Editorial

The changing landscape of cancer care – the impact of psychosocial clinical practice guidelines[†]

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Abstract

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Received: 19 January 2015 Revised: 20 February 2015 Accepted: 23 February 2015 The International Psycho-Oncology Society (IPOS) has championed the need for quality care to incorporate attention to the psychosocial concerns of cancer patients. Widespread international endorsement of distress as the '6th vital sign' is a major step towards improving access to psychosocial care and reducing the isolation and stigma experienced by many affected by cancer. However, the integration of psychosocial care into routine clinical practice also requires active multidisciplinary engagement, and demonstration that evidence-based psychosocial interventions are effective and feasible to deliver in practice. Clinical practice guidelines are valuable in this context. Typically, they provide a synthesis and evaluation of existing evidence, critically appraised by stakeholders and clinicians, presented in a way which allows for translation of research evidence into practice. Such guidelines are also tools for informing and educating those who do not have psychosocial expertise, potentially increasing the status of psycho-oncology. This paper describes the background to the development of psychosocial clinical practice guidelines in Australia as a means of understanding the factors that can underpin the evolution of attitudes and integration of psychosocial care in oncology, and considers the current status of psychosocial care in Australia and internationally, including challenges for the future. Copyright © 2015 John Wiley & Sons, Ltd.

Historical background to the development of psychosocial clinical practice guidelines in Australia

In 1993, a national inquiry was established by the Australian Government in response to complaints about perceived inequities in the care of women with breast cancer in Australia. The inquiry reported that treatment for many women was indeed fragmented and uncoordinated, and confirmed that women were not uniformly receiving optimal evidence-based care. The report further cited instances of insensitive treatment and lack of compassion, and recommended that women receive multidisciplinary care to optimise the quality of care [1]. A specific recommendation was the inclusion of counselling services as an integral part of the multidisciplinary team: 'When a woman is being treated for breast cancer, there is a real and continuing need for her to be able to communicate freely and frequently with those treating her. The required level and frequency of communication, unfortunately, is rarely available, leaving some women dissatisfied with the advice they have received and feeling that they have not been given enough time and attention' [1, p. 20]. Leading on from this was the further recommendation that there be provision of adequate funding for research to investigate the extent and severity of psychosocial morbidity and ways in which it could be addressed [1].

These recommendations provided the impetus for the National Health and Medical Research Council (NHMRC), the peak scientific body in Australia, to convene a multidisciplinary working group to review evidence about best practice and develop guidelines for clinical practice. The working group used methodology developed by the NHMRC, in particular, systematic reviews of the literature, evaluation and rating of the quality of the evidence, and extensive consultation with clinicians and consumers to ensure that recommendations had clinical relevance and utility, prior to extensive public consultation and appraisal by professional colleges [2]. The inclusion of women diagnosed with breast cancer, consumer advocates and psychosocial researchers and clinicians in the working group meant that information about the psychosocial impact of breast cancer was integrated into the document: Clinical practice guidelines for the management of early breast cancer [3].

In a further response to community concerns about the impact of breast cancer, in 1995, the Australian Government established the National Breast Cancer Centre (NBCC) to ensure that women with breast cancer received adequate psychosocial, physical and practical support through dissemination of evidence about breast cancer. In part, this was to be achieved through dissemination of the previous guidelines, for which a consumer version was also produced. In 1996, the NBCC convened a multidisciplinary group with strong consumer and psychosocial representation to develop clinical practice guidelines for advanced cancer using the previous methodology. This collaborative working environment led to such a cultural shift that the first chapter of the *Clinical practice guidelines for the management of advanced cancer* [4] provides only a brief overview of the prevalence of advanced cancer, and chapter 2 is dedicated to detailed discussion of quality of life and psychosocial issues, the impact on children and the emotional dimensions for health professionals, subsequent chapters describing clinical treatments.

Another NBCC working group, the Psychosocial Expert Advisory Group, commissioned several systematic literature reviews to more clearly define the extent of the emotional impact of breast cancer and ways in which this burden could be reduced. On the basis of the methodology described earlier [2], this group developed *Psychosocial* clinical practice guidelines: information, support and counselling for women with breast cancer, released in 2000 [5]. Recognition that many of the themes discussed in these guidelines were relevant across other tumour streams led to collaboration between the NBCC and the National Cancer Control Initiative to form a working group charged with developing 'generic' guidelines, Clinical practice guidelines for the psychosocial care of adults with cancer [Psychosocial Clinical Practice Guidelines (PCPG)] [6] launched in 2003.

Scope and content of the Psychosocial Clinical Practice Guidelines (PCPG)

Other guidelines for psychosocial care had already been produced prior to the launch of the PCPG. For example, in the USA, the National Comprehensive Cancer Network had produced guidelines for the identification and management of distress in 1997. A particular strength of these guidelines is the clarity of algorithms for clinical practice and regular updating, the latest version published in 2013 [7]. Clinical practice guidelines have also been developed in Canada and other countries.

The focus of the PCPG is somewhat different from other clinical practice guidelines in that the target audience is all members of the treatment team. The PCPG provide an overview of the emotional impact of cancer, including discussion of the interaction of physical, practical and social concerns on adjustment, designed to enhance awareness and understanding of non-experts in psycho-oncology. The PCPG highlight that the approach to provision of psychosocial support for patients with cancer is not 'one size fits all'. Consistent with the tiered model of care [8], the guidelines allude to the importance of provision of information and empathic engagement as essential components of quality care for all patients, with fewer patients requiring more specialised intervention. A key strength is inclusion of detailed practical information and evidence-based recommendations to assist oncology health professionals to confidently provide information, discuss prognosis, discuss treatment options, explore attitudes and beliefs about decision-making, and prepare patients for potentially threatening procedures and treatments. Prompts are also included to assist clinicians in preparing patients for transition from curative to palliative aims of treatment.

Whilst psychologists, social workers and other trained professionals have established skills in exploring psychosocial concerns, this is typically unfamiliar for oncologists or surgeons. Hence, examples are provided of ways to open discussion and explore concerns including practical, emotional, existential, body image and sexuality and interpersonal difficulties. Recommendations about ways of exploring depression and anxiety and risk of harm including suicidal thoughts, and details about evidence-based treatments, are also provided. This information is provided with the aim of increasing confidence of clinicians about the benefits of expert psychosocial treatment. In addition, details are provided about initiating discussion of referral for psychosocial care, a subject which may pose concern because of perceived stigma.

The PCPG were promoted nationally through a series of workshops in which local champions and consumers participated in discussion about the clinical application of the guidelines. Supporting resources included a template for documentation of identified risk factors for experiencing distress [9], a summary card [10] and a consumer version, *Cancer: how are you travelling?* [11], which was launched in 2007 with the aim of reducing stigma and enhancing mental health literacy in relation to psychosocial issues affecting patients with cancer and their families.

The changed landscape

The precise impact of the PCPG is difficult to assess; however, the landscape in Australia is now markedly different in terms of awareness of psychosocial aspects of cancer. For example, the PCPG recommendation that all patients can be assisted through good communication skills of all members of the treatment team is now widely accepted. Reliance on grants and opportunistic programmes to provide communication skills training is not sustainable, and an embedded approach through accreditation standards is advocated [12]. This has been achieved in part in Australia with the Royal Australasian College of Surgeons and Royal Australasian College of Physicians mandating that trainees in breast surgery and medical oncology, respectively, participate in communication skills training prior to obtaining their specialist qualification. These initiatives arose in direct response to the leadership of the NBCC that established a national communication skills training strategy through which evidence-based communication skills training modules were developed.

Increasing capacity and sustainability of communication skills training can be achieved with a train-the-trainer model that also has potential to improve geographic reach. In Queensland, we have trained 32 allied health professionals to facilitate communication skills training, and to date, these facilitators have delivered day-long training to over 340 health professionals across the state (which is seven times the size of the UK and two and one half times the size of Texas in the USA) focused on identifying and responding to emotional cues, one of the communication skills modules developed by the NBCC. A critical factor affecting the success of this programme has been provision of mentorship for the newly trained facilitators and co-facilitation as necessary.

Further progress in terms of standards is evident in education standards for oncology nurses and policy documents. The National Performance Development Framework for cancer nursing lists performance criteria that include 'routine assessment of psychosocial risk factors and distress' [13]. In 2011, the NBCC merged with Cancer Australia that had been established by the Australian Government in 2006. Cancer Australia is now the lead cancer control agency in Australia, and it aims to ensure that evidence informs cancer prevention, screening, diagnosis and supportive care. Cancer Australia has taken a leadership role in promotion of multidisciplinary care and psychosocial support. For example, a recent publication about care for patients with lung cancer emphasised the importance of 'promotion of psychosocial care as "everyone's business" with inclusion of specific questions about supportive care needs included in standard patient consultations' [14, p. 30].

There is an inclusive approach for clinical practice guidelines in oncology in Australia, *all* of which include psychosocial components. For example, *Clinical practice guidelines for the management of adult gliomas* has a whole chapter dedicated to psychosocial care [15]. The extent of this multidisciplinary and collaborative engagement is in no small way related to the foundations laid with the first NHMRC clinical practice guidelines and the NBCC policy of facilitation and engagement of consumers and all health professionals involved in cancer care.

Enablers

One significant enabler in Australia is the Clinical Oncology Society of Australia (COSA), perhaps a unique professional body that is multidisciplinary in composition. The 14th World Congress of IPOS in Brisbane in 2012 held in conjunction with the Annual Scientific Meeting of COSA demonstrated the benefits of multidisciplinary engagement in which cancer care encompasses both mental and physical health [16].

Stigma and misperceptions about depression and other conditions have posed critical barriers to acceptance of psychosocial care, and in Australia, there have been changes in attitudes and beliefs, attributed in part at least to beyondblue. This not-for-profit organisation was established in Australia in October 2000 to create a community response to depression, in particular, to increase understanding in the wider community. Changes in attitudes may relate to factors in addition to the media and information initiatives of *beyondblue*; however, it is striking that a survey in 2011 found that 20.1% of respondents in the community considered antidepressants to be harmful for people with depression, compared with 41.8% in 1995 [17]. Beyondblue has collaborated with organisations and foundations representing people affected by cancers such as breast, prostate cancer and brain tumours to produce information booklets providing information about the development of depression and evidence-based treatments [18].

Challenges

Barriers to the provision of psychosocial care for adults with cancer exist on many levels including lack of access to appropriately qualified health professionals [19]. An Australian survey of 26 clinical services found that 58% could offer only limited (27%) or very limited (31%) psychosocial services [20]. Hence, building capacity and improving access in psycho-oncology are critical issues. Enhancing the skills of front-line health professionals to provide psychosocial care is one means of improving capacity. An educational initiative to enhance the skills and confidence of oncology nurses in focused areas such as providing information and support for parents with advanced cancer about talking with their children has been demonstrated to be successful [21]. More recent studies are examining models of systematic screening and referral for focused psychosocial interventions [22,23], similar to work in the UK in which oncology nurses have provided treatment for depressed cancer patients [24]. However, these trained health professionals typically are based in metropolitan settings. The difficulty of providing timely high-quality psychosocial care for those who live in rural and remote areas is considerable and is not confined to Australia. Innovations include web-streaming educational initiatives and rurally delivered workshops to build health professional skills and confidence and tele-based health consultations [25]. A recent study has demonstrated the feasibility and acceptability of a phone-delivered lowintensity psychosocial intervention [26].

Some cancers are associated with increased risk of experiencing psychological distress, especially those with poor prognosis and high disease burden [27]. Perhaps to be added to this list is those cancers which might have been prevented. For example, exposure to sunlight is a known risk factor for the development of melanoma that poses a major challenge in Australia. Melanoma is the most common cancer in those aged 15 to 39 years in

Australia and the cancer most likely to lead to mortality in the 20- to 34-year age group [28]. This population is at increased risk of experiencing distress because of their young age, the incongruity of the diagnosis given their social and occupational roles, and the fact that this may have been prevented through limitation to sun exposure. Asbestos-related cancers also pose a high psychosocial burden not only because of prognosis but also because of issues of blame and compensation. The UK, France and the USA have all had high use of asbestos, but per capita of population, Australia has had the highest use of asbestos [29]. The so-called first wave (those exposed through mining and manufacturing) and second wave (those who used asbestos in industry) appear to be followed by a third wave - those who have been engaged in home renovation and maintenance without adequate protection [30]. These cancers are likely to pose ongoing challenges for provision of psychosocial care.

One of the most basic barriers to provision of psychosocial care is limited access to health insurance. In Australia, a government-funded scheme exists to provide improved access to subsidised treatment by psychologists in the community for patients diagnosed with depression; however, it is unclear about the extent to which this is used.

Maintaining currency and new initiatives

Whilst emerging evidence about specific psychosocial interventions is exciting for our field, it poses a challenge in terms of maintaining currency of clinical practice guidelines. The approach adopted by Cancer Australia has been to convene multidisciplinary expert groups to identify key topics in which new evidence has emerged for which evidence-based recommendations could be developed to supplement rather than replace existing clinical practice guidelines. In 2011, a working group reviewed the PCPG and determined that themes of suffering and fear of recurrence were clinically important areas not addressed in the guidelines and for which some evidence was now available. These topics have been the focus of critical review of the literature and development of clinical guidance that has been revised and adapted in response to public and professional consultation.

As emerging topics, it is important to note that the expert working groups determined that there was insufficient evidence to develop clinical practice guidelines and hence use of the term 'guidance'. The *Recommendations for the identification and management of fear of recurrence in adult cancer survivors* provides an overview of research in this area, the clinical relevance and emerging data about those who may be at increased risk and interventions [31]. A current randomised controlled trial in Australia is examining a manual-based intervention for clinically significant fear of cancer recurrence based on the Self-Regulatory Executive Functional Model and Relational

Frame Theory [32]. The *Clinical guidance for responding to suffering in adults with cancer* dispels the common misperception that suffering is confined to the end of life and describes the many manifestations of suffering in the clinical setting. Clinical vignettes highlight issues, and these are supported by prompts and examples of ways conversations can be initiated, in recognition that this is an area in which clinicians may lack familiarity and confidence [33].

Another initiative is a project devised by the Psychooncology Cooperative Research Group to develop guidance about screening and referral pathways for patients with depression and anxiety.

Development of standards and evaluation of impact

IPOS has promoted the integration of psychosocial care into routine cancer care, advocating for endorsement at a systems level, education of the profession and broader community, adoption of distress screening and provision of psychosocial services that are evidence-based [34]. High-level reports including from the Institute of Medicine and the National Institute for Clinical Excellence have defined standards and promoted the fundamental importance of systematic psychological assessment at key points as well as access to appropriate psychosocial support [35,36]. The Canadian Association of Psychosocial Oncology has established standards of care that include attention to clinical services, organisational standards, education, and the importance of integration across all phases including prevention and survivorship [37]. In Australia, national consensus on approaches to systematic identification of distress and referral pathways remains to be developed.

Evaluation of the extent of implementation of clinical practice guidelines and detection of change in clinical practice is complex. Tools have been developed to assist clinical services to identify and remediate gaps in their services [38], and these are likely to be particularly valuable in monitoring progress over time. The 'big picture' is critical; however, it is vital to not overlook the attitudes of individual practitioners and the status they accord psychosocial care. For example, oncology nurses describe a traditional focus on performing tasks in which 'just being' and providing emotional support may be seen as less valuable [39]. Hence, the culture of the workplace and attitudes of those in positions of authority is critical as these are seen to influence adoption of specific measures [40]. Thus, a system-wide approach to psychosocial care is important, particularly for implementation of initiatives such as screening for distress [41]. Provision of feedback about performance may lead to improvements in screening for distress, although it is not certain that this will also translate into improved delivery of psychosocial care [42].

Conclusion and recommendations

Although many clinical practice guidelines have been developed, in many countries psycho-oncology is only now emerging as a discipline and there is limited local access to integrated care [43]. A particular strength of the *Clinical practice guidelines for the psychosocial care of adults with cancer* (PCPG) is the clear presentation of evidence supporting recommendations and documentation of the methodology for guideline development – factors critical in determining integrity of clinical practice guidelines [44]. The *Clinical practice guidelines for the psychosocial care of adults with cancer* and supporting resources are practical, freely available and likely to be of benefit for developing services. The historical background

to the development of clinical practice guidelines in Australia has been provided to highlight the importance of multidisciplinary engagement and collaboration with consumers as this can shape cultural attitudes and establish an inclusive approach to psychosocial care. IPOS has recently established a Task Force on Clinical Practice Guidelines, and this will provide a clearinghouse to assist services and health professionals to obtain information about existing clinical practice guidelines and a forum for the clarification of methodology for development of new guidelines and strategies to implement these. The engagement of IPOS with WHO and Union for International Cancer Control will be an important step to assist with global implementation.

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