Palliative and Supportive Care (2016), **14**, 488–494.
© Cambridge University Press, 2015 1478-9515/15
doi:10.1017/S1478951515001273

Insufficient communication and anxiety in cancer-bereaved siblings: A nationwide long-term follow-up

ALEXANDRA EILEGÅRD WALLIN, R.N., PH.D.,[1,4,5] GUNNAR STEINECK, M.D., PH.D.,[3,4] TOMMY NYBERG, M.SC.,[4] AND ULRIKA KREICBERGS, R.N., PH.D.[1,2]

[1]Department of Women's and Child's Health, Childhood Cancer Research Unit, Karolinska Institutet, Stockholm, Sweden
[2]Ersta Skondal University College, Stockholm, Sweden
[3]Division of Oncology, Department of Clinical Cancer Epidemiology, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden
[4]Division of Oncology/Pathology, Department of Clinical Cancer Epidemiology, Karolinska Institutet, Stockholm, Sweden
[5]Dalarna University College, Falun, Sweden

(RECEIVED May 11, 2015; ACCEPTED September 22, 2015)

ABSTRACT

Objective: The purpose of this study was to examine siblings' long-term psychological health in relation to their perception of communication with their family, friends, and healthcare professionals during a brother or sister's last month of life.

Method: A nationwide questionnaire study was conducted during 2009 in Sweden of individuals who had lost a brother or sister to cancer within the previous two to nine years. Of the 240 siblings contacted, 174 (73%), participated. The Hospital Anxiety and Depression Scale (HADS) was employed to assess psychological health (anxiety). The data are presented as proportions (%) and relative risks (*RR*) with a 95% confidence interval ($CI_{95\%}$).

Results: Siblings who were *not* satisfied with the amount they talked about their feelings with others during their brother or sister's last month of life were more likely to report anxiety (15/58, 26%) than those who *were* satisfied (13/115, 11%; $RR = 2.3(1.2–4.5)$). The same was true for those who had been unable to talk to their family after bereavement ($RR = 2.5(1.3–4.8)$). Avoiding healthcare professionals for fear of being in their way increased siblings' risk of reporting anxiety at follow-up ($RR = 2.2(1.1–4.6)$), especially avoidance in the hospital setting ($RR = 6.7(2.5–18.2)$). No such differences were seen when the ill brother or sister was cared for at home.

Significance of results: Long-term anxiety in bereaved siblings might be due to insufficient communication. Avoiding healthcare professionals, especially when the brother or sister is cared for at the hospital, may also increase the risk of anxiety.

KEYWORDS: Bereavement, Cancer, Communication, Oncology, Siblings

INTRODUCTION

When a child is diagnosed with cancer, uncertainty and fear of death affect the entire family. Throughout the cancer trajectory, the ill child will naturally be the parents' main focus of concern. This may result in unintentional neglect of the other children in the family (Alderfer et al., 2010). The International Society of Pediatric Oncology (Spinetta et al., 1999) has acknowledged the sibling's need for information and involvement from the time when a brother or sister is diagnosed with cancer and throughout the illness, and in some cases even after death. The psychological health of siblings of children with cancer has been the focus of several studies, yielding conflicting findings: both psychological distress and satisfactory or better

Address correspondence and reprint requests to: Alexandra Eilegård Wallin, Dalarna University College, Högskolan Dalarna, Högskolegatan 2, 791 88 Falun, Sweden. E-mail: aee@du.se

https://doi.org/10.1017/S1478951515001273 Published online by Cambridge University Press

psychological health have been reported (Alderfer et al., 2010; Houtzager et al., 1999; Murray, 1999; Wilkins & Woodgate, 2005). At present, the available data on bereaved siblings' long-term psychological morbidity are limited. Eilegård and coworkers (Eilegård et al., 2013; Havermans & Eiser, 1994) found that bereaved siblings are more likely to suffer from sleeping difficulties, low self-esteem, and low maturity as compared to age-matched peers, two to nine years after the loss.

Several studies highlight the importance of information and involvement for siblings of children with cancer (Durall et al., 2012; Giovanola, 2005; Nolbris & Hellstrom, 2005; Wilkins & Woodgate, 2005; von Essen & Enskar, 2003; Zigmond & Snaith, 1983), but little research has been done on their impact on bereaved siblings' long-term psychological morbidity. It is well recognized that healthcare professionals find it hard to break bad news and to have discussions with the families of children with life-threatening conditions (Durall et al., 2012). Durall and coworkers (2012) also found that nurses reported ethical considerations as an obstacle more frequently than physicians, whereas physicians more often reported having difficulty finding the right thing to say.

The purpose of our study was to examine bereaved siblings' long-term psychological morbidity in relation to their perception of communication with family, friends, and healthcare professionals, both during a brother's or sister's illness and after his or her death.

Table 1. *Swedish children deceased of cancer between the years 2000 and 2007*

Children Deceased of Cancer Between the Years 2000 and 2007 in Sweden Identified in the Swedish Child Cancer Registry:
Children identified in the registry ($n = 545$)
Children with siblings younger than 18 years at follow-up in 2008 ($n = 189$)
Children with parents born outside the Nordic countries ($n = 75$)
Children born outside the Nordic countries ($n = 28$)
Children with no siblings ($n = 23$)
Children with siblings older than 25 years when the ill child died ($n = 13$)
Children with siblings younger than 12 years when the ill child died ($n = 8$)
Children ill less than a month ($n = 8$)
Children with siblings who were deceased ($n = 6$)
Children who were adopted ($n = 4$)
Children with unknown personal data in registries ($n = 3$)
Children diagnosed with cancer but died from other causes ($n = 1$)
Number of excluded children ($n = 358$)
Deceased children who fulfilled the inclusion criteria ($n = 187$)

METHODS

Procedures

Between the years 2000 and 2007, 545 Swedish children died from cancer, according to the Childhood Cancer Registry. Some 187 of these met the criteria for inclusion in our study (Table 1). We traced the deceased children and their siblings through the Swedish Population Register. Siblings were included if they were born in one of the Nordic countries, understood and spoke the Swedish language, and had an identifiable address and phone number. All siblings were 12 to 25 years of age when they lost their brother or sister. At follow-up, all were above the age of 18. For this nationwide study, 271 siblings were identified, 240 of whom were eligible for our study (see Table 2).

A letter of invitation that briefly explained the purpose of the study was mailed to bereaved siblings. A few days later, a research assistant contacted the siblings and asked if they were willing to participate. To maintain anonymity, the study-specific anonymous questionnaire and a separate response card were mailed to those who had agreed to participate.

Table 2. *Characteristics of siblings bereaved due to cancer*

Characteristics	Bereaved Siblings
Identified in registries	271
Not reachable (excluded)[#]	25
Excluded for other reasons[¤]	6
Identified eligible in registries (no. (%))	240 (100)
Reason for nonparticipation (no. (%))	
Declined to participate[**]	20
Agreed but did not participate	46
Total number of nonparticipating siblings	66 (27)
Total number of participating siblings who provided information (no. (%))	174 (73)
Sex (no. (%))	
Men	73 (42)
Women	101 (58)
Age (no. (%))	
19–23	88 (50)
24–28	59 (34)
29–33	26 (15)
Not stated	1 (1)

[#]Unknown phone number, known phone number but not reachable, lives abroad, and not reachable.
[¤]Mental retardation, death of sibling due to cause other than cancer.
[**]Bereaved: 14 men, 6 women.
19–23 years 10 men, 3 women.
24–28 years 2 men, 2 women.
29–33 years 2 men, 1 woman.

https://doi.org/10.1017/S1478951515001273 Published online by Cambridge University Press

A week after the questionnaire was sent, a combined thank-you-and-reminder card was mailed to those who had agreed to participate. If the questionnaire had not been returned by a few weeks later, the same research assistant made a phone call to ask if the participants had any problems filling out the questionnaire or needed assistance.

Measures

We employed the Hospital Anxiety and Depression Scale (HADS) (Zigmund & Smaith, 1983) to assess siblings' levels of anxiety. The HADS is a psychometrically validated self-administered scale that is often used in the clinical setting to measure patients' anxiety and depression. There are 14 questions: 7 measuring anxiety and 7 measuring depression. The score for each question ranges from 0 to 3 points, and the score for each outcome (anxiety or depression) can thus range from 0 to 21. Scores of 11 and above indicate that the individual may need medical attention. In the current paper, the term "anxiety" refers to clinical levels of anxiety—in this case, a HADS score equal to or greater than 11. Anxiety is the main outcome reported in our paper. We had previously reported on the lack of statistically significant differences in depression when comparing bereaved and nonbereaved siblings (Eilegård et al., 2013). The regional ethical review board approved the current study (No. 2007/862-31).

Statistics

In Tables 3 (before death) and 4 (after death), the questions and response alternatives are specified, and the data are shown as proportions (%) and relative risks (*RR*). Relative risks (*RR*) are presented with 95% confidence intervals ($CI_{95\%}$). Individuals with missing data were excluded in each calculation. We employed SAS software (v. 9.2) for all calculations.

RESULTS

Of the 240 bereaved siblings who were approached, 174 (73%) participated (73 men and 101 women). The characteristics of participating siblings are presented in Table 2.

Source of Information About Brother's or Sister's Illness

The vast majority of siblings reported receiving most of their information about their brother's or sister's illness at the end of life from their parents. Fewer got their information from healthcare professionals. Most siblings reported that the brother or sister with cancer was cared for at home. They also reported having been satisfied with the amount of information they received at the end of life. The vast majority trusted the information they received about the brother's or sister's illness (see Table 3).

Information and Communication Near the End of Life

The majority of siblings 110/173 (64%) reported being satisfied with how often they talked about their feelings with others during their brother's or sister's last month of life. Siblings who expressed that they would have liked to talk more reported anxiety to a greater extent than those who were satisfied: 15/58 (26%) versus 13/115 (11%), $RR = 2.3(1.2-4.5)$. During their brother's or sister's last month of life, 23 of 174 (13%) siblings avoided healthcare professionals for fear of being in their way. Anxiety was more prevalent among this group of siblings ($RR = 2.2(1.1-4.6)$) than among those who did not avoid healthcare professionals, especially in the hospital setting ($RR = 6.8(2.5-18.2)$). No correlation was seen between avoidance or non-avoidance of healthcare professionals and anxiety among those whose ill brother or sister was cared for at home (data not shown). More than half of the siblings (90/174, 52%) reported that they seldom (once a month or less) talked with others about their feelings regarding their brother's or sister's illness during his or her last month of life. Within this group, 21 (23%) reported anxiety as compared with 7 (8%) among those who discussed their feelings more frequently. This corresponds to a relative risk of 2.8 (1.3–6.2) for reporting anxiety among siblings who shared their feelings less frequently. Siblings who reported that they had on at least one occasion blamed themselves for the brother's or sister's illness (47 of 168, 28%) were at greater risk of reporting anxiety ($RR = 2.1$ (1.1–4.2)) as compared to those who never blamed themselves (see Table 3).

Communication Following the Loss

A majority of siblings (96/173, 55%) reported that they avoided talking to their parents about their deceased brother or sister out of respect for their parents' feelings following the loss. Their risk of anxiety was increased ($RR = 2.4$ (1.1–5.4)) as compared to those who talked with their parents. Siblings who reported that they shared none (23/174, 13%) or less than half (65/174, 37%) of their feelings about their deceased brother or sister with their family following the loss were at greater risk of reporting anxiety ($RR = 2.8$ (1.3–6.2)) as compared to those who shared more of their feelings. Most siblings (123/174, 71%) were content with how often they talked

https://doi.org/10.1017/S1478951515001273 Published online by Cambridge University Press

Table 3. *Information and communication before the brother's or sister's death and self-assessed anxiety* in bereaved siblings*

Questions and Response Alternatives	Proportion (%)	Proportion (%)	RR ($CI_{95\%}$)
The Brother's or Sister's Last Month of Life		Anxiety HADS ≥ 11	Anxiety HADS ≥ 11
How much of the information you got about your brother's or sister's illness came from your parents?			
Not applicable; I was too young	2/174 (1)		
Not applicable; I did not get any information at all	5/174 (3)		
No information came from my parents	3/174 (2)		
Less than half	12/174 (7)	4/22 (18)	1.2 (0.4–3.0)
More than half	69/174 (40)	24/152 (16)	
All information	83/174 (48)		
How much of the information you got about your brother's or sister's illness came from healthcare professionals (physicians, nurses, others)?			
Not applicable; I was too young	6/174 (3)		
Not applicable; I did not get any information at all	23/174 (13)		
No information came from healthcare	49/174 (28)		
Less than half	73/174 (42)	22/151 (15)	0.6 (0.3–1.2)
More than half	19/174 (11)	6/23 (26)	
All information	4/174 (2)		
Are you satisfied with the amount of information you got about your brother's or sister's illness?			
Yes, I am satisfied	94/174 (54)		
No, I would have liked to get less information	4/174 (2)	16/98 (16)	1.0 (0.5–2.1)
No, I would have liked to get more information	73/174 (42)	12/76 (16)	
Not applicable; I was too young to get information	3/174 (2)		
During your brother's or sister's last month of life, did you feel that the information you got about his/her illness was trustworthy?			
Yes	141/174 (81)	22/141 (16)	0.9 (0.4–1.9)
No	21/174 (12)	6/33 (18)	
Not applicable; I did not get any information	11/174 (6)		
Not applicable; I was too young to get any information	1/174 (1)		
During your brother's or sister's last month of life, did you avoid healthcare professionals (other than physicians) for fear of being in their way?			
Yes	23/174 (13)	7/23 (30)	2.2 (1.1–4.6)
No	145/174 (83)	21/151 (14)	
Not applicable; I was too young	6/174 (3)		
During your brother's or sister's last month of life, where did he/she spend most of his/her time?			
Hospital	62/173 (36)	10/62 (16)	1.1 (0.5–2.2)
Home	107/173 (62)	17/111 (15)	
Other place	4/173 (2)		
During your brother's or sister's last month of life, did you blame yourself for his/her illness?			
Constantly	9/168 (5)		
Three times or more	15/168 (9)		
Once or twice	23/168 (14)	12/47 (26)	2.1 (1.1–4.2)
Never	121/168 (70)	15/126 (12)	
Not applicable; I was too young	5/168 (3)		
During your brother's or sister's last month of life, how many of your close relations were negatively affected?			
All of them	14/174 (8)		
Half	16/174 (9)		
More than half	19/174 (11)	18/125 (14)	1.4 (0.7–2.9)
Less than half	35/174 (20)	10/49 (20)	
Not applicable; I had no close relations	9/174 (5)		
Not applicable; I was too young	6/174 (3)		
None	75/174 (43)		

Continued

https://doi.org/10.1017/S1478951515001273 Published online by Cambridge University Press

Table 3. *Continued*

Questions and Response Alternatives	Proportion (%)	Proportion (%)	RR ($CI_{95\%}$)
How often did you talk to others (outside your family) about your feelings about your brother's/sister's illness during his/her last month of life?			
Not applicable; I was too young	5/174 (3)		
Never	57/174 (33)		
Monthly	28/174 (16)	21/90 (23)	2.8 (1.3–6.2)
Weekly	36/174 (21)	7/84 (8)	
2–3 times/week	31/174 (18)		
Daily	17/174 (10)		
Were you satisfied with how often you talked to others (outside your family) about your feelings about your brother's or sister's illness during his/her last month of life?			
No, I would have liked to talk more	54/173 (31)		
Not applicable; I was too young	4/173 (2)	15/58 (26)	2.3 (1.2–4.5)
Yes, I was satisfied	110/173 (64)	13/115 (11)	
No, I would have liked to talk less	5/173 (3)		

The different gray shadings in the table show the combination/dichotomization of the response alternatives combined.
*Anxiety is defined in the Hospital Anxiety and Depression Scale as a score of 11 or more (HADS $\geq$ 11).

about their feelings with their family during the year before the follow-up. The risk of anxiety was increased in siblings who wanted to talk more with their family ($RR = 2.5$ (1.3–4.8)) (see Table 4).

DISCUSSION

Our study indicates that insufficient communication is associated with a sibling's risk of long-term anxiety. Siblings who were not satisfied with their communication, and in particular with their family, were more likely to report anxiety at follow-up. As mentioned earlier, the International Society of Pediatric Oncology (Spinetta et al., 1999) highlights siblings' needs for information and involvement. Nonetheless, we found that siblings avoided healthcare professionals for fear of being in their way, especially at the hospital, and this avoidance is also

Table 4. *Communication after the brother's or sister's death and self-assessed anxiety* in bereaved siblings*

Questions and Response Alternatives	Proportion (%)	Proportion (%) Anxiety	RR ($CI_{95\%}$)
Time After Death			
Did you avoid talking to your parents about your deceased brother or sister out of respect for their feelings?			
Yes	96/173 (55)	21/96 (22)	2.4 (1.1–5.4)
No	77/173 (45)	7/77 (9)	
How much of your feelings about your brother's or sister's death did you share with your family?			
Not applicable; I was too young	2/174 (1)		
None at all	23/174 (13)		
Less than half	65/174 (37)	21/90 (23)	2.8 (1.3–6.2)
Half	34/174 (20)	7/84 (8)	
More than half	24/174 (14)		
All	26/174 (15)		
The Year Before Follow-Up			
Are you satisfied with how often you have talked to your family about your feelings the previous year?			
No, I wanted to talk more	50/174 (29)	14/50 (28)	2.5 (1.3–4.8)
Yes, I am satisfied	123/174 (71)	14/124 (11)	
No, I wanted to talk less	1/174 (1)		

The different gray shadings in the table show the combination/dichotomization of answer alternatives combined.
*Anxiety is defined in the Hospital Anxiety and Depression Scale as a score of 11 or more (HADS $\geq$ 11).

https://doi.org/10.1017/S1478951515001273 Published online by Cambridge University Press

associated with an increased risk of reporting anxiety at follow-up.

Our finding that siblings avoid talking to their parents about their deceased brother or sister out of respect for their parents' feelings is in agreement with what Havermans and Eiser (1994) reported more than two decades ago. Siblings seem hesitant to bother their parents. We know of very few studies that discuss what siblings find helpful after the loss of a brother or sister to cancer. In an effort to learn more about this issue, Thompson and coworkers (2011) interviewed 41 bereaved family members (36 mothers, 24 fathers, 39 siblings) one year after the death of their child, brother, or sister to cancer. Both parents and siblings stated that social support, self-expression, and faith and religion, as well as memories of the loved one, helped them to manage their grief. Moreover, both siblings and parents expressed that they found it valuable to talk about their experience of the child's illness and death, even though it could be difficult. Notably, few parents and siblings suggested that bereaved families should seek professional support. The value of sharing feelings with others about the loss is in agreement with our findings that the siblings' perceived insufficient communication increases the risk of long-term psychological distress.

Our study revealed that a small number of siblings report they avoided healthcare professionals for fear of being in their way. This seems to be associated with an increased risk of long-term anxiety in bereaved siblings. Healthcare professionals are closely involved in the ill child's care, but they also play a role in advocating that siblings receive open and honest information and can be actively involved in the brother's or sister's end-of-life care (Giovanola, 2005; Spinetta et al., 1999) . The intense care at the end of life may frighten siblings. It appears that healthcare professionals may need to pay more attention to how they behave when caring for the seriously ill child with cancer, so as not to give siblings the impression that they are in their way, as that may impact the siblings' risk of long-term anxiety after the death of a brother or sister. Notably, most siblings in our study did not report fear of being in the way of healthcare professionals. Von Essen and Enskär (2003) interviewed nurses and parents of children with cancer, and more parents than nurses mentioned the importance of giving information to the patient's siblings and getting them involved in the process of care for a child with cancer.

According to their siblings' responses, most of the children with cancer in our study spent their last month of life at home or in some place other than a hospital. This raises questions about the impact of home care on bereaved siblings. Our findings suggest that siblings whose brother or sister was cared for at home rather than in the hospital during the last month of life were not at increased risk of reporting anxiety. It might be that siblings as well as parents of children with cancer are more aware that death is imminent when the ill child is cared for at home, and this awareness may influence their risk of reporting anxiety (Dussel et al., 2009; Surkan et al., 2006).

The literature review by McCarthy (2011) concluded that information regarding prognosis, treatment, and side effects are important for family members in order to cope with a loved one's illness and treatment. O'Shea and coworkers (2012) studied interventions used to meet the needs of siblings of children with cancer. Four main themes and six subthemes were reported, among them the theme "wanting to know," which revealed siblings' desire to know what is going on. One of the consequences noted was that siblings who were not informed were left with questions and misconceptions, which in turn led to fear and thoughts about whether they had contributed to the brother's or sister's illness in some way. Our results show that almost a third of the siblings (47/168, 28%) reported that they had on at least one occasion felt that they might be partially to blame for their brother's or sister's illness. Even though the nurses in another study identified many of the sibling's needs, they expressed divergent views about their role in meeting those needs (O'Shea et al., 2012). It appears that a majority of the nurses in that study wanted the parents to step in and take more responsibility in supporting the siblings. It might be that the best way for nurses and healthcare professionals to support the siblings of children with cancer is to keep the siblings informed and encourage parents to maintain open communications within the family throughout the illness and bereavement. Still, the question of how to best support siblings is difficult, and since the healthcare system has limited resources, nonprofit school and healthcare organizations or social networks may need to fill that gap.

Our study has both strengths and limitations. Among its strengths was the use of population-based registers, which enabled us to identify all cancer-bereaved siblings in Sweden. The high participation rate is another strength. One limitation may be the way in which the data were collected, as we do not know if psychological distress at the time of follow-up may have influenced participants' recollections of earlier events. We cannot exclude that their perceptions of the communication during their brother's or sister's last month of life might have been influenced by current anxiety rather than the communication that actually occurred. Exclusion of families born outside of Nordic countries may lessen the

https://doi.org/10.1017/S1478951515001273 Published online by Cambridge University Press

possibility of generalizing our findings beyond the studied population.

CONCLUSIONS

Our study suggests that insufficient communication is associated with a risk of anxiety in cancer-bereaved siblings over the long term. In order to reduce this risk, healthcare professionals may encourage families to talk more openly about the illness and its trajectory. This may also promote siblings' involvement in the care of their ill and dying brother or sister.

ACKNOWLEDGMENTS

We would first like to thank all the participating siblings, who helped us conduct this study by taking the time to share their experiences. The study was supported by funds from the Swedish Childhood Cancer Foundation, the Swedish Research Council, the Swedish Cancer Society, the Karolinska Institutet, and Sophiahemmet University. The funding sources had no involvement in any part of the study. The authors had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. The authors have no conflicts of interest to declare.

REFERENCES

Alderfer, M.A., Long, K.A., Lown, E.A., et al. (2010). Psychosocial adjustment of siblings of children with cancer: A systematic review. *Psycho-Oncology*, *19*(8), 789–805.

Durall, A., Zurakowski, D. & Wolfe, J. (2012). Barriers to conducting advance care discussions for children with life-threatening conditions. *Pediatrics*, *129*(4), e975–982.

Dussel, V., Kreicbergs, U., Hilden, J.M., et al. (2009). Looking beyond where children die: Determinants and effects of planning a child's location of death. *Journal of Pain and Symptom Management*, *37*(1), 33–43.

Eilegård, A., Steineck, G., Nyberg, T., et al. (2013). Psychological health in siblings who lost a brother or sister to cancer 2 to 9 years earlier. *Psycho-Oncology*, *22*(3), 683–691.

Giovanola, J. (2005). Sibling involvement at the end of life. *Journal of Pediatric Oncology Nursing*, *22*(4), 222–226.

Havermans, T. & Eiser, C. (1994). Siblings of a child with cancer. *Child: Care, Health and Development*, *20*(5), 309–322.

Houtzager, B.A., Grootenhuis, M.A. & Last, B.F. (1999). Adjustment of siblings to childhood cancer: A literature review. *Supportive Care in Cancer*, *7*(5), 302–320.

McCarthy, B. (2011). Family members of patients with cancer: What they know, how they know and what they want to know. *European Journal of Oncology Nursing*, *15*(5), 428–441.

Murray, J.S. (1999). Siblings of children with cancer: A review of the literature. *Journal of Pediatric Oncology Nursing*, *16*(1), 25–34.

Nolbris, M. & Hellstrom, A.L. (2005). Siblings' needs and issues when a brother or sister dies of cancer. *Journal of Pediatric Oncology Nursing*, *22*(4), 227–233.

O'Shea, E.R., Shea, J., Robert, T., et al. (2012). The needs of siblings of children with cancer: A nursing perspective. *Journal of Pediatric Oncology Nursing*, *29*(4), 221–231.

Spinetta, J.J., Jankovic, M., Eden, T., et al. (1999). Guidelines for assistance to siblings of children with cancer: Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology. *Medical and Pediatric Oncology*, *33*(4), 395–398.

Surkan, P.J., Dickman, P.W., Steineck, G., et al. (2006). Home care of a child dying of a malignancy and parental awareness of a child's impending death. *Palliative Medicine*, *20*(3), 161–169.

Thompson, A.L., Miller, K.S., Barrera, M., et al. (2011). A qualitative study of advice from bereaved parents and siblings. *Journal of Social Work in End-of-Life & Palliative Care*, 7(2–3), 153–172.

Wilkins, K.L. & Woodgate, R.L. (2005). A review of qualitative research on the childhood cancer experience from the perspective of siblings: A need to give them a voice. *Journal of Pediatric Oncology Nursing*, *22*(6), 305–319.

von Essen, L. & Enskar, K. (2003). Important aspects of care and assistance for siblings of children treated for cancer: A parent and nurse perspective. *Cancer Nursing*, *26*(3), 203–210.

Zigmond, A.S. & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361–370.

https://doi.org/10.1017/S1478951515001273 Published online by Cambridge University Press