Demographic characteristics, call details and psychosocial support needs of the family/friends of someone diagnosed with cancer who access Australian Cancer Council telephone information and support services

Leila Heckel, BSW, PhD [a, *], Kate M. Fennell, BPsych (Hons), MPsych (Clin), PhD [b, c, d],
Mohammadreza Mohebbi, BSc, MSc, PhD [a], Monica Byrnes, RN, MAppS [b],
Patricia M. Livingston, BA (Hons), PhD [a]

[a] Deakin University, Faculty of Health, Geelong, Australia
[b] Cancer Council SA, 202 Greenhill Road, Eastwood, South Australia 5063, Australia
[c] Flinders Centre for Innovation in Cancer, School of Medicine, Flinders University, Sturt Road, Bedford Park, South Australia 5042, Australia
[d] Sansom Institute for Health Research, University of South Australia, City East Campus, North Terrace, Adelaide 5000, South Australia, Australia

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ABSTRACT

Purpose: Community-based cancer organizations provide telephone-based information and support services to assist people diagnosed with cancer and their family/friends. We investigated the demographic characteristics and psychosocial support needs of family/friends who contacted Australian Cancer Council 13 11 20 information and support helplines.

Methods: Data collected on 42,892 family/friends who contacted a 13 11 20 service across Australia from January 2010 to December 2012 were analyzed. Chi-square analysis was used to examine associations between caller groups and reasons for calling, logistic regression to examine age and gender interaction effects.

Results: The majority of calls received were from women (81%) of middle- (40%) and high-socio-economic backgrounds (41%), aged 40–59 years (46%); 52% phoned for information on cancer diagnosis (including early detection, risk factors), 22% on treatment/disease management, and 26% phoned seeking psychological/emotional support. Information on a diagnosis was significantly more often the reason older males called, compared to female callers of any age. Overall, 32% found out about the service through Cancer Council resources or events, 20% from the media, 18% from the internet; 11% from health professionals.

Conclusions: Family/friends of persons diagnosed with cancer have specific information and support needs. This study identifies groups of family/friends to whom the promotion of this service could be targeted. Within Australia and internationally, clinicians and oncology nurses as well as allied health professionals can provide an important role in increasing access to cancer telephone support services to ensure the needs of the family and friends of people affected by cancer are being met.

1. Background

In 2012, worldwide there were 32.6 million people living with cancer, 14.1 million new cancer cases, and approximately 8.2 million people died from the disease (IARC, 2017). In Australia, almost 385,000 people were living with cancer by the end of 2010 (Cancer Australia, 2017), approximately 130,466 new cancer cases were diagnosed in 2016 (excluding basal and squamous cell carcinomas of the skin), and approximately 46,880 Australians were expected to die from the disease in 2016 (AIHW, 2016). In addition, current data highlight that Australia's increasing life expectancy with people aged 65 years or older representing 14% (3.2 million) of the total population, with similar trends being observed in other developed regions of the world (AIHW, 2013). This continuous growth of an ageing Australian population is expected to lead to

* Corresponding author. Deakin University, Faculty of Health, Geelong, Australia.

increased numbers of people diagnosed with cancer. Australian incidence of the disease is predicted to rise to approximately 150,000 by 2020 (AIHW, 2012a). Advances in early detection of cancers through age-specific screening programs, as well as innovative treatment regimens have led to a decrease in mortality rates (AIHW, 2017) and to improved survivorship rates, with 66% of Australian cancer patients surviving five years in the period of 2006—2010, compared to just 48% during 1982—1987 (AIHW, 2012b). These trends have contributed to cancer now being considered a chronic disease (Phillips and Currow, 2010).

These developments have also led to a shift from inpatient to outpatient treatment, resulting in an increase in number of people acting as informal caregivers (Lambert et al., 2013). As a result, immediate family and friends are now often required to perform a multitude of duties throughout the cancer care trajectory, including the management of symptoms and side effects, the provision of emotional support, effective communication with healthcare professionals, and the mastering of cancer-related information (Adelman et al., 2014; Ockerby et al., 2012). These family/friends often take on the role of informal caregivers and are required to provide multidimensional support, with little or no training and assistance (Ussher and Sandoval, 2008; Van Ryn et al., 2011). Consequently, caregivers' health and wellbeing can be negatively affected and caregivers have been found to experience various unmet needs throughout the cancer trajectory (Given et al., 2012; Lambert et al., 2012; Stenberg et al., 2009; Tamayo et al., 2010).

In order to assist persons with cancer and their families/friends, cancer organizations worldwide have developed telephone support services to provide free cancer-specific information and support (Arnaboldi et al., 2010; Boudioni et al., 1999; Bright, 2007; Carlsson et al., 1996; Lechner and De Vries, 1996; Montazeri et al., 1999; Rainey, 1985; Ross, 2007). These support services represent an important link between callers and healthcare services. Evaluations of cancer telephone services have demonstrated positive outcomes in terms of caller satisfaction with the provision of information and support and their helpfulness in reducing unmet needs (Dean and Scanlon, 2007; Hardyman et al., 2005; Jefford et al., 2005; Reubsaet et al., 2006; Squiers et al., 2005). In Australia, Cancer Council 13 11 20 Information and Support Services are staffed by specialist oncology nurses and/or allied health personnel based in callers' local states, providing advice and support to community members. However, little is known about family/friends who use this service, what their support needs are and whether these needs differ between gender and age groups. Therefore, the purpose of this study was to analyze the demographic composition of users of the Cancer Council 13 11 20 service who identified themselves as family/friends of persons with cancer across all Australian states in terms of age, gender and socio economic status (SES), and main reason for calling.

2. Methods

2.1. Data acquisition

Data from Cancer Councils' National Minimum Dataset (NMD) is collected by six 13 11 20 services across Australia. This process is coordinated by the National 13 11 20 Managers Group. This group comprises state based managers or a designated equivalent from each state, who oversee the collection of the NMD at each service.

2.2. Data collection and preparation

We analyzed data collected from calls made by family/friends to the Australian Cancer Council information and support service. In the NMD dataset each call is recorded as an individual contact and

was examined as such in our analysis. Repeat callers cannot be identified within the data set due to the anonymous nature of the service (in most states).

The following information from the NMD was included in the analysis (Table 1):

1. States (calls from family/friends to the telephone service within Australian Capital Territory (ACT), New South Wales (NSW), Western Australia (WA), Queensland (QLD), South Australia (SA)/Northern Territory (NT), Victoria (VIC)/Tasmania (TAS), 13 11 20 calls from the Northern Territory and Tasmania were not reported separately in the NMD but included in the SA and Victorian databases).
2. Demographic data included caller's age, grouped into four age groups (18—39, 40—59, 60—79, and 80 + years), gender (male, female), and postcode.
3. The socioeconomic status (SES) of the caller was assessed by assigning the Socio-Economic Indices for Areas (SEIFA) decile rankings (1—10) to the caller's postcode (ABS, 2006). SEIFA is a set of four indexes, each ranking different geographic areas of Australia. For each index, a score is calculated for every area based on the socio-economic conditions within that region (e.g. characteristics of people, families, and neighborhoods) (ABS, 2011). Rankings were collapsed into the following categories to represent relative advantage/disadvantage: low SES (1—3), middle SES (4—7), and high SES (8—10).
4. How did the family/friend find out about the telephone support service? Cancer Council (Cancer Council resource, event, staff member); media (TV, radio, magazines, pamphlets and other advertising); internet; health professionals; telephone book; family/friends; and community organization.
5. Was the service used before? (yes, no).
6. Reasons for calling the service (information and psychosocial support needs): correlation analysis was conducted and variables (listed below) that highly correlated with each other and/ or had similar content were grouped together into three broader categories: 1. Diagnosis (early detection/symptoms, practical issues, prevention/risk factors, possible causes, general cancer information); 2. Psychological/emotional support; 3. Treatment and management (recurrence/progression of disease).

An exemption from ethical review was granted by Deakin University Human Research Ethics Committee (number: 2013—205) as this analysis included only pre-existing and non-identifiable data.

2.3. Statistical analysis

Frequencies (percentages) were used to describe the proportion of contacts and sample characteristics (i.e. year, states/territories, type of contact, 13 11 20 service contacted before, how found out about the 13 11 20 service, information/support needs, gender, age and socio-economic status). Associations between age, gender, SES groups and information/support needs were examined using chi-square analyses. Multinomial logistic regression with three categorical outcome variables for information/support needs (dependent variable) i.e. diagnosis, psychological/emotional support and treatment/disease management, was used for evaluating age and gender (independent variables) interaction effects. Results of the analyses were considered statistically significant at $p < 0.01$.

3. Results

3.1. Contacts to the Cancer Council 13 11 20 service

A total of 202,697 calls were received during the period of