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The Secretary
Senate Community Affairs References Committee
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Canberra ACT 2600

INQUIRY INTO SERVICES AND TREATMENT OPTIONS FOR PERSONS WITH CANCER.

Submission from Professor Susan Davis MBBS, FRACP, PhD

<u>The Women's Health Program, Department of Medicine, Monash University</u>

We wish to submit regarding the following specific issues, with our model to address this public health problem being that of breast cancer as this is the commonest cancer in women.

(iii) differing models and best practice for addressing psycho/social factors in patient care, and

(v) current barriers to the implementation of best practice in the above fields; and

(b) How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:

(i) the extent to which less conventional and complementary treatments are researched, or are supported by research,

(ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies, and

(iii) the legitimate role of government in the field of less conventional cancer treatment.

With respect to the particular points we wish to address the major barrier is COMPLETE LACK OF ADEQUATE OBJECTIVE COMMUNITY DATA REGARDING CONSEQUENCES OF CANCER AND RECURRENCE RATES. To address this major impediment we are undertaking a state wide study of the physical, psychological and socio-economic consequences of breast cancer.

Background

Breast cancer (BC) is the most common cancer in women in developed countries and over the last decade there has been a dramatic increase in survival rates for this disease.

Specific statistics are not available for Australia, however, the number of people living with cancer in the US has risen from 1.5% of the population in 1971 to 3.5% in 2001, with 22% of these having had BC [1].

84 % of all women diagnosed with BC are alive after 5 years and 68% after 10 years, with younger women having a better prognosis[2]. This represents a 16% increase in survival over the last decade[2].

Amongst women in the southeastern state of Victoria, Australia, there are approximately 3,000 new cases of invasive breast cancer diagnosed each year. It has been estimated that there are approximately 28,000 breast cancer survivors in Victoria.

Thus most women diagnosed with breast cancer will survive their cancer after undergoing treatments.

SPECIFIC QUESTIONS OF THE INQUIRY:

(iii) differing models and best practice for addressing psycho/social factors in patient care, AND current barriers to the implementation of best practice in the above fields; and

Currently there ARE

- **no data FOR** breast cancer **recurrence rates** outside clinical trials as Australian Cancer Registry data is limited to diagnosis and death;
- **no long term follow up of** women after breast cancer (or other cancer) diagnosis and treatment to establish **the most common and severe short term and long term physical and psychological or socio-economic sequelae**.
- **no information as to how various therapies used by women to deal with their symptoms impact on recurrence or survival;**
- **no knowledge of how substantially new treatments for** breast **cancer affect long term health risks** in women **outside randomised control trials**

There has been no systematic follow up of what happens AFTER (breast) cancer treatment outside therapeutic trials. This is important because therapeutic trials always include a selected patient population and thus the findings can never be fully generalized. Information is needed from a broad community perspective of the real life consequences of Cancer and associated therapy.

b. How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:

(i) the extent to which less conventional and complementary treatments are researched, or are supported by research:

There is no systematic data pertaining to the frequency of use or type of complementary therapies being used by women after breast cancer (or individuals after any cancer) in Australia.

(ii) the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies:

Currently THERE IS

- **NO EVIDENCE** that complementary therapies are effective.
- no systematic evaluation of the *safety* of complementary therapies, used by women after breast cancer (or any other cancer)
- no information as to how various therapies used by women to deal with their symptoms impact on recurrence or survival;
- no knowledge of how substantially new treatments for breast cancer affect long term health risks in women outside randomised control trials

(iii) the legitimate role of government in the field of less conventional cancer treatment.

At this time the legitimate role of government is to support the systematic collection of information pertaining to cancer survivors in the community so that there is knowledge of

- what complementary therapies are being employed
- by whom
- the efficacy of these therapies
- the safety of these therapies

No meaningful recommendations or research strategies can be undertaken before this information is collected.

OUR approach at this time:

The Health and Wellbeing after Breast Cancer Study of Victoria

As breast cancer is the most common cancer in women and large numbers of individuals are affected we are systematically undertaking a prospective study to which we are inviting ALL NEWLY DIAGNOSED WOMEN WITH BREAST CANCER from June 1st 2004 to join. We will identify all women via the Victorian cancer registry data base for this study.

Our Specific Aims:

1. To investigate how many women experience significant menopausal symptoms after treatment for breast cancer (BC), and the frequency and severity of specific symptoms

2. **To document which treatments women use to manage their climacteric symptoms – including all prescription and non prescription (complementary) therapies.**

3. **To document effects of having had cancer on psychological health, family structure, employment, sexual health using validated instruments and comparing our findings to data collected from 1500 non health care seeking Victorian women.**

4. To record other physical outcomes which may occur as a result of the treatment for BC or the treatment for management of menopausal symptoms after BC. Outcomes of interest are : fractures of hip, spine or wrist; cardiovascular (CV) or cerebrovascular events; venous thromboembolic events; mood disorders.

5. To record lifestyle factors (exercise and alcohol intake), and reproductive history and examine relationships with symptoms.

6. To document the recurrence of BC over the study period

Complete study details are available on request

SIGNIFICANCE:

This study is different as it potentially involves all Victorian women newly diagnosed with BC, including women in rural regions who are rarely represented in large drug trials, and those being treated in private as well as public sector.

This study also uniquely approaches BC not as a terminal event but as a disease that has a treatment process, and with the concept that women going through, or surviving this process may have other major health issues. Even if there is a recurrence there is still a period of time where women will have health issues they will need to deal with other than their BC.
The primary outcome of this study will be the identification of the major health needs of women who have had BC, other than the disease itself. This will immediately justify targeted management strategies for the issues affecting the greatest numbers of women, specific research

into the areas of greatest need, and identification possibly of issues that may not otherwise have been considered of significance. Some of the findings from this study may also be relevant to individuals who have had treatment for other cancers, particularly other gynaecological cancers.

We will also for the first time document sites and rates of recurrence of BC in the community, and identify any factors that are associated with recurrence in the community, as opposed to within a drug trial. Such data is starkly lacking. Our findings will not determine cause and effect in terms of factors associated with recurrence, but will be important in terms of indicating directions for future research into recurrence.

As BC remains the most common cancer in women in the western world, all the outcomes of this study have enormous implications in terms of public health in Australia and elsewhere.

Support for this research:

This research is in part funded by the NHMRC however we are still seeking support from Australian and North American Funding bodies as it is a large and demanding project with important health outcomes.

Reference List

1. Rowlan J, Mariotto A, Aziz N, Tesauro G, Feuer E, Blackman D et al. Cancer survivorship, United States, 1971-2001. Morbidity and Mortality Weekly Report 2004; 53(24):526-629.

2. The Cancer Council Victoria. Breast Cancer. 34. 2002. The cancer Council of Victoria. Canstat.