The Needs of Young People who have a Parent with Cancer.

**KEY POINTS**

- Young people who have a parent with cancer identified a number of needs. These needs could be grouped into 8 broad areas: information; peer support; expressing and coping with emotions; respite and recreation; support for carers; support at work/school; family issues; and access to support services.

- The survey data revealed that 97% of young people in this sample endorsed at least one need; 90% specified 10 or more needs; and around 25% endorsed more than 50 needs.

- On average, young people endorsed approximately 36 needs each.

- Needs relating to support from their peers, respite and recreation, and being able to both express and cope with their emotions were the most salient.

- It was also found that these needs often go unmet. Eighty-seven per cent of young people in this study indicated that at least one need was unmet; 43% had 10 or more unmet needs; and around 25% had 20+ unmet needs.

- On average, each young person reported approximately 13 unmet needs.

- The three main areas where needs were not being met were: peer support; support at work/school; and expressing and coping with emotions.

- Young people aged 18-24 years reported more unmet needs than those aged 12-17 years.

- Psychological distress scores were elevated in this sample of young people.

- Approximately 43% of those aged 12-17 were in the at risk/clinically elevated ranges for emotional and behavioural problems (as measured by the Strength and Difficulties Questionnaire-Total Difficulties: SDQ-Total Difficulties) far exceeding the 15-20% reported in normative data.

- There was a positive relationship between number of unmet needs and behavioural and emotional problems (that is, the more unmet needs reported, the higher the scores on the SDQ-Total Difficulties).

- Nearly 45% of 18-24 year olds were in the at risk/clinically elevated ranges for anxiety and stress - far exceeding the 15-20% reported in normative data (as measured by the Depression, Anxiety, Stress Scale: DASS-21).

- The more unmet needs a young person reported, the higher they scored on depression, anxiety and stress.

- Overall, the study revealed that young people (aged 12-24) who have a parent with cancer report a complex array of needs, many of which go unmet. Of concern is the positive correlation between number of unmet needs and adverse mental health scores.

- It is hoped that the preliminary findings reported here will be used by health care professionals to develop and evaluate needs-based programs and resources to redress these unmet needs - in an attempt to ameliorate the negative effects of living with a parent with cancer.
THE IMPORTANCE OF NEEDS RESEARCH

IN AUSTRALIA IN 2005 THERE WERE MORE THAN 39,000 DEATHS FROM CANCER AND OVER 100,000 PEOPLE WHO WERE NEWLY DIAGNOSED - MANY OF WHOM ARE OF CHILDBEARING AGE AND ARE LIKELY TO HAVE ONE OR MORE OFFSPRING. POTENTIALLY THEN, THOUSANDS OF ADOLESCENTS AND YOUNG ADULTS ARE AFFECTED EACH YEAR BY THEIR PARENT’S CANCER DIAGNOSIS. THE PSYCHOLOGICAL COST TO THESE YOUNG PEOPLE HAS BEEN ACKNOWLEDGED AS CONSIDERABLE AND IT IS CONSISTENTLY REPORTED THAT THIS POPULATION EXPERIENCES HIGH LEVELS OF STRESS, ANXIETY AND DEPRESSION.

WHAT DO WE KNOW ABOUT THE NEEDS OF THESE YOUNG PEOPLE?

Relatively few studies have focused on the psychosocial needs of young people who have a parent with cancer. These studies have focused on the need for information and support and have not directly and systematically assessed whether or not these needs were being met. However, it is important to develop larger-scale research that investigates other potential classes of need associated with offspring’s functioning and the extent to which these self expressed needs are being met by service providers.

Such research is important for a number of reasons: it allows for a more detailed understanding of how young people who have a parent with cancer perceive, experience and express their needs; and it provides direct assessment of the type, number, and magnitude of these needs, and whether they have been met. An important application of such knowledge is in the planning of better psychosocial intervention programs and resources for this group, particularly as service providers move from service-led towards needs-led practice. Finally, needs-based research can also lead to an understanding of the factors that contribute to resilience in these young people, which may help to prevent or reduce the likelihood of developing long-term mental health problems.

THE STUDY CONDUCTED AT CANTEEN

In the first part of the study, young people were interviewed about their needs. Needs were identified in eight broad areas.

INFORMATION

Participants expressed the need to have access to information about their parent’s cancer, and for this information to be presented to them in a way that they could understand. Information was sought regarding their parent’s cancer type, treatment options and outcomes, side-effects and chances of recovery. Honest and lucid information was sought from all health care professionals, including nurses, doctors and oncologists.

“I need information about mum’s cancer that’s easy to understand, easy to access and brings information into public awareness”
PEER SUPPORT

This domain encompasses both the need to feel supported from one’s own friendship peer group, and from other young people who share a similar experience. In terms of friendship groups, participants expressed the need for friends to understand what they were going through and to be able to openly communicate with them about their cancer experience. In regard to peer support from other young people who have a parent with cancer, participants expressed the need to be able to learn from them and to feel supported by them.

EXPRESSING AND COPING WITH FEELINGS

Participants conveyed the need to be able to express how they were feeling about their parent’s cancer, and also the need for help in dealing with these feelings. Young people expressed feeling anxious, scared, sad, guilty, frustrated and angry, and indicated a desire to access professional counselling services in an attempt to better cope with this roller coaster of emotions.

“I need help with these feelings of guilt and sadness and anger and fear”

RESPITE AND RECREATION

Young people expressed the need to be involved in activities such as sports and social activities in an attempt to regain a sense of normality in their lives. This domain also encapsulates the need for occasional escapism and ‘time out’ from the pressures of having a parent with cancer.

“I just want the opportunity to be a ‘normal’ teenager sometimes”

SUPPORT FOR CARERS

For those young people who are involved in caring for a parent with cancer, a need for information and assistance with the caring and household duties was also expressed.

SUPPORTIVE EDUCATION AND WORK ENVIRONMENT

This domain speaks to the need for assistance with attending and staying on task at school, TAFE, university, and/or work. Participants expressed the desire for teachers and/or bosses to be more understanding of their situation and to act accordingly. Having access to professional support services in this environment was also mentioned.

“I need some support with my school work, like extra time to get assignments and homework done”

FAMILY FACTORS

Participants indicated the need to feel supported by their families, where open and honest communication was highlighted as key. Family access to counselling was also mentioned as a need.

ACCESS TO SUPPORT SERVICES

The negotiation of support services, including financial support and employment related support, was also mentioned by participants as an area where they required assistance.

“I wanted to know about financial support. After mum’s diagnosis she couldn’t work and it’s hard for a single mum to raise a family ... I felt really helpless”

From this information a questionnaire was developed — the Offspring Cancer Needs Instrument (or OCNI for short) — which contains 67 need questions. One hundred and sixteen young people completed this measure, along with an assessment of their psychological well-being.
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**FINDINGS**

**At a glance:**

- The majority of young people (97.4%) endorsed at least one need
- 90% specified 10 or more needs
- Approximately 25% endorsed 50+ needs.
- On average, 36.2 needs were endorsed per person.
- Further, 87% of the sample indicated that at least one need was unmet
- 43% had 10 or more unmet needs
- Just under one-quarter had 20+ unmet needs
- On average, participants reported 12.82 unmet needs.

**NEEDS/UNMET NEEDS**

Young people identified both unmet needs and needs generally within each of the need domains. The peer support (96%), respite and recreation (94%) and expressing and coping with feelings (92%) domains had the highest percentages of participant endorsement of one or more needs.

- In relation to needs that had not been met, nearly three-quarters (73%) of the young people in this sample indicated one or more within the peer support domain, 57% had one or more in the education and work environment area, and 56% reported one or more in the domain of expressing and coping with feelings.

- The top 10 needs and the top 10 unmet needs endorsed by participants are outlined below. In this sample, unmet needs concerning support from peers, access to information and dealing with feelings were the most represented domains.

<table>
<thead>
<tr>
<th>RANK</th>
<th>NEEDS</th>
<th>% NEED</th>
<th>RANK</th>
<th>UNMET NEEDS</th>
<th>% UNMET</th>
<th>% NEED</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Understanding from friends</td>
<td>86.8</td>
<td>1</td>
<td>Understanding from friends</td>
<td>44.0</td>
<td>86.8</td>
</tr>
<tr>
<td>2</td>
<td>Support from friends</td>
<td>83.6</td>
<td>2</td>
<td>Help concentrating at school/work</td>
<td>39.7</td>
<td>59.5</td>
</tr>
<tr>
<td>3</td>
<td>Have fun</td>
<td>81.3</td>
<td>3</td>
<td>Information about side-effects &amp; symptoms</td>
<td>31.0</td>
<td>53.4</td>
</tr>
<tr>
<td>4</td>
<td>Information about changes in parent’s condition</td>
<td>80.2</td>
<td>4</td>
<td>Open communication with friends</td>
<td>30.2</td>
<td>70.7</td>
</tr>
<tr>
<td>4</td>
<td>Spend more time with friends</td>
<td>80.2</td>
<td>4</td>
<td>Problems with self-esteem</td>
<td>30.2</td>
<td>80.2</td>
</tr>
<tr>
<td>6</td>
<td>Express feelings about cancer</td>
<td>75.0</td>
<td>6</td>
<td>A place to go when things got too hard</td>
<td>29.3</td>
<td>70.7</td>
</tr>
<tr>
<td>7</td>
<td>Discuss feelings &amp; fears</td>
<td>73.3</td>
<td>7</td>
<td>Support from friends</td>
<td>28.4</td>
<td>83.6</td>
</tr>
<tr>
<td>7</td>
<td>Spend time with others</td>
<td>73.3</td>
<td>8</td>
<td>Help with anxiety &amp; fear</td>
<td>27.6</td>
<td>67.2</td>
</tr>
<tr>
<td>9</td>
<td>Information about parent’s chances of recovery</td>
<td>71.6</td>
<td>8</td>
<td>To speak with a health care professional in an understandable way</td>
<td>27.6</td>
<td>42.2</td>
</tr>
<tr>
<td>9</td>
<td>Participation in social activities</td>
<td>71.6</td>
<td>10</td>
<td>To speak with a health care professional when needed</td>
<td>26.7</td>
<td>38.8</td>
</tr>
</tbody>
</table>

<sup>a</sup> percentage of participants for whom the need was currently unmet
<sup>b</sup> percentage of participants for whom the item was a need
PSYCHOLOGICAL HEALTH

• For young people aged 12-17 years there was a significant positive correlation between the number of unmet needs reported and behavioural and emotional problems - as measured by the SDQ-Total Difficulties. That is, the more unmet needs a young person reported, the higher their score on the difficulties measure.

• For young people aged 18-24 years mental health was measured using the DASS-21 (Depression, Anxiety, Stress Scale) and a significant positive correlation was found between total number of unmet needs and depression, anxiety and stress levels. That is, the more unmet needs a young person reported, the higher their scores on the three scales, indicating poorer mental health.

• Of note, 43% of 12-17 year olds were in the at risk/clinically elevated ranges on the SDQ-Total Difficulties and nearly 45% of 18-24 year olds were in the at risk/clinically elevated ranges for anxiety and stress - far exceeding the 15-20% reported in normative data.

CONCLUSIONS AND RECOMMENDATIONS

• The majority of young people surveyed expressed varied needs during this period of their lives, with over 90% indicating 10 or more needs and one-quarter of the sample endorsing 50 or more needs. Psychosocial areas that were most salient included the domains of peer support, respite and recreation, and expressing and coping with feelings.

• These results indicate that it is important to provide support and services to offspring in order to foster greater communication and interaction with peers; to alleviate the pressures of their parent's diagnosis and treatments by providing time out and recreational activities so that the young person regains a sense of normalcy in their lives; and to assist them to effectively express and cope with their emotional reactions.

• A need for information about their parent's cancer and available services were also highlighted as key areas, suggesting that age-appropriate booklets and or web based material would be beneficial.

• Understanding from friends and more lenient and understanding teachers also ranked highly, indicating that an educational program that sought to inform both peers and teachers alike of the impact of parental cancer may help to lessen distress at school for the young person.

• Importantly, the study also revealed that these needs are often not met. Around 43% of participants indicated they had 10 or more unmet needs and just under one-quarter reported 20 or more unmet needs. Most of these unmet needs related to the domains of peer support, a supportive education and work environment, carer support needs and the desire for information.

At a glance:

Overall, the study revealed that young people (aged 12-24 years) who have a parent with cancer report a complex array of needs, many of which go unmet. The preliminary findings reported may be used to inform service providers in the development and evaluation of needs-based programs to redress these unmet needs, and thus ameliorate the negative effects of living with a parent with cancer.
Research Snapshot

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• These findings are particularly pertinent in light of the pattern emerging from the unmet needs assessment and psychological distress scores: For both the 12-17 and 18-24 age brackets there was a high positive correlation between number of unmet needs and adverse mental health scores, and a higher than normal proportion of participants ‘at risk’ of psychological problems.

• Targeted interventions towards these areas of need is warranted.

This study takes an important step towards redressing the dearth of research regarding the identification of the psychosocial needs of young people who have a parent with cancer through direct needs-based research. Assessment of whether or not these needs are currently being met by service providers will also assist in program and intervention development, with the view to promote health and well being outcomes for young people who experience the protracted illness of a parent who has been diagnosed with cancer.

WHERE TO NEXT?

The development of a sensitive, psychometrically rigorous unmet needs measure for young people who have a parent with cancer will have clinical application (for e.g., enabling treating professionals to accurately estimate unmet needs in order to provide a tailored, relevant service and monitor the progress of the young person); and research application (for e.g., in providing a reliable and valid outcome measure for evaluating the effectiveness of relevant interventions).

Therefore, an important next step in the development of the OCNI as a research and clinical tool is to further examine the construct validity and reliability of the instrument. Currently, a study is underway to further assess these properties, using a broader community sample.

This research is being conducted by Canteen Australia, in conjunction with the University of Sydney and beyondblue: the national depression initiative.

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