



NATIONAL BREAST
AND OVARIAN
CANCER CENTRE

COMMUNICATION SKILLS TRAINING INITIATIVE

**DISCUSSING THE TRANSITION
FROM CURATIVE CARE
TO PALLIATIVE CARE WITH
WOMEN WITH ADVANCED
BREAST CANCER**

**EVIDENCE FROM THE LITERATURE AND
RECOMMENDED STEPS**

PREPARED BY THE NATIONAL BREAST CANCER CENTRE

FUNDED BY THE AUSTRALIAN GOVERNMENT
DEPARTMENT OF HEALTH AND AGEING

Discussing the transition from curative care to palliative care - Evidence from the literature was developed by the Peter MacCallum Cancer Centre on behalf of the National Breast Cancer Centre:

The National Breast Cancer Centre

92 Parramatta Road Camperdown NSW 2050 Australia

Locked Bag 16 Camperdown NSW 1450 Australia

Telephone +61 2 9036 3030

Facsimile +61 2 9036 3077

Website www.nbcc.org.au

Email: director@nbcc.org.au

© National Breast Cancer Centre 2005

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced by any process without prior written permission from the National Breast Cancer Centre. Requests and enquiries concerning reproduction and rights should be addressed to the Communications Manager, National Breast Cancer Centre, Locked Bag 16 Camperdown NSW 1450 Australia.

Recommended citation:

National Breast Cancer Centre. *Discussing the transition from curative care to palliative care - Evidence from the literature*. 2005. National Breast Cancer Centre, Camperdown, NSW.

Disclaimer

The National Breast Cancer Centre does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information. The National Breast Cancer Centre develops material based on the best available evidence, however it cannot guarantee and assume no legal liability or responsibility for the currency or completeness of the information.

Copies of this report can be downloaded from the

National Breast Cancer Centre website: www.nbcc.org.au

or by telephone: 1800 624 723

The National Breast Cancer Centre is funded by the Australian Government Department of Health and Ageing.

ACKNOWLEDGMENTS

The National Breast Cancer Centre (NBCC) gratefully acknowledges the support of individuals and organisations who contributed to the development of this communication skills module.

Module developers:

- Dr Penny Schofield, Peter MacCallum Cancer Centre
- Dr Anthony Love, La Trobe University
- Dr Simon Wein, Peter MacCallum Cancer Centre
- Dr Mariko Carey, Peter MacCallum Cancer Centre

NBCC Communication Skills Steering Committee:

- Professor Phyllis Butow, Director, Medical Psychology Unit, University of Sydney (Chair)
- Professor Jill Cockburn, Professor Behavioural Science, University of Newcastle
- Ms Meg Lewis, Specialist Breast Nurse, Royal Adelaide Hospital
- Mr Peter Malycha, Surgeon, Royal Adelaide Hospital
- Ms Pam Robertson, Consumer, Breast Cancer Network Australia
- Dr Jane Turner, Psychiatrist, University of Queensland

Module reviewers:

- Professor David Currow, Professor of Palliative & Supportive Services, Flinders University
- Professor David Kissane, Chairman, Department of Psychiatry and Behavioural Sciences, Memorial Sloan-Kettering Cancer Center

National Breast Cancer Centre Staff

- Dr Karen Luxford
- Dr Nicole Rankin
- Ms Caroline Nehill.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	5
INTRODUCTION	7
METHODOLOGY OF THIS REVIEW	8
THE PALLIATIVE APPROACH	9
UNDERSTANDING WOMEN'S EXPERIENCES OF ADVANCED BREAST CANCER	10
Impact of the bad news about advanced breast cancer	10
The impact of advanced breast cancer on physical functioning and quality of life	10
The impact of advanced breast cancer on psychosocial functioning	11
The impact of advanced breast cancer on family functioning	11
The Impact of advanced breast cancer on existential issues	12
Facilitating the transition from curative to palliative care	12
RECOMMENDED STEPS	16
When should I discuss the transition to palliative care?	16
How should I prepare for this discussion?	16
How do I set-up the consultation?	16
How do I begin this discussion?	17
How should I approach cultural and linguistic diversity?	18
What information do I provide?	18
How should I respond to the woman's emotional reaction?	19
How do I bring up palliative care services?	20
How can I ensure continuity of care?	22
How can I address family concerns?	22
How do I conclude the discussion?	23
Emotional impact on health professionals	23
CONCLUSIONS	25
REFERENCES	26

EXECUTIVE SUMMARY

Palliative Care focuses on improving quality of life for patients with life-threatening illness and their families. In practice, a palliative approach tends to be gradually adopted over time as the disease progresses. The challenge is how to facilitate a sympathetic transition from curative to palliative care.

The first step is to understand the woman's experience of advanced breast cancer.

- This diagnosis is more devastating than the initial diagnosis.
- Patients may continue to want futile, curative treatment.
- Women may experience a range of debilitating physical symptoms, particularly fatigue, pain, dyspnoea and delirium.
- Psychological distress, reduced quality of life and social isolation often result from the diagnosis of advanced disease and the associated symptoms.
- Women are very concerned about the impact of their disease on their family.
- Family distress and caregiver burden increases as the cancer advances.
- Children, particularly adolescent daughters, experience significant distress that may not be detected.
- Women experience existential issues related to facing their own death.

The recommended steps for facilitating the transition from curative to palliative care were based on the best available evidence, however, it should be noted that there is a paucity of research in this area, hence research was also drawn from related areas of enquiry. It is recommended that when discussing this transition these steps are followed:

- Prepare for the discussion by gathering relevant information, ensuring the setting is appropriate, asking the woman to bring family, offering a tape-recording and encouraging the woman and her family to ask questions.
- Elicit the woman's understanding of her situation and preferences for information and support by asking open-ended questions.
- Be aware of attitudes and information needs of different cultural groups.
- Provide the woman with the information that she requires using lay terms including conveying that more curative treatment would do more harm than good.
- Respond to the woman's emotional reaction with empathy.
- Negotiate new goals of care by first asking whether the woman wishes to discuss future treatment options, then introducing the role of palliative care services and providing realistic reassurances and hope.

- Maintain continuity of care by referring to the palliative care health professionals as part of the team and reassuring the patient that they will not be abandoned.
- Address family concerns by asking about how they are coping at home and if there are children, asking about their concerns.
- Conclude the discussion by summarising, checking the need for referrals, emphasising the hope-giving aspects and asking for final questions.
- Inform other members of the team about the discussion and document it.

INTRODUCTION

The goal of palliative care has been described as helping people die with dignity¹. Understandably, people find the transition from curative to palliative care a stressful experience. It is recognised as a critical moment in the cancer journey². Building health care professionals' communication skills can assist the transition through this difficult phase and increase the prospect of better outcomes for women with advanced breast cancer and their families. The aim of this communication skills module is to increase health care professionals' abilities to facilitate discussions about the transition from curative care to palliative care.

METHODOLOGY OF THIS REVIEW

The literature review was synthesised from the best available scientific evidence. A comprehensive literature search was conducted covering the relevant scientific literature from 1990 to 2003. All relevant databases, including MEDLINE, CANLIT, CINAHL, and PSYCHLIT, were searched including the following search terms: cancer, oncology, palliative care, referral, communication, breaking bad news, doctor-patient communication, death, dying and cultural attitudes. As studies in this area are relatively few, and difficult to undertake using randomized controlled trials, all relevant articles in English were collected, and subjected to a methodological review. Further searches were undertaken of references lists, and researchers commonly publishing in this field. In addition, the reference list of the “Clinical practice guidelines for the psychosocial care of adults with cancer” was inspected to ensure no relevant articles cited there had been missed.

The evidence rating system used in this literature review is based on recommendations by the NHMRC³.

- Level I Evidence is obtained from a systematic review of all relevant randomised controlled trials.
- Level II Evidence is obtained from at least one properly designed randomised controlled trial.
- Level III-1 Evidence is obtained from well-designed pseudo-randomised controlled trial (alternate allocation or some other method).
- Level III-2 Evidence is obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case control studies or interrupted time series with a control group.
- Level III-3 Evidence is obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel group.
- Level IV Evidence is obtained from case studies, either post-test or pre- and post-test.

THE PALLIATIVE APPROACH

Palliative care has been defined by the World Health Organisation as “an approach that improves the quality of life of families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”⁴. Compared to conventional care, specialist palliative care services improve patient and family satisfaction, reduce family anxiety, provide better pain control and symptom management and increase the likelihood of the patient being cared for his/her place of choice⁵ (Level 1).

The clinical challenge is how to facilitate a sympathetic transition from curative to palliative care. This transition can imply impending death to the patient and trigger fears of helplessness and abandonment by the medical profession. For advanced breast cancer, chemotherapy can sometimes be used to prolong life in a quasi-curative sense often for many months, even years. In these cases, cancer can be considered a chronic illness⁶. Hence, the traditional sharp transition point from a curative to palliative goal of care is blurred. In practice, a *palliative approach* tends to be adopted over time as the disease progresses. This philosophy acknowledges the likelihood of gradual transition, emphasising quality of life considerations and symptom control during the active treatment phase. Treatment goals will evolve from seeking a cure, to control of disease and complications, maintaining physical functioning and quality of life, and ultimately to symptom control⁷. The concept of dying with dignity moves palliative care beyond symptom control to the consideration of psychological, social, spiritual, and existential issues⁸.

In this module, the concept of palliative care is defined as encompassing “management during both acute and chronic illness and end-of-life (terminal) care”⁴. Hence, use of palliative care varies widely. A woman with breast cancer may be receiving curative treatment such as tamoxifen but with the discovery of metastatic disease may be offered palliative chemotherapy or radiotherapy treatment to prolong her survival. As such, oncologists and general practitioners may prescribe treatments with palliative intent. Patients may see a palliative care physician or nurse for a limited time to resolve a particular issue, such as uncontrolled pain. As the disease advances to the terminal phase, they may be referred to community palliative care services or a hospice for end-of-life care. Each one of these referrals is likely to be distressing as it may confer a new, more serious phase of the illness. These guidelines are intended to have applicability to each of these transition points. Parts of the guidelines may be more relevant to some transitions than others.

UNDERSTANDING WOMEN'S EXPERIENCES OF ADVANCED BREAST CANCER

IMPACT OF BAD NEWS ABOUT ADVANCED BREAST CANCER

While the news of an advanced cancer diagnosis has many similarities to earlier bad news episodes, it also has some unique characteristics.

- It is rated as more devastating than the initial diagnosis of localised disease⁹, however, expressing empathy and providing information can facilitate patient adjustment¹⁰.
- A high proportion (61%) of Australian women with advanced breast cancer indicated that they would have liked changes in the way their diagnosis of advanced disease was communicated to them¹¹.
- Patients with advanced cancer may continue to ask for futile, curative treatment. About a quarter of oncologists say that they occasionally administer a treatment that is not likely to work, in order to bolster the patient's hope¹².

THE IMPACT OF ADVANCED BREAST CANCER ON PHYSICAL FUNCTIONING AND QUALITY OF LIFE

Optimising quality of life is not only an important outcome in itself but it is also associated with longer survival amongst women with advanced breast cancer¹³ (Level III-3). Women may experience a diverse range of physical symptoms, which will require careful assessment and management to alleviate and reduce the associated psychological distress^{14, 15}. These symptoms commonly include:

- Fatigue; in advanced disease it is the most common and the most challenging to manage¹⁶.
- Pain, both neuropathic and nociceptive; critical to control, not only because of its debilitating effects but also because of its contribution to fear, depression and anxiety¹⁷.
- Dyspnoea, most commonly due to pleural effusion, lymphangitis carcinomatosa, fatigue and lung metastases¹⁸.
- Delirium, which occurs generally in the final stages of disease, can be due to a multitude of causes and can masquerade as anxiety, depression, or psychosis, hence it is frequently under-diagnosed and mismanaged¹⁹.

- Quality of life will be increasingly affected. Between 26% and 30% of Australian women with advanced breast cancer reported poor quality of life in terms of global health status and physical, role, and social functioning²⁰.

A comprehensive review of symptom management is provided in the Clinical Practice Guidelines for Management of Advanced Breast Cancer (pp 109-112)²¹.

THE IMPACT OF ADVANCED BREAST CANCER ON PSYCHOSOCIAL FUNCTIONING

Disease phase can have a profound impact on the psychological and social well being of women with breast cancer²². Specifically:

- As many as a third of women with advanced breast cancer meet diagnostic criteria for psychiatric disorders⁹.
- Depression amongst palliative care patients who did not acknowledge their prognoses has been found at rates almost three times that of those who demonstrated partial or complete awareness of their prognosis¹.
- Physical symptoms, such as fatigue and limited mobility, and restricted functioning in social and work-related roles reduce opportunities for social contact that can result in social isolation²².
- The top two unmet needs of Australian women with advanced breast cancer are psychosocial: “concerns about the worries of those close to you” (70%) and “fears about the cancer spreading” (61%)²⁰.

THE IMPACT OF ADVANCED BREAST CANCER ON FAMILY FUNCTIONING

Not only is a diagnosis of advanced breast cancer devastating for the women, but it also has a profound impact on her family and significant others.

- Caregivers for women with advanced breast cancer report that the task becomes more demanding and difficult as the disease progresses²³.
- Family distress increases as the cancer advances. This burden may be exacerbated by social isolation²⁴
- Children of women with advanced breast cancer experience significant psychological distress, particularly adolescent daughters; and parents may not be aware of this distress²⁴.

Given the impact advanced illness has on family functioning, Palliative Care Australia²⁵ recommends that the patient and their family should be recognised as the ‘unit of care’.

THE IMPACT OF ADVANCED BREAST CANCER ON EXISTENTIAL ISSUES

A woman who is given the news that her cancer is incurable is likely to face important existential questions related to the meaning of her life and the prospect of facing her own death.

- “Uncertainty about the future” was described as an unmet need by a majority of women (61%) with advanced breast cancer²⁰.
- Kissane and colleagues²⁶ have developed the concept of ‘demoralisation’ that incorporates the deep emotional pain and existential distress that accompanies loss of meaning and hope and social isolation in the terminally ill.

FACILITATING THE TRANSITION FROM CURATIVE TO PALLIATIVE CARE

There is a paucity of research relating directly to managing the transition to palliative care; hence many of the recommendations are based on findings from related areas of enquiry. Recommendations for discussing transitions from curative to palliative care are presented in Table 1.

RECOMMENDED STEPS

Table 1: Recommended Steps for discussing transitions from curative care through to palliative care

Recommended steps	Source and level of evidence
Prior to discussion	
Review all relevant information from records and test results in particular 1) prognosis & 2) therapeutic options Gather any additional information from colleagues about the person's psychosocial situation	Butow et al. ³¹ ; Schofield et al. ³²
Ensure discussion takes place in a private place with adequate, uninterrupted time for full discussion	Ptacek & Eberhardt, ³³ Schofield, et al. ³²
Offer a tape-recording of consultation	McClement & Hack ³⁶ (Level II)
Invite the woman to bring kin to the consultation, and encourage questions	Schofield et al. ³⁴ (Level III-3), Roter ³⁵ (Level II)
Elicit the woman's understanding of her situation and preferences before discussing clinical decisions	
Ask open questions to determine the woman's understanding of her disease, the purpose of recent treatment and/or tests	Baile et al. ²⁹ (guidelines), Schofield et al. ³⁴ (Level III-3)
Ask open questions with a psychological/ existential focus to determine her feelings, concerns, and goals - What concerns you most about your illness? - What has been most difficult about this illness for you? - What are your hopes, expectations and fears about the future? - As you think about the future, what is most important to you? - Is there any unfinished business in your life that you want to attend to?	Cox et al. ⁴⁰ (Level II) Lo et al. ³⁸ (guidelines) Kissane and Yates ³⁹
Assess the person's preferences for information: - How much information would you like? - What types of information would you like? I can talk about . .	Schofield, et al., ³² Hagerty et al., ³⁰ Fallowfield et al., ⁴² Fallowfield, Ford, Lewis ⁴¹
Acknowledgement of cultural and linguistic diversity	
Be aware of attitudes and information needs of different cultural groups especially in relation to discussions of prognosis and death and dying, but not be too confined by them. Individuals can step outside their cultural circle.	Huang et al. ⁶⁶ Lickiss ⁶⁷
Provide information	
Provide information simply and honestly, using lay terms and no euphemisms. Information may include: disease progression; treatment efficacy; prognosis; symptom management issues	Chapman et al ⁵⁰ , Baile et al. ²⁹ (guidelines)

<p>Sensitively convey the information that no curative treatment exists for her disease or that her disease is no longer responding to the current treatment</p> <ul style="list-style-type: none"> - More of this treatment would do more harm than good - As the seriousness of your cancer increases, it may be that you will achieve better quality of life without further chemotherapy but we continue an active focus on meeting your all of your needs with the best available treatments and support 	<p>Fallowfield et al.⁴² Baile et al.²⁹(guidelines)</p>
Respond to the woman's emotional reaction	
Allow and encourage the woman to express her feelings	McArdle, et al. ⁵² (level II) Schofield et al. ³⁴
Express empathy and listen actively	McArdle, et al. ⁵² (level II)
Wait until tears or emotional reaction subsides before moving on	
Negotiate new goals of care	
Ask whether the woman would like to discuss future treatment options today or sometime later	Hagerty et al. ³⁰
<p>Use the term "palliative care" explicitly to maintain open & honest communication</p> <p>Ask what she understands the term palliative care to mean and correct any misperceptions</p> <p>Provide relevant information about the role of palliative care appropriate to her situation i.e. symptom management and maintaining quality of life</p>	<p>Fallowfield et al.⁴²</p> <p>Lilly et al.⁵⁴(Level II)</p>
Positively promote the holistic nature of palliative care and the wide range of services provided i.e. not just symptom control	Baile et al. ²⁹ (guidelines)
Explain that effective symptom management can be given at the same time as treatment to control the spread of the cancer	Baile et al. ²⁹ (guidelines)
If a woman continues to ask for curative/current treatment, respond to emotions underlying these requests	Baile et al. ²⁹ (guidelines)
Provide realistic reassurance and positive hopes for the future eg about positive, achievable goals	Butow et al. ⁵⁵
Work from an assumption that "there is never a time when nothing can be done" to rebuild morale.	Kissane and Yates ³⁹
Continuity of care	
Refer to the palliative care health professionals as part of the woman's multidisciplinary team	Weissman & Griffe ²⁷
Explicitly state to the patient that she will receive optimal care at all times and will not be abandoned.	Baile et al. ²⁹ (guidelines)

Address family concerns	
Family members and other carers will need to be informed and understand the implications, especially caregiver burden. - What challenges and concerns would exist for you in caring for your ill relative?	Hudson, Aranda, Kristjanson, in press ⁶⁴
If the woman has young or adolescent children, ask about concerns relating to her children and clarify assistance required in discussing these issues with her children	NBCC 1997 ²⁴
Concluding the discussion	
Summarise main points of discussion and check woman's understanding	
Provide written summary (or audiotape of consultation), other written patient information	Schofield et al. ³⁴ (Level III-3)
Check for the need for other referrals - Would you like to talk about how you feel with a counsellor? - Would you like to talk about options for help at home with a social worker - Would you like to explore religious or spiritual issues with someone? - Would your children like to talk to a counsellor?	Sheard & Maguire ⁶⁸ (Level I) for psychological interventions
Emphasise hope-giving aspects of the discussion eg maximising length and quality of life; availability of up to date treatments	Butow et al. ⁵⁵
Ask if there is anything else the woman or her family wants to ask or discuss	Schofield et al. ³⁴ Roter ³⁵ (Level II)
Organise a follow-up appointment	
After discussion	
Let other members of the treatment team, especially, palliative care health professionals, the woman's general practitioner and community nurse know about the discussion and your perception of the person's understanding.	
Document discussion in medical records	

WHEN SHOULD I DISCUSS THE TRANSITION TO PALLIATIVE CARE?

By making the intent of the treatment clear and introducing notion of specialist palliative care services early after the diagnosis of advanced disease, oncologists, general practitioners and nurses who are providing treatment with palliative intent can facilitate the gradual transition to palliative care. While the palliative approach may be conceptualised as a gradual transition, the introduction of palliative care services is a distinct event. There is very little research on the triggers for a referral to palliative care

services. One study has suggested that pain control is the most common trigger for referral²⁷, and is believed by health professionals to be the symptom most usefully addressed by palliative care services²⁸. Perceptions of when is the best time to introduce palliative care services vary markedly between health professional groups, with hospital nurses favouring early referral and hospital doctors and general practitioners later referral²⁹. It has been suggested that the introduction of the palliative care team as part of the multidisciplinary team early after the diagnosis of advanced cancer, as opposed to waiting until severe symptoms emerge, may aid in the adjustment process^{27,29}. However, ultimately the timing should be guided by each individual woman's preferences³⁰.

HOW SHOULD I PREPARE FOR THIS DISCUSSION?

Gathering relevant information: Meeting the information needs of people with cancer is vital at any stage of the disease and this critical transition is no exception. The vast majority of people with cancer want as much information as possible about their diagnosis, their prognosis, and especially their treatment options^{31,32}. Hence, the first task is to review all relevant information prior to the discussion. This may include talking to colleagues involved in the woman's care to better understand her psychosocial situation or any particular concerns or issues she might have.

HOW DO I SET-UP THE CONSULTATION?

Supportive environment: It is important to ensure that the discussion takes place in a supportive environment. In a review of breaking bad news recommendations, there was general agreement that 'bad news' discussions of this type should take place in a quiet, comfortable and private location, sufficient uninterrupted time should be available to allow time for questions and discussion, and the patient should be encouraged to invite their significant others to be present³³. Australian cancer patients endorse these recommendations^{31,32}. Moreover, having significant others, usually the spouse, present to hear the bad news has been linked to lower levels of patient anxiety³⁴ (Level III-3). The woman and her family should be asked throughout the consultation whether they have any questions. Encouraging patients to ask questions has been associated with more patient questions³⁵ (Level II) and lower levels of anxiety³⁴ (Level III-3).

Audiotapes for this consultation: Studies examining the utility of audio taping consultations have produced mixed results. Overall, it seems that audiotapes are beneficial for most people with cancer, particularly those with high information needs³⁶ (Level II). However, one study found that people with poor prognoses who received an audiotape reported significantly higher psychological distress than those who did not

receive an audiotape³⁷ (Level II). The investigators concluded that the audiotape may have precluded the helpful use of 'denial' by some people. Hence, it is advised that in the context of advanced breast cancer, the provision of audiotapes is tailored to the individuals' needs and personal preferences.

HOW DO I BEGIN THIS DISCUSSION?

Understanding the woman's perspective: Eliciting the woman's understanding of her situation will establish common bearing for the health professional and woman, and provide direction to the health professional about how to address the issue of palliative care with this particular woman. Baile and colleagues²⁹ in their guidelines addressing communication issues for end of life care, recommend asking the patient to explain the purpose of recent treatments, procedures or tests so the doctor can verify that they hold a common understanding, and address misunderstandings or gaps in knowledge. Lo and colleagues³⁸ suggest that prior to discussing palliative care with patients, the doctor should ask a series of open-ended questions to elicit patients' concerns, goals and values. In this way, the doctor can acknowledge and understand the psychosocial, spiritual or existential suffering the person may be experiencing³⁹. Research shows that open-ended questions with an emotional content elicit greater expression of feelings than closed questions⁴⁰ (Level II).

Tailoring information: It is important to tailor information provision to the individual because information preferences do vary and a small proportion of people do not want a lot of information^{30,32,41,42}. These people tend to be older and have poorer prognoses⁴¹. This suggests that for women with advanced breast cancer, it is particularly important to carefully assess how much and what type of information and when it is desired, and not to assume that they wish to be told as much as possible. This is particularly true when introducing palliative care services.

HOW SHOULD I APPROACH CULTURAL AND LINGUISTIC DIVERSITY?

Most of these studies discussed above were conducted in developed countries (Australia, UK and USA) with English-speaking participants. However, there is some evidence that there are major cultural and regional differences in communication preferences about palliative care. Bruera and colleagues⁶⁵ (Level III-2) found that 93% of Canadian doctors said that the majority of their patients wanted to know about the terminal stage of their illness compared with 18% of South American and 26% of European doctors. Canadian doctors were inclined to support 'autonomy' as their

primary guiding ethical principle, whereas South American doctors regarded 'beneficence' as primarily guiding decisions about communication and care.

A qualitative study of Chinese-Australian people with cancer found that non-disclosure of poor prognosis was favoured and there was an emphasis on the family acting as mediators between the health professionals and the patient⁶⁶. Obviously, there needs to be recognition that communication, particularly in relation to palliative care, involves values and ethical principles, which are influenced by cultural diversity. However, it is prudent not to generalise, as people from a particular cultural background may vary widely in the extent to which they conform to the customs and expectations of that cultural group⁶⁷.

WHAT INFORMATION DO I PROVIDE?

Prognostic and treatment information: Limited evidence suggests that people with advanced disease tend to underestimate the extent of their disease^{43,44} and be overly optimistic about their prognosis^{43,44,45,46} (Level III-3). This may be as a result of inadequate communication between health professionals and people with advanced disease. In one study of seriously ill people, only 20% of clinician/patient pairs agreed that the doctor had communicated that the illness was fatal and in almost half (49%) the clinicians said that they had told the patients but the patients reported no communication. Better agreement was reached for life expectancy discussions; with 73% of pairs agreeing the discussion had not taken place⁴⁷. These misperceptions may also be as a result of health professionals providing a skewed estimate. Lamont and Christakis⁴⁸ found that 23% of physicians would not give a survival estimate to people with advanced cancer; 37% would give the survival estimate that they had formulated and 40% would give an estimate different from the one formulated and most of these estimates were overly optimistic. While it is reasonable to hope for a better than expected outcome, it can be helpful to prepare patients for all eventualities by considering poorer outcomes.

These misperceptions about prognosis are significant because patients who have overly optimistic perceptions of their prognosis are more likely to ask for futile, curative treatments making palliative care referrals more difficult⁴⁶ (Level III-3). Hence, if patients want prognostic information, it is important to provide them with as accurate information as possible. It has been shown in a study of people with incurable cancer that information provision related to prognosis and palliative care treatment options was not associated with increased patient anxiety⁴⁹ (Level III-3). The authors speculated that if information provision is not open, honest and detailed, patients may perceive doctors as withholding potentially frightening information. This sentiment was echoed by Fallowfield

and colleagues⁴². In their study of 1046 palliative patients, the vast majority (85%) wanted “as much information as possible, good and bad”. Over 90% of people being treated palliatively wanted to know their chances of cure and all possible treatment options. They concluded “misguided evasion or frank dishonesty may add considerably to a patient’s distress”. In keeping with providing open and honest information, Baile and colleagues²⁹ recommend in their guidelines that the doctor should sensitively convey to the patient that all curative treatment options have been exhausted with statement such as “any more chemotherapy may do you more harm than good”.

Information also needs to be provided using lay terms and euphemisms should be avoided. Recent UK research has shown that a substantial proportion of the general public do not understand words and phrases, such as ‘metastasis’ and ‘spots in the liver’ used in cancer consultations⁵⁰.

HOW SHOULD I RESPOND TO THE WOMAN’S EMOTIONAL REACTION?

An open and honest discussion about prognosis is likely to be very upsetting for the woman and her family. Health professionals should encourage emotional expression and respond with empathy. In a qualitative study of being referred to palliative care services, the inexperience and insensitivity of the doctor to patients’ emotions presenting the greatest problems. A sense of security and confidence was generated in the patients when the doctor displayed the characteristics of “the empathic professional” displaying a balance between medical competence and empathy⁵¹. Empathic encouragement of emotional expression, combined with providing information, and correcting misperceptions, has been found to reduce psychological distress in women with breast cancer⁵² (Level II). Another study found that talking about the patient’s feelings and being reassuring has been found to be associated with lower levels of patient anxiety³⁴ (Level III-3). Expressing empathy involves acknowledging the person’s feelings as valid and appropriate, with statements such as “this must be a really tough time for you”¹⁴. Active listening can assist the clinician to understand how the woman is feeling and help convey empathy. Active listening involves using eye contact, having an attentive posture, showing interest, such as nodding and making noises of agreement or encouragement, and then summarising what was said⁵³.

HOW DO I BRING UP PALLIATIVE CARE SERVICES?

Seek the woman’s preferences: In a survey of 126 metastatic cancer patients, Hagerty and colleagues³⁰ found that 33% wanted to discuss “dying and palliative care services” when first told cancer had spread; 19% said in the next few consultations; 33% said later, upon (their) request; 11% said never; and 10% were unsure. There were also a variety of

opinions about who should initiate the discussion: 45% wanted the specialist just to tell; 20% wanted the specialist to check first if the patient wanted to know; and 24% wanted the specialist to tell only if patient asks. These results indicate that the safest course of action would be to make general enquiries about whether the woman wanted to discuss future care options now or later, before initiating discussions about palliative care services.

Introduce palliative care options: In their guidelines, Baile and colleagues²⁹ recommend that after indicating that further curative treatment has a low chance of being effective, the clinician should introduce the option of effective palliative treatment options that focus not only on symptom control and a range of quality of life issues. They suggest that this transition may take some time with many patients wishing to continue with curative or anti-cancer treatments while also receiving palliative care to control symptoms. Further, he recommended that if a person continues to ask for futile treatment, that the doctor respond with empathy because the patient's emotions, often fear and desperation, need to be understood and acknowledged.

A study of people admitted to intensive care units found that patients and kin who received a series of staged discussions about treatment goals and palliative care options with the critical care team ceased futile active treatment earlier, compared with usual care, with no decrease in survival time⁵⁴ (Level III-3).

No research could be found related to introducing palliative care, using the term "palliative care" or the understanding of this term by the general public. However, several authors recommend "open and honest" communication with advanced cancer patients^{42,49}, which suggests the term "palliative care" should be used. The understanding of this term should also be probed and misperceptions corrected. There seems to be a common misconception that palliative care is synonymous with end-of-life or terminal care. While this is an important aspect of palliative care, it should be communicated that palliative care is far broader than care in the final phase of life.

Maintaining hope: Hearing the news of incurable disease is understandably devastating for most people. A qualitative study of people with advanced cancer revealed that patients believe it is crucial that doctors communicate hope as well as honest clear information in their discussions of prognosis with them⁵⁵. Fear about loss of hope may underpin the trepidation patients feel about asking for prognostic information. However, avoiding the issue or limiting prognostic information may in itself diminish hope.

Sardell & Trierweiler⁵⁶ found that patients view procedures that disguise a negative prognosis as hope reducing.

Hope has been defined as “the perception that one can reach one’s desired goals”⁵⁷ but that there is some uncertainty still attached to these perceptions. Hence, using this definition hope is not an entity in itself, but is attached to goals or potential outcomes that may change over time as circumstances evolve. Nunn⁵⁸ pointed out that “hope is associated all too commonly with unrealistic expectations” (p.231). Hence, it is critical that the messages of hope that are provided to patients are appropriate. Fostering false hope of a cure when a cure is not possible ultimately can be a source of regret as it may hinder patients and their family making sensible treatment decisions and lifestyle decisions in order to make the best use of the remaining time together⁵⁹. However, Links and Kramer⁶⁰ have asserted that, in the context of a poor prognosis, it is not necessarily inappropriate for a patient to hope for a cure even if it is highly unlikely, but messages of hope should also include more probable events such as long periods of remission and response to treatments. Strategies that successfully promote appropriate hope may make a critical contribution to discussing the transition from curative to palliative care.

Little research has been performed on how to foster hope in cancer patients. One study⁵⁶ involved 56 cancer patients rating statements describing communication procedures on a hopefulness scale. The top 5 procedures considered most hopeful were the doctor: offering of most up-to-date treatments; insisting that the patient will not be abandoned; offering to be a resource for all questions; being willing to call in other physicians if needed; and stating that there are many treatments available that can cure or slow down a cancer. Another qualitative study⁵⁵ with metastatic cancer patients identified several hope-fostering strategies. These included: the discussion of extraordinary survivors promotes hope; emphasising the positive and achievable outcomes of treatment; discussing a patient’s future in terms of a series of goals and normalising death as a natural event and encouraging preparation for this possibility.

Rebuilding morale: Kissane and Yates³⁹ have argued that addressing a person’s existential issues is crucial to the successful psychosocial care of a person with advanced disease. They suggest that existential distress can take several forms: death anxiety (fear of process of dying or death); demoralisation (sense of pointlessness and helplessness); grief (intense sadness, anger and sense of unfairness); aloneness (sense of isolation in life); loss of freedom (angst at loss of control; fear of dependence); and loss of dignity (distressed by illness, shame, fear of being a burden). Rebuilding morale requires an assumption by the treatment team that “there is never a time when nothing

can be done” to assist the person in palliative care. This assumption should underpin the discussion of the transition from curative treatment to palliative care.

HOW CAN I ENSURE CONTINUITY OF CARE?

Introducing the palliative care health professionals as part of the multi-disciplinary treatment team early can facilitate the transition from curative treatment to palliative treatment²⁷. It is important that the palliative care professionals are seen as an integral part of the treatment team, which will enhance the sense of continuity of care and allay any fears of abandonment. This permits women and their families to establish relationships with the palliative care professionals while maintaining a parallel care relationship with their oncologists. In addition, discussion of the palliative intent of life prolonging chemotherapy or radiotherapy treatment on several occasions over time by the oncologist or general practitioner may assist in the transition. Gradually, primary responsibility for care can shift to palliative care health professionals as the disease progresses. Baille and colleagues²⁹ recommend that when introducing the option of palliative care services, the physician should explicitly state that he/she will not abandon the patient.

HOW CAN I ADDRESS FAMILY CONCERNS?

Caregivers, usually a spouse or family member, must deal with unfamiliar situations and demands and many feel inadequately prepared for this role, particularly in relation to receiving guidance, support and information from health professionals^{61,62,63}. Evidence-based recommendations for information provision to family caregivers to help them assume their care-giving role have recently been developed⁶⁴. It is vital to include family members in the discussions surrounding the transition from curative to palliative care and meet their needs as well as the woman’s needs⁶⁴. In a NBCC review of the needs of children of mothers with advanced breast cancer, it was recommended that clinicians should routinely ask about the family, particularly the children’s adjustment, clarify what assistance might be needed in discussing her illness with her children, and facilitate referrals for family members as necessary²⁴.

HOW DO I CONCLUDE THE DISCUSSION?

Providing a summary of the main points of the discussion, emphasising the hope giving aspects, checking the woman’s understanding is a useful way to ensure there are no misperceptions and to signal the end of the consultation. A summary of the consultation (written or audio tape) and other patient information is wanted by many patients³³. The provision of written information in bad news consultations is associated with lower levels

of patient anxiety³⁴ (Level III-3). It is also important to check the need for referrals to other health professionals, such as to psychological services, social work or pastoral care. A meta-analysis by Sheard and Maguire⁶⁸ (Level I) showed that psychological interventions have a moderate clinical benefit for anxiety (effect size =0.36) but a weak effect for depression (effect size=0.19). However, interventions targeted at patients experiencing significant clinical distress demonstrated the strongest benefits. The discussion should be concluded by asking the woman and her family whether they have any final questions. Finally, it is important to propose a follow-up appointment to review the situation, address new concerns and questions and to reinforce a commitment to continuity of care.

A summary of the consultation should be documented in the patient's medical record. In addition, members of the woman's broader treatment team, especially, palliative care health professionals, general practitioner and community nurse should be informed about the discussion and perceptions of the person's understanding. This is likely to facilitate the provision of optimal health care and strengthen communication both between the woman and her treatment team and within the team itself.

EMOTIONAL IMPACT ON HEALTH PROFESSIONALS

Health professionals generally find it very difficult to introduce the topic of palliative care. Over 40% of oncologists from western countries reported that they "occasionally" to "almost always" withheld prognosis from patients¹². Over half said that they "occasionally" or "frequently" used euphemisms in discussing a grave prognosis, in order to maintain hope; and around a quarter said that they "occasionally" administered a treatment that was not likely to work, in order to bolster the patient's hope. In comparison to other communication tasks, oncologists tend to feel less confident about "telling patients you are replacing active therapy with symptomatic care only"⁶⁹. Health professionals also find it difficult to respond to patient emotions. Non-disclosure of feelings by terminally ill patients has been shown to be positively related to blocking behaviours among hospice nurses, while nurses who perceived that their supervisors were supportive of them engaged in less blocking behaviour⁷⁰. A number of blocking techniques can be used to limit emotional disclosure. These include directing the conversation to focus on medical issues⁷¹; changing the topic⁷²; offering reassurance without exploring the issue⁷³ and ignoring emotional cues by the patient⁷⁴.

The stress experienced by health professionals involved in the care of the seriously ill and dying has been increasingly recognised. Not only does the health professional have to deal with patients' emotions and concerns but potentially their own feelings of failure,

helplessness and frustration arising from advancing illness⁷⁵, which may be compounded by stresses in their private lives⁷⁶. Approximately one third of oncologists report high levels of emotional exhaustion⁷⁷. Burnout amongst oncologists has been found to be associated with a negative attitude towards, and low personal involvement in the organisation or the provision of palliative care for seriously ill patients⁷⁸. Levels of stress experiences by palliative care workers has been found to be lower when the staff have particular personality characteristics, such as high self-esteem and hardiness, have adequate social support, they are actively involved in work-related decision-making and they have a realistic work load^{79,80}. To prevent burnout, it is recommended that health professionals should take an active role in caring for themselves by increasing self-awareness and recognising emotional exhaustion early and taking action^{75, 76}. Various mechanisms have been proposed to manage work related stress. These include: sharing concerns with colleagues and developing strong collaborative team relationships, setting realistic work goals, developing a personal philosophy of illness and death, maintaining a balance between one's personal and professional lives, and engaging in good health habits including diet, exercise and rest⁸⁰. Communication skills training is also recognised as one of the effective mechanisms for addressing this issue^{76,81}.

CONCLUSIONS

The formal introduction of palliative care services is clearly a deeply distressing time for a woman with advanced breast cancer and her significant others. With skill and perceptive sensitivity, the anguish associated with this transition can be eased.

REFERENCES

1. Chochinov HM, Tataryn DJ, Wilson KG, Enns M, Lander S. Prognostic Awareness and the Terminally Ill. *Psychosomatics* 41 (6): 500-504, 2000.
2. McIlmurray, MB, Thomas, C, Francis, B, Morris, S, Soothill, K, Al-Hamad, A. The psychosocial needs of cancer patients: findings from an observational study. *European Journal of Cancer Care* 10: 261-269, 2001.
3. National Health and Medical Research Council *A guide to the development, implementation and evaluation of clinical practice guidelines*. Canberra: Australian Government Publishing Service, 1999.
4. World Health Organisation National Cancer Control Programmes: policies and managerial guidelines. Geneva: WHO 2002 <http://www.who.int/cancer/media/en/408.pdf>. Retrieved 19 Nov 2003-12-11
5. Hearn J, Higginson IJ. Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliative Medicine* 12: 317-332, 1998.
6. Brescia FJ., Adler D., Gray G. *et al* Hospitalised advanced cancer patients: a profile, *Journal of Pain Symptom Management* 5: 221-227, 1990.
7. Woodruff R. *Palliative Medicine*. Oxford University Press, 1999.
8. Chochinov HM. Dignity-Conserving Care – A New Model for Palliative Care: Helping the Patient Feel Valued. *Journal of the American Medical Association* 287 (17): 2253-2260, 2002.
9. Hall A, Fallowfield LJ, A'Hern RP. When breast cancer recurs: A 3 year prospective study of psychological morbidity. *The Breast Journal* 2(3):197-203, 1996.
10. Roberts CS, Cox E, Reintgen DS, Baile WF, Gibertini M. Influence of Physician Communication on Newly Diagnosed Breast Patients' Psychologic Adjustment and Decision-making. *Cancer Supplementary*74 (1): 336-341, 1994.
11. Turner, J, Kelly, B, Swanson, C, Allison, R, Wetzig, N. Psychosocial impact of newly diagnosed advanced breast cancer. *Psycho-Oncology* (in press)
12. Baile WF, Lenzi R, Parker PA, Buckman R, Cohen L. Oncologists' Attitudes Toward and Practices in Giving Bad News: An Exploratory Study. *Journal of Clinical Oncology* 20 (8): 2189-2196, 2002.
13. Coates A, Hurny C, Peterson H, Bernhard J, Castiglione-Gertsch M, Gelber R, Goldhirsch A. Quality-of-Life Scores Predict Outcome in Metastatic but Not Early Breast Cancer. *Journal of Clinical Oncology* 18 (22): 3768-3774, 2000.
14. National Breast Cancer Centre and National Cancer Control Initiative. 2003. *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, NSW.
15. Ashby MA, Kissane DW, Beadle GF, Rodger A. Psychosocial support, treatment of metastatic disease and palliative care. *Medical Journal of Australia* 164: 43-49, 1996.
16. Curt GA, Breitbart W, Cella D, Groopman JE, Horning SJ, Itri LM, Johnson DH, Miakoski C, Scherr SL, Portenoy RK, Vogelzand NJ. Impact on Cancer-Related Fatigue on the Lives of Patients: New Findings from the Fatigue Coalition. *The Oncologist* 5: 353-360, 2000.
17. Roth AJ, Breitbart W. Psychiatric emergencies in terminally ill cancer patients. *Pain and Palliative Care* 10 (1): 235-259, 1996.
18. Dudgeon DJ, Lertzman M. Dyspnea in the Advanced Cancer Patient. *Journal of Pain and Symptom Management* 16 (4): 212-219, 1998.
19. Breitbart W. Diagnosis and Management of Delirium in the Terminally Ill. In Bruera E, Portenoy RK, eds. *Topics in Palliative Care*. Vol 5. Oxford University Press, pp. 303-321, 2001.

20. Aranda S, Schofield P, Weih L, Yates P, Milne D, Faulkner R, Voudouris N. Mapping the quality of life and unmet needs of urban women with metastatic breast cancer. *European Journal of Cancer Care* (submitted Nov 2003).
21. National Breast Cancer Centre. *Clinical Practice Guidelines for Management of Advanced Breast Cancer* Camperdown: National Breast Cancer Centre 2001.
22. Hanson Frost M, Suman VJ, Rummans TA, Dose AM, Taylor M, Novotny P, Johnson R, Evans RE. Physical, psychological and social well-being of women with breast cancer: the influence of disease phase. *Psycho-Oncology* 9: 221-231, 2000.
23. Cristine M, Crooks D, Grunfeld E, Stonebridge C, Christie A. Caregiving for women with advanced breast cancer. *Psycho-oncology* 12: 709-719, 2003.
24. National Breast Cancer Centre. *Needs of children of mothers with advanced breast cancer*. National Health & Medical Research Council (NHMRC) National Breast Cancer Centre (NBCC), 1997.
25. Palliative Care Australia *Standards for palliative care provisions* (2nd Ed) Yarralumla: 1998.
26. Kissane DW, Clarke DM, Street AF. Demoralization Syndrome – a Relevant Psychiatric Diagnosis for Palliative Care. *Journal of Palliative Care* 17 (1): 12-21, 2001.
27. Weissman DE, Griffie J. The Palliative Care Consultation Service of the Medical College of Wisconsin. *Journal of Pain and Symptom Management* 9 (7): 474-479, 1994.
28. Lowden B. Introducing palliative care: health professionals' perceptions. *International Journal of Palliative Nursing* 4 (3): 135-142, 1998.
29. Baile WF, Gloger GA, Lenzi R, Beale EA, Kudelka AP. Discussing Disease Progression and End-of-Life Decisions. *Oncology* 13 (7): 1021-1035, 1999.
30. Hagerty, RG, Butow, Pn, Ellis, PA, Lobb, EA, Pendlebury, S, Leighl, N, Goldstein, D, Lo, SK, Tattersall, MHN. Cancer patient preferences for communication of prognosis in the metastatic setting. *Journal of Clinical Oncology* 22(9): 1721-1729, 2004.
31. Butow PN, Kazemi JN, Beeney LJ, Griffin A-M, Dunn SM, Tattersall MHN. When the diagnosis is cancer: Patient communication experiences and preferences. *Cancer* 77:2630-7, 1996.
32. Schofield PE, Beeney LJ, Thompson JF, Butow PN, Tattersall MHN, Dunn SM. Hearing the bad news of a cancer diagnosis: The Australian melanoma patient's perspective. *Annals of Oncology* 12: 365-371, 2001.
33. Ptacek JT, Eberhardt TL. Breaking bad news: A review of the literature. *The Journal of the American Medical Association* 276 (6): 496-502, 1996.
34. Schofield PE, Butow PN, Thompson JF, Tattersall MHN, Beeney LJ, Dunn SM. Psychological responses of patients receiving a diagnosis of cancer. *Annals of Oncology* 14: 48-56, 2003.
35. Roter, D. Patient participation in the patient-provider interaction: The effects of patient question asking on the quality of the interaction, satisfaction and compliance. *Health Education Monographs* 5(4): 281-315, 1977.
36. McClement SE, Hack TF. Audio-taping the oncology treatment consultation: a literature review. *Patient Education and Counselling* 36: 229-238, 1999.
37. McHugh P, Lewis S, Ford S, Newlands E, Rusting G, Coombes C, Smith D, O'Reilly S, Fallowfield L. The efficacy of audiotapes in promoting psychological well-being in cancer patients: a randomised, controlled trial. *British Journal of Cancer* 71: 388-392, 1995.
38. Lo B, Quill T, Tulksy J. Discussing Palliative Care with Patients. *Annals of Internal Medicine* 130 (9): 744-749, 1999.
39. Kissane D, Yates P. *Psychological and existential distress*. In M. O'Connor & S. Aranda (eds). *Palliative Care Nursing: A guide to practice* (2nd Edition). Ausmed Publications: Australia, 2003.

40. Cox A, Holbrook D, Ruter M. Psychiatric interviewing techniques VI. Experimental study: Eliciting feelings. *British Journal of Psychiatry* 139: 144-152, 1981.
41. Fallowfield L, Ford S, Lewis S. No news is not good news: information preferences of patient with cancer. *Psycho-Oncology* 4: 197-202, 1995.
42. Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. *Palliative Medicine* 16: 297-303, 2002.
43. Quirt C, Mackillop W, Ginsburg A, Sheldon L, Brundage M, Dixon P, Ginsburg L. Do doctors know when their patients don't? A Survey of doctor-patient communication in lung cancer. *Lung Cancer* 18: 1-20, 1997.
44. Sapir R, Catane R, Kaufman B, Isacson R, Segal A, Wein S, Cherny NI. Cancer patients expectations of and communication with oncologists and oncology nurses: the experience of an integrated oncology and palliative care service. *Support Care Cancer* 8: 458-463, 2000.
45. Chan A, Woodruff R. Communicating with Patients with Advanced Cancer. *Journal of Palliative Care* 13 (3): 29-33, 1997.
46. Weeks JC, Cook, EF, O'Day SJ, Peterson LM, Wenger N, Reding D, Harrell FE, Kussin P, Dawson NV, Connors Jr AF, Lynn J, Phillips RS. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *The Journal of the American Medical Association* 279 (21): 1709, 1998.
47. Fried TR, Bradley EH, O'Leary J. Prognosis Communication in Serious Illness: Perceptions of Older Patients, Caregivers, and Clinicians. *Prognosis Communication* 51 (10): 1398-1403, 2003.
48. Lamont EB, Christakis NA. Prognostic Disclosure to Patients with Cancer near the End of life. *Annals of Internal Medicine* 134 (12): 1096-1105, 2001.
49. Tattersall MH, Gattellari M, Voigt K, Butow P. When the treatment goal is not cure: are patients informed adequately? *Support Care Cancer* 10: 314-321, 2002.
50. Chapman K, Abraham C, Jenkins V, Fallowfield L. Lay understanding of terms used in cancer consultations. *Psycho-Oncology* 12: 557-566, 2003.
51. Friedrichsen MJ, Strang PM, Carlsson ME. Breaking bad news in the transition from curative to palliative cancer care – patient's view of the doctor giving the information. *Support Care Cancer* 8: 472-478, 2000.
52. McArdle JM, George WD, McArdle CS, Smith DC, Moodie AR, Hughson AVM, Murray GD. Psychological support for patients undergoing breast cancer surgery: a randomised study. *British Medical Journal* 312: 813-816, 1996.
53. Ryan H, Schofield P, Cockburn J, Butow P, Girgis A, Tattersall M, Turner J, Bandaranayake D, Bowman D. How to recognise psychological distress in cancer patients. *European Journal of Cancer Care* (in press).
54. Lilly CM, De Meo DL, Sonna LA, Haley KJ, Massaro AF, Wallace RF, Cody S. An Intensive Communication Intervention for the Critically Ill. *The American Journal of Medicine* 109 (6): 469-475, 2000.
55. Butow PN, Dowsett S, Hagerty R, Tattersall MHN. Communicating prognosis to patients with metastatic disease: what do they really want to know? *Supportive Care in Cancer* 10(2): 161-8, 2001.
56. Sardell AN, Trierweiler SJ. Disclosing the Cancer Diagnosis. Procedures that Influence Patient Hopefulness. *Cancer* 72 (11): 3355-3365, 1993.
57. Snyder CR, Simpson SC, Ybasco FC, Borders TF, Babyak MA, Higgins RL. Development and validation of the state hope scale. *Journal of Personality and Social Psychology* 70(2): 321-335, 1996.
58. Nunn K. Personal hopefulness: A conceptual review of the relevance of the perceived future to psychiatry. *British Journal of Medical Psychology* 69: 227-245, 1996.

59. The A, Hak R, Koeter G, Van der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *British Medical Journal* 321 (7273): 1376-1381, 2000.
60. Links M, Kramer J. Breaking bad news: realistic versus unrealistic hopes. *Support Care Cancer* 2: 91-93, 1994.
61. Hudson P, Aranda S, McMurray N. Intervention development for enhanced lay palliative caregiver support – the use of focus groups. *European Journal of Cancer Care* 11: 262-270, 2002.
62. Harrington V, Lackey NR, Gates MF. Needs of caregivers of clinic and hospice cancer patients. *Cancer Nursing* 19 (2): 118-125, 1996.
63. Rose KE. A qualitative analysis of the information needs of informal carers of terminally ill cancer patients. *Journal of Clinical Nursing* 8: 81-88, 1999.
64. Hudson P, Aranda S, Kristjanson LJ. Supportive information provision for palliative care families: moving toward evidenced based practice. *European Journal of Palliative Care* (in press).
65. Bruera E, Newmann CM, Mazzocato C, Stiefel F, Sala R. Attitudes and belief of palliative care physicians regarding communication with terminally ill cancer patients. *Palliative Medicine* 14: 287-298, 2000.
66. Huang X, Butow P, Meiser B, Goldstein D. Attitudes and information needs of Chinese migrant cancer patients and their relatives. *Australian and New Zealand Journal of Medicine* 29: 207-213, 1999.
67. Lickiss JN. Approaching death in multicultural Australia. *Medical Journal of Australia* 179: S14-S16, 2003.
68. Sheard T, Maguire P. The effect of psychological interventions on anxiety and depression in cancer patients: results of two meta-analyses. *British Journal of Cancer* 80 (11): 1770-1780, 1999.
69. Fallowfield L, Lipkin M, Hall A. Teaching Senior Oncologist Communication Skills: Results From Phase I of a Comprehensive Longitudinal Program in the United Kingdom. *Journal of Clinical Oncology* 16 (5): 1961-1968, 1998.
70. Booth K, Maguire PM, Butterworth T, Hillier VF. Perceived professional support and the use of blocking behaviours by hospice nurses. *Journal of Advanced Nursing* 24: 522-527, 1996.
71. Roter, D.L., et al., Communication patterns of primary care physicians. *The Journal of the American Medical Association* 277(4): p. 350-5, 1997.
72. Maguire, P. and C. Pitceathly, Key communication skills and how to acquire them. *British Medical Journal* 325: 697-700, 2002.
73. Maguire, P., Improving the detection of psychiatric problems in cancer patients. *Social Science & Medicine* 20 (8): 819-823, 1985.
74. Butow, P.N., et al., Oncologists' reactions to cancer patients' verbal cues. *Psycho-oncology* 11(1): 47-58, 2002.
75. Meier DE, Back AL, Morrison S. The inner life of physicians and care of the seriously ill. *The Journal of the American Medical Association* 286: 3007-3014, 2001.
76. Turner J, Kelly B. *The concept of debriefing and its application to staff dealing with life-threatening illnesses such as cancer, AIDS and other conditions*. In B. Raphael & JP. Wilson. (2000). Psychological Debriefing: Theory, practice and evidence. Cambridge University Press: UK.
77. Ramirez AJ, Graham J, Richards MA, Cull A, Gregory WM. Mental health of hospital consultants: the effects of stress and satisfaction at work. *The Lancet* 347: 724-728, 1996.
78. Cherny NI, Catane R. Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer. Published online 16 October 2003 in Wiley InterScience (www.interscience.wiley.com) The American Cancer Society. (2003)
79. Vachon ML. Staff stress in hospice/palliative care: a review. *Palliative Medicine* 9(2):91-122, 1995.

80. Vachon ML. Caring for the caregiver in oncology and palliative care. *Seminars in Oncology Nursing* 14(2):152-7, 1998.

81. Gordon GH. Care not cure: dialogues at the transition. *Patient Education and Counselling* 50: 95-98,2003.