68

Received at hearing
1.8.06

SUBMISSION TO SENATE COMMITTEE INQUIRY INTO GYNAECOLOGICAL CANCER

Rosalind Robertson
Senior Psychologist
Gynaecological Cancer Centre
Royal Hospital for Women
Randwick NSW 2031

This submission includes :

1. Background information about the psychosocial issues facing cancer patients generally
2. Specific issues that need addressing in a government inquiry into gynaecological cancer
    - Improved identification of distress in patient populations.
    - Gynaecological cancer & psychosocial distress
    - Improving communication about sexuality in gynaecological cancer
    - The issue of support for partner/carers of cancer patients
    - Cultural & linguistic diversity – the problems for NESB patients
    - Geographical isolation, travel & support

1. BACKGROUND

People diagnosed with cancer face a major life stress, compounded by practical, emotional & psychological problems, in addition to the physical demands of treatment.

Although cancer is a major life stress, over time many patients adjust effectively to their changed life circumstance without psychosocial interventions.

However, a significant group experience heightened distress that persists & sometimes worsens over time. (Hegelson V et al 2004)
There has been well documented, significant emotional morbidity attached to a diagnosis of cancer.

An Australian study found that 45% of cancer patients had a psychiatric disorder, & 42% were diagnosed with depression or anxiety, or both – compared with a prevalence of 9% in the general population. (Kissane DW et al 1998)

Much of the psychosocial morbidity goes undetected (Newell, Sanson- Fisher, Girgis & Bonaventura 1998 ; Fallowfield, Ratcliffe, Jenkins & Saul 2001)

Undetected & untreated patient distress can have a deleterious impact on medical outcomes, due to lack of compliance with treatment plans, decreased patient satisfaction & inflated health care costs

The benefits of early identification & intervention to minimize the psychosocial impact of cancer & it's treatment include faster recovery, fewer hospital complications & greater ability to cope with difficult treatments (Mumford, Schlesinger & Glass 1982

Treatment centres need to have in place a strategy for routine screening of patients so that early identification of psychosocial distress can be achieved.
It is therefore recommended that strategies to ensure effective screening, referral & treatment of psychosocial concerns are urgently needed

There are many self report tools that measure cancer patient's psychosocial issues across a range of dimensions & used at periods of increased vulnerability. (Girgis A & Boyes A 2005)

The psychosocial needs of cancer patients are great, and up to 40% of patients report moderate or high levels of unmet supportive care needs (Sanson - Fisher et al 2000)

Patients with advanced disease are a group with special needs & report even higher levels of unmet needs in many areas, but especially in the psychological, physical & daily living domains (Sanson- Fisher, Girgis, Boyes et al 2000 ; Aranda, Schofield et al 2005)
Research has found that 50% of patients will be clinically depressed at some point during advanced disease (Hall & Fallowfield 1996)

2. SPECIFIC ISSUES THAT NEED ADDRESSING IN A GOVERNMENT INQUIRY INTO GYNAECOLOGICAL CANCER

Identification of distress in cancer patients

Many distressed patients remain unidentified, and some studies have found that in fact few are referred for counselling or support (Fallowfield 2001 ; Ford 1994 ; Sollner 2004) However, as the number of psycho – oncology professionals involved in cancer care centres across Australia has been growing over the last 10 years, it is most likely that this trend is reversing .

Girgis & Boyes(2005) report in a recent paper that most psychosocial care is offered "reactively, that is, when the patient is in a state of crisis".
This paper recommends that a co-ordinated approach to psychosocial assessment & intervention be implemented, whereby patients are assessed at "critical time points over the cancer journey "

While the clinical practice guidelines that have been developed by NHMRC & NBCC are an important step in highlighting psychosocial problems, a number of challenges have been identified that describe a lack of integration of psychosocial services into routine care for patients with cancer. (Steginga et al Cancer Forum 2006)

This paper outlines the problems with psychosocial services – for example, the move to more outpatient care means that patients' interactions with the acute health care system may be intermittent, limiting opportunities to gain support in this setting.

The study recommends the establishment of a tiered model of psychosocial care, with triage to the appropriate level of psychosocial intervention needed by the patient at any given time during the disease trajectory.

The model has been applied in Queensland to work closely with the Queensland Cancer Fund & other community based & acute services

Because of geographic barriers in a large state there is a need for remote access services. A tele – based service has proven to be highly acceptable to patients.

There are a range of specific factors that are associated with increased risk of developing psychosocial problems after a diagnosis of cancer, It is therefore important to consider these groups carefully, as it has been found that patients are generally reluctant to self refer.

- Young patients
- Those with poor support
- Those with a history of psychological problems
- Those with a history of drug & alcohol abuse
- Those who have experienced significant negative life events

Gynaecological Cancer and Psychosocial distress

Living with a diagnosis of gynaecological cancer produces a range of distressing problems that have a profound impact on the patient's quality of life, which encompasses physical functioning, psychological functioning & physical symptoms of disease & treatments

Women with gynaecological cancers have unique problems in the oncology setting:
Gynaecological cancer places the patient at high risk of developing:

- Sexual & body image problems – body image problems may occur for example as a response to lymphoedema or coping with a stoma.
- Infertility & associated grief
- Hormonal dysfunction & often premature menopause with resulting psychosexual problems

Up to 80% of women report some degree of sexual dysfunction in the first year following diagnosis, & chronic difficulties are reported in almost 50% of patients (Andersen 1993 ; Punt 2004)

Sexual problems for women with gynaecological cancers typically include reduced libido, dyspareunia, diminished lubrication & orgasmic dysfunction & the effects of severe menopausal or disease related symptoms.

Loss of libido is the most common side effect – it is difficult to treat, because it may be a response to stress, it may reflect endocrine changes or a psychological response to treatment

Reduced libido is often a result of :

- Treatment related effects, particularly nausea & fatigue
- Anxiety & depression
- Body image problems – feelings of loss of femininity, & self esteem
- Fears about the consequences of further sexual activity
- Interpersonal/relationship difficulties

The impact of infertility & the loss of parenting potential can produce lifelong grief that is sometimes perceived as more distressing than the cancer itself.
Infertility can also have a significant negative impact on relationships

Once a diagnosis of gynaecological cancer has been made, several factors affect a woman's adjustment with respect to sexual function.
These include

- the young age of many patients with gynaecological cancer
- treatments that directly impair sexual function or pelvic organs
- treatment induced menopause

- effects of treatment on sexual desire & response
- alterations in body image
- More specifically sexual desire can be affected by the physical effects of the disease, the side effects & sequelae of treatment, psychological factors & psychosocial issues

Problems with body image such as the presence of lymphoedema or a stoma often persist long term & can be a source of on- going psychological distress

Improving communication about sexuality in gynaecological cancer

Patients strongly indicate that sexuality is an important concern that needs to be addressed but is often neglected in the cancer care setting

A large proportion of women with gynaecological cancer do not receive the information & support they need to deal with the effects of cancer treatment on sexuality (Bourgeois-Law & Lotocki 1999)

Opportunities to discuss sexual concerns with health professionals is important – this issue needs to be addressed at diagnosis by the treating doctor, because few patients will initiate discussion or questioning about sexuality issues themselves
At the time of diagnosis patients should be well informed of the potential direct effects that treatments may have on sexuality

Health professionals often have misconceptions about sexuality in their patients

- the notion that illness precludes sexuality
- the belief that sexuality is unimportant to a woman who is dealing with the rigours of treatment
- the notion that elderly patients are not interested in sex.
- the feeling that the topic is beyond the expertise of those treating the patient.

Sensitivity to the particular needs of each patient is required, with an awareness of age, culture, education & socioeconomic status

The issue of support for partners / carers of cancer patients

The extent to which a patient with cancer feels supported has been identified as an important factor in their adjustment to the disease.

The impact of a diagnosis of cancer on families & carers is a significant event in their lives and the level of stress experienced by partners of patients with cancer is reported to be comparable to, or greater than that of the patient's themselves(Clinical Practice Guidelines for the psychosocial care of adults with cancer. NHMRC 2003)

Data suggests that adjustment by patients with cancer is significantly enhanced by family & partner support (Manne SL 1998)

Evidence from the literature describes the negative impact on carers – particularly on physical, psychological & financial aspects.

But on the down side, carers of people with advanced disease have been found to have significant unmet informational needs & experience high levels of distress (Aranda, Hayman - White 2001)

Many patients& their families report inadequate information to guide decision making, & others are disadvantaged because of lack of knowledge about practical support, even when support services are available.

Increased assistance to caregivers is therefore necessary to ensure that they have information and knowledge about the disease, financial security & other psychosocial supports throughout difficult times with the patient (Girgis 2006)

Cultural and linguistic diversity

Australia has one of the most multicultural populations in the world. In the 1996 Census, 41% of the total Australian population was either born overseas or had at least one parent born overseas, & 13% born in a NESB(Non English speaking background) country.
Australians speak 193 languages. (Clinical Practice Guidelines 2003)

Language & cultural barriers, and lack of knowledge about health in general and the Australian health care system can create significant problems for many patients & their families with cancer.

Utilisation of interpreting services is one of the strategies to improve access of people with limited English skills to health services

In my experience, referrals of NESB patients for psychosocial assessment & treatment are often problematic and very limited, because of perceived difficulties with language & culture
The process of booking interpreters can present problems – for example, the time delay in waiting for a Cantonese interpreter can be up to a week.

It is important to be aware that patients from culturally diverse backgrounds may have a number of cultural sensitivities.

The concept of "support" outside family may not be well understood within a culture. Other issues may involve the way in which a diagnosis of cancer is viewed in some cultures eg. as shameful or a death sentence – therefore a great deal of sensitivity and reassurance is required when offering psychosocial support to those of culturally diverse backgrounds.

Geographic isolation & psychosocial support

Geographic barriers are a key issue in providing psychosocial support to patients.

Whilst psychosocial support is available in cancer centres at teaching Hospitals in Metropolitan areas, when the patient goes back home to a remote rural area, for example, support is almost non existent, save for a few good networks set up by consumers or the few available web sites, some of which are interactive.

The tele – based service mentioned above, which has been established in Queensland has proven to be highly acceptable to patients with cancer – the QCF Cancer Helpline received over 25,000 patient related calls in 2005 – a 36% increase in such calls over 2 years .
Triage to a tele-based cancer counselling service staffed by psychologists & nurse counsellors is also available for those patients requiring specialist care. (Steginga 2006)
This may be a very useful concept for government consideration to help overcome some of the current problems created by the tyranny of distance across Australia.

References

x Kissane DW Psychological morbidity & quality of life in Australian women with early stage breast cancer : a cross sectional survey Medical Journal of Australia 1998 : 164 (4): 192-6)
169

Pape SJ, Taylor, KL Dougherty J Morse SR Fife B Spouse support, coping & mood among individuals with cancer Ann.Behav.Med. 1999; 21: 111-21)

Girgis A & Boyes A Proactive routine monitoring and intervention to reduce the psychosocial impact of cancer therapy Clinical Psychologist, Vol.9, No.2, Nov.2005 pp. 70-73

(Manne SL Coping with a partners' cancer: adjustment at four stages of the illness trajectory. Oncol Nurs. Forum 1998 ; 25 :751-60

Aranda S, Hayman-White K Home carers of the person with advanced cancer : an Australian perspective. Cancer Nursing. 2001 ; 24 (4) 300-307

Sanson – Fisher R, Girgis A, Boyes A. Bonevski B. Burton L, Cook P. The unmet supportive care needs of patients with lung cancer. Cancer 2000 88(1) : 226-37

Hall A, Fallowfield LJ, A'Hern RP When breast cancer recurs : A 3 year prospective study of psychological morbidity. The Breast Journal. 1996 2 (3) : 197-203

Sollnar W, De Vries A, Steixner E, et al. How successful are oncologists in identifying patient's distress, perceived social support and need for psychosocial counselling? British Journal of cancer 2001 ; 84 : 179 – 185

Andersen, BL 1993 Predicting sexual & psychologic morbidity and improving the quality of life for women with gynaecological cancer. Cancer, 71 (4 Suppl.) 1678 – 90

Punt, L 2004 psychosexual problems in gynaecological malignancy in Booth, S & Bruera E (eds) Palliative care Consultations in Gynaeoncology Oxford University Press

Steginga SK, Hutchinson SD , Turner J, Dunn J Translating Psychosocial Care : Guidelines into action Cancer Forum March 2006 Vol 30, No.1

Hegelson VS Snyder P Seltman H Psychological & physical adjustment to breast cancer over 4 years : Identifying distinct trajectories of change Health Psychology 2004 ; 23 (1) : 3-15