



Australia's Cancer Helpline

An audit of utility and caller profile



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BACKGROUND

The Cancer Helpline is a telephone information and support service operated throughout Australia.

METHODS

Data from all calls received during the months of July, August and September from 2001 to 2003 were collected and analysed.

RESULTS

Over 76 000 contacts were made, mostly from women (79%). Almost half of all calls were from people with general inquiries (rather than cancer patients, their families, or health professionals). The most common cancer type discussed was breast cancer, (26% of all calls, 42% of calls from people with cancer). Diagnosed cancer patients most frequently called about treatment/management and practical issues. People with general inquiries called to obtain information about the prevention and early detection of cancer.

DISCUSSION

The helpline can complement the role of other information and support providers for people living with or concerned about cancer.

In Australia, about one in 3 men and one in 4 women will develop cancer by the age of 75 years.¹ People affected by cancer frequently report a range of unmet needs including psychological support, information, and practical and financial assistance.²⁻⁵ Partners and children of those directly affected by cancer often have the same unmet needs.²

In response, there are calls for improved access to information and support services,⁶ and each state and territory Cancer Council operates programs to meet these needs. The Cancer Helpline is an Australia wide telephone information and support service operating from each state and territory Cancer Council. Callers using the 13 11 20 telephone number are generally connected to the helpline in their state or territory capital city (which is generally staffed by oncology nurses). The helpline also educates the community on the prevention and early detection of cancer.

The National Cancer Information Service Network, (NCISN) began collecting data on incoming telephone calls to the helpline in 2001.

Methods

The NCISN compiled data between July and September 2001–2003. Privacy guidelines suggest that compiling statistics or other information for the purpose of funding, managing, planning or evaluating health services does not require approval by a

Human Research Ethics Committee, and this was not sought. No identifiable data were made available for this report or sent between services.

Results

During the months of July, August and September, 2001–2003, over 76 000 contacts were made with the Cancer Helpline. Staffing shortages precluded collecting data from the Northern Territory. The only trend apparent was an increase in calls received during July 2002 relating to the issue of hormone therapy and breast cancer. The number of contacts does not include calls received by the antismoking telephone service, 'Quit'.

Most callers (79%) were women, and most calls were from people without cancer. For 8% of the calls, the sex of the caller was not recorded. For callers with a cancer diagnosis, 72% of all callers were women (*Figure 1*). The most common cancer type discussed was breast cancer, (26% of all calls, 42% from diagnosed cancer patients) followed by prostate, nonmelanoma skin cancer, and colorectal cancer (*Figure 2*). Only 39% of callers with cancer were aged 60 years or over; the peak age group being 50–59 years (*Figure 1*).

The most common topics discussed were prevention, early detection, and risk factors (20.6%), general information

(19.3%), and treatment and management (18.6%). Diagnosed cancer patients called about treatment and practical issues most frequently (Figure 3). They also commonly discussed diagnosis and obtained psychological support. Family and friends had very similar reasons for calling the helpline.

In contrast, people with general inquiries (rather than cancer patients, their families, or health professionals) called to obtain

both information about the prevention and early detection of cancer and other general information (Figure 3). Health professionals most commonly called to obtain general information or information on practical issues. A significant percentage of these calls concerned requests for written patient information.

Discussion

Our findings are similar to other cancer telephone information services: most callers were women calling about breast cancer, and younger than the overall cancer population.^{5,7-14} This suggests that many people affected by cancer underutilise the helpline. Cancer patients were not the major group calling the service.^{5,8,9,11,14-16}

Our data provides no information about people who may underutilise the service in terms of ethnic, racial, or socioeconomic groups. We intend to redress this shortcoming, as well as client satisfaction, in the future.

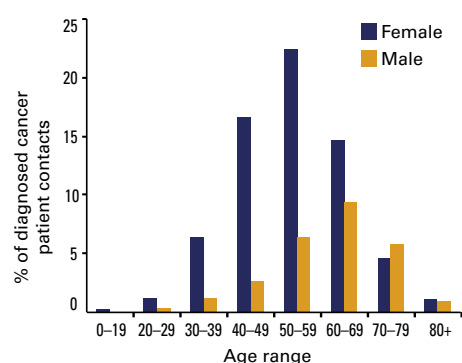


Figure 1. Diagnosed cancer patient phone contacts by age range and gender

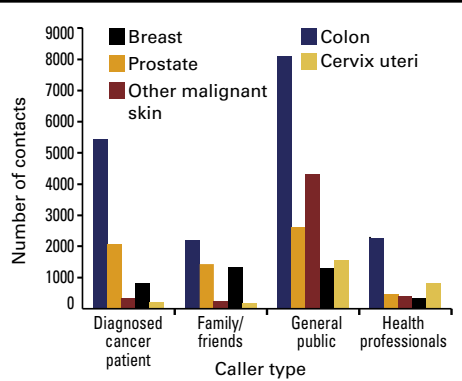


Figure 2. Caller type and cancers discussed

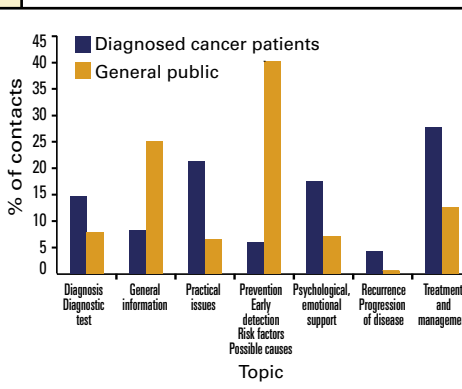


Figure 3. Topics discussed

Implications of this study for general practice

- People affected by cancer have a range of unmet needs, including information needs and emotional support.
- The Cancer Helpline services respond to a large number of callers, supplementing other information providers.
- Calls cover a range of topics: general inquiries (cancer prevention and early detection) more than specific information (individual cancer management).

Conflict of interest: none declared.

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