

Predictors of unmet needs and psychological distress in adolescent and young adult siblings of people diagnosed with cancer

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Abstract

Purpose: Predictors of psychological distress and unmet needs amongst adolescents and young adults (AYAs) who have a brother or sister diagnosed with cancer were examined.

Methods: There were 106 AYAs (12–24 years old) who completed questionnaires covering demographics, psychological distress (Kessler 10), unmet needs (Sibling Cancer Needs Instrument) and family relationships (Family Relationship Index; Adult Sibling Relationship Questionnaire; Sibling Perception Questionnaire (SPQ)). Three models were analysed (demographic variables, cancer-specific variables and family functioning variables) using multiple linear regression to determine the role of the variables in predicting psychological distress and unmet needs.

Results: Unmet needs were higher for AYA siblings when treatment was current or a relapse had occurred. Higher scores on the SPQ-Interpersonal subscale indicating a perceived decrease in the quality of relationships with parents and others were associated with higher levels of distress and unmet needs. The age and gender of the AYA sibling, whether it was their brother or sister who was diagnosed with cancer, the age difference between them, the number of parents living with the AYA sibling, parental birth country, time since diagnosis, Family Relationship Index, Adult Sibling Relationship Questionnaire and the SPQ-Communication subscale did not significantly impact outcome variables.

Conclusions: These results highlight the variables that can assist in identifying AYA siblings of cancer patients who are at risk and have a greater need for psychosocial assistance. Variables that may be associated with increased distress and unmet needs are reported to assist with future research. The results are also useful in informing the development of targeted psychosocial support for AYA siblings of cancer patients. Copyright © 2014 John Wiley & Sons, Ltd.

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Introduction

A cancer diagnosis impacts the whole family psychologically, including any siblings of the person with cancer [1–8]. Although past research has focused on families where siblings are aged under 18 years old [1–4,6,7], there is value in examining the impact on adolescent and young adult (AYA; 12–24 years old) siblings of people with cancer.¹ With young people remaining at home until they are older, there has been a shift to consider both young adults and adolescents as part of the family unit [9]. Additionally, AYA siblings often have a greater understanding of the seriousness of cancer and take on more household responsibilities [1,5], thus their lived experience is likely to be different from that of younger siblings.

Distress and unmet needs in AYA siblings of people with cancer

High levels of distress and unmet needs, and a positive correlation between them, have been reported amongst

AYA siblings [6,8,10,11]. Past studies have found higher levels of emotional and behavioural problems that are consistent with being distressed and a moderate prevalence of post-traumatic symptoms in younger siblings [6,12]. Studying levels and predictors of psychosocial distress provides a global view of the well-being of siblings, whereas studying unmet needs provides an indication of relevant practical issues that services can address. Not all studies report negative consequences for young and AYA siblings, and not all siblings are equally impacted [6,7,13]. Therefore, consistent with a recent review recommending examination of the predictors of psychosocial adjustment for young siblings of children with cancer [13], it is important to identify the relevant risk factors for developing psychological distress. Hence, this study seeks to identify potential predictors of psychological distress and unmet needs of AYA siblings of people diagnosed with cancer, to inform practice and the development of interventions.

Potential predictors of psychological distress and unmet needs

In general, children older than 12 years old (and under 18 years old) have been found to experience more loneliness [2,4], anxiety and insecurity [4], as well as higher levels of problem behaviours indicative of distress [1,3], than younger children. For AYAs, the impact of a sibling's diagnosis could be different from younger children because of increased understanding of the seriousness of the diagnosis compounded with having not fully developed the skills to cope or help [5]. Amongst adolescents, being older or younger than the sibling with cancer has been shown to have no impact on the level of behaviours indicating distress [6]. In general, it has been found that female adolescents whose brother or sister has cancer display more post-traumatic stress symptoms, anxiety, distress, loneliness, insecurity and social problems than male adolescents [4,6,13]. Other studies have found no effect for gender [2].

The quality of the sibling and family relationships may influence the impact of the cancer diagnosis on the sibling. As research into AYA sibling relationships when cancer is present is limited, it helps to draw on the literature involving siblings in healthy families. In a study examining sibling relationships amongst older adolescents and young adults (mean age = 19.8 years old), siblings who were further apart in age or the same gender had less conflict, and siblings in larger families had more rivalry and less warmth [14]. Having parents born overseas can lead to greater family burden, as cultural or linguistic differences can impact interactions with the medical system [15], or the ability to access support services [16]. Families with a single parent have a greater emotional and financial burden, and children often need to take on more responsibility [17]. It is possible that the consequences of risk factors identified in these families could be exacerbated in families with a cancer diagnosis.

Following a cancer diagnosis, siblings of cancer patients report substantial changes in their family life; they have less time with their parents (and more time with other adults), there are changes in the behaviour of their parent towards them, and changes in familial roles and responsibilities [8]. Changes in the sibling relationship following a diagnosis include decreases in companionship and increases in rivalry [8]. Existing family functioning, for example, communication styles and levels of cohesion, can influence the adaptation of young people to their sibling's diagnosis [18]. Families with greater levels of internal family support and lower levels of internal family conflict are associated with better outcomes for siblings [18]. Some young siblings report that there is an increase in closeness and cohesion in the family following a diagnosis [8]; however, it has also been found that in families with higher adaptation and cohesion, siblings experienced higher anxiety following a cancer

diagnosis [4]. About a quarter of young siblings were found to be concerned about their sibling dying, and over half reported finding the cancer treatment as scary and hard [12]. Some studies have found that anxiety decreases as the time since diagnosis increases [2,4], and a recent review found that most problems occur within 2 years of diagnosis [13].

Predictions and modelling

The purpose of this study is to explore which variables are predictors for distress and unmet needs amongst AYA siblings of people with cancer. As research into the impact of a brother or sister's diagnosis on the distress or needs of older adolescents and young adults is very limited, findings from younger siblings were used to make predictions. No previous research has looked for predictors of need amongst AYA siblings; however, because of the correlation between unmet needs and distress [10,11], it is possible that variables that impact distress may impact unmet needs. It was expected that female AYA siblings would be more negatively impacted than male AYA siblings. Previous research examining the impact of age has focused on those under 18 years old, and it is possible that the trend for difficulties increasing with age would continue for the AYA age group for siblings; however, larger age gaps between the siblings may lead to less difficulties. It is difficult to predict what impact the gender of the person with cancer has on outcomes for the sibling, although relationships with sisters appeared to impact on their siblings' well-being both positively and negatively, whereas relationships with brothers had less impact. Having parents born overseas, living with fewer parents and having more siblings may lead to more distress and unmet need. Increasing time since diagnosis is likely to decrease problems, whereas being on treatment or having relapsed is likely to increase them. Finally, although previous research is somewhat mixed, families with better functioning are likely to have fewer problems. It is not clear whether better relationships between siblings will result in resilient relationships that are protective or make the AYA sibling more exposed to distress.

Method

Participants

Siblings aged between 12 and 24 years old were eligible if they had a brother or sister (of any age) diagnosed with any type or stage of cancer within the last 5 years regardless of treatment status, who was still living. A time of 5 years since diagnosis was used as young adult patients have been found to have no decrease in distress from diagnosis to the 5-year follow-up [19], and adolescent siblings may still be distressed 2 or more years after the diagnosis [3]. AYAs were invited to complete the survey using three

recruitment approaches: (1) posters and notices directing people to an online version of the survey in two Sydney hospitals and on consumer websites; (2) paper copies of the survey were posted to new members (<12 months since joining) of CanTeen² and to people who ordered relevant resources from CanTeen; and (3) siblings of patient members of CanTeen (who were not members themselves) were invited via the patient member. As the population is limited in size, recruitment occurred over two-and-a-half-year period; between July 2009 and February 2012. Because of project resource limitations, this period could not be extended. Ethics approval was obtained from the CanTeen ethics committee and ethics boards of the participating hospitals.

Procedure

A survey assessing sociodemographic and medical information, unmet needs, psychological distress, family functioning and perceptions of the sibling relationship was used. It included a section for parental consent if the young person was aged under 18 years old. All of the measures were self-report. Participants provided information about their brother's or sister's cancer.

Outcome measures

Sibling Cancer Needs Instrument (SCNI[10,11])

The SCNI has 45 items clustered into seven domains: *information about my sibling's cancer*; *'Time out' and recreation*; *practical assistance*; *support from my friends and other young people*; *dealing with feelings*; *understanding from my family*; and *my relationship with my sibling with cancer*. Items are answered according to the sentence stem, 'I currently need...', using a four-item response scale where 1 = *No need* ('I don't have any need for help with this issue'), 2 = *Low need* ('I have a low need for help with this issue'), 3 = *Moderate need* ('I have a moderate need for help with this issue') and 4 = *Strong need* ('I have a strong need for help with this issue'). The possible range of scores is 45–180, with higher scores indicating more unmet needs. The measure has excellent internal consistency ($\alpha=0.98$) [11]. Scores were scaled to 0–100 to allow comparison between the two outcome measures [20]. A half-mean imputation rule was used for missing items in the SCNI scale: if half or more of the items of the subscale were completed, missing items were replaced by the mean of the subscale to which the item belonged. The half-mean imputation is a common approach for missing items; it is the approach used for other measures and has been shown to be a valid technique [21].

Kessler 10 (K10[22])

The K10 is a 10-item measure widely used to measure psychological distress with excellent internal consistency ($\alpha=0.93$). Participants reflect on how they have been

feeling over the last 4 weeks and respond using a 5-point scale ranging from 1 (*Never*) to 5 (*All the time*). A higher total score indicates greater psychological distress. The possible range of scores is 10–50, with higher scores indicating more distress. Scores were scaled to 0–100.

Independent variables

Sociodemographic and medical questions

Items included demographic information about the participant (e.g. age and gender), information about the family (number of children, number of parents living with the participant and country of birth for the parent), and demographic and medical information about the sibling diagnosed with cancer (e.g. age, gender, type of cancer, time since diagnosis, treatment status and relapse status).

Family Relationship Index (FRI[23])

The FRI contains 12 items that ask about the young person's assessment of general family functioning and includes the following subscales: family conflict, family expressiveness and family cohesion. For example, 'Family members really help and support me.' Participants respond using a true/false scale, and a higher total score indicates better family functioning. The possible range of scores is 0–12. Internal consistency of the subscales ranges from 0.69 to 0.78 [24].

Sibling Perception Questionnaire (SPQ[25])—Interpersonal and Communication subscales

Two factors from the SPQ domain that measure the *perceptions of disease influence* were used. The 9-item Interpersonal and 4-item Communication subscales provide respectively an assessment of sibling perceptions of the disease influence on the relationship between them and significant others, and family communication. For example, 'People are more interested in my sibling than me.' (Interpersonal subscale), and 'I can talk to my parent/s about my sibling's cancer.' (Communication subscale). Participants respond using a 5-point scale ranging from 1 (*Never*) to 5 (*Always*). Internal consistency of the subscales ranges from 0.65 to 0.86. A higher score on the Interpersonal subscale (range 9–45) indicates that the young person perceived the cancer experience to have had a negative impact on them, whereas a higher score on the Communication subscale indicates better communication (range 4–20).

Adult Sibling Relationship Questionnaire (ASRQ[14])—Intimacy and Affection subscales

The ASRQ measures participants' perceptions of their sibling's behaviour and feelings towards them, as well as their own behaviour and feelings towards their brother or sister with cancer. Although the title indicates it is designed for adults, it was developed using college-age

Table 1. Participants, brother or sister with cancer, and family demographics ($n = 106$)

	Number (%)	Mean (SD)
Participating siblings		
Gender		
Male	33 (31.1)	
Female	73 (68.9)	
Age (years)		16.6 (3.6)
Country of birth		
Australia	82 (77.4)	
New Zealand	14 (13.2)	
England	3 (2.8)	
USA	3 (2.8)	
Other	4 (3.8)	
CanTeen membership		
Member of CanTeen	68 (64.2)	
Length of membership (months)		8.3 (14.0)
Recruitment source		
Through online survey (directed by posters)	25 (23.6)	
Directly through hospitals	7 (6.6)	
New CanTeen members/ordered CanTeen resource	69 (65.1)	
Non-CanTeen Members referred by their brother or sister with cancer who is a member	4 (3.8)	
Brother or sister with cancer		
Gender		
Male	54 (50.9)	
Female	52 (49.8)	
Age and time		
Age when survey completed (years)		14.4 (5.11)
Age at time of diagnosis ^a (years)		13.1 (5.1)
Time since diagnosis (months)		16.2 (13.8)
Cancer type ^b		
Leukaemia	38 (35.8)	
Hodgkin's lymphoma	15 (14.2)	
Brain	14 (13.2)	
Bone and soft tissue	13 (12.3)	
Reproductive	12 (11.3)	
Other	19 (17.9)	
Patient treatment stage		
Recently diagnosed	2 (1.9)	
On treatment	70 (66.0)	
Finished treatment	32 (30.2)	
Unsure	2 (1.9)	
Patient relapse status		
Never relapsed	90 (84.9)	
Has relapsed	15 (14.2)	
Missing	1 (0.9)	
Number of years participant is older than brother or sister with cancer		4.0 (2.9)
Family demographics		
Number of siblings living with participant		
0	16 (15.1)	
1	37 (34.9)	
2	32 (30.2)	
3	12 (11.3)	
4–8	8 (8.4)	
Number of parents living with participant		
0	8 (7.5)	
1	27 (25.5)	
2	71 (67.0)	

(Continues)

Table 1. (Continued)

	Number (%)	Mean (SD)
Country where mother was born		
Australia	71 (67.0)	
New Zealand	15 (14.2)	
UK	6 (5.7)	
USA	2 (1.9)	
Asia	6 (5.7)	
Mainland Europe	3 (2.8)	
Middle East	2 (1.9)	
Africa	1 (0.9)	
Country where father was born		
Australia	71 (67.0)	
New Zealand	14 (13.2)	
UK	9 (8.5)	
USA	2 (1.9)	
Asia	6 (5.7)	
Mainland Europe	4 (3.8)	

^aCalculated from other data.^bSome people had more than one type of cancer.

students, thus it was considered appropriate.³ The 6-item Intimacy and 6-item Affection subscales are both from the Warmth domain. These subscales measure the participant's perceptions of the closeness and openness of affection between themselves and their sibling with cancer. For example, 'How much do you talk to this sibling about things that are important to you?' (Intimacy subscale) and 'How close do you feel to this sibling?' (Affection subscale). Participants respond using a 5-point scale ranging from 1 (*Hardly anything*) to 5 (*Extremely*). The internal consistency of both subscales is excellent (Intimacy, $\alpha = 0.91$; Affection, $\alpha = 0.92$). The possible range of scores is 6–30 for both the ASRQ-Intimacy and ASRQ-Affection scales, with higher scores indicating warmer relationships.

Statistical analysis

Predictors of distress and unmet needs were assessed by multiple linear regression. We fitted three models *a priori*, on the basis of our knowledge of unmet needs and distress in young people. All models included the gender and age of the participant. The first model was based on demographic variables, that is, the age difference between the siblings, the number of siblings, the gender of the sibling with cancer, whether the parents were born overseas, and the number of parents living with the participant. The second model focused on cancer-specific variables, that is, time since diagnosis, current treatment status and whether the sibling had relapsed. The final model addressed family functioning variables. This was measured using three scales: the FRI, the ASRQ (Intimacy and Affection subscales) and the SPQ (Interpersonal and Communication subscales). Nonlinearity in all continuous predictors was assessed using univariate fractional polynomials [26]. All analyses were performed in SAS version 9.2 [27], and statistical significance was set at 0.05.

Table 2. Means and standard deviations for predictor and outcome measures

Measure	Unscaled mean score (SD)	Scaled (0–100) mean score (SD)
K10 (unscaled range: 10–50)	24.2 (9.0)	35.13 (22.8)
SCNI (unscaled range: 45–180)	103.3 (35.1)	43.2 (26.0)
FRI (range: 0–12)	6.6 (2.9)	
ASRQ-Intimacy (range: 6–30)	16.9 (6.2)	
ASRQ-Affection (range: 6–30)	22.4 (5.3)	
SPQ-Communication (range: 4–20)	12.3 (3.9)	
SPQ-Interpersonal (range: 9–45)	20.3 (7.6)	

K10, Kessler 10; SCNI, Sibling Cancer Needs Instrument; FRI, Family Relationship Index; ASRQ, Adult Sibling Relationship Questionnaire; SPQ, Sibling Perception Questionnaire.

Results

Participants

There were 106 participants who were eligible for the study.⁴ Of these, 100 completed all items for the outcome SCNI, and 98 completed all items for the K10. Missing data rates were less than 10% for all of the variables. Demographic details are presented in Table 1.

Outcome and independent variable descriptives and regression modelling

Mean and standard deviations for all measures are presented in Table 2. The results of the regression models are shown in Table 3.

Age and gender of AYA sibling

Age and gender of the AYA sibling were included in all the models but had no significant effect on distress or unmet needs in any of the models.

Demographic variables

The first model found no significant effects on unmet needs or distress. That is, within the model, participant gender or age, whether it was their brother or sister who was diagnosed with cancer, the age difference between siblings, the number of siblings within the family, birth country of parents and the number of parents the young person lives with did not significantly impact levels of distress or unmet need.

Cancer-specific variables

The second model found that AYAs had significantly higher unmet needs when their sibling was on treatment (13.5 points; 0.52 SD) or had relapsed (16.0 points; 0.62 SD), illustrating the impact of these variables on unmet needs. Neither the gender or age of the AYA sibling nor time since diagnosis had a significant impact on distress or unmet needs.

Family functioning variables

The SPQ-Interpersonal subscale had a significant effect on both unmet needs and distress. An increase of one

standard deviation on the SPQ-Interpersonal subscale resulted in an increase of 14.4 points on the unmet needs scale (0.55 SD) and an increase of 12.9 points on the distress scale (0.57 SD), illustrating the impact of this variable on levels of both unmet needs and distress. Participant gender and age, FRI, ASRQ-Intimacy, ASRQ-Affection and SPQ-Communication did not significantly impact levels of distress or unmet needs.

Discussion

This study sought to identify risk factors for developing higher levels of distress or unmet needs in AYA siblings of cancer patients through three models. These models considered demographics variables, variables associated with the cancer diagnosis and family functioning variables including sibling relationship quality. Although the significance level was set at 0.05, because of the limited research into unmet needs and distress of AYA siblings of cancer patients, we will also discuss trend findings as these provide impetus for further investigation.

AYA age and gender

The effect of AYA age and gender was examined in all three models and had no significant impact on levels of unmet needs or distress. The previous research has found that following a sibling's cancer diagnosis, female adolescents generally have more psychosocial difficulties than male adolescents [4,6,13] and adolescents have more psychosocial difficulties than younger children [1–4]. It seems that across this older age group, the effect of gender present amongst younger siblings is not present. Two studies examining distress amongst adolescents and young adults with cancer (15–39 years old) found no effect for gender on distress when other variables were taken into account [28,29], supporting the idea that for young people impacted by cancer who are at the older end of the 'young' age range, their gender is less important than for children and younger adolescents. The results of this study suggest that within the AYA age range, age itself does not predict distress or unmet needs, validating the decision to view this population as one group. In the third model where the quality of the sibling relationship and family functioning were included, a trend effect for age was found indicating that older AYAs may have slightly lower unmet needs. As it had been anticipated that age would have an effect, additional post hoc analyses examining the effect of age on each SCNI domain were conducted, finding that an increase in age was associated with lower needs for support from others.⁵ Taken together, these results suggest that older siblings may have less need for support from others or be less impacted by family dynamics.

Table 3. Predictors of distress and unmet needs (regression coefficients and 95% confidence intervals (CI))

	Needs (SCNI; possible range 0–100)			Distress (K10; possible range 0–100)		
	Coefficient	95% CI	p-value	Coefficient	95% CI	p-value
Model 1: demographic variables						
Female sex	7.9	–3.9, 19.7	0.2	6.6	–4.1, 17.3	0.2
Age	–1.3	–2.9, 0.2	0.1	0.6	–0.7, 2.0	0.4
Age difference with sibling	1.2	–0.1, 2.4	0.06	0.5	–0.7, 1.6	0.4
Number of siblings	1.4	–3.0, 5.7	0.5	0.7	–3.4, 4.7	0.7
Affected sibling is female	–10.2	–20.8, 0.5	0.06	–5.5	–15.0, 4.1	0.3
≥1 parents not born in Australia	3.6	–7.0, 14.1	0.5	2.4	–7.1, 11.9	0.6
Living with			0.5			0.5
2 parents	6.0	–16.1,		7.9	–11.8, 27.5	
1 parent	4.7	28.1		6.2	–4.7, 17.1	
0 parent	ref	–7.6, 17.0		ref		
Model 2: cancer-specific variables						
Female sex	–3.0	–14.6, 8.6	0.6	1.2	–9.2, 11.7	0.8
Age	–1.0	–2.4, 0.5	0.2	0.9	–0.3, 2.2	0.1
Time since diagnosis (months)	–0.2	–0.6, 0.2	0.4	–0.3	–0.6, 0.1	0.2
Currently on treatment	13.5	1.4, 25.6	0.03*	2.7	–7.9, 13.3	0.6
Relapsed	16.0	1.5, 30.5	0.03*	12.4	–0.6, 25.3	0.06
Model 3: family functioning variables						
Female sex	–1.6	–11.3, 8.1	0.7	–0.6	–9.5, 8.3	0.9
Age	–1.2	–2.4, 0.1	0.08	0.8	–0.3, 2.0	0.2
FRI (range 0–12)	0.7	–0.7, 2.2	0.3	0.2	–1.1, 1.6	0.7
ASRQ-Affection (range 6–30)	1.3	0.0, 2.7	0.05	0.7	–0.5, 1.9	0.3
ASRQ-Intimacy (range 6–30)	–0.2	–1.3, 0.9	0.7	–0.2	–1.2, 0.9	0.8
SPQ-Communication (range 4–20)	–0.5	–1.8, 0.7	0.4	–0.1	–1.2, 1.1	0.9
SPQ-Interpersonal (range 9–45)	1.9	1.3, 2.5	<0.0001*	1.7	1.1, 2.3	<0.0001*

The p-value is for the hypothesis test of H_0 : coefficient = 0.

K10, Kessler 10; SCNI, Sibling Cancer Needs Instrument; FRI, Family Relationship Index; ASRQ, Adult Sibling Relationship Questionnaire; SPQ, Sibling Perception Questionnaire.
*significant $p < 0.05$.

Demographic variables model

In the first model, none of the variables were found to significantly impact levels of distress or unmet needs. However, there is a trend effect on the levels of unmet need associated with the age difference between siblings, suggesting the AYA sibling may have greater levels of unmet need as the age difference increases. This contrasts the previous literature involving families without a cancer diagnosis that found increased sibling conflict present for those closer in age [14]. The impact of age difference between siblings on unmet needs and distress when one has been diagnosed with cancer has not previously been investigated, particularly amongst siblings in the AYA age range and is of interest for future research. This trend effect of higher levels of unmet needs may be due to the siblings having different interests that are harder to accommodate, the AYA siblings perhaps being given less information and having less involvement in their brother or sister's treatment or the young person with cancer supporting their sibling less.

The size of the family, the gender of the brother or sister with cancer, the number of parents the AYA sibling lives with and the country that the parents were born in, all had no effect on distress or unmet needs. Although unexpected, this is important as it indicates that AYA siblings can experience high levels of unmet need and

distress even when potential issues associated with these variables are not present. It is possible that the range of countries that parents were born in were not sufficiently different from Australia to have an impact on their children. Future studies could examine the impact of more diverse backgrounds.

Cancer variables model

The AYA siblings have significantly higher levels of unmet need when their brother or sister with cancer is on treatment or has relapsed. There is also a large trend effect of relapse on distress levels. Previous research with siblings aged between 10 and 20 years old found high levels of distress associated with concerns about their brother or sister dying from cancer and feelings that the cancer treatment was scary [12]. Clearly, relapse raises fears associated with death, resulting in more unmet needs and distress. Additionally, when the brother or sister is in treatment, they are likely to be away from home and the parents may have less time to spend with the AYA sibling leading to higher unmet needs. It seems that time since diagnosis is not a sensitive enough measure of the cancer impact as it had no effect on unmet needs or distress; instead, it appears that treatment stage and relapse status are more useful predictors of unmet needs than time since diagnosis.

Family functioning model

The SPQ-Interpersonal subscale, which indicates the level of attention the young person perceived they received within the family and from others, explained some of the variance in levels of distress and unmet needs. Other measures of the sibling relationship or family functioning had no significant impact on the outcome variables, although the ASRQ-Affection subscale that measures closeness, caring and friendship between siblings had a trend effect on levels of unmet needs. These results indicate that the AYA's perception of the level of attention they received is more relevant than general family functioning or the relationship with their sibling. It is possible that if family relationships become closer following the diagnosis, then associated benefits and negatives counteract each other resulting in no net effect on distress. The potential impact of sibling affection on unmet needs could be explored in depth in future research.

Limitations and future research

The sample size limited the number of variables that could be included within one model. It was also not possible to examine the longitudinal impact of variables on distress or unmet needs as the study design is cross-sectional. The cultural backgrounds of the participants were not very diverse, limiting the generalizability of the results. A larger scale longitudinal study that captured greater numbers of families from culturally and linguistically diverse backgrounds, who may have divergent needs and views, would be a useful extension of this study. To adequately study diverse backgrounds, additional measures of diversity could be used to more fully describe this variable, such as acculturation.

Clinical implications and conclusions

This study helps to highlight which variables predict that an AYA sibling may be at greater risk of psychological distress or unmet needs. AYA siblings who indicate concerns with interpersonal relationships and interactions with significant others in light of their brother or sister's diagnosis, or whose brother or sister is on treatment or relapses, should be considered for assessment and possible intervention. Also of interest are the variables that are not associated with distress or unmet needs. For example, time since diagnosis is not a predictor when treatment stage and relapse status are considered, highlighting that it is the particular treatment status and not merely time since diagnosis that is important. Fam-

ily variables such as family structure and country of birth of the parents have no impact on distress or unmet needs, indicating that all family types are potentially in need of support. Understanding the role of these variables can help to identify young people who have a greater need of support services and greater risk of developing more serious psychological problems. Responses on the SCNI can be used to identify which areas an AYA sibling needs particular help.

This study examined a range of variables that could predict levels of psychological distress and unmet needs amongst AYA siblings of people with cancer, an understudied group. It found that relapse status, treatment status, and perceived changes in relationships within the family and externally, all impact levels of unmet needs and that perceived changes in these relationships also impact levels of distress. Understanding the potential impact of these variables assists in identifying at-risk AYAs and in the provision of appropriate support services.

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Conflict of interest

None of the authors have any conflict of interest. The corresponding author has full control of all primary data and agrees to allow the journal to review the data if requested.

Notes

1. AYA siblings of cancer patients shall be referred to as *AYA siblings*. The term *young siblings* shall be used when referring to siblings under the age of 18.
2. CanTeen is the Australian Organisation for Young People Living with Cancer.
3. Additionally, personal communication with the questionnaire authors indicated that the scale was suitable for the 12-year-old to 24-year-old age range.
4. The main reason for exclusions was time since diagnosis being greater than 5 years ($n = 15$). The other reasons were participant incorrect age ($n = 1$) and participant bereaved ($n = 1$).
5. Only the 'Support from others' domain was significantly correlated with age, with increasing age being associated with fewer unmet needs ($p = 0.01$, $\rho = -0.16$).

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