ONCOLOGY
SOCIAL WORK AUSTRALIA

EXCELLENCE IN PSYCHOSOCIAL ONCOLOGY

Submission to Senate Inquiry

MARCH 2005

The Role of Oncology Social Work

In

Australian Cancer Care

CONTENTS

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

INQUIRY INTO SERVICES AND TREATMENT OPTIONS
FOR PERSONS WITH CANCER

TERMS OF REFERENCE

A) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

i) The efficacy of a multi-disciplinary approach to cancer treatment

Based on current evidence the only option for quality cancer care is a multidisciplinary approach as it is well demonstrated in: -

1. Improving survival outcomes
2. Improving treatment outcomes
3. Reducing the fragmented experience of the cancer patient ("cancer lottery" syndrome)
4. Improving quality of life post diagnosis
5. Improving patient process of care
6. Improving patient satisfaction and a sense of maintaining a "locus of control".
7. Supporting family caregiver's role

ii) The role and desirability of a case manager/case co-coordinator to assist patients and/or their primary care givers.

In the last decade from 1991 to 2001 cancer incidence grew by 34%; at the same time deaths increased by 17.4%.[1] Thus due to improved treatments more people are living with cancer. This has put an increased load on service providers.

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[1] Australian Institute of Health and Welfare Cancer in Australia 2001. December 2004. AGPS.

The availability of a strong multi-disciplinary approach to the management of those living with a cancer will by implication ensure that: -

1. The principles of case coordination, case-management, continuity of care and optimal healthcare will be achieved.
2. Minimises the likelihood of the "cancer lottery" phenomena occurring where it is a matter of luck as to whether a cancer patient obtains the appropriate expertise.
3. Result in improved efficiencies and efficacy of medical treatment, psychosocial care and improved models of access and equity.

iii) Differing models and best practice for addressing psycho/social factors in patient care

Oncology social workers are the largest providers of psychosocial services in Australia. With current existing resources they can in theory provide: -

1. **Incidence:**

   Approximately 3.12 patient contact hours to each newly diagnosed patient (This has been calculated on 80% clinical contact time for an estimated 46 weeks per annum for 200 oncology social workers throughout Australia seeing 88,398 new cases as recorded in 2001[2]).

   OR

2. **Prevalence:**

   Approximately 1.56 hours per annum could be allocated to each existing patient being treated for cancer, i.e. 'active prevalence'[3]. This does not include any separate time spent with a family member. (This figure is based on 80% clinical contact time for an estimated 46 weeks per annum for 200 oncology social workers throughout Australia seeing 176,796 existing cases as recorded in 2001[4]. If the calculation were to include all those living with cancer, there is an allocation of .4 hours per person, not including any time for family members).[5]

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[2] Ibid

[3] Brameld KJ, Holman CDJ, Threlfall TJ, Lawrence DM, DeKlerk NH Increasing' active prevalence' of cancer in Western Australia and its implications for health services. 2002 Vol26 (2) 164-169

[4] Australian Institute of Health and Welfare Cancer in Australia 2001. December 2004. AGPS.

[5] Total prevalence is calculated as around eight times the incidence, i.e. for 2001, 88398 x 8= 707184. 'Active prevalence' as defined by WA epidemiologists is twice the number of incidence cases, i.e. 88398 x 2= 176796.

Leadership for best practice multi-disciplinary cancer care has been provided by the United States for over 30 years. In this time they have consolidated a service delivery structure compromising a cancer physician, cancer nurse, oncology social worker and consultant psychiatrist/psychologist. In this way they have recognised the need to address the social and emotional needs of all their patients.

As early as 1980 a controlled study cited as a model of good research demonstrated that one health care provider addressing psychosocial need and maintaining contact over a six month period with a patient more rapidly reduced negative affect, created a more realistic outlook on life, increased the numbers returning to work and saw improved activity pattern [6].

A properly structured specialist oncology psychosocial service should do the following as a minimum:

1. Identify those amongst the cancer population with special needs
    - Those for whom their social circumstances and availability of support are limited and therefore are at risk, these maybe patients who are not married including the widowed (30%), those who have dependent children (25%), those who are themselves primary family caregivers (20%) and those for whom family caregivers are working (40%)[7].
    - Those who will not have a guaranteed access to cancer treatments including indigenous Australians; those with a multicultural background and recent arrivals; those living in rural and/or remote areas; those with intellectual and cognitive impairment.
2. Identify amongst the newly diagnosed cancer population those with elevated psychosocial distress through routine screening. Professor Jimmie Holland has recently recommended that psychosocial distress be added as the 6th Vital Sign in medicine and at all clinical consultations patients be asked, “How distressed have you been today and over the past few days scored 1 – 10?” This simple method

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[6] Gordon, W.A., Freidenbergs, I., Diller, L., Hibbard, M., Wolf, C., Levine, L., Lipkins, R., Ezrachi, O. and Lucido, D. (1980) Efficacy of psychosocial intervention with cancer patients. Journal of Consulting & Clinical Psychology **48**, 743-759.

[7] Data from The Canberra Cancer Quality of Life Project 1996-2005. CM Burns unpublished data from a PhD in progress, Patients with Advanced Cancer and their Family Caregivers Perception of Treatment and Support Services .

ensures distress is assessed and its management integrated into total care.[8]

3. Offer a range of specialist interventions that would include: -
    - Information and education
    - Assistance in identifying personal social and emotional issues
    - Managing symptoms of anxiety and depression
    - Social support
    - Advocacy

4. Tackle the challenge of demonstrating gold standard evidence based psychosocial interventions in Australian cancer services, that is, a randomised controlled trial (RCT).

    Other types of controlled trials may also be required given our unique combination of national health insurance, State/Territory run health services and, population which includes a large multicultural segment and small but significant number of geographically isolated people.

    This will require a substantial increase in investment in the high-grade specialist multi-disciplinary research team: Clinical practitioners (medical nursing, psychology, social work), epidemiologists, bio-statisticians, sociologists and anthropologists.

An increase in ‘active prevalence’ (i.e. those surviving their cancers but having ongoing treatment) plus an overall increase in the incidence of cancer and a chronic under-investment in the public health system has resulted in a degradation of psychosocial care services to cancer patients. This has resulted in a “lottery” service provision and led to a chaotic fragmented delivery of care.

As health professionals who are witnesses to this cycle, we have been both saddened and dismayed by its impact on patient general wellbeing and quality of life.

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[8] J. Holland. Psychosocial Distress: The 6th Vital Sign. Discussant. 7th World Congress of Psycho-Oncology, August 2004.

iv) Differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians

Research to assist in the development of appropriate services to both Indigenous Australians and those who are geographically isolated has only recently begun. What we do know already is that health services are distinguished by a strong multidisciplinary approach, overlapping and changing roles of team members, relatively high degree of G.P. substitution, extended clinical skills and awareness of public health.

We have yet to develop cancer services for these groups that incorporate this unique health practice.

v) Current barriers to the implementation of best practice in the above fields.

As oncology social workers we believe the under-investment in the public health system has led to a direct degradation of psychosocial care of cancer patients.

This has also resulted in widespread demoralisation of the embryonic oncology social work sub-discipline.

This in turn has meant an inability to further research and improve clinical practices as we have been swamped by clinical loads. There has been around a 50% cut in allied health service provision in the last decade.

All of this has led to a leadership vacuum amongst oncology social workers contributing to the debate on psychosocial and cancer care.

RECOMMENDATIONS

Some simple and immediate steps to redress this past history are: -

1. As a matter of urgency to upgrade psychosocial services, targeted funds are required for additional oncology social workers in teaching hospitals, in the outer city health services, in the State and Territory regional services and in rural and remote areas. We estimate that a increase of $15,000,000 over five years would begin to have a long term impact on the provision of coordinated psychosocial care services for all patients diagnosed with cancer and their family care givers by restoring a professionally focused culture of care.

2. To establish a national system of accreditation of cancer services which would also include standards for psychosocial care and thereby begin to ensure that minimum staffing levels and appropriately qualified professionals are available to those diagnosed with a cancer and their caregivers.

3. Allocation of funds to universities for post-graduate courses on oncology social work including the special needs of indigenous, rural and remote, and multicultural communities.

4. Allocation of a five year capacity building program for social work to build research capacity within the profession along the model of general practice and public health initiatives such as PHCRED and PHERP already supported by the Commonwealth.

INTRODUCTION

Social Determinants of Health

In 1998 the World Health Organisation Europe stated that 'Medical care can prolong survival after some serious diseases, but the social and economic conditions that affect whether people become ill are more important for health gains in the population as a whole' [9]

The World Health Organisation cites social and economic disadvantage, unemployment, stressful social and psychological environment, the impact of early life experiences, the importance of social cohesion and dangers of social exclusion, addiction and poor food and transport as crucial factors in the health of nations[10].

The diagnosis of cancer for one family member creates an environment of stress and distress for that person and their family. The importance of social, emotional and economic support at that time cannot be underestimated in terms of its preventative effects both then and for the family's future. The NCCI (2003, p.9) makes the point that indirect costs (costs other than health costs) are 'unmeasured and often ignored' and 'are generally much greater than the costs of treatment'[11]. A USA study of elderly patients with cancer estimated the cost of informal caregiving to be $1200 per patient. Transport costs in Australia provide an inequitable burden for patients who do not live near major tertiary cancer centres.

The Importance of Social Connection

The importance of social connectedness was first confirmed in the 1970's with a series of highly influential papers [12] [13]. Intensive theoretical research into social support then created taxonomy, with three distinctive components – information, emotional support and practical care (instrumental)[14]. Population studies in the USA and Europe during the same period measured the characteristics of social ties to evaluate possible relationships with disease and demonstrated those with low social support and loose social ties risked

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[9] Wilkinson, R. & Marmot, M., eds. 1998, Social Determinants of Health: The Solid Facts, World Health Organisation Europe pg 9.

[10] Ibid

[11] Clinical Oncology Society of Australia, The Cancer Council of Australia & The National Cancer Control Initiative, 2003, Optimising Cancer Care in Australia: Executive Summary, Recommendations, Action Items, Melbourne, February.

[12] Cassel, J. (1976) The contribution of the social environment to host resistance: the Fourth Wade Hampton Frost Lecture. [Review] [43 refs]. American Journal of Epidemiology **104**, 107-123.

[13] Cobb, S. (1976) Social support as a moderator of life stress. Psychosomatic Medicine **38**, 300-314.

[14] House, J.S. and Kahn, R.L. (1985) Measures and Concepts of Social Support. In: Cohen, S. and Syme, S.L. (Eds.) Social Support and Health, pp. 83-108. New York:Academic Press Inc.

earlier death [15] [16] [17] [18] [19] [20]. During the 1990's cancer clinical studies confirmed the link between social isolation and earlier death [21] [22]. Women with breast cancer had high mortality risk if they lacked a social network[23]. In Australia, a study of Canberra patients with a range of cancer disease in an advanced stage lived longer if they had four or more people with whom they could share their feelings[24]. One important study has examined pathways by which social networks might influence health and have found lack of emotional support was related to a higher death rate in the six months following a myocardial infarction[25].

While Australia's health status ranks among the best in the world, there are substantial inequalities within the country highlighted by the example that if all the people enjoyed similar health to those of Northern Sydney, there would be 5000 fewer premature deaths per annum in NSW.[26]

Australian and New Zealand researchers have highlighted the significance of place in rural health research suggesting it may be a determinant of health[27]. Australian researchers examining the social origins of health and well being have emphasized the importance of culture [28]. This refers to the web of meanings, beliefs, and values that define how we see the world and our place in it. Healthy cultures bind societies together, and help us makes sense of our

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[15] Berkman LF, Syme SL (1979) Social networks, host resistance, and mortality: a nine-year follow-up study of Alameda County residents. Am J Epidemiol 109: 186-204

[16] Blazer DG (1982) Social support and mortality in an elderly community population. Am J Epidemiol 115: 684-694

[17] House JS, Robbins C, Metzner HL (1982) The association of social relationships and activities with mortality: prospective evidence from the Tecumseh Community Health Study. Am J Epidemiol 116: 123-140

[18] Kaplan GA, Salonen JT, Cohen RD, Brand RJ, Syme SL, Puska P (1988) Social connections and mortality from all causes and from cardiovascular disease: prospective evidence from eastern Finland. Am J Epidemiol 128: 370-380

[19] Orth-Gomer K, Johnson JV (1987) Social network interaction and mortality. A six year follow-up study of a random sample of the Swedish population. J Chronic Dis 40: 949-957

[20] Seeman TE, Kaplan GA, Knudsen L, Cohen R, Guralnik J (1987) Social network ties and mortality among the elderly in the Alameda County Study. Am J Epidemiol 126: 714-723

[21] Reynolds P, Kaplan GA (1990) Social connections and risk for cancer: prospective evidence from the Alameda County Study. Behavioral Medicine 16: 101-110

[22] Brummett BH, Barefoot JC, Siegler IC, Clapp-Channing NE, Lytle BL, Bosworth HB, Williams RB, Jr., Mark DB (2001) Characteristics of socially isolated patients with coronary artery disease who are at elevated risk for mortality. Psychosom Med 63: 267-272

[23] Hislop TG, Waxler NE, Coldman AJ, Elwood JM, Kan L (1987) The prognostic significance of psychosocial factors in women with breast cancer. J Chronic Dis 40: 729-735

[24] Burns CM, Craft PS, Roder DM Does emotional support influence survival? Findings from a longitudinal study of patients with advanced cancer. 2004. Supportive Care in Cancer. Online date of publication 7 December 2004.

[25] Berkman LF, Leo-Summers L, Horwitz RI. Emotional support and survival after myocardial infarction. A prospective, population-based study of the elderly. Ann.Intern.Med. 1992;117:1003-9.

[26] Sainsbury, P & Harris E: Understanding the causes of health inequalities: incorporating persona, local, national, and global perspectives. 2002 NSW Public Health Bulletin Vol 13, No 6.

27 Dixon J & Welch N Researching the Rural-Metropolitan Health differential Using the 'Social Determinants of Health". Aus.J.Rural Health (2000) 8.254-260

28 Eckersley, R, Dixon J, Douglas B (editors) The social origins of health and wellbeing. 2001 . Melbourne. Cambridge University Press.

lives[29]. Further, for those with serious illness, health and community services provide the glue that enable people now to spend most of their time at home[30]. Lewis and Leeder from the University of Sydney emphasized that when caring becomes a primary task of health services, it binds the sick and disabled to their community in the face of their alienation from everyday life, and forestalls a sense of abandonment. [31]

Social work is in the position to link the social and medical in health care. It recognizes that social support is a key factor in health [32] [33] [34] in preventing illness and in recovering from or living with ill-health[35] [36] [37]. Social workers bring a ‘uniquely social dimension to the delivery of services in health care’[38] as it is their core work to address these issues with individuals. Their training ensures they have the capacity to listen to the individual stories of people in distress, assist them to identify their problem, help them make meaning of their experience while exploring with them sources of support.

The relationship of social capital and public expenditure in Australia has been poorly understood in the last few decades as governments have based their policy initiatives on past experience rather than future needs, with an emphasis on ‘microeconomic reform’. The impact on human services has been misguided with attempts to let market forces determine appropriate levels of services[39]. The National Medical Health and Research Council have however recently sought, from the Australian research community, ideas in preventative healthcare and for strengthening Australia’s social and economic fabric. Despite the overwhelming evidence of the importance of social connection, medical practitioners have few effective strategies for identifying those at social risk of isolation, or in considering the potential of community development strategies for addressing these issues. The Australian Division

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29 Eckersley, R Culture, health and wellbeing in Eckersley, R, Dixon J, Douglas B (editors) The social origins of health and wellbeing. 2001. Melbourne. Cambridge University Press pg 51-70.

30 Burns CM, Dixon T, Smith WT, Craft PS “Patients with advanced cancer and family caregivers’ knowledge health and community services, in a longitudinal study”. 2004. Health and Social Care in the Community. Volume 12 Issue 6 Page 488

31 Milton J Lewis and Stephen R Leeder, "Where to from here? The need to construct a comprehensive national health policy." Australian Health Policy Institute. Commissioned Paper Series 2001/01

32 Berkman, L. F. 1985, "The Relationship of Social Networks and Social Support to Morbidity and Mortality," in Social Support and Health, S. Cohen & S. L. Syme, eds., ACADEMIC PRESS, INC., New York, pp. 241-262.

33 Cobb, S. 1976, "Social support as a moderator of life stress", Psychosomatic Medicine, vol. 38, pp. 300-314.

34 Berkman LH & Kawachi I: Social Epidemiology, 1st Edition. New York :Oxford University Press. 2000

35 Maunsell E, Brisson J, Deschenes L. “ Social support and survival among women with breast cancer”. Cancer 1995; 76:631-7

36 Krumholz HM, Butler J, Miller J, Vaccarino V, Williams CS, Mendes de Leon CF et al. “Prognostic importance of emotional support for elderly patients hospitalised with heart failure”. Circulation 1998; 97:958-64.

37 Williams, S. and Kent, G. (1996) Patients' disclosure of a diagnosis of cancer: issues in obtaining social support. Journal of Cancer Care 5, 135-139.

38 Schofield, V., 2001, ‘Health social work’, in New Zealand Social Work: Contexts and Practice, Ed M, Connolly, Oxford University Press, Auckland, New Zealand. P 156.

[39] Quigan J, Social capital and public expenditure in Australia, in 2002 NSW Public Health Bulletin Vol 13, No 6

of General Practice in recently submitting its ideas to the NHMRC drew attention to the potential role of social work in general practice as follows:

"Social support: GP referrals to social workers

> …. The management of chronic illness frequently also relies upon the support of a family caregiver. Large numbers of Australians are involved in care-giving: between 120 and 170 households per thousand are involved with around 50 per thousand intensively so at any one time[40] [41]. Principal or primary carers carry out their roles within a more extensive network of family and friends who provide a good deal of secondary support. Their health and well-being is now being studied[42]. The role of the carer in a triad of care between the physician, the patient and family caregivers is being discussed anew in the literature. Identification of a health professional with communication skills in psychosocial assessment, family dynamics and health liaison will prove of increasing assistance as ambulatory care in the tertiary sector impacts on general practice. Although a number of initiatives are starting to look at GP referrals to psychologists and other allied health professionals, social workers are still underutilised in this regard. Yet, their contribution and ability to act as a bridge between health sectors, health and social services, and health and family welfare, has been well established in the USA and in Australia.
>
> A project to look at psychosocial assessment, coordination of services, and indicators for referral to social workers as members of the multidisciplinary team in General Practice may be of value."

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[40] Schofield, H.L., Herrman, H.E., Bloch, S., Howe, A. and Singh, B. (1997a) "A profile of Australian family caregivers: diversity of roles and circumstances". Australian & New Zealand Journal of Public Health **21**, 59-66.

[41] Howe, A.L., Schofield, H. and Herrman, H. (1997) "Caregiving: a common or uncommon experience?" Social Science & Medicine **45**, 1017-1029.

[42] Herrman, H., Singh, B., Schofield, H., Eastwood, R., Burgess, P., Lewis, V. and Scotton, R. (1993) "The health and wellbeing of informal caregivers: a review and study program". Australian Journal of Public Health **17**, 261-266.

SOCIAL WORK ROLE

The central emphasis of the social work role is on enhancing the reciprocal relationship of the person within their environment. It is concerned with generating a macro and micro perspective. The goal is not only to ensure that people are able to access existing resources but also to change environmental structures and constraints that hinder optimal access. It is also concerned with 'how physical, psychological and social difficulties and differences affect a client's sense of identity and feelings of competence, self-esteem and well-being' [43].

At the micro level a problem and capacity focused approach is equally important. Solving problems with a client in crisis is essential to well being and carries an ethical imperative. However, more than simple answers to current problems are required and social workers focus also on building client strengths and changing situations so that future problems are avoided and meaningful lives are developed and enjoyed [44].

Four key types of practice models are taught in health social work: the membership model, psychodynamic/existential model, cognitive-behaviourist model of practice, and the adaptation model[45]. As social workers gain practice, they develop heuristic reasoning[46] and integrate their early training frequently blending their approaches in response to patient need [47] [48] [49] [50]

Membership Model: In brief, the membership model grew out of the social connection literature and was formally discussed in social work by Falck and Carlton in their focus on social membership as a defining attribute of human beings[51] [52] [53] Hartman's family systems theory stressed the need to evaluate family functioning[54].

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[43] Van Heugten, K., 2001, 'Social work: It's role and task', in New Zealand Social Work: Contexts and Practice, Ed M, Connolly, Oxford University Press, Auckland, New Zealand.

[44] McMillen, J,C., Moris, L.,& Sherraden, M. 2004, 'Ending social work's grudge match: Problems versus strengths' Families in Society: The Journal of Contemporary Social Services, vol.85, no.3, July –September.

[45] CM Burns Psychosocial needs of patients in Australia diagnosed with cancer: towards evidence based practice. A review of the literature. Masters Thesis. University of Sydney. October 2000.

[46] Feinstein, A. R. 1999, "Multi-item "instruments" vs Virginia Apgar's principles of clinimetrics", Arch.Intern.Med., vol. 159, no. 2, pp. 125-128.

[47] Scott, D. (1990) Practice wisdom: The neglected source of practice research. Australian Social Work

[48] Goldstein E. (1995) Ego Psychology and Social Work Practice, New York: Free Press.

[49] Goldstein H(1990) The knowledge base of social work practice: Theory, wisdom, analogue, or art? Families in Society -in-Society.

[50] Carlton, T.O., Falck, H.S. and Berkman, B. (1984) The use of theoretical constructs and research data to establish a base for clinical social work in health settings. Soc. Work. Health Care **10**, 27-40.

51 Falck H.S. (1988) Social Work: The Membership Perspective, New York: Springer.

Psychodynamic/Existential Model: The psychodynamic/existential model of practice is grounded in Rogerian counselling first introduced by Carl Rogers in the 1940's and emphasises a person centred approach that provides unconditional positive regard and an empathic therapeutic encounter[55]. Social work theorists have subsequently stressed the need that patients can have to explore their existential plight when faced with their mortality[56]. Narrative theory has in recent times offered a new framework for evolving practice to which many women in particular have responded positively[57] [58].

Cognitive-Behaviourist Model: The cognitive-behaviourist model of practice introduced independently in three continents during the 1950's emphasizes adaptation. One of the individual's important resources, their cognitive development, is harnessed in the therapeutic situation to assist them in dealing with feelings and psychological states. The fundamental goal has a twin orientation – of firstly assisting individuals appraise their situation and secondly help them to cope with it. People suffering from anxiety and depression have been found to respond most effectively to this approach. Three psychological theories underpin the model of practice – Ellis' rational-emotional therapy; Beck's cognitive therapy; and Meichenbaum's stress-inoculation training[59] [60] [61].

Adaptation Model: The adaptation model: ecosystem has been the most significant influence in social work practice in the past two decades[62]. Its originality lies in its use of ecology as a practice metaphor, thus moving away entirely from the practice concerns of psychopathology that had dominated the profession for most of the twentieth century. The model breaks sharply from the medical-disease metaphor that locates people's problems within the person. In contrast, the ecological perspective provides an adaptive, evolutionary view of human beings in constant interchange with all elements of their environment. Goodness-of fit, following on from Darwin's concept of fit, is a key element in the conceptual framework. It is when there is an upset in the usual adaptive balance of goodness-of-fit in the complex transactions between people and their environments that stress is created.

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52 Carlton, T.O. (1990) Genetics, group life, and social work with groups in health care practice: a need for knowledge and skill. Health Soc. Work. 15, 83-86.

53 Falck, H.S. (1987) Social and psychological care before and during hospitalization. Soc. Sci. Med. 25, 711-720.

54 Hartman A. and Laird J (1983) Family Centred Social Work Practice, New York: Free Press.

55 Carl R. Rogers. On becoming a person; a therapist's view of psychotherapy. 1961 Boston: Houghton Mifflin.

56 Siporin, M. (1985) Current social work perspectives on clinical practice. Clinical Social Work Journal

57 Williams, J.B.W. and Lanigan, J. (1999) Practice guidelines in social work: A reply, or "our glass is half full.". Research on Social Work Practice -on-Social-Work-Pract.

58 Witkin, S.L. (1991) Empirical clinical practice: A critical analysis. Social Work

59 Ellis A.et al (1977) Rational Emotive Behaviour Therapy, Div of Counselling.

60 Beck A.T. et al (1976) Cognitive Therapy and the Emotional Disorders, New York: international uni Press.

61 Meichenbaum D (1985) Stress Innoculation Training, New York: Pergamon Press.

62 Germain C.B. and Gitterman.A (1980) The Life Model of Social Work Practice, New York: Colombia University Press.

Thus it is the stresses in living that provide the social work profession with a unique and responsive social purpose: to strengthen the adaptive capacities of individuals and primary groups, and influence environments so that transactions promote growth and development. The model provides a sophisticated structure and higher order capacity for successful use in the health care setting. Its applicability to the Australian cancer setting has been explored and evidence from the international medical literature supporting its conceptual foundations has been presented [63].

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[63] Burns CM Proposed Clinical Model of Psychosocial Cancer Care The Canberra Hospital 6th Scientific Meeting, 2001.

KEY ISSUES IN THE CANCER CONTINUUM

Cancer involves a changing, complex set of conditions and key concerns are:

- 'The threat to survival and the physical, emotional and intimacy issues that are involved
- The changes in values and outlook on life and the spiritual and philosophical aspects of the experience
- The social, financial and physical resources regarding the costs of cancer…'[64].

ONCOLOGY SOCIAL WORK

Brief History of Involvement

Social Workers have been working alongside cancer physicians and cancer nurses for over thirty years. They were admitted to the Clinical Oncological Society of Australia in 1985 and have provided sessions in their annual scientific meetings since that time. Social Work research, mainly qualitative, has been innovative and opened new areas of study and practice. Examples are:

- 1987 Cancer support groups and evaluating psychosocial outcomes.
- 1989 Kim Hobbs – patients understanding of disease and treatment and implications for information. Cathy Marshall – Homecare services.
- 1990 A session on working with culturally different clients.
- 1991 Suzanne Baxendal and Prasuna Reddy - Impact of Cancer on the Family.
- 1993 the Social Work Group invited an overseas speaker – Professor Leslie Fellowfield, who introduced workshops on communicating with the cancer patients that has become a core concern in COSA.
- Legal issues in best caring for oncology patients and their families (C Holland 1993-4)
- 1994 Victoria Jones and Kate Burns reported on the first cancer consumer group
- 1995 – Lucinda Daly – presented on the Special Needs of Aboriginal Patients.

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[64] Stearns, N.M., Lauria, M.M., Hermann, J.F., & Fogelberg, P.R., 1993, Oncology Social Work: A Clinician's Guide, The American Cancer Society.

Since that time many and various expansive definitions have been added to the term psychosocial cancer care. COSA papers continue to evidence this:

- The needs of families with dependent children (C Holland 1996 - 2002,
- The use of expansive therapeutic programs (C Holland 2002).
- Sexuality issues for patients and partners (K Todd and C Holland 2004)

Clinical Practice

In cancer care, patient suffering – the fear of psychic disintegration – demands that clinical professionals respond with empathy and insight. There is a need to acknowledge the duality of the cancer experience namely, immediate presenting problems surrounding social and treatment issues, together with the underlying existential plight of living with uncertainty, and the ever-present awareness of possible mortality[65]. Patients respond in a myriad of different ways. Clinical skill lies in the judgment of the professional to identify which aspects of practice are pertinent to the individual situation.

A health promotion approach recognises that an emotional response to a cancer diagnosis is normal. Addressing distress and social, physical, spiritual and environmental needs through the cancer journey improves quality of life for the patient and their family and their capacity to accept and endure treatment. Oncology social workers therefore have a commitment to screening, assessment and varied intervention strategies. These allow for the identification of, and response to, current and potential future problems as patient and caregivers' psychosocial needs change as a result of the disease process and treatment [66].

Screening

Social workers in both the USA and parts of Australia have undertaken psychosocial screening of patients in order to identify those with social, economic, financial and transport need, and those with psychological and emotional distress [67] [68][69] [70] [71]. Two instruments in the USA have been proven

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65 Muzzin LJ et al The experience of cancer (Review) (125 refs).1994. 4 Social Science and Medicine 38 1201 – 1208.

66 Zabora, J., 2004, 'A problem solving model: An innovative method to C.O.P.E. with challenges inpatient and family care', Working with Challenging Situations: Oncology Social Work in the 21st Century, Canberra, November.

67 Berkman, B., Bedell, D., Parker, E., McCarthy, L.,Rosenbaum, C. (1988) Preadmission screening: an efficacy study. Soc.Work.Health Care 13, 35-50.

68 Berkman, B., Rehr, H. and Rosenberg, G. (1980) A social work department develops and tests a screening mechanism to identify high social risk situations. Soc.Work.Health Care 5, 373-385.

69 Epstein, J., Turgeman, A., Rotstein, Z., Horoszowski, H., Honig, P., Baruch, L. and Noy, S. (1998) Preadmission psychosocial screening of older orthopedic surgery patients: evaluation of a Social Work Service. Soc.Work.Health Care 27, 1-25.

70 Saltz, C.C., Schaefer, T. and Weinreich, D.M. (1998) Streamlining outpatient geriatric assessment: essential social, environmental and economic variables. Social Work in Health Care 27, 1-14.

to be of substantial benefit for screening patients with cancer and have been recommended for use here subject to validation on our unique population[72] [73] [74].

Interventions: Assessment

Interventions begin with an assessment of a client's issues and needs. Some interventions, such as financial issues, may be brief. Others, such as counselling, may continue throughout a cancer journey particularly if the journey is short, or occur periodically at crisis points when specific issues need to be addressed [75]. Interventions are likely to be most effective when clients and social workers are knowledgeable about the comprehensive nature of needs within a cancer setting, and social workers use their skills to respond competently and flexibly.

Much work has been done on the importance of communication skills in cancer care. Australian clinicians and researchers have provided world leadership in the past decade[76]. [77]The fear held by many doctors that confirmation of a cancer diagnosis would harm a patient has been laid to rest in western society. Early studies in Australia and the USA confirmed most people want to know as much as possible about their disease[78]. Studies in the ensuing twenty years have found patients have often been dissatisfied with the amount and quality of information they receive [79] [80] [81]. In a recent review of patients newly diagnosed with cancer, the importance of information giving was stressed enabling patients to gain control, reduce anxiety, improve

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72 Zabora J. BrintzenhofeSzoc K. Jacobsen P. Curbow B. Piantadosi S. Hooker C. Owens A. Derogatis L. A new psychosocial screening instrument for use with cancer patients. [Journal Article] Psychosomatics. 42(3):241-6, 2001 May-Jun.

73 Paterson AG. Trask PC. Schwartz SM. Deaner SL. Riba M. Holland J. Fleishman SB. Breitbart W. Screening and treatment of distress.[see comment]. [Letter] Journal of Consulting & Clinical Psychology. 69(2):339, 2001 Apr.

74 Holland J, Sepulveda C, Zabora J, Katib Jamal, Grassi L, et al Psychosocial distress: the 6th Vital Sign. From Identification to Intervention. Abstract 117 at 7th International Psych Oncology Conference. August 2004.

75 (Stearns et al, 1993).

76 Tattersall, M. H., Butow, P. N., & Clayton, J. M. 2002, "Insights from cancer patient c communication research", Hematol. Oncol. Clin. North Am., vol. 16, no. 3, pp. 731-743.

77 Tattersall, M. H., Butow, P. N., & Ellis, P. M. 1997, "Meeting patients' information needs beyond the year 2000", Support. Care Cancer, vol. 5, no. 2, pp. 85-89.

78 Reynolds, P.M., Sanson-Fisher, R.W., Poole, A.D., Harker, J. and Byrne, M.J. (1981) Cancer and communication: information-giving in an oncology clinic. British Medical Journal Clinical Research Ed . 282, 1449-145.

79 Butow, P. N., Dunn, S. M., & Tattersall, M. H. 1995, "Communication with cancer patients: does it matter? [Review] [50 refs]", Journal of Palliative Care, vol. 11, no. 4, pp. 34-38.

80 Jenkins, V. A., Fallowfield, L J., & Poole, K. 2001, "Are members of multidisciplinary teams in breast cancer aware of each other's informational roles?", Qual.Health Care, vol. 10, no. 2, pp. 70-75

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compliance with treatment, help them create realistic expectations, promote self care and participation, and generate feelings of safety and security[82].

Studies have now found that too little information has a number of effects amongst which are dissatisfaction with care, reduced well being including elevated anxiety and depression and a greater likelihood of pursuing alternative therapies[83].

Social work interventions are based on the development of a therapeutic relationship with clients and carers. When other things are equal, there is evidence that the nature of the relationship in counselling is a more important determinant of effectiveness than the clinical strategy employed[84]. The reflective/reflexive practice of social work, whereby the relationship between client and clinician is counted as an intervention in itself, also contributes to client health[85] [86].

Interventions: Individual Counselling

Two early Australian studies confirmed that patients concerns were focused upon the side effects of treatment including nausea, emesis, general apprehension, through to fatigue and their functional and social aspects of quality of life[87] [88]. However a recent study in France that replicated these studies found a shift in patient concerns. They now rated the impact on their family and partner as the most severe side effect (in comparison to number 10 ranking in the original study). They also gave high priority in their ratings to the effect on work and social activities including loss of sexual feeling[89].

Psychological distress has been measured systematically in many studies[90]. A major social work study in the USA confirmed the prevalence of widespread

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82 Mills ME & Sullivan K The importance of information giving for patients newly diagnosed with cancer: a review of the literature. J Clin Nurs 1999; 8: 631-42

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90 CM Burns Psychosocial needs of patients in Australia diagnosed with cancer: towards evidence based practice. A review of the literature. Masters Thesis. University of Sydney. October 2000.

psychological distress across the care continuum[91]. Thus oncology social workers in general have in the past decade worked with patient fears that centred firstly on threat to life and secondly to quality of life. These include the '"five D's" – death, disability, disfigurement, dependence and destruction of relationships'[92]

Interventions: Family Counselling

Oncology Social Workers have been acknowledging the importance of the family in cancer care since the early 1990's.[93]

Rolland's (1994) family-systems model highlights the importance of recognising the inter-relationship between family life cycle and illness and health belief systems in chronic illness in families[94]. It is crucial to be aware of the complex interweaving of developmental issues between life cycles of the illness, the individual and family.

Social workers also use a problem-solving model where 'problems are defined as specific life circumstances that demand responses for adaptive functioning … using the acronym COPE for Creativity, Optimism, Planning and Expert Information' [95] [96]. This skill based educational approach collaborates with patients and families, assisting them to understand the nature of the problems they are experiencing and direct their coping efforts at the difficult nature of those problems, the distress they are experiencing as a result, or both.

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[91] Zabora, J.R., Blanchard, C.G., Smith, E.D., Roberts, C.S., Glajchen, M., Sharp, J.W., BrintzenhofeSzoc, K.M., Locher, J.W., Carr, E.W., Best-Castner, S., Smith, P.M., Dozier-Hall, D., Polinsky, M.L. and Hedlund, S.C. (1997) Prevalence of psychological distress among cancer patients across the disease continuum. Journal of Psychosocial Oncology 15, 73-87.

[92] (Stearns, op cite, p.52).

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[95] Zabora op cite.

[96] Bucher JA. Loscalzo M. Zabora J. Houts PS. Hooker C. BrintzenhofeSzoc K. Problem-solving cancer care education for patients and caregivers. [Journal Article] Cancer Practice. 9(2):66-70, 2001 Mar-Apr

Interventions: Group Counselling

Social workers offer a variety of group opportunities in Australia. Both Victorian and South Australian social workers have discussed their benefits in international forums [97] [98] [99]. These include educational and information groups for example 'Living with Cancer'; therapeutic groups founded on for example supportive expressive therapy [100] [101] [102]or psychoneuroimmunolgy principles.

The impetus for joining support groups in early studies identified lack of appropriate support from family, friends and caregivers[103] [104]. But over time, the benefits explored in behavioural groups where relaxation, meditation or guided imagery techniques have been used has seen a wider participation.[105] [106] [107] [108]. In recent years, directly or indirectly supporting peer groups and activity-focused groups for specific disease sites has widened the opportunities for social support.[109] [110]

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[107] Burish, T.G. and Jenkins, R.A. (1992) Effectiveness of biofeedback and relaxation training in reducing the side effects of cancer chemotherapy. Health Psychology **11**, 17-23.

[108] Baider, L., Uziely, B. and De-Nour, A.K. (1994) Progressive muscle relaxation and guided imagery in cancer patients. General Hospital Psychiatry **16**, 340-347.

[109] Discussions with consumer members of various groups of which some hundreds now exist in Australia.

[110] Boesen EH, Frederiksen K, Thomsen BL, Dahlstrom K etal. Psycho-educational intervention for patients with cutaneous malignant melanoma: a replication study. J Clin Oncol 2005;23:1270-1277.

Interventions: Instrumental Support

Research since 1990 has continued to confirm that there is widespread unmet need in Australia for supportive care for patients with cancer. [111] [112] [113]

The social worker assists the patient and carers identify and utilise existing resources, obtain information and advocate for access to resources when eligibility is in question or the resources do not exist. In helping clients gain access to resources, they are able to deal more effectively with the multiple stresses that arise from cancer treatment and illness processes.

Financial services: Cancer patients tend to be younger than many other patients in the hospital setting with a disabling chronic illness[114]. They may have dual responsibilities to both dependent children and elderly parents. Frequently there are two incomes coming into the household. With the diagnosis of cancer it is common for both incomes to cease as one spouse becomes ill and the other takes up the role of carer.

For many patients they have never been reliant on any type of public support before, and their first contact with Centrelink can be confusing, humiliating and even degrading. There are numerous reasons for delays, such as, lateness by an employer in providing evidence that the employment has ceased, or the loss of an item of identification such as a birth certificate. Delays in receiving Centrelink income deplete savings, and patients sometimes present with a disconnection notice from an essential provider such as power suppliers.

Social Workers are essential in providing guidance, assistance and advocacy with Centrelink, and in assisting with applications to charitable sources such state Cancer Councils, for financial relief. Centrelink incomes can be half or even one-third the previous wages. Younger patients often move back home with parents to receive support and because they can no longer afford their rent.

Access to money is an essential value in our community and financial disadvantage can be accompanied by a sense of shame and embarrassment. Social Workers can provide the support and counselling required in this situation while facilitating the administrative processes.

At the 2004 COSA Conference a young man representing cancer patients described with much feeling the harsh and unsympathetic treatment he had received from a bank handling his mortgage. With social work assistance he

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[113] Foot G, Sanson-Fisher R. Measuring the unmet needs of people living with cancer. Cancer Forum. 19 131-135.

[114] Daly L, Oncology Social Work as a Speciality. Presented at Clinical Oncology Society of Australia. Sydney. 1989

might have been able to negotiate a reduction to interest only payments, if necessary with reference to the Banking and Financial Services Ombudsman. See advocacy.

Advocacy Services: Social Workers frequently advocate for their patients. Letters of support are regularly requested by organisations to confirm the facts given verbally or even in writing by patients. Letters are written:

- To banks regarding variations of mortgage and loan repayments.
- To superannuation funds regarding release of funds
- To creditors explaining a financial situation and requesting time to pay
- To state housing departments regarding priority housing for people forced to relocate to capital cities.
- To immigration authorities to expedite arrival of relatives for deathbed farewells or to act as carers.
- To courts to explain the situation and request delay of hearing or consideration of mitigating circumstances.
- And even to Qantas regarding compassionate fares.

Legal Services: Social Workers are often called upon to give general guidance and advice to patients regarding making a Will or Enduring Power of Attorney. They are involved when patients require Guardianship and administration, and can be consulted regarding assessment of mental competency.

Discharge Planning Services: Social workers are well placed to identify patient needs and constraints and develop a plan that collaborates with patient, family and community resources and strengths. Discharge planning brings together processes already outlined across the continuum of care. In this way social, instrumental, administrative, spiritual and emotional needs culminate in a plan for discharge from in or out patient care.

Interventions: Bereavement Care

After a death social workers may be called on to assist a family to organise and pay for a funeral, provide information regarding notification to Centrelink and applying for a bereavement package – and at the same time provide bereavement support and counselling when required. This is a typical situation to illustrate the uniquely social work contribution to patient care by providing resource information, assisting with bureaucratic processes, and using psychosocial therapies.

Interventions: Education

The Social Worker, as part of the multi-disciplinary team plays a vital role in the education of the newly diagnosed cancer patient.

The patient is faced with an enormous learning curve. Not only do they need to learn about the disease and the possible treatments, they also need to negotiate a number of issues that arise as a result of their diagnosis e.g. finances, accommodation, carer options, assistance at home.

The patient’s life is usually thrown into turmoil and it is the Social Worker with the previously described training outlined under Interventions that is best placed, not only to advocate but also to educate patients and their families, in order that they may better negotiate this “new “ environment.

In addition to this role, Social Workers in Cancer Care are often involved in a more formal education process. Social Workers are frequently presenters at *Living With Cancer Programs* where coping strategies aimed at dealing with areas such as loss and anxiety are addressed.

Furthermore at a different level, Social Workers play an important role in ongoing education of the multi-disciplinary team. It is the Social Worker who has the unique primary focus of the psychosocial needs of patients and their carers/families. It is therefore part of our role to be constantly educating other team members about grief and loss issues and crisis intervention techniques.

Social Work Services in Paediatric Oncology

The paediatric oncology experience is unique, in relation to its impact on the patient and the extended family system. As such, the oncology social work role is somewhat different to that offered to adult patients.

Over the past thirty years, improvement in paediatric cancer treatment and associated increased survival rates has seen a shift in viewing the paediatric cancer diagnosis as fatal, to being a life-threatening medical condition. Associated treatment regimens are often intense and prolonged, impacting significantly on the family system. Given family life-cycle issues, these implications can include:

Patient – diagnosis and treatment care needs, treatment compliance, developmental needs, impact of educational progress, isolation from peers, and relationships with family members, impact of self esteem and self concept, experience of treatment as a traumatic event, long-term physical and emotional effects of treatment.

Siblings – fear and concern for the sick sibling and for self, need for an appropriate developmental understanding of the cancer, loss of contact with sibling and parents related to treatment demands, loss of sense of importance of self within the family and social network.

Parents – increased parental care demands related to treatment needs, trauma related to child's diagnosis and treatment, undermining of confidence in parental role, associated loss of employment and income, impact on marital relationships, increased childcare needs for siblings, strain on family finances and practical resources.

An understanding of the unique needs of adolescents with cancer and their families is only beginning to be established, with an associated growing trend of developing separate adolescent oncology units.

An improvement in paediatric oncology survival rates has seen growth in the paediatric cancer survivor population. It has been estimated that 1:1000 young adults in the community will be a survivor of childhood cancer. There can be physical, cognitive and psychosocial consequences associated with being a paediatric cancer survivor, and thus this cohort requires ongoing monitoring and support.

The Paediatric Oncology Social Work Role

The social work role is integral to the provision of support related to the paediatric cancer experience. All paediatric oncology units in Australia have a number of social work staff on their teams, working with the patient, siblings and parents to address both practical and emotional needs. Utilising a Family Centred Approach, social workers generally carry out a psychosocial assessment at diagnosis, identifying family background details, pre-existing family challenges, support networks and resources available, coping strategies utilised by families, and challenges related to the cancer diagnosis, treatments and prognosis. In collaboration with the family, areas requiring support can then be targeted and addressed. Social work staff members continue to work with families as appropriate during the course of the cancer experience, with intense periods of contact often being required at diagnosis, during transplant, at relapse, during palliation and after death.

In carrying out this role, social workers require a vast working knowledge of areas including family systems, child development, trauma, chronic illness, mental health, loss and grief, child protection and cultural issues.

The social worker provides a number of services including assessment, counselling (individual patient, parent or other family member, family and group), education, advocacy and referral. Paediatric oncology social workers are increasingly initiating research into the psychosocial impact of childhood cancer.

Palliation and Bereavement Care in Paediatric Oncology

The death of a child has been described as the most traumatic experience a family can suffer[115]. Studies have shown that parental grief is more intense in nature and for a greater duration[116]. Bereavement support to families, whilst a child receives palliative care and following the child's death has been associated with less complicated grief experiences[117]. Health care professionals are in a prime position to support parents and other family members during a child's illness and play a vital role in bereavement follow-up of families where a child has died [118] [119] [120] [121] [122]. As cancer remains one of the leading causes of childhood death, palliation and bereavement care remain a core service of the paediatric oncology unit.

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[115] Johnson, L. C., R. B, et al. (1993). "The Development of a Comprehensive Bereavement Program to assist Families Experiencing Pediatric Loss." Journal of Pediatric Nursing: 146-152.

[116] Rando, T. A. (1983). "An investigation of grief and adaptation in parents whose children have died from cancer." Journal of Pediatric Psychology 18(1): 3-20.

[117] Ibid

[118] Johnson op cit.

[119] Neidig, J. and P. Dalgas-Pelish (1991). "Parental grieving and perceptions regarding health care professionals' interventions." Issues in comprehensive pediatric nursing 14: 179-191.

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Preferred Model of Practice

There are two guiding principles central to ensuring effective oncology social work practice and better patient outcomes in terms of psychosocial care.

Patient Centred Care and an Integrated Cancer Service: In order for care to be patient centred and integrated it is essential that integration with a person's life outside of the illness or medical treatment is accepted as a core service principle. This must include understanding and consideration of a person's role and obligations within family and community (particularly, but not only, for Indigenous Australians) and his or her spiritual, employment, legal, financial, custodial and housing needs.

Patients and families will, in collaboration with the oncology social worker, assess the impact of these elements on their health, and vice versa, and take steps to address them. In this way social workers provide care that meets key objectives in patient centred care, because it is tailored to meet specific psychosocial issues nominated by individual cancer patients and their carers and minimises the psychosocial impact of cancer.

Integrated Multi-disciplinary Care: Integrated multi-disciplinary care is the first recommendation in 'Optimising Cancer Care in Australia[123]. Definitions of multi-disciplinary are often used to mean different things and this can be confusing. Here it is used to denote clinical collaboration between allied health, nursing, medical and other health professionals.

It is important to be aware however that 'a culture of collaboration does not just happen. It must be formed and fashioned by many hands'[124]. Strengths in a collaborative approach include a sharing of interdisciplinary expertise that creates better understanding of patient and family needs and resources and increasing the options and skills available to find solutions to problems. It also provides professional support and shares the responsibility in making complex ethical decisions [125].

There are also impediments to be overcome because of the introduction of a variety of personal and professional perspectives into the decision making process. Abramson and Mizahi cite role confusion, role competition and turf issues as potentially problematic because of the sacrifice of autonomy in teamwork [126]. Similarly, tensions may arise from the differing values, goals and culture of each profession. Issues of power and gender need to be addressed to ensure effective integrated multi-disciplinary care.

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[123] NCCI, 2003 op cite.

[124] Seaburn, D.B., Lorenz, A.D., Gunn, W.B., Gawinski, B.A. & Mauksch, L.B., 1996, Models of Collaboration, Basic Books, New York. Pg 26.

[125] Abramson & Mizrahi T, 1996, 'When social workers and physicians collaborate: Positive and negative interdisciplinary experiences', Social Work, vol.41, no.3, pp.270-281.

[126] Abramson and Mizahi, T., 1996 op cite

Integrated multi-disciplinary care is beneficial to patients and families when members understand that professional tensions will arise and are healthy. Team members need to learn ways to recognise tensions and agree upon consistent strategies to manage them.

Multidisciplinary approach Paediatric Oncology Social Work: Best practice dictates that support is provided to the 'family unit' in relation to a paediatric cancer diagnosis. To achieve this standard, all Australian paediatric oncology units adopt a multi-disciplinary approach to care. Teams involve medical and nursing staff, and a cast of allied health professionals including social workers, occupational therapists, psychologists, music therapists, child activity coordinators, and hospital school staff. This collaborative model works to minimise the short term and long term impact the paediatric cancer experience on the patient, siblings, parents and extended family members.

CAREGIVERS AND CANCER CARE

Caregivers play a central role in cancer care. Their centrality is recognized by the oncology social worker, as are their needs also for psychosocial support.[127] This section addresses their role and the unique issues they confront where there is a cancer diagnosis.

Family Caregivers and Cancer Care

There are unique features amongst the cancer caregiving population. Reviewing the cancer studies it was found that between 60-70% of caregivers are spouses, 20-25% are adult daughters, and the remainder are either parents caring for ill children, or other family/and friends caring for patients who are unmarried. Around one third of caregivers are male in the cancer population, a higher figure than in the general caregiver population in which women predominate[128].

Early gerontology research identified caregiver burden, documented social, psychological and physical health consequences and described caregivers as 'hidden patients' [129]. A groundbreaking social work study however helped shift the research focus to caregiver well being. They argued that by using well-identified generic categories of physical health, mental health, social participation and financial resources, normative comparisons could be made[130]. They found that caregivers were more likely to experience problems with mental health and social participation.

Early clinical studies in paediatric oncology had emphasised the role of the family as integral team members. When USA studies commenced in adult cancer groups to examine the impact on the family, eleven separate issues were identified. They can be clustered into four broad domains: health status, information needs, social support and psychological adjustment[131]. A review of communication in the cancer setting highlighted the families' main problems as those of concealment of feelings, acquiring information and coping with helplessness[132]. The family's key problem was confirmed as the need for

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[127] Blanchard, C. G., Albrecht, T. L., & Ruckdeschel, J. C. 1997, "The crisis of cancer: psychological impact on family caregivers", Oncology (Huntingt), vol. 11, no. 2, pp. 189-194.

[128] Kate Burns, Wayne Smith, Paul Craft: Cancer Family Caregiving: Findings from an Australian Study. August 2001. Report to the Commonwealth Department of Health and Ageing, Palliative Care Program. Canberra.

[129] Oleson, V.L (1989) Caregiving, ethical and informal: emerging challenges in the sociology of health and illness. [Review} [59refs]. Journal of Health and Social Behaviour **30** 1-10

[130] George, L.K. and Gwyther, L.P (1986) Caregiving well being: a multidimensional examination of family caregivers of demented adults. Gerontologist **26**, 253-259

[131] Lewis, F. M. 1986, "The impact of cancer on the family: a critical analysis of the research literature", Patient Education & Counselling, vol. 8,no. 3, pp. 269-289.

[132] Northouse, P. G. & Northouse, L. L. 1987, "Communication and Cancer: Issues confronting patients, health professionals, and family members", Journal of Psychosocial Oncology, vol. 5,no. 3, pp. 17-45.

medical information in regard to cancer and the course of the disease [133]. All studies identified the marked difficulty in both obtaining information and understanding what was happening, and some specifically noted family difficulty in making contact with the physician. Access to information remains a problem in some cancer services worldwide. However, marked changes have occurred in the culture of Australian cancer services and family members now often attend clinical consultations[134]. But it is more likely to happen with spouses, and the 30% of patients who rely on others, mostly adult daughters, are less likely to be accompanied[135]

Psychological exploration of the dynamics of the care situation have identified that personality factors can determine caregivers' perceptions of their experience for example, optimism has been confirmed as a personality trait that independently predicts outcomes[136]. Understanding caregiver well being is being helped by self-efficacy theory demonstrating how beliefs regulate human functioning[137] [138]

Feminist scholarship has also provided a stimulus to an expansion of the framework for examining caregiving. Hidden from gaze until recently, how the caregiver defines, acts on and organizes around illness and health has now begun to be examined[139]. Oleson outlined food preparation, emotional management, monitoring health practices and teaching as productive work in caring for people who were ill. With appropriate information, patient/family decision-making can ensure the tasks of assistance with self-care and the conducting of medical care are blended with those of the health team[140].

Family matters that embrace emotional care tasks; financial management and the provision of social support have thus begun to be understood as structured efforts that need to be tailored to individual patient and family need[141].

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[133] Houts, P. S., Rusenas, I., Simmonds, M. A., & Hufford, D. L. 1991, "Information needs of families of cancer patients: a literature review and recommendations", Journal of Cancer Education, vol. 6,no. 4, pp. 255-261.

[134] Catherine M Burns, Wayne T Smith, Tracy Dixon, Paul S Craft, Dorothy Broom, Caregiver Knowledge of Treatment Intent in a Longitudinal Study of Patients with Advanced Cancer, (See Editorial 617-619) Supportive Care in Cancer, 11: 629-637

[135] Catherine M. Burns, Tracy Dixon, Wayne T Smith, Paul S Craft, Patients with advanced cancer and family caregivers knowledge of health and community services in a longitudinal study. Health and Social Care in the Community. **12** (6) 488-503

[136] Stiefel, F. 1995, Flims 95: the united psychotherapeutic interventions of psycho- oncology [editorial], Supportive Care in Cancer, vol. 3,no. 4, pp. 215-216.

[137] Bandura A Social foundations of thought and action: a social cognitive theory. Prentice-Hall series in social learning theory. 1986

[138] Bandua A Self-Efficacy. The exercise of control. 1997

[139] Ungerson, C. 1995,"Gender, Cash and informal Care: European Perspectives and Dilemmas, Journal of Social Policy, vol. 24, pp. 5-31.

[140] Oleson VL op cit.

[141] Nijboer, C., Tempelaar, R., Sanderman, R., Triemstra, M., Spruijt, R. J., van den, & Bos, G. A. 1998, Cancer and caregiving: the impact on the caregiver's health. [Review] [66 refs], Psycho-Oncology, vol. 7,no. 1, pp. 3-13.

Preliminary evidence from a very recent meta—analytic investigation of the relationship between the psychological distress of cancer patients and their caregivers, confirms a positive association between patient and carer psychological distress (r=0,35, p, 0.0001). It indicated that patients and carers did not experience significantly more or less psychological distress than one another (p=0.64). The evidence suggested that early intervention with the patient and their carer could prevent later development of psychological distress in both members.[142]

Rural and Remote Patients and Their Family Caregivers

Rural health studies have identified major difference in health between rural and metropolitan Australians. Death by suicide and injury, motor vehicle accidents, asthma, diabetes and infant mortality are notably higher than those experienced in metropolitan areas.[143] While there appears to be little evidence for a rural-urban health differential in cancer and cancer risk, two recent studies in South Australia and NSW identified consistently poorer survival among rural and remote residents and recommended further study [144] [145].

This substantial disadvantage in survival could well be due to the problems of access and equity for rural/remote cancer patient and their family. A study of the needs of rural and remote women traveling to the city for breast cancer treatment confirmed they spent an average of six weeks or more away from home[146]. Only a little clinical research has been undertaken, but a series of qualitative studies by the research team[147] of Dr Pam McGrath, a social worker, has identified that transport/travel, isolation from home, family and friends, increased costs of accommodation, loss of employment opportunities because of having to relocate for block periods and major disruptions to family, work and lifestyle all group to their serious disadvantage in the Australian health system[148] [149] [150]. While tyranny of distance places a unique

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[142] Hodges, L.J., Humphris G.M., Macfarlane, G A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. Social Science and Medicine 2005. Vol 60 1-12.

[143] Australian Institute of Health and Welfare. Health in Rural and Remote Australia. Canberra: Australian Institute of Health and Welfare, 1998.

[144] Wilkinson D & Cameron K. Cancer and Cancer risk in South Australia: What evidence for a rural-urban health differential? Aust.J Rural Health (2004) **12**. 61-66

[145] Jong KE, Smith DP, Yu XQ, O'Connell DL, Goldstein D, Armstrong BK Remoteness of residence and survival from cancer in New South Wales MJA Vol 180 618-622

[146] Davis Cindy, Girgis A, Williams P and Beeney L "Needs assessment of rural and remote women travelling to the city for breast cancer treatment." 1998. Australian and New Zealand Journal of Public Health. Vol 22, 5 525-527.

[147] www.mcgrathresearch.net.au

[148] McGrath P, Patterson C, Yates P, Treloar S, Oldenburg B & Loos C A Study of Post diagnosis breast cancer concerns for women living in rural and remote Queensland. Part 1: Personal Concerns. Aust.J. Rural Health (1999). 7 34 -42

[149] Pam McGrath "Its horrendous – but really, what can you do?" Preliminary findings on financial impact of relocation for specialist treatment. Australian Health Review. Vol 23 No 3, 2000.

[150] McGrath P and Seguerra J The Patient Transit Assistance Scheme: A consumer's Perspective. Aust.J. Rural Heatlh (2000) 8, 232-238.

burden on patients, rural communities provide strong, informal network, providing substantial emotional and practical support.[151]

Social workers are well placed to identify the rural person/family, provide timely assessment of need and then provide the family with appropriate information and support to meet their needs. If early links are established with the local GP and community nurse at the time of diagnosis, they can be sustained through to post-treatment phase and coordinated care achieved.[152] For patients in the palliative phase of care, information is even more important. Recent Australian research confirms the need for health professionals to take responsibility to empower families by ensuring appropriate information is provided to them[153].

Accommodation Facility for Rural Patients in SA: Greenhill Lodge (GHL) is owned and operated by The Cancer Council SA. It provides accommodation and support to rural patients traveling to Adelaide for cancer treatment/health care services. Guests are predominately from SA but also include rural Victoria, NSW and those from the Northern Territory. People traveling more that 100km from Adelaide are eligible for reimbursement through the Patient Assistance Transport Scheme. Guests staying at GHL usually stay for 6 –8 weeks for radiotherapy or are here for chemotherapy treatment, follow up visits or investigation.

In 2002 this service was expanded to include a Coordinator Support, Accommodation Facility. This position was established in line with recommendations from various reports including Optimising Cancer Care in Australian and the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer to provide psychosocial support to people with cancer and their families[154].

The position provides support to guests and their carers including, information access to and coordination of services, counselling and advocacy. Two important issues have emerged for the coordinator of this service in the last two years:

- Complexities around the national insurance system. Payments and reimbursements are organised in such a way that many people can have cash flow problems
- Clarity of information in regard to treatment choices.

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[151] McGrath P, Patterson C, Yates P, Treloar S, Oldenburg B & Loos C A Study of Post diagnosis breast cancer concerns for women living in rural and remote Queensland. Part 1: Support Issues. Aust.J. Rural Health (1999). 7 43-52

[152] McGrath Post-treatment support for patients with haematological malignancies: findings from regional, rural and remote Queensland. 2000 Australian Health Review. Vol 23, No 4 142-150

[153] Wilkes, L White, K. & O'Riordan L Empowerment through information: supporting rural families of oncology patients in palliative care. Aust.J.Rural Health (2000) **8**, 41-46.

[154] National Health and Medical Research Council "Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer" 2000. AGPS. Canberra

This position is currently filled on a 20-hour per week basis. Within this position, there is also the role of coordinator of volunteers for the accommodation facility. The purpose of this program is to provide social activities for guests and their carers. Most people are far from home at a time of acute stress and the aim is to provide a supportive community environment.

The quarterly reports indicate that the main areas of need for guests are psychosocial and emotional support, financial assistance and practical supports.

Transport

The patient assistance transit scheme was administered at a federal level, but was transferred to the States in 1967. As a consequence they are now a hotchpotch of inequity, poorly managed, with budget lines that are not adjusting sufficiently rapidly to respond to the growing numbers of cancer patients and their families[155]. As a consequence the schemes are not widely promoted and a myriad of bureaucratic detail flails the already strained nerves of patients and their families.

The schemes can disadvantage those who fall outside the eligibility criteria, for example, in Victoria people quality for assistance when they live more than 100 kms one way from treatment, in NSW it is 200kms and this is variable across Australia. If those who fall even 5 kms under the limit there is no entitlement to assistance. A person therefore could be driving 95 kms a day each way for 4 weeks of cancer treatment and receive no financial aid. The social worker is often the one who tries to find other financial support options for this group. For those few oncology social workers based in regional settings, probably less than a dozen throughout the whole of Australia, there is the advantage they offer of knowing their local and regional support options.

Outreach support is also important here. The social worker often provides a lot of support and planning to the rural person while they are still receiving treatment, so they can be as well organized as possible before having to return home. This may be in the form of researching the local region to locate potential sources of support. It may be ‘educating/up skilling’ the local generalist nurse or counsellor on the individual needs of the cancer patient and preparing them for their return. Many city and regional based cancer social workers would find that they are often providing longer-term support/or follow up to the rural/isolated person, as there is nothing appropriate locally for that person. Tele counselling is an important option available. Tele-group support is a more recent phenomenon, which social workers are able to employ in their kit of support options to this client group.

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[155] McGrath The administration of the Patient Transit Assistance Scheme: equity and access from the medical superintendents’ perspective. 2001. Just Policy. No 22. June 48 –54.

Several tele- support pilots are in process currently, one involving the Social Workers at The Peter McCallum Cancer Institute with isolated young adults.

Remote health in Australia is just beginning to be researched. John Wakerman offered an important definition in this emerging discipline, "Its practice in Australia is characterised by geographical, professional and, often, social isolation of practitioners', a strong multidisciplinary approach, overlapping and changing roles of team members, a relative high degree of GP substitution, and practitioners requiring public health, emergency and extended clinical skills." [156]

The General Practice Rural Incentives Program (GRIP) established in 1992 has attempted to address the challenges of providing a well-trained medical workforce for Australians living outside the major metropolitans areas[157]. The problems are magnified as the distance expands from tertiary centres. The comprehensive national study undertaken in the mid 1990's confirmed the findings from individual state studies, namely that of the professional isolation. However, the strengths were clinical diversity, professional autonomy and the rural lifestyle[158]. The opportunities for social work to contribute to general practice have been acknowledged by a number of senior academics in the field.[159] A number of federal government initiatives could provide a platform for a specialized social work contribution including the Primary Health Care Research and Education Development scheme (PHCRED).

Indigenous Patients and Their Family Caregivers

To summarise, the National Breast Cancer Centre (NBCC) noted in the first report in 1996 all the available information about Aboriginal and Torres Strait Islander women that much that was available was biased, inaccurate and incomplete[160].

However good data from the South Australian cancer registry indicated that age standardised cancer mortality rates for all cancers are higher among Aboriginal and Torres Strait Islander residents of South Australia than other Australians. The data showed that Aboriginal and Torres Strait Islanders in South Australia are found to have lower primary cancer survival rates[161]. Research from the NBCC also indicated that rates of participation in early detection programs were low, and Aboriginal and Torres Strait Island women appeared to be less likely to receive or complete treatment for their disease.

Consultations in a number of different reports led to recommendations for strategies to improve the situation that included local control of health

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[156] Wakerman John. Defining remote health. Aust.J Rural Health (2004) **12**, 210-214.

[157] Holub, L. Williams B. The General Practice Rural Incentives Program, development and implementation: Progress to date. Aust. J. of Rural Health 1996; **4** 117-127

[158] Strasser RP, Hays RB, Kamien M, Carson D Is Australian Rural Practice Changing? Findings from the National Rural General Practice Study. (200) Aust.J.Rural Health. **8,** 222-226

[159] Kate Burns – personal conversation.

programs, need for programs to be holistic and not focused on breast cancer in isolation from other health issues and be delivered where possible by women as part of women's business. Screening mammography was a challenge, as it is seen as culturally inappropriate and difficult to access. Information remains a challenge, as many women from remote settlements do not use English as their first language.

In a two-year study funded by the National Health and Medical Research Council (NHMRC), Dr Pam Mcgrath and her research team developed a generic model for Indigenous palliative care. Its guiding principles were drawn from the insights of Indigenous people and health care workers interviewed throughout Northern Territory. "The model was affirmed through the democratic process of national peer-review by experts in Indigenous health. The generic model stands as a base line of information to be applied by service providers to their own unique circumstances. As every service is different, there will be great variation in the detail used in the specifically developed model for each service. There will be great diversity on such issues as needs, obstacles, resources, geography, populations and service aims. Such diversity will be reflected in different confirmation of factors underpinning the model development for each service. Thus, the view is of a 'Living Model' – the generic model providing a firm foundation which can be applied to the needs of the plethora of services involved in providing Indigenous palliative care" [162].

This research offers a model for future efforts to develop cancer services for Indigenous people. Currently they face the burdens of all remote people in having to undertake their treatments in Darwin, Adelaide, Perth or Brisbane and need to travel thousands of kilometres. These problems, common to all rural people, are amplified by the distance to be traveled, the disjunction of moving from supportive remote communities to large, bustling, insensitive hospital settings and create psychological trauma for many people.

Special needs include the provision of respect and support, providing care with sensitivity and information sharing that is built upon trust. The need for improved discharge planning is paramount.

Recommendations for the employment of more Indigenous people to be employed in the health system is strongly supported by Oncology Social Work Australia.

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[160] Carrick S, Clapham K, Paul C, Plant A, Redman S, Breast cancer and Aboriginal and Torrest Strait Islander women. National Breast Cancer Centre. Sydney. 1996.

[161] Epidemiology of Cancer in South Australia. South Australian Health Commission, Adelaide. 1997.

[162] McGrath P, Watson J, Derschow B, Murphy S, Rayner R 'Indigenous Palliative Care Service Delivery – A Living Model. Executive Summary. www.mcgrathresearch.net.au

Multicultural Patients and Their Family Caregivers

Culture refers to a shared system of meanings – the shared beliefs, knowledge, values, symbols, and way of life that emerge in the course of group experience and transmitted from one generation to another. To become a member of a social group, one must learn to behave in an acceptable manner according to cultural norms created and maintained by that group[163].

Whereas racial characteristics are inherited and immutable, ethnicity refers to the cultural distinctiveness of a group that is changeable over time.[164] "An ethnic group is a social group with a shared cultural distinctiveness, linguistic, religious, etc and a sense of a separate and collective identity while living within a larger society. By definition, all residents of Australia are members of one or more ethnic groups."[165]

Sociologists consider it natural for humans to be ethnocentric having learned how to behave from the group with whom they live and interact. Australian government policy has promoted cultural relativism as a way of giving all cultural groups equal standing. In the health area however, this can create tensions as the biomedical view of health collides with long-standing beliefs such as the Greek humoral theory, the holistic yin-yang balance theory of the Chinese, and the Ayurvedic medical theory of India.

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[163] Cordia Chu Cross-cultural health Issues in Contemporary Australia. 1998. Ethnicity and Health; 3 ½ 125-134

[164] Giddens A Sociology. 2nd Ed. Cambridge. Policy Press 1993.

[165] Cordia Chu, pg 127, op cit.

The Urgent Need for Multicultural Research and Publication: Researchers in the Australia, UK, Canada and the USA have been engaged in extensive efforts to find the best way of measuring race and ethnicity for their government censuses. There is considerable debate about the cultural characteristic questions used in the 2001 UK Census[166]. This measurement effort is fundamental to the accuracy of all our health statistics, including the current measure of birthplace by which cancer statistics are recorded. Furthermore, the effort to provide accurate religious affiliation is still being addressed[167]. Resolution of this matter will provide a good deal of assistance for both cancer clinical researchers and ultimately for translational research with for example, health protocols for dying patients.

Attitudes and beliefs are known to impact on health practices[168]. Ethnographic research is increasingly being seen as an important way forward in understanding different community beliefs about cancer. A recent report has found Chinese-Australians were frequently holding both Western biomedical explanations for cancer together with traditional Chinese beliefs, despite high acculturation[169]. In Canada women from South Asian countries were found to be less likely to use early-detection cancer strategies. Further, the woman's role within the family was important in her ability to make autonomous health decisions[170].

Recommendations have also been made to the Commonwealth Palliative Care Program to support the undertaking of an Australia-wide survey of attitudes to death and dying to improve our understanding of the differences held amongst our diverse population, and provide insights for health professionals in their caring role[171].

Communication in Culturally Diverse Societies: Research into the complex issues of cancer management in a multicultural society continues to be sparse. Butow, Tattersall and Goldstein in reviewing communication issues stressed the importance of physicians finding a balance between under-

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[166] Aspinall PJ "The New 2001 census Question Set on Cultural Characteristics: is it useful for the monitoring of the health status of people from ethnic groups in Britain? 2000. Ethnicity and Health. Vol 5 (1) 33-40.

[167] ibid

[168] Kate Burns. Information Giving to Patients Receiving Treatment for their Advanced Cancer: a review of the literature. September 2002. Report to the Commonwealth Department of Health and Ageing, Palliative Care Program.

[169] Yeo SS Meiser B, Barlow-Stewart K, Goldstein, Tucker K, Eisenbruch M. Understanding community beliefs of Chinese-Australians about cancer: initial insights using an ethnographic approach. 2005. Psycho-Oncology **14** 174-186.

[170] Bottorff JL, Johnson JL, Bhagat R, Grewal S, Balneaves LG, Clarke H, Hilton BA Beliefs related to breast health practices: the perception of South Asian women living in Canada. 1998. Soc Sci Med Vol 47. (12) 2075-2085.

[171] Kate Burns. Information Giving to Patients Receiving Treatment for their Advanced Cancer: a review of the literature. September 2002. Report to the Commonwealth Department of Health and Ageing, Palliative Care Program.

informing and overloading the patient[172]. For instance, there has been considerable debate within the international literature on the issue of whether the cancer diagnosis should be told, for while this is a given in western society, it is not accepted as culturally appropriate in many societies.[173] It is acknowledged that there appears to be some sensitivity to this issue within Australian cancer medicine, as a Melbourne survey confirmed that 11% of patients, all of whom were from non-English speaking backgrounds were not aware of their cancer diagnosis[174]

Religion and culture are important in determining attitudes to information, the role of the physician, and patient-doctor relationship, and family members' role when someone is sick[175] [176]. An Australian study that explored preferences for cancer information found religious beliefs were important: those who believed that God can influence the development and progression of their disease wanted less information ($p<0.0001$).[177]

Cultural Competence: An Australian research team undertaking multicultural studies discussed the influence of cultural beliefs concerning inheritance of cancer. Despite modernization, strongly held beliefs were held in regard to inheritance, kinship and descent and the cultural determinants of 'risk' of cancer as part of traditional beliefs[178]. Cultural competence will require understanding of the differing cultural views about genetic information including discordant beliefs that an individual may hold. They highlighted as a result of their study, the need for clinicians to understand family structures, including the role of senior family members.

Increasingly, it is understood there will need to be increased investment in multicultural education and information beyond the translation of documents from English to other languages. State governments are responding with websites highlighting services to migrant groups and facilitating rapid dissemination of research findings.

End of Life Decision-Making: International communication adds to modern complexity as families compare treatment across the globe. In a very recent report of a large European survey of physicians' attitudes towards end-of-life decision, doctors in Belgium, Denmark, Italy, the Netherlands, Sweden,

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[172] Butow PN, Tattersall MHN, Goldstein D, Communication with cancer patients in culturally diverse societies 317-329 in Surbonne, A. & Zwitter, M. 1997, in Communication with the Cancer Patient. Information and Truth. Annals edn, vol. 809 New York Academy of Sciences. New York.

[173] Surbonne, A. & Zwitter, M. 1997, in Communication with the Cancer Patient. Information and Truth. Annals edn, vol. 809 New York Academy of Sciences., New York.

[174] Chan, A. and Woodruff, R.K. (1997) Communicating with patients with advanced cancer. Journal of Palliative Care **13**, 29-33.

[175] Gordon., D. Embodying illness, embodying cancer. 1990 Cult. Med Psychiatry**. 14.** 275-297

[176] Ali, N.S. and Khalil, H.Z. (1996) Cancer prevention and early detection among Egyptians. Cancer Nursing **19**, 104-111.

[177] Butow, P. N., Maclean, M., Dunn, S. M., Tattersall, M. H., & Boyer, M. J. 1997, "The dynamics of change: cancer patients' preferences for information, involvement and support", Ann.Oncol., vol. 8, no. 9, pp. 857-863

[178] Eisenbruch M, Yeo SS, Meiser B, Goldstein, Tucker K, Barlow-Stewart K Optimising clinical practice in cancer genetics with cultural competence: lessons to be learned from ethnographic research with Chinese-Australians. 2004

Switzerland and Australia only had agreement in regard to alleviation of pain and symptoms. Other medical decisions that may result in the hastening of death were found to vary considerably from country to country[179].

Hospice and Palliative Care: A qualitative study of the experience of non-English-speaking hospice patients and their families in a Queensland community service, explored their experience with the dying[180]. The main issues raised by the participants were not dissimilar to those identified in other mainstream studies: the hardship in caring for loved ones who were dying when hospice was not available, the lack of referrals to appropriate services, the difficulties of talking about issues of death and dying and the fear of the responsibility of caring for a loved one at home.

Language barriers however were cited as an important problem. Interpreter services are not easily accessible. Dying raises sensitive emotional and spiritual issues not easily communicated in a language other than one's ethnic language. Exploring talking about dying drew attention to the "Western way" of informing people directly that they were dying which was described as 'too abrupt', 'terrifying' and 'blunt'.[181]

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[179] Miccinesi G, Fischer S, Paci E, Onwuteaka-Philpsen, BD, Cartwright C, van der Heide, A, Nilstun T, Norup M, Mortier F Physicians' attitudes towards end-of-life decision: a comparison between seven countries. 2005. Soc Sci Med 1961-1974

[180] McGrath P, Vun M, McLeod L Needs and experiences of non-English-speaking hospice patiens and their families in an English-speaking country. 2001. American Journal of Hospice and Palliative Care. Vol 18 (5) 305 –312.

[181] Ibid

SYSTEMIC CHALLENGES

HEALTH AND CLINICAL POLICY ISSUES

Workforce Planning

The cost cutting mentality has led to a blinkered approach to workforce planning. Anecdotal evidence indicates it is almost two decades since serious projections for allocation of staff resources was used in the health system. Cancer incidence grew by 34% through the 1990's. No hospital in this country increased its allocation of psychosocial resources to match that increase in numbers of people requiring assistance. While specialist cancer medical workforce planning has kept somewhat on track, and ditto for some areas of nursing, the lessons to be learnt from mismanaged radiotherapist workforce planning already should be taken on board in considering workforce planning in the psychosocial areas of cancer. Furthermore, the short-sighted efforts of providing targeted Commonwealth funding for breast cancer nurses only without considering the impact on oncology nursing overall should be another lesson in incoherent cancer workforce planning.

The promise that was there in the early 1990's for a professional career in the sub-specialty of oncology social work was destroyed as Managers of Social Work departments struggled to maintain service provision and demanded the freedom to deploy staff at will. Social workers who had undertaken post-graduate study specializing in cancer topics could suddenly find themselves deployed into any other area that an administrator felt staff was needed! Neither social work nor psychology departments in Australia have committed to a sub-specialty of cancer psychosocial services. One could describe as whimsical, the commitment to the skills base in both disciplines. Most departmental models still operate on an out of date acute care model. Ambulatory care receives cursory staff deployment. Given that most cancer care has now been undertaken at the outpatient level for over a decade this lack of strategic thinking has led to the problem of most people being unable to access psychosocial services. We have a situation where we can provide 3. 5 hours on average for a new patient diagnosed with cancer. Or if social workers primarily focus on those already in the system, we can offer 1.6 hours on average per year to each patient and their family.

Given that we have so much individual and community responsibility in cancer psychosocial care, it seems to be inconsistent and conflictual to have no program or financial administrative responsibility for the better management of cancer psychosocial care in most regions of Australia. The recently established model in the NSW Cancer Institute shows promise.

OSWA supports a national accreditation for cancer centres. We also support a system of registration and membership that reflects both the worker commitment to the profession and the Australian commitment to the worker.

Research

A Research Capacity Building Initiative should aim to embed a research culture in Australian social work practice and ensure evidence-based practice is achieved within a generation.

The PHC RED Strategy offers such a successful model: the Australian Government Department of Health and Ageing's *Primary Health Care Research Evaluation and Development* (PHC RED) *Strategy* sought to embed a research culture in Australian general practice specifically and Australian primary health care more generally.

A research-based culture in oncology social work will result in an increasing emphasis on rapid utilisation of proven methods of specific interventions. Australia's clinical psychosocial cancer culture is primarily derivative relying almost entirely upon studies undertaken in the USA and the UK despite the fact that both health systems are substantially different in their service delivery. The opportunity to test models of practice both singularly within the profession and as part of multidisciplinary team efforts in both the primary health care setting and the tertiary sector is the only way Australia health professionals will respond appropriately to the needs of their own people.

A number of recent national initiatives have been aimed at meeting the increased demands placed on the health system including such programs as the Divisions of General Practice Program, GP and other community health accreditation, the Enhanced Primary Health Care Package, GP Evaluation Program, Coordinated Care Trials, Hospital in the Home, and the Chronic Disease Self Management Program. Despite the fact that social workers are essential health providers in most of the nominated areas, these programs have been distinguished by a lack of identified social work input.

The benefits of research capacity building are the guarantee over time that a core group of research practitioners will acquire the skills to improve day-to-day clinical practice. The Institute for the Advancement of Social Work Research (IASWR) was founded in the USA in 1993 in response to the crisis in the development of research resources identified by a Task Force on Social Work Research. We have no doubt that any such similar inquiry would find that Australian clinical social work research was in the same state of disrepair. Indeed anecdotal evidence suggests that Australian health services research is twenty years behind the USA and Canada.

Australian researchers have already begun to consider new strategies for learning clinical skills in the medical domain acknowledging the need to re-evaluate clinical teaching methods[182]. Health social work must similarly

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[182] Rolfe IE & Sanson-Fisher RW Translating learning principles into practice: a new strategy for learning clinical skills. 2002 Medical Education. **36**: 345 - 352

address its curriculum and its teaching methods. Building research capacity is the first building block.

Professional Development

Oncology social workers are expected to be knowledgeable about oncologic disease and their treatments, psychosocial implications for individuals and families, appropriate interventions and available community and government resources. Oncology social workers must have knowledge of the usual course of cancer and its treatment so that patients and families can be helped to anticipate and deal with changes in family life.

In the United States oncology social workers are expected to be graduates from a masters program and have had prior employment of field placement experience in a health setting.

No agreed standards have yet been developed for Oncology Social Work in Australia. It is expected that the recently formed organisation will make this a top priority in its negotiations with universities and employer bodies.

Professor Barbara Berkman from Harvard University in the USA has devoted her senior professional years to the challenge of social work education. Almost a decade ago she wrote a prescient article about the implications for social work practice and education.[183] She noted the western health system had been based on a paradigm of unpredictable acute simple disease. In the case of cancer this has become an untenable model as patients increasingly enter the health system with a need for care from multiple sources – surgeons, medical and radiation oncologists, haematologists, general practitioners, social workers, psychologists and at times psychiatrists. Cancer has become a chronic illness. Many factors influence the course of the individual's experience: social, psychological, physical environment, genetic makeup, and hospital accessibility. Most people now rely on a primary network of community-oriented care as well as the tertiary hospital system. In the USA, it is the social worker who is considered to provide the patient with continuity of care working across both systems.

Furthermore, senior professionals at the Massachusetts General Hospital, Boston wrote in 1996 that they recognised that in the medical hospital system social workers would need to be clinical specialists – sophisticated and adaptable practitioners who could work flexibly under minimal supervision. "The valued social work practitioner will be an independent player on the health care team who assumes a significant role which no other member of

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[183] Berkman B The emerging health care world: implications for social work practice and education. 1996. Social Work. 42 (5): 541-51.

that team is equipped to take." [184] They noted that the current training was not sufficient to create this role.

In 2003 the issue of practice competencies in social work health care education was discussed and recommendations for greater integration of practicum and classroom education were recommended. Three key competencies were identified: self-directed practice, population-based practice, and a refocus on basic skills. This development in social work in the USA provides a model of disciplined learning that acknowledges the basis of professionalism as demonstrated in the past few centuries in the two oldest professions Medicine and Law.

The New York Academy of Medicine in a recent study identified the need for increased synergy between the two components of graduate social work education: field experience and classroom instruction. A new educational model – the Practicum Partnership program, designed to better integrate field and classroom is being tested at six sites. Early results from over 300 graduates are promising[185]. Recruitment sought to reflect the diversity of modern populations including exposure to older adults and to ensure their practicum where possible took them across the continuum of care.

Importantly, what this current effort notes is the amount of investment required. 900 hours of practice relies upon a mentorship program – which in times of tough fiscal accountability means this segment must be acquitted as a budget item. Medical and nursing schools have already begun to reform their course offerings and trainings in the field, entering into collaborative agreements with health systems that clearly identified the contribution made. All behavioural health educators – social work, psychology, physiotherapy have been struggling to address the challenge.

This report emphasises that the conceptual gap between classroom education and practice in the field is often exacerbated by physical separation – focusing on strengthening the coordination between field and class is the first step toward improved synergy of practice and university content.

OSWA has already begun discussions about the training for oncology social workers. Commonwealth support for practicum revision, integrated with research capacity building, and identified mentorship programs would make an immediate difference to the quality of the next generation of graduates. In the emerging highly competitive labour shortage market, such efforts will repay dividends.

The young social worker can be shaped, sculptured so that their professional development directly reflects what the community defines as the cancer needs

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[184] Berkman B, Bonander E, Kemler B, Rubinger MJ, Rutchick I, Silverman P Social work in the academic medical center: advanced training – a necessity. Social Work in Health Care. 1996 24 (1-2): 115-135.

[185] Volland PJ, Berkman B Educating Social Workers to Meet the Challenge of an Aging Urban Population: a Promising Model. 2004. Academic Medicine Vol 79 (12) 1192 - 1196

of the Australian community. The embryonic system of clinical learning needs to be managed with a post-graduate course within a national structure. Research should foster exploratory work in interest areas that reflect Australian need and guarantee applicability to our health system.

The politics of balance are best managed by scientific research and specification of need at all levels – microscopic and macroscopic – State and Commonwealth. Reciprocity and mutual commitment are the key values needed. All this service the interest of one’s grandmother, father, daughter, brother and tests the vision of our current audience.

APPENDIX

A Brief History

Oncology Social Work In Australia

Oncology social workers have practiced as a sub-specialty of the social work profession since the mid 1970's. They were formally acknowledged as a professional contributing member to the overall care of those living with a cancer when they were admitted as a specialist group to the Clinical Oncology Society of Australia (COSA) in 1985. Over the next 10 years, oncology social workers contributed to the development of cancer services and the improved delivery of psychosocial care at many levels of practice. There were active State oncology social work groups in New South Wales, Victoria, South Australia and Queensland. Practising social workers in other less populous States were connected through the annual COSA Scientific Meetings that were held in different locations around Australia.

In the mid 1990's with the substantial economic limitations placed on health services both at the Federal and State levels the profession was severely challenged. There was significant downsizing within health settings as social work was identified as a 'dispensable' service. This in turn, significantly impacted on numbers in the profession and a dilution of its contribution in the field of psychosocial care. This loss of experienced oncology social workers, limited the capacity of the profession to contribute to the public debate on the development of cancer services and provision of essential psychosocial services.

At the end of 2002 the two existing State groups (Victoria and New South Wales) met to discuss re-establishing a national network of oncology social workers. It was agreed that this would be an important step for the profession and the cancer delivery system. During 2003, a group of State representatives (N.S.W., Victoria, South Australia, Tasmania, Western Australia, Northern Territories, Queensland and A.C.T.) communicated via e-mail and phone to fashion a national association.

On Australia Day 2004, Oncology Social Work Australia was formally launched via a web page (http://www.oncologysocialworkaustralia.com) and a listserve to enable all oncology social workers to communicate nationally.

In a period of less than 12 months our membership has grown to 110 and we anticipate that it has the capacity to include between 200 and 250 practicing professional oncology social workers.

Within 12 months (2004) we have been active in a number of areas including:

1. The ongoing development of the web page to meet the professional needs of our profession.
2. The development of a national post-graduate specialist university qualification (either certificate or diploma) with a major School of Social Work at one of the main metropolitan universities.
3. Establishment of a professional educational oncology social work exchange program with the international Association of Oncology Social Work (http://www.aosw.org) that is based in the United States.
4. Joint Project with the National Cancer Control Initiative on introducing the new "Clinical Guidelines for the Care of Adults with a Cancer" to cancer service providers (medical, nursing, allied health, etc) in various clinical settings whether they are hospital based, or in community or palliative care settings.
5. The running of the inaugural national oncology social work conference in Canberra in at the end of 2004.
6. Contributing to the ongoing debate and development of psychosocial services to those with a cancer at both the State and Federal level.

In 2005 our group that has still only existed for 12 months has begun to look at: -

1. Expanding the professional development options available for its members.
2. Exploring the development of a research strategy.
3. Planning its second national conference that will be held in Brisbane in November 2005.
4. Initiating a project to complete a "Handbook of Oncology Social Work Practice in Australia".
5. Creating of a formal structure in place of an interim model accepted by all membership.

In the near future we anticipate exploring a formal association with the international Association of Oncology Social Work, which will add benefits to having a membership with Oncology Social Work Australia. These benefits include their research based professional journal (The Journal of Psychosocial Oncology), on-line courses and access to many other useful professional resources.

Despite the substantial setbacks of the mid 1990's, we as a group of specialist social workers in the field of psychosocial care to those diagnosed with a cancer, are of the view that we are on track in contributing significantly to cancer treatment and management.

Ivan Hochberg

OSWA Interim Convenor