

Evidence-based psychosocial clinical practice guidelines for women with breast cancer

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Summary

Women diagnosed with breast cancer suffer significant emotional morbidity in addition to the medical aspects of the disease. Research shows that up to 45% of women suffer from anxiety or depressive disorders that can impact their own functioning, as well as that of their family. Therefore, the psychosocial needs for women diagnosed with breast cancer are an important consideration in providing medical care. Based on the best available evidence on the psychosocial aspects of breast cancer management, the Australian National Health and Medical Research Council's (NHMRC) National Breast Cancer Centre Psychosocial Working Group developed clinical practice guidelines for application by all members of the treatment team. This multi-disciplinary working group included oncologists, psychiatrists, surgeons, general practitioners (GP's), nurses and consumers. These guidelines are simple, patient specific and user friendly. The aim of this paper is to introduce these evidence-based psychosocial clinical guidelines to health professionals involved in the care of women with breast cancer. The ultimate goal of introducing these guidelines is to improve psychosocial and quality of life outcomes for these women and their families.

摘要

除了疾病本身，患乳癌的婦女還受到顯著的心理困擾。研究顯示45%的病人患有焦慮或抑鬱，對其個

人和其家庭的正常生活造成影響。治療乳癌時要考慮婦女的心理社會需要。根據現有最好的證據，澳洲國家健康醫學研究會全國乳癌中心心理社會工作組(NHMRC)給治療組的會員制定了臨床指引。這個綜合工作組包括有癌症專家、精神科醫生、外科醫生、全科醫生、護士和顧客。這些指示簡單、易用和針對病人需要。這份報告是為治療乳癌婦女的專業人士提供有證據有基礎的心理社會臨床指引，最終目標是改善乳癌婦女及家人的生活質素。

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Introduction

Breast cancer is a major health concern, being the most frequently diagnosed cancer in women. In Hong Kong, over 1,600 women are diagnosed each year, which represents 17.5% of all newly diagnosed female cancers, with rates appearing to increase steadily over the past decade.¹ The diagnosis and treatment of breast cancer have significant implications for most women, and often cause a range of physical and psychosocial sequelae, which profoundly impact on a patients' quality of life.^{2,3} There is evidence that approximately one patient in two with breast cancer experiences psychiatric morbidity.⁴

Medical treatment for breast cancer is a complex process involving multiple options and a variety of possible outcomes. In order to make the "best" treatment choice, as well as to cope with the illness impact, women increasingly request more information. Women are only able to participate as they wish in clinical decisions if they have access to such information. The accessibility of such information remains a major unmet need in Hong Kong.^{5,6} As a result, it is important to identify ways for members of the diagnostic and treatment teams to provide informational and emotional support for these women. Clinical guidelines are one approach to improve the quality of care received by patients.

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Psychosocial issues relating to breast cancer – a local study

A local study, which explored the meanings of breast cancer held by Chinese women, indicated that the impact of breast cancer changed over the course of illness trajectory.⁷ Initially, women perceived the diagnosis of breast cancer as the possibility of death. The unanticipated threat of death was an unbelievable shock to these women, and generated great uncertainty about the future. Confirmation of the diagnosis presented the women with the task of making a treatment choice. Yet, many of them felt emotionally overwhelmed by the bad news and uncertain about their options for the best treatment. Following treatment, the women experienced the negative impact of treatment-induced changes in appearance as a barrier to rehabilitation. During the post-treatment phase, surviving breast cancer did not mean a victory over the disease, but an ongoing journey living with the uncertainty of cancer recurrence. This local study suggested that it is important for health professionals to regularly assess and address women's feelings and concerns throughout their breast cancer illness.

As a member of the diagnostic and treatment team, GPs play a significant role in providing medical and psychosocial care for women with breast cancer, from diagnosis to recovery. There is evidence that Hong Kong women with breast cancer often seek informational support from their GPs.⁸ It is important for GPs to effectively provide this support. The aim of this paper is to introduce these evidence-based psychosocial clinical guidelines, developed by the Australian National Health and Medical Research Council's (NHMRC) National Breast Cancer Centre Psychosocial Working Group, to Hong Kong GPs, oncologists and surgeons involved in the care of women with breast cancer. We are confident that introducing NHMRC guidelines to Hong Kong is an appropriate approach as there is evidence that Chinese and Caucasian women ascribed similar meanings to the breast cancer experience.⁷ Lam and Fielding⁷ postulated that the similar illness experience between Chinese and Caucasian women may be due to the fact that Hong Kong's health care system closely follows the Western biomedical paradigm, so the impacts of diagnostic and treatment-related procedures are similar.

National psychosocial clinical practice guidelines

Clinical guidelines are systematically developed statements to help practitioner and patient decisions about appropriate health care for specific circumstances.⁹ The Australian psychosocial clinical practice guidelines for women with breast cancer are the first comprehensive guidelines to cover all psychosocial aspects of breast cancer management. These guidelines were developed by a multi-disciplinary group including oncologists, psychiatrists, surgeons, GPs, nurses and consumers and were developed based on the best available evidence about the psychosocial aspects of breast cancer management.¹⁰ The guidelines use the evidence rating system developed by the NHMRC's Standing Committee on Quality of Care and Health Outcomes (QCHOC) to assess the strength of research evidence in reviewing the literature. Most of these recommendations are based upon level I (meta-analysis) and level II (randomised controlled trials) evidence.¹⁰

The guidelines provide evidence based recommendations on the provision of information, the integration of quality of life issues into care, minimising the social and psychological impact of breast cancer on these women and their families, and strategies for the identification and management of women experiencing significant emotional distress.¹⁰ In this paper, we only present the recommendations on the provision of information as there is evidence that Hong Kong women express the need for informational support from their GPs.⁸ The complete NHMRC Psychosocial Clinical Practice Guidelines are available online at <http://www.health.gov.au/nhmrc/publications/synopses/cp61syn.htm>

General interactional skills

In Hong Kong, as in Australia,¹⁰ women with breast cancer repeatedly report a desire to be well informed. Effective communication between a clinician and a woman with breast cancer can contribute to significant improvements in psychological adjustment, decision making, treatment compliance, and satisfaction with care. The guidelines also state that effective communication not only involves providing information, but also includes a process of individually tailored explanation, problem solving, and acknowledgement of the woman's feelings.

For clinicians working with people with cancer, there has been little acknowledgement of the difficulties

involved in breaking bad news, discussing prognosis, preparing a woman for potentially threatening procedures and providing on-going emotional and social support. These guidelines benefit clinicians by providing recommendations about effective practices in psychosocial care **Table 1**.

Table 1: General interactional skills

The following skills should be considered in any consultation with women with breast cancer:

Supportive communication

- Asking the woman if she would like someone to be with her during the consultation.
- Show regard and concern for the woman by using appropriate verbal and non-verbal behaviour, including sitting attentively and facilitating the woman's responses.
- Use verbal and non-verbal behaviours that are appropriate to a woman's age and cultural background.
- Express empathy and listen actively.
- Allow and encourage the woman to express her feelings (e.g. crying, talking about concerns, fears, anger, anxieties, etc.).
- Handle embarrassing or disturbing topics directly and sensitively.

Delivering medical information in plain language

- Assess a woman's understanding before providing additional information.
- Explain difficult terms and avoid medical jargon.
- Use explicit categorisation (provide information clearly grouped in specific topics).

Strategies to aid recall and understanding

- Actively encourage questions and seek understanding.
- Make use of simple diagrams and pictures where appropriate.
- Repeat and summarise important information.
- Reinforce important information by using one or more of the following aids:
 - Writing down relevant information.
 - Taping the consultation as needed and if wanted.
 - Sending the woman a summary letter as follow-up.

Ongoing support

- Assess the woman's level of family or social support.
 - Provide the names and contact details of relevant persons or organisations to obtain more information.
 - Refer to a specialist breast nurse or other relevant professional support as required.
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Disclosing diagnosis

The way in which the diagnosis is disclosed affects the woman's understanding of the illness, as well as her later psychological adjustment.¹⁰ Most women prefer to be told all of the information about their disease, even if it is bad news. The best approach is to tailor the information to the individual woman's needs. In addition, the guidelines state that the initial diagnosis is only the first step in communicating bad news with a woman with

breast cancer. Subsequent news such as cancer recurrence or metastases may be even more difficult to communicate than the initial diagnosis.

A diagnosis of breast cancer is difficult for all the people involved. For the clinician, the delivery of the news may be one of the most difficult things she/he does. For the women, the way the news is delivered may affect her understanding of the disease and also her longer-term psychological adjustment.¹⁰ Local studies support the preference for full and frank information about cancer by the majority **Table 2**.^{5,6}

Table 2: Recommended steps for telling a woman she has breast cancer, a recurrence or metastases

These steps are recommended in conjunction with the general interactional skills in **Table 1**.

Prior to discussing diagnosis, recurrence or metastases

- Ensure the news is given in person, in a quiet, private place and allow enough uninterrupted time.
- Encourage a second person to be present if appropriate.
- Arrange to provide other methods to convey the information (e.g. written materials, videotapes, tapes of consultations, etc.).

When providing the information

- Assess the woman's understanding of her condition and the woman's personal preference for information.
- Briefly explain the process by which the diagnosis was reached.
- Provide information simply and honestly, using lay terms without euphemisms.
- Avoid the notion that 'nothing can be done'.
- Clearly indicate that the woman will have the final decision regarding her care.

Emotional and supportive role

- Encourage the woman to express her feelings (e.g. crying freely, talking about concerns, fears, anger, anxieties, etc.) and respond to her feelings with empathy.
- Address disturbing or embarrassing topics directly and with sensitivity.
- Assess the type and level of assistance that may be required, such as financial, transport or childcare assistance.
- Provide information about support services.

Concluding the discussion

- Summarise main points of the consultation and assess the woman's understanding.
- Ask if there is anything further the woman would like to discuss.
- Offer assistance to tell others difficult news.
- Indicate your availability for contact to address any questions or concerns and arrange a further appointment to review the situation within a stated time period (e.g. within 24 hours to two weeks).

After discussing a diagnosis, recurrence or metastases

- Document information given to the woman and family members
- Let others, particularly the woman's general practitioner, know the extent of information given and your perception of the woman's understanding.

Adapted from How to Break Bad News, by the NSW Cancer Council¹¹ and NHMRC. Clinical Guidelines for the Management of Early Breast Cancer.¹²

Discussing prognosis

The guidelines urge women to actively take part in their treatment decisions. To do this, women should be given "adequate information about all pertinent matters, including even low probability of risk in a form which promotes understanding".¹⁰

There is no clear evidence about the impact of communication of risk on subsequent psychological adjustment.¹⁰ However, there is evidence that the way of communicating the risk of cancer recurrence and relative risk reduction can influence the treatment choices the woman make. The guidelines state that women want to know both the positive and negative aspects on the issue of survival. Two approaches to discussing survival are mentioned in the guidelines. One approach is to give women all the relevant information.

Another approach is to inform women what type of prognostic information is available and ask them how much of the information they want to receive. The guidelines recommend that prognosis should be discussed in relation to the outcomes of each treatment option and by focusing on the hope-giving aspects of each option.

The way information is given may be as or more crucial to these women than the content itself. The way clinical information is presented or framed by clinicians may influence the treatment choice made by these women.¹⁰ Again, the few local studies done on this topic indicate significant numbers of people with cancer do not have the opportunity to discuss with their doctor about their diagnosis or treatment, indicating a significant unmet need in this area **Table 3**.

Table 3: Recommended steps for discussing prognosis with women with breast cancer

These steps are recommended in conjunction with the general interactional skills in **Table 1**.

Offering prognostic information

Consider offering information prior to commencing treatment:

- Ask first if the woman wants to be given information on prognosis (e.g. 'I can tell you what happens to most women in your situation. Would like me to do that?') and what she currently understands and expects.

Aspects of prognosis to discuss

Adhere to the woman's stated preference for information about prognosis.

If desired, provide the:

- Staging details and their implications for prognosis.
- Chances of being cured or that cancer will never return.
- Likely benefits and risks of adjuvant therapy.
- Chance of the cancer shortening the woman's life compared to other life events (e.g. heart disease).
- Average and longest survival times, emphasising a range rather than a single time point.

How to discuss prognosis

- Preface any prognosis estimate with its limitations:
 - Explain that you cannot predict how the woman as an individual will respond to the illness and its treatment.
 - Provide an initial estimate of prognosis based on available information; explain how this may be revised by additional information (suggest a time frame for when additional prognostic information is likely to be available).
- Use mixed framing (give chances of cure first, and then chances of relapse).
- Present information in a variety of ways (words, statistics, graphs):
 - Combine verbal estimates (e.g. small) with a numerical estimate as well.
 - Provide verbal explanations of survival graphs.
- When explaining relative risk reduction, provide several examples of calculations:
 - Only use statistical terminology (i.e. median, hazard risk ratio) if a woman is familiar with these concepts.

Concluding the discussion

- Summarise main points of the consultation and reassess the woman's understanding.
- Emphasise hope-giving aspects of the information, such as extraordinary survivors.
- Indicate your availability for contact to address any questions or concerns and arrange a further appointment to review situation within a stated time period.

Adapted from Lobb et al.¹³ Communication of prognosis in early breast cancer. NHMRC National Breast Cancer Centre.

Update Article

Discussing treatment options: providing information and choice

Women with breast cancer need to be able to access accurate and reliable information about treatment options.¹⁰ Information about chances of cure, spread of disease, the cancer, treatment options, the likelihood that the treatment will be a success, and its possible side effects are important to these women. There is evidence

that women who perceived themselves to be poorly informed were twice as likely to be depressed and/or anxious one year post-diagnosis as those who perceived themselves to be adequately informed.¹⁰ The guidelines suggest that the way in which the information be presented to these women needs to be carefully planned. Importantly the opportunity to follow up with a clinical nurse specialist can "assist understanding and reduce psychological morbidity" **Table 4.**¹⁰

Table 4: Recommended steps for effectively discussing treatment options with women with breast cancer

These steps are recommended in conjunction with the general interactional skills in **Table 1.**

Information about treatment

- Explain to the woman using language that she understands what treatment options are available and ask how much detail she would like about each option.
- Tailor the information to the woman's needs and preferences for information content and detail, which may include a discussion of the expected outcomes of each treatment option and the major side-effects of each treatment.
- Use a variety of media to provide information about treatment options (e.g. written information, videotapes, tapes of consultations, etc.).
- Ask the woman to talk about the concerns she has regarding different options.

Decision-making about treatment

- Ask the woman how much she would like to be involved in decision-making and adhere to this decision.
- If the woman is by herself ask whether she would like to discuss treatment options with family or friends and tell the women that there is an opportunity for them to be involved in treatment decisions.
- Assure the woman that there is enough time to consider the treatment options and offer to arrange for her to come back with a decision.
- Be aware that the woman's preferences may change over time -decision-making should not be seen as a once-only event.

Emotional and supportive role

- Encourage the woman to express her feelings (e.g. crying freely, talking about concerns, fears, anger, anxieties, etc.) and respond to her feelings with empathy.
- Address disturbing or embarrassing topics directly and with sensitivity.
- Provide information about support services.

Concluding the discussion

- Summarise main points of the consultation and assess the woman's understanding.
- Ask if there is anything further the woman would like to discuss.
- Offer assistance to tell others difficult news.
- Indicate your availability to address any questions or concerns and arrange a further appointment to review the situation within a stated time period (e.g. within 24 hours to two weeks).

After discussing a diagnosis, recurrence or metastases

- Document information given to the woman and family members.
- Let others, particularly the woman's general practitioner, know the extent of information given and your perception of the woman's understanding.

Adapted from Cockburn J.¹⁴ Effectively discussing treatment options with women with breast cancer. NHMRC National Breast Cancer Centre.

Conclusion

The primary focus of the psychosocial clinical practice guidelines is to improve psychosocial and quality of life outcomes for woman diagnosed with breast cancer and her family. These outcomes include information and

satisfaction with care, psychological outcomes, and social functioning.¹⁰ As the incidence of breast cancer increases in Hong Kong, and our data on the women's experiences finds parallels with the Australian experience, the hope is that clinicians and women will utilise these evidence-based guidelines, thereby improving outcomes. ■

Key messages

1. The diagnosis of breast cancer can be devastating to a woman, because all the normal reactions to cancer are worsened due the changes in her physical appearance.
2. As many as 50% of women suffer from psychological distress after a diagnosis of breast cancer.
3. There is strong evidence that clinicians can improve woman's understanding, ability to make decisions, and mental and physical health.
4. Evidence suggests ways whereby clinicians can achieve these goals.
5. Psychosocial care should be a part of physical care for the best outcomes.

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