Submission to the
Senate Community Affairs Reference Committee

Inquiry into Services and Treatment Options
For Persons with Cancer

(With particular reference to Items (a) (i), (iii), (v) and (b) (i), (ii)of Terms of Reference)

From the Australian Psychological Society

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Introduction

The Australian Psychological Society has a strong interest in, and commitment to, the various aspects of health in Australia. Through its membership of Psychologists (over 14,000), who function as practicing clinicians, academic researchers and educators, managers and government advisors, it exercises considerable presence and influence in this domain. As a result, it has well-developed, research-based views on cancer services. It is grateful for the opportunity to represent its members and wider-community of psychologists' views to the Senate Committee.

The APS views health programs from three perspectives: appropriate services, appropriate providers of those services, and structural solutions to achieve the optimal combination of the two. The overriding philosophy driving the issues of appropriate services is that of evidence-based practice. This sets a standard for clinical interventions and programs that determines their appropriateness on the basis of clinical research and trials. It also provides guidelines for the funding, spread and location of services based upon established clinical practice and knowledge.

Providers of these services are determined on the principle of selecting those professionals best trained and experienced to provide that service. It involves not only selection but identifying training and development programs to support and disseminate that expertise. Finally it involves investigating and trialling models of delivery that optimally combine appropriate treatments with the best providers in a cost effective and efficient manner.

The APS supports its members with a structure of specialist colleges that facilitate professional development across the range of specialisation (academic, industrial, sport, forensic, developmental, clinical).

The submission that follows focuses on aspects of the treatment of cancer and the management of cancer patients to which psychosocial approaches and psychological interventions can make a significant contribution. It first makes some broad comments about multidisciplinary care [Item (a) (i)] and then focuses on the evidence-based practice surrounding psychosocial and psychological practice [Item (1) (iii)]. The submission then raises some questions around research evidence and gaps in research. It then goes on to identify those specific aspects of the psychosocial model and those psychological interventions known to contribute significantly to assisting sufferers of cancer. Some brief reference to alternative therapies [Item (b)] is also made. Contributions to the understanding of cost effectiveness and psychological interventions are then included. The conclusion focuses on the need for collaborative work not just at the multidisciplinary care level but to include psychosocial experts and non-medical groups (especially psychologists) more extensively in policy development, research priorities and budgetary allocation. Issues related to barriers to good practice are raised as much by implication or in passing [Item (a) (v)].

Multidisciplinary care

The concept of multidisciplinary care is fundamental to all areas of health service provision and especially so with the treatment of cancer. The following reasons are commonly agreed to be the fundamental reasons for the support of multidisciplinary care and considered integral to good clinical practice by this Society.

1 Treating a patient for all aspects of their physical, mental and social well-being is as vital for the sufferer of cancer as with all other health disorders. Given the multitude of expertise required to achieve this, it is impossible for one person or one profession to achieve the extent of holistic management without multidisciplinary care.

2 Experience has shown us that professionals inevitably focus on their area of expertise and can only exercise moderate expertise at best and pay lip service at worst to other areas of professional service.

3 Where multidisciplinary care works most effectively there is a benefit to assessment, diagnosis, treatment planning, patient management and health outcomes that is greater than just the accumulation of services. There is clearly an interactive effect that may be hard to measure but is certainly supported by repeated anecdotal experience, if not randomised clinical trials, throughout the health system. Professionals benefit from the input of other professionals in a way that heightens awareness and increases analytical and problem-solving expertise by extending understanding of the variety of issues feeding into the patient's condition.

4 Probably one of the most successful and important elements of multidisciplinary care is its impact on the patient. Not only is there a sense conveyed to the patient of the system’s commitment to managing all aspects of the patient’s life, but if the team is managed effectively, the patient is able to listen to the contributions of the specialty and is able to respond to, or at least appreciate, the input of each and the breadth of the ultimate process of decision making and planning. The sense of confidence and respect thus instilled in the patient can have marked impact on treatment adherence and ultimate outcomes.

5 One the aspects of multidisciplinary care, that may not have immediate benefit to the patient but most certainly has long-term benefits for the whole system of health care, is that the multidisciplinary teams are an excellent training environment for less experienced practitioners or even trainees. It not only provides a great environment for practical case training, but also is a great exposure to, and reinforcer of, the benefits of multidisciplinary care.

Psychological Interventions and Treatment of Cancer: The Evidence

Cancer is one of the leading causes of death in Australia (over 36,000 per year) with 88,000 new cases diagnosed each year (The Cancer Council

Australia). Treatment of the disease is often traumatic for patients and their families and a large number of people who are afflicted by cancer experience psychological morbidity related to the diagnosis and treatment process (Luebbert, Dahme, & Hasenbring, 2001). A large meta-analytical study found that psychological interventions help patients to better manage the distress and anxiety of diagnosis and treatment, helps them to make appropriate decisions regarding treatment, improves treatment adherence and leads to improved quality of life (Fawzy, Fawzy, Arndt, & Pasnau, 1995).

In essence, the research strongly supports the benefits of psychological interventions and in assisting with cancer morbidity. There is little evidence (but some promising progress) regarding the benefits of psychological interventions to mortality period. This research is still in its infancy but would benefit significantly from a greater collaboration between psychology and immunology i.e. between psychologists and medical specialists in the field and the laboratory. One study showed immune response changes following psychological interventions which may in turn increase survival rates (Larson, 2000; van der Pompe, 1997).

Specific psychological interventions have been found to improve functioning for individuals with cancer. There is evidence that group psychological interventions for cancer patients improve the quality of life of many patients and in some instances they may prolong life (Andersen, Golden, & Deanna, 2001; Cunningham & Edmonds, 1996). Baum and Andersen (2001) also summarised the literature and concluded that behavioural interventions aimed at modifying beliefs and behaviour can affect whether people develop cancer, responses to treatment, quality of life, and life expectancies.

Luebbert et al. (2001) conducted a meta-analysis on 15 studies looking at the effects of relaxation training in reducing symptoms and improving emotional adjustment in acute non-surgical cancer patients. They reported that the relaxation intervention led to a significant reduction of tension, depression, anxiety and hostility in the patients and improved the overall mood of patients undergoing difficult treatment options such as chemotherapy, radiotherapy and bone marrow transplantation.

A second meta-analytical study of 38 randomised studies which included a social cognitive approach to treatment for cancer patients found that social and cognitive psychological interventions led to significantly higher scores on quality of life measures than did treatments that did not include this approach (Graves, 2003). Survival rate is probably the key indicator of successful intervention. A review by Garssen and Goodkin (1999) evaluating 38 prospective studies looking at psychological factors and cancer progression identified convincing support for a positive effect of psychological treatment on survival rates for cancer patients.

Literature reviews have also been conducted looking at specific types of cancer. Women who have been treated for breast cancer may, in addition to psychological difficulties experienced by other cancer patient groups, experience body image concerns and poor sexual functioning. A literature review by Glanz and Lerman (1992) identified cognitive therapy, social support, supportive information, and the development of coping strategies as predictors of better outcome for this patient group.

Large reviews and meta-analytical studies support the efficacy of psychological interventions to improve the quality of life of patients with cancer. Psychological interventions help them to better deal with the illness and treatment, but evidence also suggests that it may lead to increases in survival rates and lower rates of service utilisation.

It is worth noting at this point that the solid evidentiary base has led to the creation of psychosocial practice guidelines issued by the peak bodies such as the National Breast Cancer Centre, for which we would advocate wider adoption and mandatory implementation.

Limitations in the Research base

Much of the evidence reported in the literature uses the NHMRC "levels-of-evidence" approach or something similar. According to this approach the highest level (Level I) occurs when there is positive evidence from a systematic review of randomised trials. The problem with this approach is that it does not take into account the distinction between "efficacy" - evidence from randomised trials - and "effectiveness" - the ability to still get the good results observed in research in real world service delivery settings. This distinction is important in health research but becomes critical in considering psychosocial service impacts.

The other obvious gap in both the research and treatment interests is that produced by the emphasis on breast cancer. Other forms of cancer, such as prostate cancer and bowel cancer, deserve both a research and treatment program development emphasis.

One study was based on a survey from a non-surgical oncology clinic (Lintz et al. 2003) of 210 male patients with prostate cancer who completed various surveys and questionnaires that examined their support and psychological care needs. The data showed that significant unmet need exists across a number of domains in the areas of psychological and health system/information. The more commonly reported needs were fears about cancer spreading, concerns about the worries of those close to them, and changes in sexual feelings.

Another project about improving quality of life in men with prostate cancer (Lepore et al. 2003) randomly assigned men who were recently treated for prostate cancer (N=250) into a control group, a group education intervention (GE), or a group education-plus-discussion intervention (GED). Both GE and GED increased prostate cancer knowledge, reduced concerns around sexual problems for men when compared to men in the control condition. Men in the treatment conditions were more likely to remain steadily employed and demonstrated better physical functioning and more positive health behaviours.

What is missing is a consideration of implementation challenges. What are the services currently operating on the ground? To what extent do they use the interventions that have an evidence-base in research? If services that have evidence from well-controlled studies appear to still provide benefit in real-world service delivery then this should be emphasised. If it is not possible to judge whether the services with research evidence can be feasibly run in Australia then this should be stated as it leads to recommendations for a research agenda.

Specific Areas Where Psychological Intervention Can be Vital

1 **Adherence.** As many of the treatment interventions for cancer are disruptive, if not invasive, guidelines on strategies for encouraging adherence to treatment is a significant issue. So much of the success of treatment and the alleviation of patient distress relies on behaviour management and change. Psychology is the study of human behaviour and psychologists with clinical training are the experts in managing difficult behaviour, improving coping skills and reducing distress.

There is often an artificial distinction made in medical treatments between what might be called "physical treatments” and "psychosocial treatments". This is an artificial distinction in so many ways as the two overlap significantly both in terms of the processes themselves and in terms of the client's response to both. This overlap is not additive but interactive in its impact so that success in both is vital to overall success.

Any consideration of the successful treatment of cancer needs to include work on strategies for adherence to treatment or life-style changes (theoretical perspectives covering TTMC, SRM - illness perceptions etc.).

2 **Pain Management**. Any consideration of the treatment of cancer needs to include a recognition of the psychological techniques available for pain management. Some of the common strategies found to be very effective in the hands of a trained clinician include controlled breathing techniques, distraction, cognitive disputations (catastrophising thinking) and hypnotherapy.

3 **Treatment of Negative Mood.** Cancer, like many other major chronic diseases**,** can be significantly affected by (if not exacerbated or caused by - see heart disease) mood disorders such as depression and anxiety. Often these aspects are overlooked in the focus on the physical nature of the complaint and treatment interventions undermined. It is now well established in terms of evidence-based practice that psychological interventions for depression and anxiety (cognitive behavioural therapy and interpersonal therapy) are at least as effective as drug treatments if not more so. Certainly in combination they are a very powerful instrument of patient support.

4 **Self-Management Interventions.** Self-management involves the person with a chronic illness adopting activities, such as self-monitoring regular symptom checking procedures (breast screening, pap tests) and active management of symptoms, and lifestyle changes, such as treatment adherence and using support resources, to promote good health.

Self-management can be challenging to implement but outcome studies demonstrate a positive effect on medical, emotional, and functional outcomes (for example, see Browning & Thomas, 2003; Nodhturft, Haley & Price, 2003). Self-management outcomes are particularly good when practitioners and patients work collaboratively.

Self-management is based on four principles:

- Illness management skills are learned, self-directed behaviours;
- Motivation and self-confidence regarding illness management determine, in large measure, how well a patient is able to live with the illness;
- The social environment in the family, the workplace and the healthcare system can support or impede self-care;
- Adapting to the illness is improved by monitoring and responding to changes in the state of the disease, the symptoms and the patient's emotions and functioning.
  (Von Korff, Gruman, Schaefer, Curry & Wagner, 1997)

There are five core self-management skills: decision making, problem solving, utilisation of resources, forming partnerships with health care providers, and taking action.

Although the evidence suggests that self-management is a positive approach to treating chronic illness including cancer, there are a number of barriers to implementing self-management strategies in patient groups. These include the fact that treatment for chronic illness is often focused on clinical results rather than looking at lifestyle issues. Treatment is often reactive and unplanned and fails to educate, train and support patients. Moreover, there are no formalised referral pathways from primary care to clinic or community based self-management training and support programs.

5 **Managing communication.** It should be recognised that, especially in the early stages of receiving information about the implications of a diagnosis of cancer, many patients feel they have been relentlessly overwhelmed with information from their doctors when they are not yet ready to receive it. Psychologists have contributed to the theory and research of patient-doctor communication and have been instrumental in creating evidence-based training programs for improving communication. Work in this field by Australian researchers such a Professor Robert Sanson-Fisher and Professor Phyllis Butow is recognized worldwide (e.g., Lobb, Butow, & Tattersall, 1999). Communication training is an area in which psychologists can play an important role in the provision of best practice in cancer care.

6 **Complementary therapies.** This topic is undoubtedly one of the more controversial in the field of cancer care. A full discussion of the issues is beyond the scope of this submission. However, several key points can be made. As we have indicated, open communication is a vital part of providing quality care to cancer patients. Many patients have questions about how to best manage their problems and will have heard about methods that are widely used by fellow sufferers. Doctors are advised to talk with their patients about complementary therapies in an informed manner that is not dismissive of either the methods or the patients. Doctors thus need to inform themselves better about the evidence base for complementary therapies such as hypnosis, homeopathy, acupuncture, psychological interventions and meditation etc which can be very useful in treating the pain, nausea and anxiety associated with cancer and its treatment. They also need to be clear about discriminating between approaches such as these and those that are less clearly supported by sound evidence.

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Cost Savings For Psychological Intervention With Cancer

According to the AIHW, cancer accounts for 13 per cent of health costs which on the basis of cost reported in 2003, this amounts to $13.3 billion (*Report on Government Services, 2003*). The major components of this cost were medication (28 per cent), specialist services (20 per cent) and hospitalisation (21 per cent). According to the Cancer Council, cancer costs $2.7 billion in direct health system costs (5.7per cent).

A comprehensive Australian epidemiological study examined the impact of various factors on cancer costs and included in this study were psychological interventions like CBT and longer-term psychotherapy. The study used as its core measure the DALY – measure of time impaired by disability associated with a disorder (DALY = disability adjusted lost years). The factors impacting on the disruption of ones life by cancer were evaluated and compared. The overall finding was that psychological intervention had a significant effect on reducing DALYs – some 15 per cent.

There is no suggestion that saving DALYs converts directly to cost savings but the reduced dependence on medication for pain and related symptoms and repeated visits to specialists would be a clear consequence of effective interventions. Based on the $13.3.billion and an even more conservative estimate of 10 percent, it is possible to suggest a 1.3 billion per cent saving on costs.

Conclusions

There have been a number of specific suggestions and recommendations within components of this document regarding recommended projects, initiatives and research that this Society feels should be adopted. Because of the Society's commitment to evidence-based practice, the positive findings of much of the research indicate directions in treatment intervention and patient management along the lines that the research indicates. The Society strongly feels that the role of psychosocial interventions and psychology practitioners in medical treatment settings has been largely under-utilised in the Australian community. We would therefore seek a role for our members, and psychological clinicians generally, in the area of health psychology to become standard members of cancer treatment teams.

In general, we would reiterate that the concept of multidisciplinary care, strongly endorsed in this submission and in our psychological practice guidelines, represents a belief that psychologists have a significant role to play as members of effective multidisciplinary teams. However, the principle that lies behind equality of membership within multidisciplinary teams needs to be applied to the broader setting of policy, research funding and project endorsement. In other words, there needs to be greater representation of all groups involved in multidisciplinary healthcare on the major policy development, research funding and project endorsement bodies.

We thank you again for the opportunity to contribute to this very important Senate committee.

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