

- and consumers. Australian Commission on Safety and Quality in Health Care, Sydney, 2010.
26. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. Australian Commission on Safety and Quality in Health Care, Sydney, 2011.
27. Clinical Excellence Commission. The Patient Based Care Challenge. CEC, Sydney, 2010.
28. Luxford K. The forgotten tenet: client focus and quality improvement in health care. *Building Quality In Health Care*. 2010;4(2):10-12.
29. Hall TL. More than the sum of our parts. *Med J Aust*. 2012;197(9):522-523.

PSYCHOSOCIAL ASPECTS OF DELIVERING CANCER CARE: AN UPDATE

Phyllis Butow,¹ Afaf Girgis,² Penelope Schofield.³

1. Psycho-Oncology Co-operative Research Group and Centre for Medical Psychology and Evidence-based Decision-Making, School of Psychology, University of Sydney NSW, Camperdown, New South Wales.
2. Department of Nursing and Supportive Care Research, Peter MacCallum Cancer Centre, Victoria, Australia, and Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Victoria, Australia.
3. Ingham Institute for Applied Medical Research, South Western Sydney Clinical School, University of New South Wales, NSW, Australia
- Email: phyllis.butow@sydney.edu.au

Abstract

Cancer patients face psychological and physical challenges after diagnosis, and can benefit greatly from appropriate psychosocial care. This paper presents a brief history of psychosocial oncology care and recent developments in Australia. Consumers, doctors, nurses, allied health and psychosocial health professionals have all played an important role in this area. Some highlights include: the Australian psychosocial clinical practice guidelines; the development of key patient reported outcome measures; documentation of stress and burnout in oncology health professionals; the development and evaluation of communication resources; a recent focus on survivorship; and a growing body of intervention research which is aiming to be clinically feasible and implementable. The Clinical Oncological Society of Australia hosted the first psycho-oncology professional group in Australia, supporting the development of psychosocial guidelines for adolescents and young adults and undertaking key work in survivorship and rural issues.

Cancer patients face practical, emotional and psychological demands in addition to the physical effects of their disease and treatment. Challenges include existential fears following diagnosis with a life-threatening disease, treatment decision dilemmas, pain, discomfort and functional impairment associated with the disease and its treatment, and body image changes associated with cancer treatment. A cancer diagnosis can impact on patients' physical and psychological health, sexuality, finances, relationships and ability to continue in roles at home and work.¹ Further, the disease affects not only the patients, but their families and carers, who can experience as much or greater distress as the patient themselves.²

The number of people diagnosed with cancer in Australia is set to increase from just over 100,000 per annum in 2012 to 150,000 by 2020. Efficient, effective and clinically feasible supportive care interventions are required to both reduce morbidity in this growing population, as well as assist in preventing the high rate of burnout reported by front-line oncology staff.³ This article will present a brief history of psychosocial oncology care in Australia and describe recent developments within the field, highlighting Australian achievements, and the important role that

the Clinical Oncological Society of Australia (COSA) has played.

Establishing psycho-oncology

Psychosocial care is broadly provided in Australia by specialist psychosocial staff (psychiatrists, psychologists and social workers), as well as front-line medical, allied health and nursing staff in oncology and palliative care. While social work has had a significant and ongoing role in oncology since the beginning of the 20th century,⁴ psycho-oncology is a relatively young discipline internationally, emerging only 40 years ago in Europe and the US. In Australia, the first psycho-oncology clinical interest group was formed under the auspices of COSA in 1996 by Stewart Dunn, becoming an incorporated society (OzPos) in 2008. Psychosocial research began in 1986 within the state Cancer Councils' behavioural research units, and has matured with the emergence in 2004 of the Psycho-Oncology Co-operative Research Group (PoCoG), one of the 14 national cancer clinical trial groups funded by Cancer Australia, coming together under the umbrella of COSA.

Consumers have walked hand in hand with Australian cancer researchers to advance the field of psycho-oncology

since the establishment of the first national breast cancer consumer group in 1996-97, now known as the Breast Cancer Network of Australia. The National Breast Cancer Centre (now auspiced under Cancer Australia) – led the first consumer advocacy training course in Australia, and Cancer Council NSW developed consumer research grant review criteria and training. Both of these initiatives contributed to consumers having a front and centre place at the table at which research funding decisions are made in Australia.

Consumers were heavily involved in advocating for the first Australian (and still the most comprehensive internationally) evidence-based clinical practice guidelines for the psychosocial care of women with breast cancer, and more broadly, adults with cancer.⁵ These comprehensive guidelines were initially developed by the National Breast Cancer Centre with endorsement from the National Health and Medical Research Council, and are now being maintained and updated by Cancer Australia. They are complemented by the recent production by COSA of guidelines for health professionals in the psychosocial management of adolescents and young adults (AYA) diagnosed with cancer.⁶ These guidelines have provided an important basis for the development of psychosocial services in Australian cancer centres.

Much of the early Australian psychosocial research was focused on achieving a better understanding of the psychosocial, as well as physical impacts of cancer, with Australian researchers at the forefront of developing rigorous measures of 'unmet needs' in the early 1990s;⁷ and describing the levels and predictors of unmet needs in sizable populations of cancer patients.⁸ As increasing evidence of the impact of cancer on other groups came to the fore, Australian researchers responded with development of psychometrically rigorous measures which more specifically targeted other groups, including patients with advanced cancer,⁹ cancer survivors who were some time post-treatment,¹⁰ and the partners and caregivers of cancer survivors.^{11,12} These measures have been widely used internationally.

Patient-centred care

Understanding the impact of caring for people with cancer and the training needs of the health professional workforce has also been a significant area of advancement in psycho-oncology.^{13,14} In 2007, COSA commissioned a survey of its membership to determine levels and predictors of burnout, with results indicating high levels of emotional exhaustion in 33% of participants with direct patient contact and in 27% of those with no direct patient contact. Importantly, one of the main predictors of burnout was perceived to be the need for communication skills training.¹⁵ National Breast Cancer Centre played a leading role in developing and promoting communication skills training for oncology health professionals in Australia, developing train-the-trainer workshops and teaching modules; and COSA has also strongly supported the delivery of communication skills training workshops associated with its annual meeting.

It is now well recognised that health professional-patient communication is critical to quality patient care and challenging for both health professionals and patients.¹⁶ Australian cancer patients place effective doctor communication high on their list of priorities for care. In an early study assessing the perceptions of 232 ambulatory cancer patients, doctor-patient communication dominated the top 10 aspects of care regarded as important. Over 99% of patients emphasised the importance of receiving quality information about their cancer, having the opportunity to ask their doctor questions and receiving empathy and reassurance from their health care team. The outcomes of patient dissatisfaction with communication have been well documented as including non-compliance with medical advice, doctor shopping, increased uptake of complementary and alternative medicines, poorer mental adjustment and general dissatisfaction.¹⁷⁻²⁰

Australian researchers have played a key role in contributing to the oncology communication literature by developing resources for patients to increase their involvement in care (such as information booklets, decision aids and question prompt lists). Butow and Tattersall are recognised internationally as pioneers in this field, conducting many of the first randomised control trials.^{21,22} Australia also led the way in conducting one of the first communication skills training trials, which was led by the late Jill Cockburn.^{23,24}

With an increasing number of people living with and beyond a cancer diagnosis, one of the most recent international priority areas for the field of psycho-oncology has been the study of 'cancer survivorship', the period of time following potentially curative treatments for cancer. The release of the landmark US Institute of Medicine report, *'From cancer patient to cancer survivor: Lost in transition'*,²⁵ has prompted significant international activity in the survivorship space, including in Australia. The November 2009 issue of *Cancer Forum* was dedicated to cancer survivorship,²⁶ and in 2010, COSA hosted the inaugural Survivorship Workshop, bringing together stakeholders in cancer survivorship service delivery and research from across Australia. It was clear that much activity was occurring in this space across Australia and with the continuing interest of COSA members in this area, COSA Council approved the formation of a COSA Survivorship Group in November 2012.

As a community, Australian psycho-oncology researchers have shifted in the last 5 to 10 years from doing largely descriptive research identifying adverse psychosocial outcomes for people with cancer as a problem, and defining the dimensions and characteristics of this problem, to undertaking rigorous randomised control trials of supportive care/psycho-educational interventions which aim to solve the problem. In this way, we are again at the forefront of an international impetus to determine clinically feasible and sustainable ways to improve the psychosocial outcomes for people with cancer. Rob Sanson-Fisher has been largely responsible for this push to convert the focus of research from descriptive to intervention trials.

Quality of Life

A systematic review of the type of research output in psycho-oncology and quality of life, found that only a small proportion of research was intervention work and this had changed little in 10 years.²⁷

Randomised control trials of supportive care/psycho-educational interventions is difficult research. There are stringent methodological requirements, including: recruiting large samples to detect modest effect sizes; loss to follow-up due to patient illness or death; implementing complex interventions which adhere to protocol; variation in usual care across treatment centres; and many others.

Moreover, journals are often reluctant to publish negative trials that are frequent in this field.²⁸ Despite these hardships, Australians have embraced the necessity to conduct randomised control trials in order to improve psychosocial outcomes for patients. There are now key research hubs around Australia whose core business is the conduct of randomised control trials in psycho-oncology, for example: PoCoG, currently conducting a multi-centre study of an intervention to reduce the impact of fear of cancer recurrence; Peter McCallum Cancer Centre, evaluating nurse delivered interventions; Cancer Council Queensland, evaluating nurse, psychologist and peer led interventions; the University of Queensland, evaluating exercise and lifestyle change interventions; and Sydney Children's Hospital, evaluating interventions for paediatric cancer patients.

Prospects

Our next challenge is fostering practice changes - implementing supportive care/psycho-educational interventions that are clinically feasible and have a strong evidence base, demonstrating their positive impact on patient outcomes. Some leading Australian work has been undertaken to evaluate the feasibility and impact of routine screening for distress and communication of these results to the patient and treatment team, such as the early randomised control trial of Dr Sue-Anne McLachlan et al,²⁹ and the later work by Greg Carter and Kerrie Clover et al in Newcastle.³⁰

In summary, psychosocial issues in cancer are now well on the Australian cancer agenda, widely included in cancer plans and a priority area in clinical services. There is a strong and thriving psychosocial research program in Australia. COSA has played a significant role in supporting and acknowledging the growth in this area.

References

1. Massie MJ, Holland JC. Diagnosis and treatment of depression in the cancer patient. *J of Clin Psychiatry*. 1984;45(3):25-9.
2. Girgis A, Lambert S, Waller A, Johnson C, Currow D. Physical, psychosocial, relationship and economic burden of caring for people with cancer: A review. *Journal of Oncology Practice*, Epub ahead of print, Dec 4 2012. doi:10.1200/JOP.2012.000690
3. Shanafelt T, Dyrbye L. Oncologist burnout: causes, consequences and responses. *JCO* 2012;30(11):1235-41.
4. Pat Fobair, LCSW, MPH. Historical Threads in the Development of Oncology Social Work. *J Psychosoc Oncol*. 2009;27(2):155-215. doi: 10.1080/07347330902775301. PMID: PMC2664972. NIHMSID: NIHMS90133

5. National Breast Cancer Centre and National Cancer Control Initiative. Clinical practice guidelines for the psychosocial care of adults with cancer. National Breast Cancer Centre, Camperdown, NSW. 2003.
6. COSA AYA Interest group. Evidence-based guidance for Australian health professionals on priority issues in AYA cancer management and care [internet]; Currently under development. Will be available at: [http://wiki.cancer.org.au/australia/COSA: Psychosocial_management_of_AYA_cancer_patients](http://wiki.cancer.org.au/australia/COSA:Psychosocial_management_of_AYA_cancer_patients)
7. Bonevski B, Sanson-Fisher R, Girgis A, Burton L, Cook P, Boyes A, et al. Evaluation of an instrument to assess the needs of patients with cancer. *Cancer*. 2000;88(1):217-225.
8. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P, et al. The unmet supportive care needs of patients with cancer. *Cancer*. 2000;88(1):226-237.
9. Rainbird KJ, Perkins JJ, Sanson-Fisher R. The needs assessment for advanced cancer patients (NA-ACP): A measure of the perceived needs of patients with advanced, incurable cancer. A study of validity, reliability and acceptability. *Psycho-Oncology*. 2005;14:297-306.
10. Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, Lo SK, et al. The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology*. 2007;16:796-804.
11. Girgis A, Lambert S, Lecathelinais C. The Supportive Care Needs Survey for Partners and Caregivers of Cancer Survivors: Development and Psychometric Evaluation. *Psycho-Oncology*. 2011;20(4):387-393. doi:10.1002/pon.1740
12. Hodgkinson K, Butow P, Hobbs KM, Hunt G, Lo SK, Wain G. Assessing unmet supportive care needs in partners of cancer survivors: the development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN). *Psycho-Oncology*. 2007;16:805-13.
13. Girgis A, Sanson-Fisher RW, McCarthy WH. Communicating with patients: Surgeons' perceptions of their skills and need for training. *Aust N Z J Surg*. 1997;67(11):775-780.
14. Dimoska A, Girgis A, Hansen V, Butow PN, Tattersall MH. Perceived difficulties in consulting with patients and families: A survey of Australian cancer specialists. *MJA*. 2008;189(11):612-615. Available at: www.mja.com.au/public/issues/189_11_011208/con_tents_011208.html
15. Girgis A, Hansen V, Goldstein D. Are Australian oncology health professionals burning out? A view from the trenches. *Eur J Cancer*. 2009;45(3):393-399. doi:10.1016/j.ejca.2008.09.029.
16. Wiggers JS, Donovan KO, Redman S, Sanson-Fisher RW. Cancer patient satisfaction with care. *Cancer*. 1990;66:610-16.
17. Hayners BDW, Taylor DL, Sackett DS. Compliance in Health Care. John Hopkins University Press. Baltimore, MD 1979.
18. Kasteler J, R, Olsen DM, Thetford R. Issues underlying prevalence of "doctor-shopping" behaviour. *J. Health. SOC. Behav* 1976.
19. Ployn JFA, Rickman RM, Van Brunschot J, Den Borne HW. Cancer patients' personality characteristics, physician-patient communication and adoption of the Moerman diet. *Soc Sci Med*. 1985;20:831-847.
20. Melleman E, Krabbendam PJ, Anyas AA, Koops JS, Sleijfer DT, Vermeij A. The significance of the doctor-patient relationship in coping with cancer. *Soc Sci Med*. 1984;18(6):475-80.
21. Pitkethly M, MacGillivray S, Ryan R. Recording or summaries of consultations for people with cancer (Review). *The Cochrane Collaboration* 2008; Issue 3.
22. Kinnersley P, Edwards A, Hood K, Ryan R, Prout H, Cadbury N, et al. Interventions before consultations to help patients address their information needs by encouraging question asking: systematic review. *BMJ*. 337, 2008
23. Butow P, Cockburn J, Girgis A, Bowman D, Schofield P, D'Este C, et al. Increasing oncologists' skills in eliciting and responding to patients emotional cues: an evaluation of a communication skills training program. *Psycho-oncology*. 2008;17(3):209-218
24. Girgis A, Cockburn J, Butow P, Bowman D, Schofield P, Stojanovski E, et al. Improving patient quality of life and psychological morbidity: Evaluation of a consultation skills training program for oncologists. *Patient Education and Counselling*. 2009;77(3):456-62.
25. Hewitt M, Greenfield W, Stovall E, editors. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington: The National Academies Press, 2005.
26. Cancer Forum, November 2009, Vol 33 Issue No 3: Survivorship
27. Bailey LJ, Sanson-Fisher R, Aranda S, D'Este C, Sharkey K, Schofield P. Quality of life research: Types of cancer publication output for cancer patients, a systematic review. *Eur J Cancer Care*. 2012;19(5):581-8.
28. Song F, Parekh S, Hooper L, Like YK, Ryder J, Sutton AJ, et al. Dissemination and publication of research findings: An updated review of related biases. *Health Technology Assessment (Winchester, England)*. 2010;14 (8):iii, ix-xi, ix-193. doi:10.3310/hta14080. PMID 20181324.
29. McLachlan SA, Allenby A, Mathews J, Wirth A, Kissane D, Bishop M, et al. Randomized trial of coordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. *JCO*. 2001;19(21):4117-25.
30. Carter G, Lewin T, Rashid G, Adams C, Clover K. Computerised assessment of quality of life in oncology patients and carers. *Psycho-Oncology*. 2008;17(1):26-33.