

PAPER

Levels of unmet needs and distress amongst adolescents and young adults (AYAs) impacted by familial cancer

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Email: researchteam@canteen.org.au**Abstract****Objective:** To describe levels of, and relationships between, distress and psychosocial unmet needs in adolescents and young adults (AYAs) with a family member with cancer.**Methods:** Adolescents and young adults (12-24 years old) with a living sibling or parent with cancer participated. Participants completed demographics, the Kessler 10 (K10) distress scale and the Sibling or Offspring Cancer Needs Instruments. Descriptive statistics were obtained for all measures, item-level frequencies were examined to identify common unmet needs, and relationships between distress and unmet needs were explored.**Results:** Average sibling (N = 106) and offspring (N = 256) distress levels were in the high range (K10total = 22-30), with 29.6% and 31.6% in the very high range (K10total = 31-50), respectively. Siblings had mean = 19.7 unmet needs (range 0-45), 66% had ≥10 unmet needs, and 44% of the 45 needs were unmet on average. Offspring had mean = 22.4 unmet needs (range 0-47), 77% had ≥10 unmet needs, and 48% of the 47 needs were unmet on average. Strong positive correlations were found between K10 distress and the number of sibling/offspring unmet needs ($r = 0.599$ and $r = 0.522$, respectively, $P = .00$).**Conclusions:** Australian AYA siblings and offspring impacted by familial cancer experience high levels and numbers of unmet needs and substantial distress. Strong associations were found between increased distress and more unmet needs. Distress levels were comparable to AYAs seeking treatment for mental health issues. Insights into the type and number of needs experienced by AYA siblings and offspring will facilitate development and delivery of targeted, age-appropriate interventions, and resources for these vulnerable and underserved young people.**KEYWORDS**

cancer, distress, offspring, sibling, unmet needs

1 | BACKGROUND

Cancer-related distress and unmet needs have been explored to varying degrees in adult and paediatric patient, caregiver, and family populations.¹⁻³ More recently, this has extended to adolescents and young adults* (AYAs) impacted by familial cancer.⁴⁻⁹ Given that approximately 21 000 Australian AYAs have a parent diagnosed with

cancer every year, and another 1000 have a sibling diagnosed with cancer,¹⁰⁻¹³ research in this area is critically important.

Mental health problems constitute approximately 50% of disease burden for AYAs in the general population,¹⁰ and they have the highest incidence of mental illness of any age group.¹⁴ The added burden of familial cancer can severely challenge AYAs' developing coping skills, and many siblings and offspring experience distress,

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behavioural issues, and unmet needs.^{8,9,15-19} Needs reported for siblings and offspring of cancer patients include open, honest communication, information about the cancer, help coping with emotions, understanding from friends, support from other young people with similar experiences, and support to maintain their interests and activities.^{4,6,20}

Long-term quality of life can be impacted,^{16,21} and posttraumatic stress (PTS) is common, with 49% of AYA siblings of cancer survivors reporting mild PTS and 32% reporting moderate-to-severe PTS up to 10 years posttreatment.²² There is also evidence of increased risk of internalising problems amongst offspring.²³ Crucial education and life-skill development can be disrupted,¹⁵ and desires to support and remain close to family may conflict with natural progression to independent life and development of personal values and identity.¹⁹ No other quantitative distress-related or unmet needs data has been reported for these populations despite its value for informing service development and policy decisions. Given this, we recently developed and validated measures of unmet needs amongst AYA siblings⁵ and offspring⁷ and collected data on distress and needs in these populations. Using previously reported data,^{5,7} the objectives of the current paper were to:

1. Describe levels of distress experienced by AYA siblings and offspring impacted by familial cancer using methods used in Australian population-level reports,
2. Describe the proportions of unmet needs reported in each unmet need domain by siblings and offspring and identify the needs reported as unmet by most siblings and offspring, and
3. Describe the relationship between distress and number of unmet needs for sibling and offspring.

Presenting levels of distress experienced by AYAs impacted by familial cancer in a format concordant with AYA population-level data will facilitate comparison of their risk of adverse outcomes relative to their peers. Additionally, greater understanding of the number and types of needs reported by these AYAs and how they relate to the distress they experience will facilitate development of relevant interventions and services.

2 | METHODS

2.1 | Participants

Young people aged 12 to 24 years were invited to participate if they had a living sibling or parent/caregiver examined with any type or stage of cancer in the previous 5 years.

2.2 | Procedure

Participants were invited to complete online or paper surveys via: (1) notices displayed at 3 Sydney hospitals, in 2 cancer consumer newsletters, and on oncology consumer websites; (2) postal invitations to new members of CanTeen[†] (members for <12 months), people who ordered relevant resources from CanTeen and members of Camp Quality[‡]; and

(3) postal invitations to siblings of patient members of CanTeen (who were not members themselves). This enabled contact with a diverse sample of young people.

Ethical clearance was obtained through CanTeen and hospitals involved in the study (HREC/09/RPAH/29, HREC/09/CIPHS/24). Parental consent was sought for participants <18 years of age.

2.3 | Measures

2.3.1 | Distress

The Kessler 10 (K10)²⁴ is a widely used 10-item psychological distress measure. It has very high internal consistency (Cronbach $\alpha = 0.93$) and very good discrimination (area under the curve = 0.85) in adult populations.²⁵ While it has not been validated in Australian adolescent populations, it has been used with Australians as young as 11 years old in nationwide studies¹⁰ and a Chinese-language K10 has also been validated with adolescents.²⁶ Participants reflect on how they felt over the last 4 weeks and respond using a 5-point scale (1 = "never" to 5 = "all the time"). Total scores range between 10 and 50 (higher scores reflect greater distress) and are reported in 4 bands: low (10-15), moderate (16-21), high (22-30), and very high (31-50).¹⁰ These bands have been used in Australian population-level mental health reports and will facilitate comparisons between the current samples and the broader Australian population.^{10,27}

2.3.2 | Unmet needs

Two measures of unmet needs were used; the Sibling Cancer Needs Instrument (SCNI)⁵ and the Offspring Cancer Needs Instrument (OCNI).⁷ The SCNI has 45 items, the OCNI 47 items. Both have 7 domains and are answered on a 4 point scale (1 = "no need" to 4 = "strong need"). Possible SCNI scores range from 45 to 180 and 47 to 188 for the OCNI, with higher scores indicating greater levels of unmet need. See Table 2 for domain names and measure composition and Table 3 for sample item content. The SCNI domain internal consistencies range from 0.78 to 0.94, and overall test-retest reliability is 0.88.⁵ The OCNI domain internal consistencies range from 0.89 to 0.96, and overall test-retest reliability is 0.73.⁷

Items in each domain were summed to obtain domain scores and all items summed to obtain total scores. Consistent with previous needs research,²⁸ responses were dichotomised into no/low need and moderate/strong need. Combined moderate/strong needs are referred to as "unmet needs" throughout this paper. Proportions of unmet needs are calculated for each domain, and the overall measure by counting items where a moderate/strong need is indicated in each domain/overall and dividing this by the total number of items in the domain/overall measure.

2.4 | Statistical analyses

Means, standard deviations, and ranges were obtained for K10 total scores. Counts and proportions were obtained for the K10 bands and the proportion of the sample with ≥ 1 and ≥ 10 SCNI or OCNI unmet needs. Mean proportions of unmet needs amongst siblings and offspring were also calculated. Item-level frequencies were examined to identify SCNI and OCNI unmet needs endorsed by more than

50% of the participants to identify commonly endorsed needs. Relationships between K10 distress and counts of unmet needs were explored using Pearson correlations. Analyses were conducted using SPSSv22.

3 | RESULTS

3.1 | Participants

Four hundred five AYAs impacted by familial cancer responded (siblings = 123, offspring = 282). Seventeen siblings and 16 offspring not meeting eligibility criteria were excluded, leaving 362 participants: 106 siblings ($M_{\text{age}} = 16.6$ years, 68.9% female) and 256 offspring ($M_{\text{age}} = 16.1$, 73.0% female). The majority were Australian born (Siblings = 77.4%, Offspring = 93.4%). Sixty-four per cent of siblings and 50% of offspring were CanTeen members (mean membership length—siblings = 8.3 months, offspring = 2.5 months). Mean age for brothers/sisters with cancer was 14.3 years and 54.7% of parents with cancer were 40 to 49 years old. See Table 1 for participant demographics.

3.2 | Levels of distress (K10)

Mean K10 distress scores were 24.2 (SD = 9.0, range 10-50) for siblings and 25.2 (SD = 9.8, range 10-50) for offspring. The number and proportion of siblings in each band were: low = 17 (17.3%), moderate = 25 (25.5%), high = 27 (27.6%), and very high = 29 (29.6%). The number and proportion of offspring in each band were: low = 52 (20.8%), moderate = 47 (18.8%), high = 72 (28.8%), and very high = 79 (31.6%).

3.3 | Unmet needs

The mean number of unmet needs for siblings was 19.7 (SD = 14.1, range 0-45), 91.7% had ≥ 1 unmet need, and 65.6% had ≥ 10 unmet needs. The average proportion of unmet needs was 43.7%.

The mean number of unmet needs for offspring was 22.4 (SD = 13.4, range 0-47), 95.1% had ≥ 1 unmet need and 76.8% had ≥ 10 unmet needs. The average proportion of unmet needs was 47.6%.

Average proportions of unmet needs in each domain are reported in Table 2 and unmet needs reported by more than 50% of respondents in Table 3. Three unmet needs endorsed by more than 50% of siblings related to the "Information About my Sibling's Cancer" domain, 3 to the "Time Out and Recreation" domain, and 1 each to the "My Relationship with my Sibling with Cancer, Dealing with Feelings" and "Support from my Friends and Other Young People" domains. Seven unmet needs endorsed by more than 50% of offspring related to the "Information about my Parent's Cancer" domain, 4 to the "Dealing with Feelings" domain, 3 each to the "Time Out and Recreation, Family Issues" and "Support from Other Young People" domains, and 2 to the "Support from Friends" domain.

3.4 | Relationship between distress and unmet needs

Strong significant correlations were found between distress scores and the number of unmet needs reported by both siblings ($r = 0.599$, $P = .000$) and offspring ($r = 0.522$, $P = .000$).

4 | DISCUSSION

Fifty-seven per cent of siblings and 60% of offspring reported high or very high levels of distress as assessed by the K10 in our sample. While no single source of Australian normative K10 data are available for the whole AYA age range, data for 16- to 24-year-olds in the general Australian population indicates that 9% have high or very high levels of distress¹⁰ while other data indicate that 19.9% of Australian 11- to 17-year-olds experience high or very high levels of distress.²⁷ Both used the K10 and reported using the same distress bands as the present study. Therefore, using these Australian population-level reports, the proportion of AYA siblings and offspring with high or very high distress is 3 to 6 times greater than in the general population, and comparable to AYAs seeking treatment for mental health issues.²⁹ This is substantial and adds to previous literature indicating that young people with a sibling with cancer suffer negative psychosocial consequences, including emotional and behavioural problems, loneliness, and lower quality of life.^{20,30,31} Some evidence suggests siblings' acute emotional distress may recede relatively quickly.¹⁶ Offspring similarly experience emotional and behavioural problems because of parental cancer, with psychopathologies identified in approximately one-third of adolescent offspring; however, evidence is less abundant, and time taken to return to normal distress levels has not been established.^{8,19,32}

Despite using a conservative standard for determining whether a need was met or unmet on the SCNI and OCNI, whereby a low level of need was not considered to be different from no need, levels of unmet need were still high amongst siblings and offspring with 44% and 48% of needs unmet on average, respectively. Noteworthy is the result that while 9 items on the SCNI were endorsed as unmet by more than 50% of sibling participants, 22 items on the OCNI were endorsed as unmet by more than 50% of offspring participants. Overall, information needs appeared to be important for both siblings and offspring, with both groups endorsing the highest number of unmet needs in this domain. Needs for time out and recreation were present for both groups, as were needs related to dealing with feelings and support from friends and other young people. Needs related to the relationship with the ill sibling were also prominent for siblings while needs related to family issues were strongly endorsed by offspring. These are useful targets for support provision.

Similar to previous publications reporting a strong positive relationship between levels of distress and SCNI and OCNI total and scale scores,^{5,7} strong positive correlations were found between distress and the number of unmet needs for siblings and offspring. This suggests that higher levels of distress are experienced by those both with more unmet needs and with stronger levels of need. However, given the indeterminate causality of this relationship, the connection between distress and needs warrants further investigation.

TABLE 1 Demographic characteristics of participating siblings/offspring and their family member with cancer (n = 362)

Participating Young People	Siblings n = 106		Offspring n = 256	
	M	SD	M	SD
Age, y	16.6	3.6	16.1	3.2
CanTeen membership length, mo ^a	8.3	14.0	2.5	3.9
	n	%	n	%
Gender				
Male	33	31.1	69	27.0
Female	73	68.9	187	73.0
Country of birth				
Australia	82	77.4	239	93.4
New Zealand	14	13.2	4	1.6
England	3	2.8	5	2.0
USA	3	2.8	-	-
Other	4	3.8	8	3.1
Aboriginal/Torres Strait Islander ^b	-	-	8	3.1
Lives with family member with cancer ^b	106	100	230	79.3
CanTeen member	68	64.2	128	50.0
Family members with cancer	Brothers/sisters n = 106		Parents/guardians n = 256	
	M	SD	M	SD
Time since diagnosis, mo	16.7	16.3	16.2	13.8
	n	%	n	%
Gender ^c				
Male	54	50.9	80	38.3
Female	52	49.8	174	68.0
Most common cancer types ^d				
Bone and soft tissue	13	12.3	14	5.5
Bowel	0	0	33	12.9
Brain	14	13.2	10	3.9
Breast	0	0	108	42.2
Head or neck	1	0.9	15	5.9
Leukaemia	38	35.8	18	7.0
Lung	0	0	17	6.6
Hodgkin lymphoma	15	14.2	4	1.6
Non-Hodgkin lymphoma	6	5.7	12	4.7
Reproductive	12	11.3	12	4.7
Other	12	11.3	57	22.3
Treatment stage				
Recently diagnosed	2	1.9	13	5.1
On treatment	70	66.0	161	62.3
Finished treatment	32	30.2	66	25.8
Unsure	2	1.9	16	6.3
Relapse status ^e				
Never relapsed	90	84.9	179	70.2
Has relapsed	15	14.2	71	27.8

^aLength of membership available for 64 sibling and 126 offspring members.

^bNot collected from siblings.

^cGender not reported for 2 family members with cancer.

^dSome family members had more than one cancer.

^eRelapse status not reported for 6 family members with cancer.

TABLE 2 The SCNI and OCNI domain structure and average proportion of unmet needs reported by siblings and offspring (N = 362)

Domain	Abbreviation	Concerns the Need:	N Items in Domain	Average % Needs Unmet
Sibling Cancer Needs Instrument (SCNI)				
Information about my sibling's cancer	INFO	For information about their sibling's cancer, treatment, side effects and recovery, presented in an easily understood, age-appropriate format	8	46.7
"Time out" and recreation	TOR	To "have a break"/"time out" from the pressures of the cancer experience and participate in activities including sports or social events to regain a sense of normality	6	46.1
Practical assistance	PRAC	For support with daily-living/practical issues including household chores, work/education-related support and connection with relevant support services	3	24.2
Dealing with feelings	FEEL	To be able to express feelings about their sibling's cancer, its impact on their life and their needs for help dealing with feelings including sadness, anxiety and anger	8	43.4
Support from my friends and other young people	SF/OYP	To feel supported/understood by friends, able to discuss the cancer experience and spend time with other young people with similar experiences	8	44.9
Understanding from my family	UFAM	To feel supported/acknowledged by family, able to spend time with family and able to communicate with them about the cancer experience	5	31.6
Relationship with my sibling with cancer	RSIB	For help with issues involving their relationship with their sibling with cancer and navigating challenges in that relationship	7	46.8
Offspring Cancer Needs Instrument (OCNI)				
Information about my parent's cancer	INFO	For information about their parent's cancer, treatment, side effects and recovery, presented in an easily understood, age-appropriate format	9	56.5
"Time out" and recreation	TOR	To "have a break"/"time out" from the pressures of the cancer experience and participate in activities including sports or social events to regain a sense of normality	5	50.6
Practical assistance	PRAC	For support with daily-living/practical issues including household chores, work/education-related support and connection with relevant support services	7	33.9
Dealing with feelings	FEEL	To be able to express feelings about their parent's cancer, its impact on their life and their needs for help dealing with feelings including sadness, anxiety and anger	13	45.7
Family issues	FAM	To feel supported by family, communicate openly and honestly about their parent's cancer and know how to behave around the parent with cancer	4	51.1
Support from my friends	SF	To feel friends understand what they are going through and be able to communicate with friends about the cancer experience	4	52.5
Support from other young people	SOYP	To feel supported by/learn from other young people of a similar age who have experienced parental cancer	5	49.3

Offspring appeared to have similar needs to adult caregivers of cancer patients who have previously reported high needs in relation to information about things such as the patient's condition and treatment, managing emotions, obtaining support, balancing their own needs with those of the patient, employment, and decision-making.³³⁻³⁶ This suggests AYA offspring adopt a caregiver identity when their parent has cancer, potentially because of increased responsibilities to care for themselves and others. Ensuring that parents and health care professionals are aware of these needs and support options may lessen the burden and psychosocial impact on these young people.

While this study included participants from across the full Australian AYA age range, few other distress and needs studies have done so despite the potential predictive value of age amongst AYAs. For example, previous modelling using the current data indicated that for offspring, being older is related to greater distress and being younger is related to more unmet need for support from other young people with similar experiences.^{8,9} Inclusion of a broad age range in future studies may highlight important age-dependant predictors of distress and needs and will ensure that intervention development and service delivery can be targeted to suit all AYAs impacted by familial cancer.

4.1 | Clinical implications

The unmet needs of AYA siblings and offspring appear to differ substantially from those of AYA cancer patients, with unmet physical and daily living needs understandably most often identified amongst patients, followed by psychological, health system, information, care, and support needs.³⁷ Understanding differences in needs between these groups will assist support organisations and health services in targeting interventions and resources. In the current study, participants' high unmet needs associated with cancer-related information, friends' understanding, having "time out," and opportunities to spend time with other young people with similar experiences, suggests that information resources about the cancer experience, efforts to foster understanding amongst friends of AYAs impacted by familial cancer, and provision of respite programs and opportunities to connect with other young people impacted by cancer may be particularly helpful. Further, high unmet needs for dealing with feelings and family relationships, along with the high levels of distress, suggest that the provision of counselling and psychological interventions would be of benefit to these young people.

TABLE 3 Unmet needs reported by more than 50% of sibling/offspring participants (n = 362)

Item Number	Domain	SCNI or OCNI Item Wording: Sentence Stem: <i>I currently need ...</i>	Participants Reporting Unmet Need	
			n	%
SCNI (siblings n = 106)				
5	INFO	Information about the impact that the cancer and treatment may have on my sibling's life in the future	64	60.4
7	INFO	Information about the side effects of my sibling's treatment	62	58.5
21	S-FR/OYP	Support from my friends	58	54.7
2	INFO	Information about my sibling's condition—good or bad	57	53.8
9	TOR	To be able to have fun	56	52.8
11	TOR	Somewhere to go when it gets too hard to deal with my sibling's cancer	55	51.9
13	TOR	To have time to look after myself and focus on my own needs	54	50.9
29	FEEL	Help with feelings about the possibility that my sibling with cancer might die	53	50.0
41	R-SIB	To have "time out" with my sibling away from "the cancer"	53	50.0
OCNI (offspring n = 256)				
6	INFO	Information about the chances of my parent's recovery	170	66.4
2	INFO	To be informed about my parent's condition	167	65.2
9	INFO	Information about what to do if I notice a particular side-effect or symptom in my parent with cancer	166	64.8
5	INFO	Information about my parent's cancer and its impact on their life	158	61.7
26	FEEL	To learn ways of coping with the added stress placed on my family	157	61.3
7	INFO	Information about the side effects of my parent's treatment	154	60.2
36	FEEL	Help with my feelings about the possibility that my parent might die	151	59.0
22	TOR	To be involved in activities that distract me from the way that my parent's cancer makes me feel	146	57.0
21	TOR	To be able to have fun	144	56.3
30	FEEL	To be able to express how I feel about my parent's cancer, without worrying about upsetting people	142	55.5
3	INFO	To be able to get information about my parent's cancer in a way that I can understand	141	55.1
11	FAM	To feel that I can talk openly with my family about my parent's cancer	140	54.7
44	S-OYP	To talk to someone my own age who has been through a similar experience with cancer	139	54.3
41	S-FR	Support from my friends	136	53.1
42	S-FR	My friends to feel comfortable talking to me about my experience with my parent's cancer	135	52.7
47	S-OYP	To be able to learn from other young people who have been through a similar experience with cancer	135	52.7
8	INFO	Information about what happens after my parent comes home following treatment	134	52.3
12	FAM	To feel that my parents were being open with me about what was going on regarding my parent's cancer	132	51.6
25	TOR	To spend more time with friends	132	51.6
10	FAM	To feel that I have support from my family regarding my parent's cancer	130	50.8
28	FEEL	Help dealing with sadness related to my parent's cancer	129	50.4
43	S-OYP	The opportunity to spend time with other young people affected by their parent's cancer	129	50.4

Abbreviations: OCNI, Offspring Cancer Needs Instrument; SCNI, Sibling Cancer Needs Instrument.

Currently for offspring, a manualised, group-based acceptance and commitment therapy program focussing on psychosocial and information needs is being evaluated,³⁸ while a 2009 systematic review identified some encouraging outcomes from a small number of interventions for siblings focussed on enhancing, coping, family communication, medical knowledge, peer support, and providing recreation.³⁹ With growing evidence of the impact of familial cancer

on AYAs and their unmet needs, greater focus on developing and evaluating interventions for these young people is warranted.

4.2 | Limitations

Immigrants and males were underrepresented in the current sample relative to their representation in the Australian population.⁴⁰ While

the proportion of Aboriginal and Torres Strait Islander offspring participants was approximately in line with their representation in the Australian population, this information was not available for sibling participants. Culturally and linguistically diverse populations may face different or additional needs and potentially higher distress because of challenges in accessing support compatible with their cultural identity and language needs. Findings may not be representative of these populations and further investigation is suggested.

Given the self-selection recruitment strategy used, it was not possible to measure response rate or report reasons for nonparticipation. Finally, although approximately two-thirds of sibling and half of offspring participants were members of a support organisation for AYAs impacted by cancer, >80% of siblings and almost all offspring members had joined <12 months prior and, as previously reported elsewhere, no significant differences were found between members and nonmembers on study measures or recruitment method.^{5,7}

4.3 | Conclusion

This study provides important additional evidence that Australian AYAs impacted by familial cancer experience high levels and numbers of unmet needs and substantial distress. Comparisons between the current sample and previously reported Australian population-level data indicate AYAs impacted by familial cancer experience 3 to 6 times the levels of high or very high distress. These levels are similar to Australian AYAs seeking treatment for mental health issues.²⁹ Given these indications of heightened distress, further investigation is warranted to clarify AYA sibling and offspring risk of poorer psychosocial outcomes relative to their peers. Strong associations between increased distress and more unmet needs were found for both siblings and offspring. While unmet needs were high for both groups, offspring had particularly high numbers of unmet needs on average and reported the highest proportion of unmet needs in the information domain, highlighting the need for robust cancer-related education and information resources for this population. Conversely, siblings reported the highest proportion of unmet needs concerning their relationship with their sibling. Interventions for siblings should include supporting and strengthening this relationship. These insights into the type and number of needs experienced by AYAs impacted by familial cancer can facilitate the development and delivery of appropriately targeted, age-appropriate interventions and resources to these vulnerable and underserved populations.

CONFLICT OF INTEREST

The authors declare no conflict of interest in the conduct or publication of this work.

ENDNOTES

* The Australian definition of adolescents and young adults according to the Australian Institute of Health and Welfare includes those aged 12 to 24 years.¹⁰

† CanTeen is the Australian national support organisation for young people (12-24 years) living with cancer.

‡ Camp Quality is an Australian national support organisation for children (0-13 years) living with cancer and their families.

REFERENCES

1. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. *Cancer*. 2000;88(1):226-237.
2. Sloper P. Predictors of distress in parents of children with cancer: a prospective study. *J Pediatr Psychol*. 2000;25(2):79-91. <https://doi.org/10.1093/jpepsy/25.2.79>
3. Lambert SD, Harrison JD, Smith E, et al. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. *BMJ Support Palliat Care*. 2012;2(3):224.
4. Patterson P, Millar B, Visser A. The development of an instrument to assess the unmet needs of young people who have a sibling with cancer: piloting the Sibling Cancer Needs Instrument (SCNI). *J Pediatr Oncol Nurs*. 2011a;28(1):16-26. <https://doi.org/10.1177/1043454210377174>
5. Patterson P, McDonald FEJ, Butow P, et al. Psychometric evaluation of the Sibling Cancer Needs Instrument (SCNI): an instrument to assess the psychosocial unmet needs of young people who are siblings of cancer patients. *Support Care Cancer*. 2014a;22(3):653-665. <https://doi.org/10.1007/s00520-013-2020-3>
6. Patterson P, Pearce A, Slawitschka E. The initial development of an instrument to assess the psychosocial needs and unmet needs of young people who have a parent with cancer: piloting the Offspring Cancer Needs Instrument (OCNI). *Support Care Cancer*. 2011b;19(8):1165-1174. <https://doi.org/10.1007/s00520-010-0933-7>
7. Patterson P, McDonald FEJ, Butow P, et al. Psychometric evaluation of the Offspring Cancer Needs Instrument (OCNI): an instrument to assess the psychosocial unmet needs of young people who have a parent with cancer. *Support Care Cancer*. 2013;21(7):1927-1938. <https://doi.org/10.1007/s00520-013-1749-z>
8. McDonald FE, Patterson P, White KJ, Butow PN, Costa DS, Kerridge I. Correlates of unmet needs and psychological distress in adolescent and young adults who have a parent diagnosed with cancer. *Psychooncology*. 2016;25(4):447-454. <https://doi.org/10.1002/pon.3942>
9. McDonald FEJ, Patterson P, White KJ, Butow P, Bell ML. Predictors of unmet needs and psychological distress in adolescent and young adult siblings of people diagnosed with cancer. *Psychooncology*. 2015;24(3):333-340. <https://doi.org/10.1002/pon.3653>
10. Australian Institute of Health and Welfare. Young Australians: their health and wellbeing 2011. Australian Institute of Health Welfare, Canberra 2011.
11. Australian Institute of Health and Welfare. Australian cancer incidence and mortality books. AIHW, Canberra 2016.
12. de Vaus D. Diversity and change in Australian families: statistical profiles. Australian Institute of Family Studies, Melbourne, Australia 2004.
13. Australian Bureau of Statistics (ABS). Census QuickStats. ABS. http://www.censusdata.abs.gov.au/census_services/getproduct/census/2011/quickstat/0. 2011
14. Patterson P, McDonald FEJ, Orchard P. A new Australian online and phone mental health support service for young people living with cancer. *Australas Psychiatry*. 2014b;22(2):165-169. <https://doi.org/10.1177/1039856213519144>
15. Alderfer MA, Long KA, Lown EA, et al. Psychosocial adjustment of siblings of children with cancer: a systematic review. *Psychooncology*. 2010;19(8):789-805.
16. Houtzager BA, Grootenhuis MA, Caron HN, Last BF. Quality of life and psychological adaptation in siblings of paediatric cancer patients, 2 years after diagnosis. *Psychooncology*. 2004;13:499-511. <https://doi.org/10.1002/pon.759>
17. Woodgate RL. Siblings' experiences with childhood cancer: a different way of being in the family. *Cancer Nurs*. 2006;29(5):406-414.
18. Heffernan SA, Zanelli AS. Behavior changes exhibited by siblings of pediatric oncology patients: a comparison between maternal and sibling descriptions. *J Pediatr Oncol Nurs*. 1997;14(1):3-14.

19. Visser A, Huizinga GA, van der Graaf WT, Hoekstra HJ, Hoekstra-Weebers JE. The impact of parental cancer on children and the family: a review of the literature. *Cancer Treat Rev*. 2004;30(8):683-694.
20. Wilkins KL, Woodgate RL. A review of qualitative research on the childhood cancer experience from the perspective of siblings: a need to give them a voice. *J Pediatr Oncol Nurs*. 2005;22:305-319.
21. Buchbinder D, Casillas J, Krull KR, et al. Psychological outcomes of siblings of cancer survivors: a report from the Childhood Cancer Survivor Study. *Psychooncology*. 2010;20(12):1259-1268. <https://doi.org/10.1002/pon.1848>
22. Alderfer MA, Labay LE, Kazak AE. Brief report: does posttraumatic stress apply to siblings of childhood cancer survivors? *J Pediatr Psychol*. 2003;28(4):281-286.
23. Osborn T. The psychosocial impact of parental cancer on children and adolescents: a systematic review. *Psychooncology*. 2007;16:101-126.
24. Kessler RC, Andrews G, Colpe LJ, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med*. 2002;32:959-976.
25. Kessler RC, Barker PR, Colpe LJ, et al. Screening for serious mental illness in the general population. *Arch Gen Psychiatry*. 2003;60(2):184-189. <https://doi.org/10.1001/archpsyc.60.2.184>
26. Chan SM, Fung TCT. Reliability and validity of the K10 and K6 in screening depressive symptoms in Hong Kong adolescents. *Vulnerable Child Youth Stud: An International Interdisciplinary Journal for Research, Policy and Care*. 2014;9(1):75-85. <https://doi.org/10.1080/17450128.861620>
27. Lawrence D, Johnson S, Hafekost J, et al. The mental health of children and adolescents. Report on the second Australian child and adolescent survey of mental health and wellbeing. Department of Health, Canberra., Canberra. 2015.
28. McDowell ME, Occhipinti S, Ferguson M, Dunn J, Chambers SK. Predictors of change in unmet supportive care needs in cancer. *Psychooncology*. 2010;19(5):508-516. <https://doi.org/10.1002/pon.1604>
29. Rickwood D, Telford N, Parker A, Tanti C, McGorry P. Headspace-Australia's innovation in youth mental health: who are the clients and why are they presenting? *Med J Aust*. 2014;200(2):1-4. doi:0.5694/mja13.11235
30. Hamama R, Ronen T, Feigin R. Self-control, anxiety, and loneliness in siblings of children with cancer. *Soc Work Health Care*. 39(1-2):129-4939(1-2):129-492000;31(1):63-83.
31. Murray JS. Understanding sibling adaptation to childhood cancer. *Issues Compr Pediatr Nurs*. 2000;23(1):39-47. <https://doi.org/10.1080/014608600265200>
32. Krattenmacher T, Kuhne F, Fuhrer D, et al. Coping skills and mental health status in adolescents when a parent has cancer: a multicenter and multi-perspective study. *J Psychiatr Res*. 2013;74:252-259.
33. Adams E, Boulton M, Watson E. The information needs of partners and family members of cancer patients: a systematic literature review. *Patient Educ Couns*. 2009;77:179-186. <https://doi.org/10.1016/j.pec.2009.03.027>
34. Sklenarova H, Krümpelmann A, Haun MW, et al. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer*. 2015;121(9):1513-1519. <https://doi.org/10.1002/cncr.29223>
35. Hwang SS, Chang VT, Alejandro Y, et al. Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. *Palliat Support Care*. 2003;1(04):319-329. <https://doi.org/10.1017/S1478951503030475>
36. Butow PN, Price MA, Bell ML, et al., The Australian Ovarian Cancer Study G, The Australian Ovarian Cancer Study Quality of Life Study I. Caring for women with ovarian cancer in the last year of life: a longitudinal study of caregiver quality of life, distress and unmet needs. *Gynecol Oncol*. 2014;132(3):690-697. <https://doi.org/10.1016/j.ygyno.2014.01.002>
37. Dyson GJ, Thompson K, Palmer S, Thomas DM, Schofield P. The relationship between unmet needs and distress amongst young people with cancer. *Support Care Cancer*. 2012;20:75-85. <https://doi.org/10.1007/s00520-010-1059-7>
38. Patterson P, McDonald FEJ, Ciarrochi J, et al. A study protocol for Truce: a pragmatic controlled trial of a 7 week acceptance and commitment therapy program for young people who have a parent with cancer. *BMC Psychiatry*. 2015;3(1). <https://doi.org/10.1186/s40359-015-0087-y>
39. Prchal A, Landolt MA. Psychological interventions with siblings of pediatric cancer patients: a systematic review. *Psychooncology*. 2009;18:1241-1251.
40. Australian Bureau of Statistics. 1370.0—measures of Australia's progress, population. Australian Government, Canberra, Australia 2010.

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