

The Sibling Cancer Needs Instrument (SCNI): Evaluation of an Instrument to Assess the Needs of Young People who have a Sibling with Cancer

Purpose and benefit of the research

We have been developing a questionnaire that taps into the needs of young people¹ who have a sibling with cancer, the Sibling Cancer Needs Instrument (SCNI), 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 young people who have a sibling with cancer 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 sibling with cancer to allow timely and relevant provision of services.

Project description

Although it has been acknowledged that the impact of a sibling's cancer on a young person is substantial, research has tended to focus on describing their 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 have not 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 sibling with cancer or assess 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 siblings 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) 10 areas in which young people who have a sibling with cancer identified a need. These areas related to: peer support (from friends) peer support (from those with a similar experience), information regarding their sibling's cancer, expressing and coping with feelings, respite and recreation, acknowledgement and attention for self, involvement in the cancer experience, instrumental support, sibling relationship support, and access to support services. From this information an unmet needs instrument was constructed (the SCNI). It was also found that, of the 71 young people surveyed, almost 70% of participants indicated that they currently had at least one unmet need. On average, those that did have at least one unmet need, reported 13 unmet needs. Needs that related to 'peer support (from friends)', 'acknowledgement and attention for self' and 'access to support services' 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 sibling with cancer.

Aims and objectives

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

Methodology

The quantitative study will employ a survey method, consisting of the SCNI, demographic items, and measures of psychological distress and family functioning.

Expected completion date: April 2010

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