

THE PSYCHO-ONCOLOGY CO-OPERATIVE RESEARCH GROUP

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Abstract

The Psycho-oncology Co-operative Research Group was conceived in response to the recognised need to develop the capacity and coordinated collaboration to conduct large-scale, multi-centre psycho-oncology and supportive care research. In 2005, it was successful in achieving infrastructure funding for two years from the Cancer Institute NSW and has already achieved a national membership of 75.

The Psycho-oncology Co-operative Research Group's mission is to improve the outcomes of patients experiencing a diagnosis of cancer, their families and carers through evaluation and implementation of psychosocial and supportive care interventions for patients, carers, health professionals and the health care system.

It is hoped that the Psycho-oncology Co-operative Research Group will attract leading researchers and psycho-oncology health professionals and will facilitate a flow of increased collaborations and the development of high-quality psycho-oncology research with strong links to the clinical cancer community. It has the potential to become a leading group for psycho-oncology research, attracting research collaborations from around the globe.

Psychological distress and disorder in cancer patients

Optimal care of the patient with cancer incorporates effective physical and psychological care, through diagnosis and treatment, long-term survivorship, recurrence and death. A diagnosis of cancer is a threat to life itself, generating turmoil in the lives of patients diagnosed with the disease^{1,2} as they, and their families, struggle to define and resolve the series of meanings and decisions that confront them.^{3,5} A cancer diagnosis and treatment may also impact on patients' psychological and physical health, sexuality, body image, finances, relationships and their ability to continue in their roles at home and at work.⁶

People with cancer suffer significant emotional morbidity. An Australian study conducted by Kissane and his colleagues⁷ found that 45% of cancer patients had a psychiatric disorder and 42% were diagnosed with depression or anxiety, or both (compared to a prevalence of 9% in the general population). While the prevalence of clinical disorder varies from study to study, almost all cancer patients report some distress associated with their illness and its treatment. Many patients also lack information about their illness and possible support services. Recent studies measuring stress levels of patients with colon and prostate cancer and their partners indicate that partners experience significantly more distress than patients and receive less support,⁸ while patients themselves often report family needs and issues as their biggest concern.

It is known that psychosocial concerns and morbidity often go undetected and are under-treated in the oncological setting.³ Strategies to ensure effective screening, referral and treatment of psychosocial concerns are urgently needed. Our current response to

these levels of distress and morbidity are inadequate. Up to 40% of patients report a range of unmet needs.⁹

In summary, there is a continuing need to explore the psychosocial needs, understanding of cancer and barriers to care for patients and their families. Several recent reports have highlighted the importance of, and current deficiencies in, psychosocial care of cancer patients. In the 1997 National Cancer Control Initiative report, *Cancer Control Towards 2002*, psychosocial care was identified as one of the 13 actions recommended for priority implementation.¹⁰ Recent policy documents, for example the *NSW Cancer Care Model* and the *National Cancer Control Plan Priorities for Action in Cancer Control 2001–2003*, have stated that improving the psychosocial care of cancer patients in Australia is a national priority.^{11,12}

Cancer and its treatment has a considerable impact on a person's quality of life (QoL) which encompasses physical functioning, psychological functioning, social interaction and physical symptoms of the disease and its treatment.^{13–17} The importance of assessing QoL in cancer patients is recognised particularly for those receiving treatment, whether standard or experimental, and there is a need to establish collaboration between psychosocial researchers and clinical trials groups to effectively explore patients' needs in this area.

Psycho-oncology research

The research climate has shifted in Australia over the past 15 years towards providing greater support for psychosocial research. This has resulted, in part from the improvements in cancer treatment, leading to an increasing focus on improving QoL as well as extending life. The influence of consumer groups in Australia, who place a priority on psychosocial concerns, has influenced funding bodies. The establishment of the

Psycho-oncology Group within the Clinical Oncological Society of Australia (COSA) gave this discipline credibility within the multi-disciplinary clinical setting. In NSW, a clinical support/interest group of psychologists working in cancer has been meeting for 10 years. Similarly in Victoria, there is a thriving group, the Victorian Psycho-oncology Group, which is dedicated to improving psychosocial care for cancer patients through the development and exchange of research ideas and the promotion of collaborative research. With the expansion in psycho-oncology services occurring as a result of the policy documents described above, the total workforce in this field is expanding rapidly and will continue to do so in the next few years.

There are several psycho-oncology research groups in Australia with international reputations in this arena, which have been enormously productive despite limited infrastructure support. However, the infrastructure to enable collaboration and implementation of large-scale research has been, until recently, insufficient. It is only through strong foundations and a commitment to research in this area that collaborations will flourish. The existing expertise is disparate and collaboration has been opportunistic rather than coordinated and comprehensive.

Formation of the Psycho-oncology Co-operative Research Group (PoCoG)

PoCoG was conceived in response to the recognised need to develop the capacity and coordinated collaboration to conduct large-scale, multi-centre psycho-oncology and supportive care research. In 2005, PoCoG was successful in achieving infrastructure funding for two years from the Cancer Institute NSW, as a state organisation with the expectation that within that time, it would become self-funding and national in scope. The group has already achieved a national membership of 75.

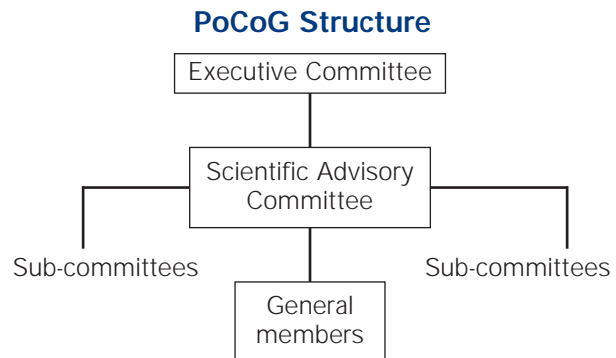
It is hoped that PoCoG will attract leading researchers and psycho-oncology health professionals and will facilitate a flow of increased collaborations and the development of high-quality psycho-oncology research with strong links to the clinical cancer community. PoCoG has the potential to become a leading group for psycho-oncology research, attracting research collaborations from around the globe. A great advantage of a collaborative network is the formal and informal mentoring of junior researchers that occurs as an integral part of this process.

PoCoG's mission is to improve the outcomes of patients experiencing a diagnosis of cancer, their families and carers through evaluation and implementation of psychosocial and supportive care interventions for patients, carers, health professionals and the health care system.

The aims of PoCoG are:

1. To bring together researchers, clinicians, health care professionals and consumers with an interest in psycho-oncology to foster collaboration and the exchange of ideas.
2. To develop large-scale, multi-centre psycho-oncology studies of clinical relevance and importance which would be difficult for any one team to mount.

3. To develop formal links with cancer clinical trial groups to facilitate quality of life and psychosocial sub-studies.
4. To promote psycho-oncology research and support emerging new researchers in this area.



Currently located within the University of Sydney, PoCoG is managed under the broad direction of an Executive Committee comprising the Chair (Professor Phyllis Butow) and Coordinator (Dr Rebecca Hagerty) of PoCoG, Chair of the Psychosocial Group in COSA (Professor Afaf Girgis), COSA liaison (Haryana Dhillon) and two nominees from the Scientific Advisory Committee (SAC), currently Professor Kate White and Dr Michael Jefford. The Executive is responsible for day-to-day management, financial and administrative issues, liaison with other trials groups and general central coordination.

The SAC comprises 34 Australian and New Zealand members representing the disciplines of psychology, health research, medical, radiation and surgical oncology, social work, psychiatry, biostatistics, palliative care and nursing, as well as consumer interests. This committee will oversee the direction of PoCoG and lead the establishment and enhancement of links with cancer trials groups within Australia and review protocols submitted to PoCoG. The first PoCoG SAC meeting was held at the COSA Annual Scientific Meeting in Brisbane in November 2005.

PoCoG membership is open to clinicians, allied health professionals and researchers in Australia and New Zealand with an interest in psycho-oncology research. An application form is available by contacting the coordinator and there is no charge to join the group. Members benefit from access to PoCoG resources and review processes, links to others involved in psycho-oncology research, newsletters, the Annual General Meeting and the planned biannual scientific meeting to be held in conjunction with the Behavioural Research in Cancer meeting currently auspiced by the Cancer Council behavioural groups.

Activities

PoCoG is conducting a series of focus groups with associated professional groups regarding priority research questions that are clinically relevant. From this process, one psycho-oncology protocol has been developed which will be open for recruitment and

submitted to NHMRC for funding in early 2006. Two further protocols are under development.

Equally importantly, PoCoG is committed to working with other cancer trial groups to initiate new sub-studies concerning QoL and psychosocial issues within their existing and planned trials. The merits of establishing one centralised QoL/psychosocial clearing house/coordination centre, servicing the needs of all cancer trials groups in Australia, are great. The importance of assessing QoL in cancer patients is well recognised, however, each trials group on its own lacks the funds and personnel to develop this expertise. Furthermore, working with a range of trials groups provides an opportunity to conduct cost-effective QoL/psychosocial studies where major questions can be answered without additional recruitment and infrastructure costs. Several Australian QoL studies are currently running in this manner (for example with the Australian Ovarian Cancer Study). There is also evidence that recruitment and compliance is greater in clinical trials when QoL assessment is included because patients feel that these concerns are being addressed.

Attracting research funding for such trials remains difficult and for individuals with limited infrastructure is a major challenge. In addition, the granting bodies in Australia and internationally are increasingly promoting the importance of collaborative, large-scale, multicentre research. Dissemination research is also emerging as a key issue, however this is difficult to conduct in single institutions. For these reasons, the formation of PoCoG is timely, providing a forum to potentially improve the already impressive psychosocial research productivity in Australia.

Summary

The Psycho-Oncology Co-operative Research Group will add significant value to existing research, and allow a quantum leap forward in the strength and innovation of research within this area. The activities of PoCoG will have benefits not only for psycho-oncology research in this country, but through its QoL coordinating centre for every cancer trials group. This will ensure that research

and guideline development for new treatments appropriately consider QoL trade-offs. Cancer patients, their carers and families and cancer staff will all benefit from a strong Psycho-Oncology Co-operative Research Group in this country. We expect to have at least three trials funded and recruiting by the end of 2006. □

References

1. Massie MJ, Holland JC. Diagnosis and treatment of depression in the cancer patient. *J Clin Psychiatry*. 1984 45: 25-28.
2. Zabora J, Brintzenhofesoc K, Curbow B, Hooker C, Piantadosi, S. The prevalence of psychological distress by cancer site. *Psycho-Oncology* 2001(10) 19-28
3. Parle M, Jones B, Maguire P. Maladaptive coping and affective disorders among cancer patients. *Psych Med*. 1996; 26(4): 35-744.
4. Parle M, Maguire, P. Exploring relationships between cancer, coping, and mental health. *J Psychosoc Oncol*. 1995; 13(1-2): 27-50.
5. Weisman AD, Worden JW. The existential plight in cancer: Significance of the first 100 days. *International Journal of Psychiatry in Medicine*. 1976; 7(1): 1-15.
6. Zampini K, Ostroff JS. The post-treatment resource program: portrait of a program for cancer survivors. *Psycho-Oncology*. 1993; 2(1-19).
7. Kissane DW et al. Psychological morbidity and quality of life in Australian women with early-stage breast cancer : a cross-sectional survey. *Medical Journal of Australia*. 1998 ; 164 (4) :192-6.
8. Blood GW et al. Spouses of laryngeal cancer: caregiver strain and burden. *J Commun Disorders*.1994; 27: 19-35.
9. Sanson-Fisher R, Girgis A and the Supportive Care Review Group. The unmet supportive care needs of patients with cancer. *Cancer*. 200088, 1: 226-237.
10. National Cancer Control Initiative, Australia, Report, Cancer Control Towards 2002, 1997.
11. New South Wales Department of Health, Optimising Cancer Care Management: A Cancer Care Model for NSW. 1999.
12. National Cancer Control Initiative, Australia, Priorities for Action in Cancer Control 2001-2003.
13. de Haes JC et al. The quality of life of cancer patients: a review of the literature. *Soc Sci Med*. 1985; 20:809-17.
14. Hammerlid E et al. Health-related quality of life in long-term head and neck cancer survivors: A comparison with general population norms. *Br J Cancer*. 2001; 84:149-56.
15. Joly F et al. Late psychosocial sequelae in Hodgkin's disease survivors: a French population-based case-control study. *J Clin Oncol*. 1996; 14:2444-453.
16. Zabora J et al. Prevalence of psychological distress among cancer patients across the disease continuum. *J Psychosocial Oncol*. 1997; 15:73-87.
17. King M et al. Quality of life three months and one year after first treatment for early stage breast cancer: Influence of treatment and patient characteristics. *Qual Life Res*. 2000; 9:789-800.