The Offspring Cancer Needs Instrument (OCNI):
Evaluation of an Instrument to Assess the Needs of Young People who have a Parent with Cancer.

Purpose and benefit of the research

We have been developing a questionnaire that taps into the needs of young people[1] who have a parent with cancer (the Offspring Cancer Needs Instrument: OCNI) – and assesses whether these needs are being met. The main purpose of the current study is to evaluate this measure. We are also interested in finding out what other factors might affect young people's needs, such as family and psychological functioning.

We hope to increase understanding among health care professionals and service providers of the issues faced by offspring by: (a) highlighting their current needs and (b) informing the industry of whether or not these needs are being adequately addressed.

Hence, the overall aim is to provide a tool to quickly and reliably assess unmet needs of young people who have a parent with cancer to allow timely and relevant provision of services.

Project description

Although it has been acknowledged that the impact of parental cancer on offspring is substantial, research has tended to focus on describing sons and daughters' functioning within the family unit, and on disturbances to their coping ability, psychological functioning, and development. These descriptions have afforded some insight into the emotional and psychological difficulties these young people face - but they haven't directly identified their psychosocial needs, thus offering only limited guidance to service providers.

To date, relatively few studies have attempted to identify the needs of young people who have a parent with cancer and none have assessed whether or not these needs are being met. Therefore, this type of research is important for a number of reasons: (a) it allows for a more detailed understanding of the issues faced by offspring of cancer patients and (b) it provides direct assessment of the type, number and magnitude of current needs.

CanTeen recently conducted such a needs-based investigation and identified (through qualitative interviews) 8 areas in which young people identified a need. These areas related to: information regarding their parent's cancer, peer support (similar experience and friends), expressing and coping with feelings, respite and recreation, support for carers, family factors, supportive education and/or work environment, and access to support services. From this information an unmet needs instrument was constructed (the OCNI). It was also found that, of the 116 young people surveyed, nearly 50% had elevated scores on depression and anxiety, and almost 90% of participants indicated that they currently had at least one unmet need. On average, young people reported 13 unmet needs. Needs that related to 'expressing and coping with emotions', 'peer support', and 'information' were the most endorsed as being unmet needs. An important application of such knowledge is the provision of practical information for use in planning better psychosocial intervention programs for this group.

The goal of the current study is to continue this research and produce a sensitive, thorough and sound unmet needs assessment measure for young people who have a parent with cancer. This research is being conducted by CanTeen Australia, in conjunction with the University of Sydney and *beyondblue: the national depression initiative.*

Aims and objectives

1. To evaluate the psychometric properties of an unmet needs assessment measure for young people who have a parent with cancer – the Offspring Cancer Needs Instrument (OCNI).
2. To provide a tool to quickly and reliably assess the unmet needs of young people who have a parent with cancer.
3. To establish the prevalence of psychological distress (depression and anxiety) and unmet needs in young people who have a parent with cancer;
4. To explore predictors of unmet needs and psychological distress in young people who have a parent with cancer.
5. To better inform service providers of the needs and issues facing offspring who have a parent with cancer.

[1] The term 'young people' refers to adolescents and young adults aged 12-24 years

Methodology
The quantitative study will employ a survey method – consisting of the: the OCNI (psychosocial unmet needs scale); and measures of psychological distress; family functioning; and demographic items.

Expected completion date: April 2010

The University of Sydney