies identifying concerns about not seeing their children grow up (Level QS).^{2,49} In a study of 273 young women with breast cancer, participants expressed concerns about their child's genetic risk, when information should be provided to them about that risk and who should disseminate that information (Level IVa).⁵¹ With respect to preferences for information, women in this study suggested that children should first be provided with genetic risk information between the ages of 13 and 18 and the majority believed that the parent should provide such information.⁵¹ However, a report prepared for the National Breast and Ovarian Cancer Centre suggests that young women report finding it difficult to discuss their illness with their children.⁵²

Social isolation and support

Social isolation and stigmatisation has not been quantitatively assessed. However, several qualitative studies suggest that women's feeling of isolation specifically because of their age was exacerbated by circumstantial events, including breast cancer campaigns aimed at women over 50 years; support groups primarily made up of post-

menopausal women; and rural women having to stay in urban treatment clinics away from their families for extended periods of time (Level QS).^{2,4,31} Evidence from a study of 101 young women with breast cancer suggests a significant positive correlation between women's perception of their social support and their quality of life (Level IVa).⁵³ However, a longitudinal study of newly diagnosed young women has reported a significant decrease in the size of younger women's social networks five years following diagnosis (Level III).³⁰

In one cross-sectional study, lesbian women were significantly more likely to report both their partners and friends to be more supportive than heterosexual women, with lesbian women's friends providing helpful advice on medical, financial and family issues. However, heterosexual women reported receiving more support from relatives, including feeling that they had more relatives they could rely on for assistance with daily tasks than lesbian women (Level III).³⁵

Employment

A breast cancer diagnosis can affect a range of factors in young women's lives, including their careers, financial status and ability to acquire insurance. Whilst many women with breast cancer continue to work during and after their illness,^{4,54,55} the proportion who do work is lower than those without breast cancer, according to a large study of 5728 women (150 of whom reported having breast cancer). However, those who did work were more likely to work more hours than the women who had reported not having breast cancer (Level III).⁵⁴

Career is a major part of many young women's lives at the time of diagnosis compared with older women.⁵⁴⁻⁵⁶ However, evidence regarding the effect of breast cancer on young women's employment status is contradictory. A qualitative study of 18 young women with breast cancer (Level QS)⁴ and a descriptive study of 378 women of varying ages with breast cancer (Level IVa)⁵⁶ suggest a range of effects, including career limitations and changes in work conditions. A Canadian study of 649 young breast cancer survivors and 890 young women in a population-based comparison group inferred that the value breast cancer survivors place on their employment was altered by their illness.^{55,56} However, another study of 119 women who were pre-menopausal at the time of their diagnosis showed that the disease had no or very little effect on their employment (Level IVa).⁴⁸

Insurance

One Level IVa Canadian study of 378 women of all ages with breast cancer found that when asked about insurance, half of the participants did not respond. However, those who did respond indicated that they had been refused or offered insurance with higher premiums; this was experienced for life insurance (17.9%), extended health insurance (7.7%) and private disability insurance (4.4%).⁵⁶

NEEDS OF FAMILY MEMBERS

The majority of research in this area has focussed on the needs of children of mothers who had breast cancer, with a review of literature focussing specifically on mothers with advanced breast cancer. A review commissioned by the NBCC⁵² commented that, of the many factors that influenced the emotional impact on children of having a mother with cancer, a major variable is the developmental stage of a child. The review concluded that 'young children may entertain guilty beliefs about their own contribution to their mother's cancer. They may be fearful about their own safety, and worried about the disintegration of the family. Another prominent focus is their concern about the health of the well parent'.⁵²

'Children in the middle years report a range of concerns, including disruption in their lives and estrangement from their friends. They may be expected to take on more domestic responsibilities, which may mean that they are unable to engage in activities outside the family, yet contact with friends may provide a powerful counter to the burden of domestic cares. One review suggested it is important that children in this age group be offered the opportunity to perform tasks consistent with their abilities, and that they be encouraged to engage in other 'normal' activities. Provision of information about the disease and treatments is also important for this age group'.⁵²

The literature attests to a major vulnerability for adolescent children of mothers with breast cancer, particularly daughters, this being postulated to relate in part to their identification with their mother, and consequent changes to their sense of self and sexuality.⁵² Research suggests a complex range of concerns and emotions for adolescent girls⁵⁷, including feeling that their mother's illness was their fault, and feeling torn between leading their own lives and spending time with their mother. Changes in role responsibilities became causes of anxiety ranging from some girls not willing to take on the responsibilities; to others who were upset when that role was taken away from them when their mother was well again.

A case-control study of 60 daughters of mothers with breast cancer and 60 matched comparison women (average age 42.4 years) found that the daughters of women with breast cancer showed 'significantly less frequent sexual intercourse, lower sexual satisfaction, and greater feelings of vulnerability to breast cancer, and they could identify a greater number of symptoms of breast cancer. No differences between groups were found in psychological symptoms, coping styles, breast self-examination practices, mammography practices, health knowledge, or body-image ratings (Level III)'.⁵⁸

Adolescents may perceive that the disease carries some social stigma, and they may feel anxious about their own risk of developing breast cancer⁵² and about possible recurrence of their mother's cancer.⁵⁷ There also seems to be an increased incidence of anxiety and depression in adolescent children of women with breast cancer. As this group perceives that they receive little support from their parents, use of family meetings and family therapy may be a worthwhile avenue to answer their concerns and validate their

contribution, and allow an opportunity for problem solving. Clearly, the provision of information is also crucial.⁵²

There is little research on the impact of breast cancer on partners of younger women. However, one study of 73 people with cancer and 39 of their partners suggests that male partners were more likely than the patients to be distressed about the possibility of the patient dying (Level IVa),⁵⁹ and a second review suggests that partners have difficulties with new roles that they undertake when their partner is ill (Level IVa).⁶⁰ In the case of family members of advanced cancer patients of all ages, severe family anxiety was predicted by being the spouse of the person dying, or caring for a partner who was young and more recently diagnosed (Level IVa).⁶¹

NEEDS OF SPECIAL GROUPS

There is very little empirical evidence relating to the needs of special groups. Hence, this section of the module is less evidence based, but still provides useful information to assist in communicating with younger women with breast cancer. Much of the information reported in this section is taken from the NBCC's *Clinical practice guidelines for the management and support of younger women with breast cancer*,¹ as no more recent evidence on this issue was identified that was specific to young women with breast cancer.

Cultural sensitivities

[NB: The section on Cultural Sensitivities is copied directly from the *Clinical practice guidelines for the management and support of younger women with breast cancer*.¹]

Women from linguistically or culturally diverse backgrounds, especially those whose first language is not English, will need special strategies in place if they are to receive adequate information and be involved in decision making. While these specific needs and sensitivities will vary, there are a number of issues that are likely to be important.

Women from some cultural backgrounds may have specific beliefs that affect their attitudes to treatment. For example, in some communities, cancer is viewed as fatal and/or shameful and members of the community may assume that the patient cannot function in their usual capacity, causing gradual isolation.

Clinicians should also be aware of different cultural attitudes to death and dying, and the role of the woman's religious beliefs and those of her family should be explored. Younger women may be faced with complex issues if family members have expectations about the woman's role in making treatment decisions.

If the woman is not fluent in English, it is important to use a qualified and appropriate interpreter, rather than family or a hospital staff member. The Translating and Interpreting Services (TIS) provides telephone translating services through the Doctors Priority Line. Translators can be accessed straight away or booked for a later time. For

doctors or specialists in private practice who are providing services that are claimable under Medicare, this translating service is free of charge. Where available, information about breast cancer should be provided to women in their own language. There may be an extra burden placed on a young woman if she has to translate information about her health to her parents or other family members if English is not their first language.

In some communities, women may have a strong preference for care from a female health care provider. In some indigenous communities, breast cancer is perceived as women's business. Special care should be taken to discuss treatment options and to provide female doctors where possible. The use of Aboriginal Health Workers may also be of value in assisting indigenous women during treatment.¹

Women from rural and remote areas

The terms 'rural' and 'remote' in this literature review describes women with breast cancer who reside outside a metropolitan area where treatment centres are located (primarily 100 kilometres or more from treatment centres). However not all studies reported in this section adopt the same definition of 'rural'. The studies in this section are mostly Australian and are also primarily not specific to young women, but may be helpful to consider when communicating with younger women.

An Australian study of 100 women with breast cancer found that rural women had to travel for consultations with the oncologist, due to a lack of doctors at their location (Level IVa).⁶² Furthermore, a study of 80 rural and remote Australian women with breast cancer found that 83% were required to stay away from home to get breast cancer treatment and 18% were able to commute to their treatment facility daily (Level IVa).⁶³ On average, women with breast cancer from rural and remote areas of Australia are estimated to spend six weeks away from their homes during radiotherapy treatment, and three weeks away while receiving chemotherapy, according to an Australian study of 204 women (Level IVa).⁶⁴

Financial assistance information is available through The Cancer Council Australia or by contacting the Cancer Helpline. Each state has established their own means of financial assistance for rural women. However, data from a population-based survey of 204 Australian women with breast cancer indicated that only 30% of rural women received enough information about financial support for travel; and that of the 50% to 60% of women who did not receive financial assistance, almost 30% were not even aware it existed and 13% felt the process was too complicated, hence 76% requested more information be provided regarding travel and accommodation assistance (Level IVa).⁶⁴

Women are reported to receive information primarily from their doctors or nursing staff.⁶³ However, the literature on women from rural areas provides mixed results regarding information and support needs and how well these are being met. A study of 100 women with breast cancer found that many women had high or moderate levels of unmet needs regarding information on their health and illness, and that rural women were two and half times more likely to report requiring some form of aid with physical and daily living than

urban women (Level IVa).⁶² In an Australian study, two-thirds (67%) of 80 rural Australian women with breast cancer had used support services (either breast cancer support volunteers or support groups).⁶³ However, in another Australian population-based study, two-thirds (67%) of the 204 rural women with breast cancer reported not receiving enough information about the practical and emotional support available near treatment centres; and only 9% reported that they were provided with resources specific to rural women. Almost a third (30%) of the women felt that residing in the country limited their access to health related information. Furthermore, although a majority reported that they had received sufficient support during their diagnosis and treatment phases, only 34% of women felt that they received sufficient emotional and practical support whilst away from home.⁶⁴

As reported in the *Clinical practice guidelines for the management and support of younger women with breast cancer*,¹ Davis *et al*⁶⁴ suggest that women with breast cancer in rural areas 'should be offered referral to a social worker or welfare officer for practical support, including information and advice about applying for government financial assistance for travel and accommodation costs'.

CURRENT PRACTICE OF ADDRESSING ISSUES OF PARTICULAR RELEVANCE TO YOUNGER WOMEN WITH BREAST CANCER

There is very little research that has specifically explored how well younger women with breast cancer perceive their information and support needs to be met.

Information and support for the women themselves

One qualitative Australian study which interviewed 24 young women with breast cancer reported that they felt they did not receive sufficient information at the time of their diagnosis; and that those who were provided with information felt that it was insufficient or did not specifically cater to their needs.⁵

Another Australian qualitative study of 18 young women with breast cancer also reported that their support needs were unmet.⁴ Women expressed a preference for receiving emotional support from professional counsellors rather than volunteers at the hospitals during treatment, but that if volunteers were used to provide support, women preferred younger volunteers. They also expressed a need for more non-hospital based support services that provided lifestyle support, including diet education, exercise, information on complementary therapies and stress management. Overall a need for a more 'holistic approach to psychosocial, sexual wellbeing and physical health' was identified.⁴ They also identified a priority for age-appropriate support groups during and after treatment, noting that some young women felt alienated or isolated at support groups because they were younger than others who attended (Level QS).⁴

Information and support for the families

One qualitative study of 276 women with breast cancer attending focus groups reported that many women felt that there was not sufficient support for their families and that they had to rely on friends and family because outside or professional support could not be obtained.⁶ The women recommended that support services and information should be tailored to incorporate partners and children.

A survey of 260 sisters and daughters of women with breast cancer found that two-thirds reported wanting more information regarding genetic testing. An average of half the women felt that 40% of their overall needs were not met. They perceived their general information needs to be more important than their support needs and they also felt that their informational needs were typically more met than their support needs. Sources of information were typically print media (pamphlets and magazines), general practitioners and physicians (Level IVa).⁶⁵

INTERVENTIONS TO FACILITATE DISCUSSION AND SUPPORT

Although no studies have been conducted to specifically evaluate interventions to facilitate communication with younger women, some of the findings of the Cochrane review on *Communication skills training for health care professionals working with cancer patients, their families and/or carers*⁶⁶ are relevant to this topic. The review reports on three trials involving 347 health professionals: 'one provided an intensive three day course then assessed oncology doctors interacting with 640 patients; a second provided a modular course then assessed role plays with oncology nurses; the third was modular and assessed outcomes with clinical and simulated interviews and patient questionnaires'.

In summary, the review concluded that 'training programs assessed by these trials appear to be effective in improving some areas of cancer care professionals' communication skills'. Results reported that, compared to non-attendees, course attendees used significantly more:

- focused questions
- open questions
- expressions of empathy
- appropriate cue responses
- emotional speech, particularly regarding anxiety and distress.

A recent review of the literature on how to recognise and manage psychological distress in people with cancer⁶⁷ has identified the following methods as more likely to increase the frequency and identification of patient cues that will assist in addressing psychological issues:

- listen to the patient with an open mind
- allow patients to speak their concerns without interrupting
- be open to the idea that patients may express psychological distress
- be patient-led, ie take the consultation in the direction the patient leads

- acknowledge patients' concerns and respond empathically
- use questions appropriately
- use words that have emotional content
- make direct requests for self-disclosure
- summarise patient statements/clarify patient needs
- be willing, and have the confidence to tackle psychological issues
- consider the use of external aids, such as question prompt sheets, or questionnaires that measure quality of life.⁶⁷

RECOMMENDATIONS FOR COMMUNICATING WITH YOUNGER WOMEN WITH BREAST CANCER

The following are some general and specific recommendations that have been developed based on the current available evidence. Recommendations from the NBCC's *Clinical practice guidelines for the management and support of younger women with breast cancer* are provided in Appendix A.

GENERAL PRINCIPLES FOR EFFECTIVE COMMUNICATION

Setting up the consultation

1. Ensure that the discussion will take place in privacy.
2. Ensure as much as possible that there will be no interruptions (for example switch off mobile phones and pagers; inform staff).
3. Check first how much information the patient wants to be given about the different issues relevant to younger women.
4. Check if the patient would like to have a friend or relative present.
5. Check if the patient would like another medical person present (if applicable).

Throughout the consultation

6. Adopt an honest and straightforward yet sensitive approach.
7. Encourage a collaborative relationship with the patient (for example provide opportunity to ask questions).
8. Use the most up-to-date information and, if desired, explain its source.

Finishing the consultation

9. Summarise the main points at the end of the consultation.
10. Check that the patient has understood your summary. This is best done by asking the woman to repeat back what she has heard, rather than asking her 'Do you understand?'
11. Check the patient's emotional reaction to the information.
12. Inform the patient of available support.
13. Organise a review appointment.
14. Inform the patient of your availability and contact details in case of further questions.

SPECIFIC RECOMMENDATIONS

Addressing general information needs

1. It is useful for clinicians and members of the treatment team to be aware of, and recommend, good-quality Internet sites.¹
2. Provide an information pack at the point of diagnosis comprising relevant resources, for example the NBOCC's *A guide for women with early breast cancer*.
3. Allow women time to reflect on their treatment options before having to make a decision.
4. Needs change over time, so clinicians should revisit issues during follow-up consultations. The amount of information desired also changes over time, so this needs to be checked on a number of occasions, particularly at points of change, such as completion of treatment.
5. Provide a range of information resources, such as in-consultation materials, take-home booklets and decision aids, and audio and videotape material.
6. Women prefer to receive information from their specialist. Ensure that key information is delivered in the consultation, as well as in written or visual materials.

Information about fertility, menopause, sexuality and body image

7. If desired by the woman, discuss the likelihood of genetic factors playing a role in the woman's cancer, and the risks to her family. If appropriate, refer to genetic counselling services. Also if appropriate, provide advice and support to woman in disclosing genetic information to her family.
8. If desired by the woman, discuss the impact of treatment on menopause, fertility, sexuality and body image prior to treatment; and correct inaccurate perceptions, acknowledging the limitations of data (for example conflicting data) and informing women of new clinical trials.
9. If desired by the woman, discuss the impact of future pregnancies on prognosis and provide advice about contraception.
10. Develop referral networks of fertility and menopause specialists and sex or relationship therapists that have a good understanding of oncology issues to refer your young patients to, if appropriate, prior to the commencement of treatment.
11. Do not assume that the importance women place on fertility/menopause issues is directly related to their age or whether they have children at the time of diagnosis
12. Do not underestimate the emotional impact of premature menopause or loss of fertility.
13. Breast conserving surgery is likely to result in fewer body image problems than mastectomy. Hence, this option should be offered to all women who are eligible. Women who are not eligible for breast conserving surgery or who choose to have a mastectomy should be counselled about potential changes in their body image and, where appropriate, offered reconstructive therapy.

14. 'Younger women are more likely than older women to opt for breast reconstruction following mastectomy. Women should be provided with detailed information about immediate and delayed breast reconstruction options before treatment commences so they have the opportunity to consider the procedure adequately and make informed decisions'.¹
15. Chemotherapy options which reduce the risk of infertility and premature menopause should be presented, along with their associated risks.
16. Offer information about the effectiveness of treatments for menopausal symptoms should they occur.
17. Provide information about the possibility of weight gain associated with chemotherapy, and evidence of the benefit of exercise in reducing weight gain and improving body image.
18. Explain that although it is contrary to the advice they are likely to be given by friends and family, exercise has been demonstrated to reduce fatigue associated with chemotherapy.

Providing support

19. Be aware that younger women are at increased risk of developing psychological morbidity. Be vigilant in asking about the woman's emotional responses, check risk factors (eg previous diagnosis of anxiety and/or depression, having young children, migrant status, and being single) and offer referral when necessary to specialist psychosocial services.
20. Familiarise yourself with the support groups available locally either face-to-face or by telephone and inform the woman about these.

Helping the family

21. Enquire about the support needs of the woman's family, as well as herself. Offer services for the woman's family as well as herself.
22. Young mothers living with breast cancer should be offered assistance about what, if and when to tell their children about their cancer.
23. Interventions which enhance children's understanding through age appropriate resources such as storytelling, literature, and play materials are vital for this age group. In addition, a key issue is providing information to parents about the range of emotional concerns often experienced by children in this age group.
24. Interventions with visual aids and other materials with child oriented language should be utilised to facilitate discussions between children and parents regarding the illness.
25. Use of family meetings and family therapy may be a worthwhile avenue to answer adolescents' concerns, validate their contribution and allow an opportunity for problem solving. The provision of information is also crucial.

Issues for women from rural or remote areas, or of different cultural backgrounds

26. Younger women who are required to travel significant distances or to be away from home for extended periods of time may face difficulties with caring for young children, organising household responsibilities or maintaining paid work. Health professionals should explore the concerns of women living in rural and remote areas, including their ability to access assistance for travel and accommodation, which may have a direct impact on treatment decisions.
27. Younger women from different cultures may have different needs to those born in Australia. Use formal translation services when talking with women who do not speak English, and where possible, provide written information translated into their language. Explore understanding of the cause and treatment of breast cancer and correct misconceptions. Be sensitive to cultural expectations of treatment decision-making, and death and dying.

Consultation skills training

28. Health professionals involved in the management of younger women with breast cancer should attend communication skills training programs which cover general skills, and issues specific to communicating with younger women.

APPENDIX A

Guideline recommendations from the Clinical practice guidelines for the management and support of younger women with breast cancer.¹

Guideline recommendation	Level of evidence
Younger age has been associated with physician delay in referral for investigation of breast symptoms. For this reason, young women presenting with breast symptoms should be evaluated by means of the triple test approach to exclude or establish a diagnosis of cancer.	III-2
Assessment of emotional concerns of younger women at diagnosis of breast cancer ensures early identification of distress so that appropriate interventions can be offered.	III-2
Radiotherapy after breast conserving surgery is recommended as it significantly reduces the risk of local recurrence. For younger women, treatment with radiotherapy should also include a boost of radiation to the tumour bed, which further halves the local recurrence rate.	II
Clinicians should advise younger women that the benefit of chemotherapy is greater the younger the women's age. Chemotherapy will reduce the risk of recurrence by about one-fifth in women aged 60 to 69 years, but by nearly two-fifths in women under the age of 40.	I
Younger women with hormone receptor positive tumours should be advised that disease-free survival is significantly better when chemotherapy disrupts ovarian function, whether temporarily or permanently.	III-2
Endocrine therapy is recommended for all women aged 35 years or younger who have hormone receptor positive tumours, irrespective of whether or not they receive chemotherapy	I
Combined endocrine treatment (LHRH agonist plus tamoxifen) is superior to LHRH agonist treatment alone in premenopausal women with advanced breast cancer in terms of length of survival.	I
Younger women should be advised about the relative effectiveness and safety of different treatments for menopausal symptoms resulting from chemotherapy or endocrine therapy	II
Induced ovarian failure is an outcome of chemotherapy treatment for some younger women, resulting in infertility and onset of menopausal symptoms. Clinicians should openly discuss fertility before treatment, and outline the probability of menopause based on the woman's age and treatment regimen. Women who wish to consider childbearing after treatment should be offered referral to a specialist with expertise in fertility treatment prior to the commencement of treatment.	II
Premenopausal women should be informed that their decision to have a child subsequent to a breast cancer diagnosis will not, as far as current evidence indicates, alter their risk of recurrence or overall survival.	III-2
Younger women, and indeed those of all ages, should be informed that moderate exercise has the potential to reduce fatigue and improve emotional wellbeing, even during radiotherapy or chemotherapy/	II

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