TRANSLATING PSYCHOSOCIAL CARE: GUIDELINES INTO ACTION

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Abstract

Clinical practice guidelines for the management of psychosocial distress in people with cancer have been produced in Australia and North America and these provide a framework for the provision of psychosocial care for patients with cancer and their families. However, psychosocial care is not yet a routine part of oncology care and within the psychooncology literature there is little practical advice about the best way to achieve this. This article describes a community-based approach to this challenge that builds on existing resources and responds to the concerns of those working in the field. It is proposed that this approach provides a way forward in translating evidence-based psychosocial care practice guidelines into routine oncology care.

The diagnosis and subsequent treatment of cancer is a major life stress that is followed by a range of well described psychological, social, physical and spiritual difficulties. Further, the overall experience of cancer can be seen as a series of stressful events as the person moves through the illness continuum from diagnosis, to treatment and rehabilitation or palliation. Responsive and well targeted psychosocial care is essential to assist people coping with cancer and their families to successfully negotiate and manage these events and to be well prepared and supported for any future health threats. Thus, psychosocial care services need to be responsive across the illness experience and accessible beyond the acute treatment setting.

In response to the increasing recognition of psychosocial care as an integral part of best practice oncology care, various groups in North America and Australia have developed clinical practice guidelines for such care.7-10 While these guidelines are an important step in placing the issue of psychosocial care clearly on the clinical agenda, a number of challenges remain to the implementation of such guidelines, not the least of which is a lack of awareness of the existence of the guidelines among health professionals. A number of explanations have been proposed to explain the lack of integration of psychosocial services into routine care for patients with cancer. First, clinicians tend to overlook psychosocial needs, such that many distressed patients remain unidentified, with few referred for counselling or support. 11-13 Second, patients' desire for support has been found to not correlate to their levels of psychological distress.¹⁴ Thus, relying on patients to self-refer is likely to leave many high distress patients unidentified and unassisted. Third, psychooncology is often under-funded within the acute health care system and this further limits patients' access.15 Fourth, the move to outpatient care where possible means that patients' interactions with the acute health care system may be more intermittent and less time intensive, thereby potentially limiting opportunities to gain support within this setting.

In this regard, community-based organisations provide

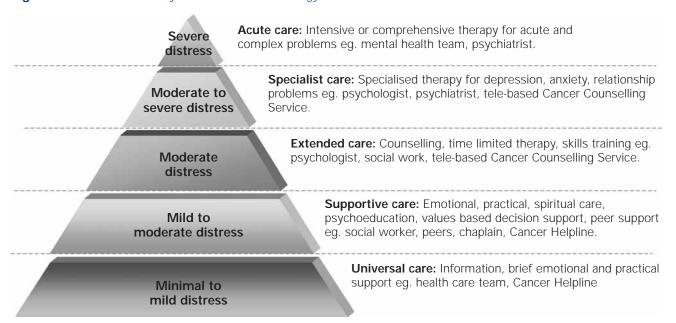
an ideal setting for the dissemination of evidence based practices through the integration of practical experience with science.¹⁶ Accordingly, to address the question of how to best integrate support services in a manner consistent with evidence-based guidelines for psychosocial care we adopted a two pronged approach. First, a triage and stepped care model was developed to provide a systematic method of assessing and referring cancer patients and family members to appropriate psychosocial care services. 17,18 Importantly this model was imprinted on an existing highly successful Cancer Helpline information and support service providing for broad access and community impact. Second, a training package was developed for health professionals that integrated the National Health and Medical Research Council (NHMRC) Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (2003) with a stepped care approach.

Stepped care for people coping with cancer: Queensland Cancer Fund tiered model

Although cancer is a major life stress, over time most people diagnosed with cancer adjust effectively to their changed life circumstances without clinical intervention. However, a significant group (as many as one third) experience heightened distress that persists or even worsens over time. 19 As well, many partners of cancer patients report high levels of distress, sometimes even greater than that of the patients, and for some this distress may persist. 20,21 Thus, it is important to identify those patients and family members experiencing, or at risk of greater distress and refer them to more intensive psychosocial therapies.^{8,22} Within this process it is also important to assess individuals' preferences and supportive care needs and from this systemically refer patients to the type of psychosocial service that would be expected to most closely match their needs. This stepped care approach maximises the effectiveness and efficiency of health services resource allocation.¹⁷

The tiered model of care is a stepped care approach that aims to match the patient's or family member's level of distress and expressed need to an appropriate level of

Figure 1: Tiered Model of Psychosocial Care in Oncology



psychosocial intervention. 18 (see Figure 1) Triage to the appropriate levels of intervention can be undertaken using a range of methods from an in-depth clinical interview to psychometric screening. 22-24 As need or distress increases, the level of care also increases with five levels of care outlined, from universal care for all patients, to acute care for patients with complex needs. On this view, universal care is standard care and should be offered to anyone affected by cancer, both patients and relevant family members. This level of care includes: provision of cancer-related information; brief support from a health care professional in the treatment team and referral to a cancer-related telephone helpline; and information focused interventions such as patient education. Supportive care, the next level in this tiered model, includes services such as: psycho-educational interventions, in either individual or group format; decision support that may be delivered by a Cancer Helpline or other trained health professional; and emotional support provided by a trained peer volunteer or a peer-led support group.

Extended care refers to more focused counselling and active skills training, for example, teaching specific skills such as problem solving or anxiety management. Another component might include structured group therapy facilitated by a trained health professional. Specialist care refers to specialised interventions provided by a health professional with extensive psychosocial training and includes individual or couple therapy for people with mood or anxiety disorders or significant relationship/sexual problems. Finally, acute care is appropriate for complex cases in which extreme distress or multiple problems require acute intervention from, for example, a multidisciplinary mental health team.

These levels of care provide a general guide, but it is of principal importance to listen and respond to what patients say about the level of support they feel they need. There should also be particular awareness of

patients and families that may be predicted to have higher levels of need based on risk factors such as a pre-existing psychiatric disorder, poor social support or advanced disease. The tiered model is based first on the assumption that individuals differ, with regards to both their support needs and the type of services that they would prefer to receive or access. Second, it is assumed that support needs change and differ over time so there is an imperative to check on needs and distress regularly during treatment and follow-up. Finally, it is proposed that health professionals aim to be patient centred, flexible in approach, well connected to psychosocial care referral networks and work within the scope of their clinical practice.

In Queensland, this model has been applied to underpin the integration of Queensland Cancer Fund (QCF) services with other community based and acute services. Queensland has a population of four million in a state close to seven times the geographic size of the United Kingdom, which has a population of approximately 60 million. The Queensland population is concentrated on the eastern seaboard, with 56% of people living outside of the state capital Brisbane and close to 30% living outside of the (relatively) more populous south-east corner. Thus, geographic barriers are a key issue with a need for remote access services. Consistent with this, tele-based services have proven to be highly acceptable to people with cancer in Queensland with the QCF Cancer Helpline receiving over 25,000 patient related calls in 2005, demonstrating a 36% increase in such calls over the past two years. The Cancer Helpline is staffed by health professionals with specialised training in understanding and responding to the psychosocial needs of cancer patients and in decision support and provides universal and supportive care to patients and families at no cost. A database with over 1600 community and acute settings services listed underpins the Cancer Helpline service to support referral to accessible services appropriate to callers' needs.

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As well, triage to a tele-based Cancer Counselling Service staffed by clinical psychologists and masters' trained nurse counsellors is applied to provide extended and specialist care for Helpline clients who have higher levels of distress or expressed need. Triage is undertaken using client interview and a single item verbal screening question assessing global distress. 9,22 Since its inception in May 2004 to November 2005, the Cancer Counselling Service has received over 700 referrals and will extend to provide face-to-face counselling in 2006. Table 1 overviews the pattern of client demographics and presenting problems for this service for the first 12 months of operation. At intake assessment, most clients demonstrated moderate to severe distress (78%), with 9% assessed as having minimal to mild distress and 13% as having severe distress. This data suggests that triage from the Cancer Helpline is effective in appropriately matching client need to the intervention level of the Cancer Counselling Service.

Translating evidence into clinical practice: educating health professionals about psychosocial care

Problematically, although the Cancer Helpline provides a 'no cost' service to the consumer, professional referral to the service remains low with only 5% of callers advising that they received the Helpline contact details from their treating health professional team and most indicating they found the contact details in the telephone directory. These figures are consistent with research showing that many health professionals have a low appreciation of patients' support needs and are infrequent referrers to psychosocial support services. 11-¹³ Clinical practice guidelines aim to address such issues, but unless they are widely disseminated and integrated into practice they will have little influence on health professionals' behaviour. 16 Thus, unless dissemination is paired with practically focused training, efforts to encourage adoption of such practices may be unsuccessful. To address this problem we developed a workshop training program designed increase health professionals' to understanding of the clinical relevance of the NHMRC Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (2003). This training program specifically targeted the following issues: 1) knowledge about the psychosocial support needs of cancer patients and their families; 2) the concept of stepped care as outlined in the tiered care model; 3) knowledge of local psychosocial care referral networks; and 4) attitudes towards integration of psychosocial care into usual practice.

The workshop was designed as a two hour presentation that was jointly delivered in three regional Queensland locations by two of the present authors (JT and SKS). The tiered model of care is overviewed with reference to a number of case study scenarios including patients with different need and distress levels. These scenarios are then linked to relevant sections of the NHMRC guidelines, to illustrate how this document can be practically relevant for individuals' practices.

Table 1: Client demographics and presenting problems for the cancer counselling service

Demographic variable		%
Age	M=50 yrs (range 20 to 85 yrs)	
Gender	Female	80
	Male	20
Geographic residence	Brisbane	46
	Regional	54
Client type	Patient	59
	Family/carer	41
Cancer type	Breast	32
	Colorectal	16
	Lung	10
	Prostate	9
	Brain	7
	Other	26
Presenting problem		%
	Adjustment to cancer	20
	Bereavement	16
	Anxiety	15
	Depression	12
	Family relationships	11
	Other: eg. survivorship,	
	physical symptoms,	27
Note: N. 444	relationship issues	26
Note: N=444.		

Participants' pilot data from the workshops showed a highly positive endorsement of this approach with the tiered model of care viewed as clinically relevant. Follow-up data indicated positive changes in participants' knowledge and attitudes to psychosocial care with a full report currently in preparation. A DVD version of the workshop program is in planning for 2006, as well as further workshop roll-outs in Queensland regional and metropolitan settings.

Conclusion

Cancer has a powerful emotional impact on patients and their families throughout the continuum of diagnosis, treatment and survival, and palliative care. Psychosocial care is integral to quality cancer care. However, psychosocial care should not be a 'one size fits all' service – matching resources and services to the needs of patients and families makes for effective use of resources and is likely to promote optimal adjustment of patients and their families. The dissemination and wide spread adoption of evidence-based public health and clinical programs into action remain an unresolved challenge. The tiered model of care provides a link between evidence based clinical guidelines and actual clinical practice, and between community and acute care settings.

References

- Andersen Bl. A Biobehavioral Model for Psychological Interventions. In: Baum A, Andersen BL, editors. Psychosocial Interventions for Cancer. Washington: American Psychological Association; 2001. p. 119-141.
- Frost MH, Suman VJ, Rummans TA, Dose M. Physical, psychological and social well-being of women with breast cancer: The influence of disease phase. Psycho-Oncology 2000;9:221-231.

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- Kornblith AB. Psychosocial adaptation of cancer survivors. In: Holland JC, editor. Psycho-Oncology. New York: Oxford University Press; 1998. p. 223-254.
- Steginga SK, Occhipinti S, Gardiner RA, Yaxley J, Heathcote P. A Prospective Study of Men's Psychological and Decision-Related Adjustment after Treatment for Localized Prostate Cancer. Urology. 2004;63:751-756.
- Zabora JR, Brintzenhofeszoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. Psycho-Oncology. 2001;10:19-28.
- Smith MY, Redd WH, Peyser C, Vogl D. Post -traumatic stress disorder in cancer: A review. Psycho-oncology. 1999;8:521-537.
- Canadian Association of Psychosocial Oncology. Standards: Canadian Association of Psychosocial Oncology: Canadian Association of Psychosocial Oncology; 1999.
- 8. Carlson LE, Bultz BD. Cancer distress screening: Needs, methods and models. Journal of Psychosomatic Research. 2003;55:403-409.
- National Comprehensive Cancer Network I. Practice Guidelines in Oncology-v.1.2002: Distress Management (Rep. No. Version 1): National Comprehensive Network Inc.; 2002.
- National Breast Cancer Centre, National Cancer Control Initiative. Clinical practice guidelines for the psychosocial care of adults with cancer: National Health and Medical Research Council; 2003.
- Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. British Journal of Cancer. 2001;47:388-399.
- Ford S, Fallowfield L, Lewis S. Can oncologists detect distress in their outpatients and how satisfied are they with their performance during bad news consultations? British Journal of Cancer. 1994;70:767-770.
- Sollner W, De vries A, Steixner E, et al. How successful are oncologists in identifying patients distress, perceived social support, and need for psychosocial counselling? British Journal of Cancer. 2001;84:179-185.
- Sollner W, Maislinger S, Konig A, de Vries A, Lukas P. Providing psychosocial support for breast cancer patients based on screening for distress within a consultant-liaison service. Psycho-Oncology. 2004;13(12):893-897.

- Carlson LE, Bultz BD. Efficacy and medical offset of psychosocial interventions in cancer care: Making the case for economic analyses. Psycho-Oncology 2004;13(12):837-849.
- Kerner J, Rimer B, Emmons K. Dissemination research and research dissemination: How can we close the gap? Health Psychology. 2005;24(5):443-446.
- Haaga DAF. Introduction to the special section on stepped care models in psychotherapy. Journal of Consulting and Clinical Psychology. 2000:68(4):547-548.
- Hutchison S, Steginga SK, Dunn J. The tiered model of psychosocial intervention in cancer: a community based approach. Psycho-Oncology In Press.
- Helgeson V, S, Snyder P, Seltman H. Psychological and physical adjustment to breast cancer over 4 years: Identifying distinct trajectories of change. Health Psychology. 2004;23(1):3-15.
- Cliff AM, Macdonagh RP. Psychosocial morbidity in prostate cancer: II.
 A comparison of patients and partners. British Journal of Urology International 2000;86:834-839.
- 21. Ey S, Compas BE, Epping-Jordan JE, Worsham N. Stress response and psychological adjustment in patients with cancer and their spouses. Journal of Psychosocial Oncology. 1998;16(2):59-77.
- 22. Holland JC. Preliminary guidelines for the treatment of distress. Oncology (Huntington) 1997;11(11A):109-14; discussion 115-7.
- Roth AJ, Kornblith AB, Batel-Copel L, Peabody E, Scher HI, Holland JC. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. Cancer. 1998;82(10):1904-8.
- Zabora JR. Screening procedures for psychosocial distress. In: Holland JC, editor. Psycho-Oncology. Oxford: Oxford University Press; 1998. p. 653-661.
- Andersen BL. Psychological interventions for cancer patients to enhance the quality of life. Journal of Consulting and Clinical Psychology. 1992;60:552-568.