



What young people need when a family member dies of cancer

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Abstract

Purpose This study uses the newly developed Bereaved Cancer Needs Inventory to identify the unmet psychosocial needs of adolescents and young adults who have experienced the death of a parent or sibling to cancer, and to explore the relationship between unmet needs and psychological distress.

Methods In total, 278 bereaved offspring and 38 bereaved siblings (12–25 years) completed the 58-item Bereaved Cancer Needs Inventory (BCNI) and the Kessler psychological distress scale (K10).

Results Bereaved offspring reported 27 unmet needs on average (SD = 16.87, range: 0–58); 94% indicated at least one unmet need, with 80% indicating 10 or more needs. Bereaved siblings reported 23 unmet needs on average (SD = 17.30, range: 0–57); 97% indicated at least one unmet need, with 68% indicating 10 or more needs. For both bereaved offspring and siblings, the needs for “support from other young people” and “time out and recreation” were most frequently reported as unmet. Approximately half of all participants reported high to very high levels of psychological distress. There was a significant positive relationship between the number of unmet needs and the psychological distress score on the K10 for both groups.

Conclusions Bereaved offspring and bereaved siblings report unmet psychosocial needs across many domains, which are associated with their levels of psychological distress. Findings suggest the BCNI may be used by healthcare professionals to identify unmet needs and direct clients to the appropriate services, resources, or support; with the intent to reduce their risk of mental illness and psychological distress.

Keywords Unmet needs · Cancer · Bereavement · Offspring · Siblings · Adolescents and young adults

Introduction

The death of a parent or sibling due to cancer is one of the most stressful life events that adolescents and young adults (AYAs¹; 12–25 years) can experience [1–4]. However, the literature on the experiences and needs of AYAs bereaved by familial cancer is limited: few studies have directly investigated the psychosocial

needs of this population, and interventions available to this population tend not to be specific to either the AYA age group or the cancer situation [5]. Previous research developing and validating needs measures for non-bereaved AYAs affected by a parent or sibling’s cancer has allowed for robust and efficient assessment of this population’s needs in both research and clinical settings, facilitating the development and evaluation of effective interventions and targeted service provision (e.g., [6]). The development and validation of a comparable measure of bereaved AYAs’ needs thus represents an important foundational step in understanding and supporting this population through their bereavement experience.

Previous studies exploring the needs of AYAs bereaved by familial cancer have used qualitative methods, including open-ended questions and interviews [7–9]. For example, Patterson and Ranggandhan’s [8] qualitative questionnaire asked 62 bereaved AYAs to identify five needs, why each was a need, if the need was unmet, and how the unmet need made them feel. The needs identified were categorised into seven themes: support and understanding, coping with feelings, talking to people with similar experiences, information, “time out” from the cancer

¹ The Australian Institute of Health and Welfare (2011) definition of adolescents and young adults includes those aged 12–24 years. Because CanTeen offers services up to 25 years of age, the AYA age group ranged from 12 to 25 years.

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situation, space and time to grieve, and help with household responsibilities. These themes were echoed in Nolbris and Hellström's interviews with children and young adults bereaved by a sibling's cancer [9] and Alvariza and colleagues' nationwide survey of bereaved young adults [7]. While these studies have identified many issues related to the unmet psychosocial needs of AYAs who have experienced the death of a parent or sibling to cancer, thus far there has been no systematic approach to measuring these needs.

Drawing from the themes identified by Patterson and Rangandhan [8], and further informed by a literature review and stakeholder consultations, the Bereaved Cancer Needs Inventory (BCNI) was developed to provide a comprehensive quantitative measure of unmet needs of young people bereaved by familial cancer. The ability to assess and quantify unmet needs is important in both research and clinical practice. In clinical settings, the BCNI allows clinicians to comprehensively assess and identify bereaved young people's unmet needs in order to provide targeted care, including identifying and triaging those who may benefit from additional support. Moreover, research into the nature and prevalence of unmet needs in this population can inform service provision, guiding the development of resources and interventions to address these needs.

This study uses the BCNI to provide a descriptive analysis of the levels of, and relationships between, psychosocial unmet needs and distress in AYAs who have experienced the death of a parent or sibling due to cancer. Findings are reported separately for bereaved offspring and bereaved siblings, in order to identify potential differences in levels and patterns of unmet needs. Research questions were as follows:

- RQ1. What are the most common unmet needs reported by AYAs bereaved by familial cancer?
- RQ2. Are there differences in the levels of psychological distress and unmet needs reported by bereaved offspring and bereaved siblings?

Additionally, in accordance with previous research on non-bereaved AYAs affected by familial cancer, it was hypothesised that:

H1. Higher numbers of unmet needs on the BCNI will be associated with increased levels of psychological distress.

Method

Participants

This study included bereaved AYAs (12–25 years) who had experienced the death of a parent or sibling due to cancer

Table 1 Demographics for the bereaved offspring and bereaved siblings, including the frequency and percentage for gender, age, type of cancer, and time since death

Variable	Offspring		Sibling	
	Frequency	Percent	Frequency	Percent
<i>n</i>	278	–	38	–
Gender				
Female	192	69.10	25	65.79
Male	84	30.20	13	34.21
Age (years)				
11–17	201	72.30	30	78.95
18–25	69	24.82	8	21.05
Type of cancer				
Adenocarcinoma	10	3.60	–	–
Breast	8	2.88	–	–
Bone	7	2.52	1	2.63
Bowel	25	8.99	1	2.63
Brain and CNS	23	8.27	14	36.84
Cholangiocarcinoma	6	2.16	–	–
Cervical	5	1.80	–	–
Colon	3	1.08	–	–
Ewing's sarcoma	–	–	5	13.16
Kidney	4	1.44	–	–
Leukaemia	7	2.52	6	15.79
Lung	27	9.71	–	–
Lymphoma	29	10.43	2	5.26
Melanoma	23	8.27	–	–
Multiple	20	7.19	–	–
Myeloma	8	2.88	–	–
Oesophageal	6	2.16	–	–
Ovarian	5	1.80	2	5.26
Pancreatic	16	5.76	–	–
Prostate	3	1.08	–	–
Stomach	8	2.88	–	–
Other	31	11.15	8	21.05
Time since death				
< 6 months	102	36.69	14	36.84
6–12 months	53	19.06	5	13.16
12–24 months	59	21.22	6	15.79
> 24 months	64	23.02	13	34.21

within the last 5 years, and who had accessed services provided by CanTeen² (the Australian organisation for young people living with cancer). Data was excluded if participants completed the BCNI more than 5 years after their parent's death.

² CanTeen provides support to AYAs who have cancer, have a parent or sibling with cancer, or who have had a parent (bereaved offspring) or sibling (bereaved sibling) die due to cancer.

Measures

Bereaved Cancer Needs Inventory

The 58-item Bereaved Cancer Needs Inventory (BCNI) was used to assess the unmet psychosocial needs of bereaved offspring and siblings. Each of the 58 questions in the BCNI starts with the sentence stem ‘I currently need...’, with items covering 8 domains: information (4 items), time out and recreation (6 items), practical assistance (5 items), support from friends (4 items), support from other young people (5 items), support (7 items), dealing with feelings (16 items), and family (11 items, see Table 3 for all items). Where necessary, the terms ‘parent’ and ‘sibling’ were interchanged within items that were specific to bereaved offspring or bereaved siblings (e.g., ‘I currently need help dealing with sadness related to my *’s death’). Participants then indicate the extent of each need on a four-point scale (1 = ‘no need’, 2 = ‘low need’, 3 = ‘moderate need’, 4 = ‘strong need’). As per previous reporting on needs of non-bereaved offspring and siblings [6, 10], when reporting on numbers of unmet needs participants’ responses were dichotomised into no need (‘no need’/‘low need’) and an unmet need (‘moderate need’/‘strong need’). The measure had excellent internal consistency in this study (Cronbach’s $\alpha = 0.98$).

Kessler Psychological Distress Scale

The Kessler Psychological Distress Scale (K10) [11] is a ten-item self-report measure assessing the frequency of feelings of depression and anxiety over the previous 4 weeks (1 = ‘none of the time’–5 = ‘all of the time’; for a detailed overview of the K10, see [11, 12]). Andrew and Slade [12] evaluated the K10 using normative Australian data and confirmed its validity for measuring psychological distress. Based on their results, participants’ scores in our study were categorized into low (10–15), moderate (16–21), high (22–29), and very high (30–50) levels of psychological distress [12, 13]. In this study, the K10 had excellent internal consistency (Cronbach’s $\alpha = 0.96$).

Procedure

Data was collected over a 3-year period as part of CanTeen’s routine psychosocial assessment and review process, which is used for both individual-level provision of targeted services and system-level quality assurance. Upon first accessing CanTeen services, AYAs complete an assessment with a psychosocial support worker (either in-person, online or via phone); they are informed that their information may be used to help improve the support CanTeen offers and in communication to others about how CanTeen helps. Consent (including parental consent for those under 18 years) is obtained for the use of data for quality assurance and clinical services; the secondary use of this data for research purposes is consistent with the Health Records and Privacy Act 2002.

For bereaved offspring and bereaved siblings, the routine psychosocial assessment includes the completion of the BCNI. All bereaved young people were provided with information about the BCNI and discussed the purpose, aims, and relevance of the measure for them and CanTeen, before indicating consent and completing first the BCNI, then the K10 measure of distress. At the completion of the survey, contact details for CanTeen and other support services (e.g., Lifeline and Kids Helpline) were provided. The CanTeen support workers then used the contents of the survey to develop an individual support plan. Analysis was completed using a de-identified database, and the study was approved by the CanTeen Ethics Committee (Approval No. CEC15.002).

Analyses

The prevalence of each unmet need was assessed by calculating the proportion of participants who endorsed each item of the BCNI as unmet. To compare levels of distress (K10) and unmet needs (BCNI) between bereaved offspring and bereaved siblings, a MANOVA was conducted. Finally, bivariate Pearson correlations were used to examine the relationship between psychological distress and unmet needs.

Table 2 Differences in the mean number of needs within each domain identified as unmet by bereaved offspring and bereaved siblings

Domain (total number of items)	Offspring			Sibling			Difference	
	<i>M</i>	<i>SD</i>	%	<i>M</i>	<i>SD</i>	%	<i>F</i>	<i>p</i>
Information (4)	1.67	1.45	41.91	1.82	1.61	45.39	.57	.45
Time out and recreation (6)	3.47	2.17	57.43	3.11	2.28	51.75	.51	.48
Practical assistance (5)	1.86	1.59	36.83	1.32	1.38	26.32	2.90	.09
Support from my friends (4)	2.00	1.61	49.46	1.76	1.65	44.08	.66	.42
Support from other young people (5)	3.03	2.00	60.00	2.82	2.19	56.32	.33	.57
Support (7)	3.23	2.31	45.48	2.32	2.34	33.08	4.21	.04
Dealing with feelings (16)	7.61	5.33	46.04	5.97	5.39	37.34	2.44	.12
Family (11)	4.60	3.85	41.91	3.57	3.72	31.58	2.26	.13

Table 3 The mean, standard deviation, and percentage of participants who identified each item as an unmet need for offspring and siblings

Domain	Item content	Offspring			Sibling		
		M	SD	Unmet (%)	M	SD	Unmet (%)
	I currently need...						
Information	1. To be informed about grief and loss in a way that I can understand	2.12	0.95	34.89	2.13	1.02	36.84
Information	2. To learn about the different feelings, I might have following my *'s death	2.27	0.97	39.21	2.26	1.11	44.74
Information	3. To have information on how to talk to others about my *'s death	2.55	1.05	54.32	2.39	1.13	47.37
Information	4. Access to information about support services that are available to me	2.23	1.01	39.35	2.34	1.07	52.63
Time-out and recreation	5. To be able to have fun	2.88	1.08	68.12	2.79	1.04	71.05
Time-out and recreation	6. To be involved in activities that distract me from the way that my *'s death makes me feel	2.71	1.08	60.88	2.53	0.98	55.27
Time-out and recreation	7. To feel like a 'normal' young person, which it seems I've lost because of my *'s death	2.62	1.08	53.99	2.50	0.98	47.37
Time-out and recreation	8. Somewhere to go when it gets too hard to deal with my *'s death	2.56	1.08	56.16	2.47	1.06	52.63
Time-out and recreation	9. To have 'time-out' from the extra duties that I have taken on at home	2.45	1.08	47.83	2.03	1.08	31.58
Time-out and recreation	10. To have time to look after myself and focus on my own needs	2.70	1.02	60.15	2.53	1.06	52.63
Practical assistance	11. Help concentrating on tasks at school, TAFE, university or work	2.62	1.09	57.09	2.50	1.16	55.27
Practical assistance	12. My teachers and/or boss to understand my situation and be more flexible	2.17	1.04	39.64	1.97	0.89	26.32
Practical assistance	13. Assistance with jobs and chores around the house	1.81	0.95	23.27	1.58	0.76	10.53
Practical assistance	14. Assistance with knowing how to budget money	2.03	1.08	33.45	1.61	0.82	15.79
Practical assistance	15. Assistance with developing my independence	2.07	1.00	32.73	1.84	1.08	23.68
Support from friends	16. My friends to understand what I am going through	2.40	1.04	45.82	2.13	0.99	39.47
Support from friends	17. Support from my friends	2.38	1.08	47.27	2.21	1.14	39.47
Support from friends	18. To know how to talk to my friends about my experience with my *'s cancer	2.44	1.05	49.45	2.21	1.04	44.74
Support from other young people	19. My friends to feel comfortable talking to me about my experience with my *'s death	2.64	1.11	57.46	2.42	0.95	52.63
Support from other young people	20. The opportunity to spend time with other young people affected by their *'s cancer	2.73	0.99	61.09	2.63	1.05	63.16
Support from other young people	21. To be linked in with a social support network with others who share a similar experience	2.57	0.97	56.73	2.32	1.09	47.37
Support from other young people	22. To feel supported by other young people who have a similar experience with cancer	2.57	0.99	54.18	2.42	1.15	57.89
Support from other young people	23. To be able to learn from other young people who have been through a similar experience	2.79	0.99	68.00	2.61	1.08	57.89
Support from other young people	24. To talk to someone my own age who has been through a similar experience	2.76	1.00	63.27	2.50	1.11	55.27
Support	25. To learn ways of coping with the added stress placed on my family	2.62	1.03	59.13	2.45	1.03	47.37
Support	26. To have someone close to discuss my feelings about my *'s death	2.35	1.05	46.35	2.05	0.93	34.21
Support	27. To talk with a counsellor/psychologist/social worker	2.25	1.08	41.97	1.82	0.90	26.32
Support	28. Help dealing with other people's reactions regarding my *'s death	2.29	1.05	42.34	1.92	0.91	31.58
Support	29. Help learning how to cope with my grief and sadness	2.54	1.07	54.01	2.08	1.02	34.21
Support	30. Someone to 'talk about any questions I have about death, dying and mortality'	2.07	1.00	32.48	1.79	0.88	23.68
Support	31. Help making plans for the future	2.41	1.05	46.72	2.11	1.06	34.21
Dealing with feelings	32. Help dealing with sadness related to my *'s death	2.41	1.02	47.21	2.18	1.01	39.47
Dealing with feelings	33. Help dealing with feeling guilty that I am still here and my * is not	2.14	1.06	36.43	2.18	1.04	42.11
Dealing with feelings	34. Help dealing with feeling guilty that I do not feel sad	2.08	1.04	34.94	2.00	1.01	34.21
Dealing with feelings	35. Help dealing with feeling guilty when I am having fun	2.14	1.05	34.57	1.82	0.87	23.68
Dealing with feelings	36. To know how to prepare for times when my feelings of grief or sadness return	2.63	1.05	60.23	2.29	1.06	47.37
Dealing with feelings	37. To be able to express how I feel about my *'s death, without worrying about upsetting people	2.60	1.11	57.25	2.16	1.08	34.21
Dealing with feelings	38. To be able to talk about how I am going without feeling guilty	2.34	1.12	45.35	1.97	0.92	28.95
Dealing with feelings	39. Help dealing with negative changes in my self-esteem as a result of my *'s death	2.44	1.10	48.70	2.11	1.06	34.21
Dealing with feelings	40. Help dealing with feelings of anger related to my *'s death	2.41	1.12	46.84	1.89	1.01	28.95
Dealing with feelings	41. Help with feeling lonely or left behind	2.46	1.11	49.07	2.24	1.05	36.84
Dealing with feelings	42. Space and time to grieve	2.38	1.09	47.96	2.24	1.10	42.11
Dealing with feelings	43. Help with being hopeful about the future	2.36	1.11	46.47	2.05	1.04	34.21
Dealing with feelings	44. Help with worries and anxiety I have about my own health	2.43	1.12	47.96	2.13	1.14	39.47
Dealing with feelings	45. Help with worries that I have that someone else I love with die	2.58	1.13	54.65	2.32	1.12	44.74
Dealing with feelings	46. Help with feelings of uncertainty now that my * has died	2.36	1.05	46.84	1.92	0.85	31.58

Table 3 (continued)

Domain	Item content	Offspring			Sibling		
		M	SD	Unmet (%)	M	SD	Unmet (%)
Dealing with feelings	47. Help dealing with regrets about things I wish I had said or done	2.64	1.09	56.88	2.45	1.20	55.27
Family	48. To feel that I have support from my family regarding my *'s death	2.07	1.03	33.96	1.86	0.95	21.62
Family	49. To feel that I can talk openly with my family about my *'s death	2.21	1.09	39.93	1.84	0.87	24.32
Family	50. Help understanding that members of my family may respond to grief differently	1.99	0.99	30.22	1.97	0.99	29.73
Family	51. Help with adjusting to changes in relationships within my family	2.25	1.09	41.04	1.89	0.99	27.03
Family	52. To feel connected to family members who are still with me	2.26	1.12	44.03	1.95	1.01	24.32
Family	53. For other family members to be open and honest about how they are feeling	2.34	1.08	45.90	2.00	0.94	32.43
Family	54. Someone to talk to me about what life will be like for our family now	2.04	1.04	31.72	1.84	0.90	21.62
Family	55. To know how to support other family members	2.37	1.11	49.25	2.24	1.09	45.95
Family	56. To feel connected to my family member who has died	2.42	1.12	50.00	2.27	1.19	37.84
Family	57. For my family to acknowledge that this is happening to me too	2.16	1.11	38.06	2.16	1.12	43.24
Family	58. Help dealing with the loss of my relationship with my *	2.58	1.10	55.97	2.38	1.26	48.65

Results

This descriptive analysis included 278 bereaved offspring (69% female; $M_{AGE} = 15.78$, $SD_{AGE} = 3.26$) and 38 siblings (66% female; $M_{AGE} = 15.58$, $SD_{AGE} = 2.94$) who completed the BCNI questionnaire at CanTeen. The time since bereavement ranged from 11 days to 5 years for bereaved offspring ($M_{MONTHS} = 15.21$, $SD_{MONTHS} = 14.73$) and bereaved siblings ($M_{MONTHS} = 19.36$, $SD_{MONTHS} = 17.87$). Further demographic details are included in Table 1.

Unmet needs

Nearly all bereaved offspring (93.66%) and bereaved siblings (97.30%) indicated at least one unmet need, with 80.22% of bereaved offspring and 67.57% of bereaved siblings endorsing 10 or more unmet needs. On average, bereaved offspring had 27.26 (SD = 16.87, range 0–58) unmet needs, with 4.71% indicating they had no unmet needs and 2.36% suggesting all 58 items were unmet. Bereaved siblings had an average of 22.86 unmet needs (SD = 17.30, range 0–58) with 5.26% indicating they had no unmet needs and 2.36% indicating that all 58 items were unmet.

Table 2 displays the percentage of unmet needs identified within each domain. For both bereaved offspring and bereaved siblings, the domains with the highest proportion of unmet needs were ‘support from other young people’ and ‘time out and recreation’, while the domain with the lowest percentage of unmet needs was ‘practical assistance’. The mean, standard deviation, and the percentage of times an item was selected as unmet need are presented in Table 3. The top 10 unmet needs for bereaved offspring and siblings are presented in Table 4. It is also important to note that all items were identified as an unmet need by multiple participants.

Unmet needs and levels of psychological distress

On average, bereaved offspring had high levels of psychological distress ($M = 24.36$, $SD = 9.35$, Range = 10–50) and bereaved siblings had moderate levels of psychological distress ($M = 22.14$, $SD = 7.76$, Range = 10–37). A large portion of bereaved offspring (57.31%) and bereaved siblings (48.65%) reported high to very high levels of distress and only 20.97% and 21.62% reporting low levels of distress, respectively. Given the observed differences in the number of unmet needs and levels of distress reported by bereaved offspring and bereaved siblings, a MANOVA was conducted to explore differences between the two groups on BCNI domains and K10 scores (Table 2). Results indicated that there was a significant effect of group (bereaved offspring vs. bereaved sibling) on the combined dependent variable of unmet needs and distress (Wilks’ Lambda = .239, $F_{9,294} = 104.074$, $p < .001$; partial eta squared = .761), but differences between groups were only

Table 4 Ten most common unmet needs reported by bereaved offspring and bereaved siblings (item number and domain in parentheses)

Bereaved Offspring	Bereaved Siblings
1. To be able to have fun (5- TOR)	1. To be able to have fun (5- TOR)
2. To be able to learn from other young people who have been through a similar experience (23- S-YP)	2. The opportunity to spend time with other young people affected by their *'s cancer (20- S-YP)
3. To talk to someone my own age who has been through a similar experience (24- S-YP)	=3. To feel supported by other young people who have a similar experience with cancer (22- S-YP)
4. The opportunity to spend time with other young people affected by their *'s cancer (20- S-YP)	=3. To be able to learn from other young people who have been through a similar experience (23- S-YP)
5. To be involved in activities that distract me from the way that my *'s death makes me feel (6- TOR)	=5. To be involved in activities that distract me from the way that my *'s death makes me feel (6- TOR)
6. To know how to prepare for times when my feelings of grief or sadness return (36- DWF)	=5. Help concentrating on tasks at school, TAFE, university or work (11- PRAC)
7. To have time to look after myself and focus on my own needs (10- TOR)	=5. To talk to someone my own age who has been through a similar experience (24- S-YP)
8. To learn ways of coping with the added stress placed on my family (25-S)	=5. Help dealing with regrets about things I wish I had said or done (47- DWF)
9. Help concentrating on tasks at school, TAFE, university or work (11- PRAC)	=9. Access to information about support services that are available to me (4- INFO)
10. 47. Help dealing with regrets about things I wish I had said or done (47- DWF)	=9. Somewhere to go when it gets too hard to deal with my *'s death (8- TOR)
	=9. To have time to look after myself and focus on my own needs (10- TOR)
	=9. My friends to feel comfortable talking to me about my experience with my *'s death (19- S-FR)

NB. Numbers and acronyms in brackets denote the item number and domain of each need. DWF = Dealing with feelings; INFO = Information; PRAC = Practical assistance; S = Support; S-FR = Support from friends; S-YP = Support from other young people; TOR = Time out and recreation

significant for the ‘support’ domain, where bereaved offspring endorsed significantly more needs as unmet than bereaved siblings ($F_{1,302} = 4.210, p = .041$).

Bivariate Pearson correlations indicated a strong positive relationship between the total number of unmet needs reported on the BCNI and levels of psychological distress on the K10 for bereaved offspring ($r(265) = .58, p < .001$) and bereaved siblings ($r(35) = .64, p < .001$). That is, participants who reported greater levels of psychological distress also reported a higher number of unmet needs.

Discussion

This study provides further evidence of the psychosocial needs of bereaved offspring and bereaved siblings, with findings indicating that these young people experience high levels of unmet needs (particularly in the domains of ‘support from other young people’ and ‘time out and recreation’) which are associated with heightened psychological distress. Results secondarily support the use of the BCNI as a suitable measure for assessing the needs of bereaved young people, with endorsement of items across all eight domains (information, time out and recreation, practical assistance, support from friends, support from other young people, support, dealing with feelings, and family) evidencing their relevance to this population.

Commonalities were evident in the needs of bereaved offspring and bereaved siblings: for both groups, the domains with the most salient needs were ‘support from other young people’ and ‘time-out and recreation’, while the top individual need was ‘the need to have fun’. Bereaved offspring’s second most endorsed need was ‘to be able to learn from other young people who have been through a similar experience’ while bereaved

siblings’ was ‘the opportunity to spend time with other young people affected by their sibling’s cancer’. This suggests that both bereaved AYA offspring and siblings need greater support from young people who have similar experiences [14]; at a time when bereaved AYAs may feel like no one else can understand their grief, this may help to normalise their feelings and reduce loneliness and isolation from their peers [5, 15–17]. Specialised grief and bereavement camps are uniquely placed to address needs in both domains, as they create space to connect with other young people with similar experiences and allow opportunities for time out and recreation [5]. While some interventions are available to AYAs bereaved by familial cancer and appear to have positive impacts, the majority do not cater specifically for either the AYA population or the cancer experience [5, 15], and they may, therefore, be inadequate in addressing the most salient needs of this group.

Some differences between bereaved offspring and bereaved siblings emerged when considering the top ten needs endorsed as unmet by each group—for example, needs for ‘my friends to feel comfortable talking to me about my experiences with my *'s death’ and ‘to feel supported by other young people who have a similar experience with cancer’ were amongst the ten most common unmet needs for siblings, but not for offspring. However, these needs were generally endorsed as unmet by a similar proportion of each group. Exceptions to this were the need for information about available support services, which was more common in bereaved siblings, and the need to know how to prepare for recurring feelings of grief, which was more common in bereaved offspring. Similarly, while bereaved offspring appeared to report more unmet needs (particularly regarding practical assistance, support, dealing with feelings, and family) and higher levels of distress, this difference was only significant for unmet

needs regarding support—a domain covering coping with and talking about grief and bereavement. The disparities between offspring and siblings' needs appear greater in bereaved than in non-bereaved AYAs [6] and suggest that the loss of a parent may be associated with greater familial and psychosocial disruption, (e.g., logistical and practical challenges, shift in family structure, taking on adult responsibilities [18]) above and beyond the grief of losing a close relative. However, caution is needed when interpreting these findings due to the low number of siblings included; it is unclear whether results will replicate, or if further differences between groups would emerge with a larger sample of bereaved siblings.

Approximately half of the bereaved AYAs in this study reported high to very high levels of psychological distress. These results are consistent with previous research which indicated that non-bereaved offspring and non-bereaved siblings were three to six times more likely to experience high to very high levels of psychological distress compared with their peers in the general population [6]. Further, bereaved offspring and siblings' levels of psychological distress were strongly related to their number of unmet needs; this result mirrors previous findings from non-bereaved offspring [19, 20] and siblings [21, 22]. This highlights the need for support services to focus on meeting the needs of bereaved AYAs as they are positively associated with their psychological distress [3, 4, 23]. As adolescence and young adulthood is a critical period for the onset of mental illness [24], identifying the risk factors associated with more severe psychosocial impacts of bereavement should be a priority for health care professionals. The BCNI will allow health care professionals to assess the unmet needs of bereaved AYAs and help them direct their clients to the appropriate services, resources, or support; with the intent to reduce their risk of mental illness and psychological distress.

The BCNI represents the first comprehensive psychosocial needs-based inventory for bereaved offspring and bereaved siblings who have experienced the death of a parent or sibling to cancer. Further work is currently underway to validate the psychometric properties of the BCNI to determine its validity and reliability, establishing it as an effective measure of the unmet needs of bereaved young people for use in research and clinical practice.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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