

# Factors affecting recruitment and participation of bereaved parents and siblings in grief research

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This study examined participation factors in a study of families ( $N = 84$ ) within 1 year of a child's cancer-related death. Specific aims were to examine associations between: (a) recruitment variables (number of phone calls made to eligible families, number of calls answered by eligible families) and participation rates (study agreement and refusal) and (b) characteristics of deceased children (gender, age, length of illness, time since death) and participation rates. Characteristics of deceased children did not differ between participating and non-participating families. Researchers made significantly fewer calls to participating versus refusing families. Participating families most often agreed during the first successful call connection, and more calls did not mean more recruitment success. Thus, it is reasonable to limit the number of calls made to bereaved families. Despite recruitment challenges, many bereaved parents and siblings are willing and interested to participate in grief research.

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Vulnerable populations of bereaved parents and siblings are decreasing in number due to medical advances, yet it has been estimated that more than 100 000 children die each year from cancer worldwide.<sup>1</sup> Research to improve health and decrease suffering of these significant and high-risk populations is critical, but recruitment challenges serve as potential threats to such studies. For example, participation in cancer clinical trials is generally low among adults, and enrollment of individuals from racial or ethnic minority populations and rural communities is even lower.<sup>2</sup> Issues are magnified when considering children as research participants.<sup>3</sup> Children with chronic illness and healthy siblings may refuse study participation because they do not want to talk with healthcare professionals, lack interest, or have other engagements.<sup>4</sup> Researchers sometimes encounter difficulties gaining access to child participants because of protective

gatekeepers (e.g. parents, clinical providers), who are reluctant to consent or refer potential child participants.<sup>4</sup>

Recruitment for grief studies presents unique methodological and ethical challenges, with bereaved children representing a doubly vulnerable population. Some bereaved parents have reported their research participation as 'positive'.<sup>5</sup> However, multicenter studies with bereaved parents may encounter ethical issues (e.g. difficulty ensuring privacy, minimization of potential risks to participants), as well as logistical challenges (e.g. maintaining adequate training and support of research staff and working with multiple institutional review boards).<sup>6</sup> Some grief studies using proactive recruitment strategies (e.g. identification of eligible participants through hospital records, referrals, organizations/support groups, death records) do not always determine or report participation rates.<sup>7-11</sup> In studies utilizing reactive recruitment strategies (e.g. advertisements on bereavement websites or in public locations/newspapers), it is

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difficult to determine the number of eligible participants who were notified about the study via advertisement but who did not respond (e.g. passive refusal). Thus, true participation rates are often unable to be determined.<sup>12–16</sup>

Other challenges in grief studies include ascertainment bias, low participation rates, and small sample sizes, which can limit generalizability and transferability.<sup>9,11,13,15,17–21</sup> Few studies report their a priori criteria for number of unsuccessful attempts to contact families before determining that they are unable to be located.<sup>22</sup> Rarely do grief studies report the actual number of attempts to contacts bereaved families, the number of successful contacts, or factors associated with study participation, which would be helpful and inform the conduct of future studies.

The purpose of this study was to examine recruitment variables (i.e. number of phone calls made to eligible families, number of calls answered by eligible families), characteristics of deceased children (i.e. gender, age, length of illness, time since death), and subsequent participation rates (i.e. study agreement and refusal) in a study of siblings and parents after a child died of cancer. Specific aims were to: (a) examine associations between recruitment variables and participation rates and (b) examine associations between characteristics of deceased children and participation rates.

## Methods

This research was part of a longitudinal study of families following the death of a child from cancer. In the larger study, bereaved parents and siblings were recruited during the first year post-death. Potential participants were identified from cancer registries at three children's hospitals in the USA and Canada to reduce ascertainment bias. Eligible families (a) had a bereaved sibling 8–17 years old, (b) were fluent in English, and (c) lived within 100 miles of the hospital. Adopted, half-siblings, and step-siblings were eligible if the sibling had regular, ongoing contact with the child who died. Data collection involved visits to bereaved siblings' schools and homes in the first year after the death, followed by another home visit 1 year later.

## Procedures

Prior to recruitment, approval was obtained from the institutional review boards at the participating hospitals. Three to 12 months post-death, attending physicians mailed families a letter of introduction for the study, which included a toll-free phone number to call if they did not want to be contacted by study personnel. Families who did not opt out were telephoned by a senior study staff member 2–3 weeks after the letter was mailed. There was no

predetermined limit for number of contacts attempted to reach each family. After contacting families, staff members described the study and answered any questions. Data collection for consenting families included a school assessment in bereaved siblings' classrooms, followed by a home assessment in the first and second year post-death.

To extract data for this paper, research assistants or project coordinators at each of three data collection sites examined their family recruitment logs or contact sheets (paper forms documenting family contact information) to identify the families for whom call attempts were documented during the recruitment process. Call attempts were defined as any phone call made to eligible families resulting in connection or no connection with family. From this subset, recruitment variables (i.e. number of phone calls made to eligible families, number of calls answered by eligible families) were retrieved and documented from family recruitment logs or contact sheets. Then, family identification numbers for this subset were sent to the data management center to request participation rates (i.e. study agreement and refusal) and characteristics of deceased children (i.e. gender, age, length of illness, time since death) already documented for the larger study from cancer registry information. Thus, this paper includes cross-sectional, demographic, and recruitment data collected from this subset of families, for whom we documented call attempts during the recruitment process.

## Participants

Eligible participants within this subset included 84 bereaved families. Deceased children averaged 11.5 years of age ( $SD = 4.9$ ) with median 16 months ( $min = <1-145$ ) from diagnosis to death, and 61% ( $n = 51$ ) were male. Determination of study eligibility ranged from <1 to 14 months ( $M = 6.5$ ,  $SD = 2.8$ ) after the death.

Of the 84 eligible families, 68 (81%) participated in at least one phase of the study. Parent and sibling demographic data were collected from the 51 families, who participated in the first home assessment which typically occurred 12 months ( $SD = 3.52$ ; range 6–24) post-death. Parents (51 mothers and 36 fathers) averaged 41 years of age ( $SD = 7.33$ ), and 88% ( $n = 75$ ) were white. Parents had approximately 14 years ( $SD = 2.36$ ) of education. Sixty-two (71%) parents were married. The majority of family ( $n = 26$ , 30%) annual income ranged from \$50 001 to \$75 000. Average family socioeconomic status ( $M = 45.23$ ,  $SD = 25.10$ ), computed using the revised Duncan reflected clerical, sales, and service occupations.<sup>23</sup> Siblings averaged 12 years of age ( $SD = 2.67$ ) and were primarily female (53%,  $n = 27$ ) and

white (81.6%,  $n = 40$ ). Forty (78%) siblings were full brothers or sisters to the deceased.

### Analysis

Frequency distributions were used to summarize the nominal study variables including refusals and gender of the participants. Continuous data (e.g. time from diagnosis to death, number of calls) were heavily skewed; therefore, median, minimum, and maximum values, as well as the 25th and 75th interquartile ranges (IQRs) representing the middle 50% of the data values in a particular distribution are used to describe those variables. Likelihood chi-square statistics were used to test for differences in nominal (e.g. gender) characteristics between the group who agreed to participate and the group who refused. Mann–Whitney tests were used to compare the distributions of continuous variables between those two groups.

### Results

During recruitment of the 84 eligible families, research staff made a total of 361 calls. Family members answered a total of 147 (41%) calls. Sixty-eight (81%) families agreed to participate, while 16 (19%) actively or passively refused. A range of 1–21 calls (Median = 3; IQR = 1.3, 5.0) were made to each family, who ultimately agreed to study participation. Parents in these families typically agreed to participate during the first call connection (IQR = 1.0, 2.0). Two to 18 calls (Mode = 3, Median = 4; IQR = 3.0, 7.5) were made to families who ultimately refused; they answered a median 2.0 (IQR = 1.0, 2.0) calls. The *number of calls made* to eligible families who ultimately agreed to participate was significantly less compared with families who ultimately refused ( $U = 352.50$ ,  $z = 2.21$ ,  $P = 0.027$ ). The difference between the *number of calls answered* by eligible families who ultimately agreed to participate compared with those who refused was not statistically significant ( $U = 482.00$ ,  $z = 0.77$ ,  $P = 0.441$ ). Characteristics of the deceased child and illness are summarized by the participation groups in Table 1. There were no statistically

significant differences in those characteristics between the groups. Comparison of information available from cancer registries indicated there were no group differences in the deceased child's demographic characteristics between families who did and did not participate.

### Discussion

A better understanding of factors influencing recruitment and participation of vulnerable bereaved populations is crucial to advance the science of palliative care. This study examined recruitment variables, characteristics of deceased children, and participation rates from a convenience sample of bereaved parents and siblings within the first year of a child's death to cancer. Characteristics of deceased children (i.e. age, gender, length of illness, time since death) did not differ between families who chose to participate in the study and those who did not participate. However, significant differences were discovered between the number of calls made to participating versus refusing families, which is informative to future grief studies.

A key finding in our study was that significantly more call attempts were made to refusing families than those who agreed to participate; however, significant differences were not found between the number of calls answered by participating and refusing families. Participating families most often agreed during the first successful call connection. Interestingly, we typically only made two successful contacts with families who ultimately refused study participation, yet many more call attempts were needed to obtain successful contact with these families. This is likely because some refusing families did not actively refuse participation, but often did not respond after our second successful call connection and were eventually determined as a passive refusal. Other families suggested that it was not a good time currently but agreed to a later phone call (e.g. 'not now, but you can check back in about a month'); rarely did these cases result in study participation. Study participation may have been too difficult for some bereaved families during the first year of their child's death. Perhaps, these

**Table 1 Study participation and deceased child characteristics**

Deceased child characteristics	Agreed ( $N = 68$ )	Refused ( $N = 16$ )	$P$ value
Gender			0.329
Male ( $n = 51$ , 60.7%)	43 (63.2%)	8 (50.0%)	
Female ( $n = 33$ , 39.3%)	25 (36.8%)	8 (50.0%)	
	Median (IQR)	Median (IQR)	
Age at death (years)	11.7 (7.9, 15.0)	12.8 (9.5, 16.4)	0.196
Length of illness (months)	16.0 (10.3, 43.7)	14.5 (8.2, 50.8)	0.968
Time since death (months)	6.0 (5.0, 8.0)	7.0 (4.3, 9.8)	0.368

Gender:  $\chi^2_{(df=1)} = 0.95$ ,  $P = 0.329$ ; age:  $U = 430.50$ ,  $z = 1.29$ ,  $P = 0.196$ ; length illness:  $U = 540.50$ ,  $z = 0.04$ ,  $P = 0.968$ ; time since death:  $U = 465.50$ ,  $z = 0.99$ ,  $P = 0.368$ .

families did not want or know how to say ‘no’ to the study and find it easier to passively refuse. This may be particularly true when studies are conducted through the child’s treating institution. The possibility of obtaining participation was greatly diminished after more than three unsuccessful contacts and may not justify the persistent efforts from study personnel or the potential risk of being intrusive to bereaved families. Thus, it may be appropriate for investigators to determine a passive refusal after three unsuccessful call attempts (e.g. family does not respond or return calls after researcher leaves three messages), similar to previous studies.<sup>22</sup>

Our study supports the successful recruitment strategy of proactively identifying eligible participants through hospitals’ cancer registries, sending an introductory letter to potential participants, including an ‘opt out’ phone number, followed by calling potential families 2 weeks later. The importance of including an ‘opt out’ opportunity for vulnerable groups is supported by previous studies.<sup>24,25</sup> However, there is the potential to lose many willing participants if studies rely on recruitment strategies that require families to opt-in. For example, grief studies using ‘opt in’ approaches (participants only contacted if they responded to an introductory letter) have reported low participation rates of 29 and 35%.<sup>17,18</sup> This suggests that proactive recruitment methods with the inclusion of an ‘opt out’ opportunity may be a more successful strategy that can minimize ascertainment bias for future grief studies.

Our high participation rate also speaks to the willingness of bereaved parents and siblings, a doubly vulnerable population, to contribute to research. Although each family received a monetary incentive, participants’ desire to help other bereaved individuals seemingly served as motivation to participate. Some participants reported that the study was a helpful and positive experience,<sup>26</sup> which has been previously reported by bereaved spouses.<sup>5,27</sup> Bereaved family members have also reported that helping other bereaved individuals and contributing to research were leading factors for choosing to participate in a study.<sup>27</sup> However, some institutional review boards require certain periods post-death before allowing researchers to contact bereaved family members. Lengthy consent processes can also be required, with additional conditions for vulnerable groups, which can induce greater burdens on study participants. More work is needed to better inform researchers and institutional review boards on how to best protect vulnerable human subjects while also ensuring that bereaved families have an opportunity to be heard and included in research.

Important to note is that our participating families agreed to study participation on average at 6 months

post-death. Our recruitment attempts began at 3 months post-death, which speaks to the challenging recruitment process as it sometimes took months to reach families and obtain a decision regarding study participation. Although recruiters followed protocol scripts during phone conversations with potential participants to describe study information, sensitivity to the individual nature of each family is important. For example, flexibility regarding data collection site (e.g. home, library, church) and scheduling (e.g. evenings during week, weekends) is critical to participation.

Researchers must give careful attention to selecting and training study staff at all data collection sites. Detailed study manuals, role play prior to interactions with possible participants, regular research team meetings, and team debriefing sessions are critical to successful studies that are sensitive to the needs of bereaved individuals at a vulnerable time. Recruiters can help potential participants realize their opportunity to help other bereaved family members in the future. However, family members who do not wish to participate may need reassurance that participation may not be universally helpful to all eligible individuals. Study staff can support these family members in their decisions and reduce possible guilt felt by those who do not wish to volunteer.

Limitations to our study included use of a convenience sample. Results may not generalize to other grief populations as our study was specific to childhood cancer deaths. Because recruiters tend to call families on certain days of the week or times of day, we were unable to use that data in our analyses to inform best days and times to call bereaved families. More formal protocols for documenting call attempts or recruiter characteristics (e.g. years of experience, clinical training, age, race matched to family) could help inform recruitment in future studies.

More evidence is needed to better understand the needs of vulnerable populations, such as bereaved parents and siblings, during research study recruitment and participation. Future studies could examine recruitment and participation characteristics in vulnerable populations other than bereaved siblings and parents. Studies could also examine recruitment and participation variables related to other causes of death (e.g. death from acute illnesses or chronic conditions other than cancer). Research should also give attention to improving researcher–participant communication and examine subsequent recruitment and participation outcomes. Overall, findings from this study advance current knowledge related to recruitment and participation of bereaved family members and offer suggestions for future research.

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