



Clinical Methods

Recruiting bereaved parents for research after infant death in the neonatal intensive care unit^{☆,☆☆}



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ABSTRACT

Understanding parental experiences following infant death in the neonatal intensive care unit (NICU) is a high research priority and a necessary first step to improving health services. However, recruiting bereaved parents to discuss their experiences on such an extremely sensitive topic can be challenging and research procedures must be planned carefully in order to get an adequate sample. There is little published in the literature detailing specific strategies for recruiting bereaved parents for grief research, especially strategies for contacting parents and identifying factors that might affect participation. The purpose of this paper is to describe the process of recruiting bereaved parents into a qualitative research study exploring parental NICU experiences and grief responses following infant death. We describe a successful recruitment plan that led to the enrollment of difficult to recruit participants such as fathers, and individuals representing minorities and those from lower socioeconomic (SES) groups. Bereaved parents of infants after a NICU hospitalization should continue to be recruited for research studies for their unique perspectives and valuable insights about the devastating experience of infant death. Participants in this study reported more benefits than harm and the results addressed a critical gap in the literature.

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1. Introduction

Recruiting participants for research on sensitive topics, particularly topics that delve into deeply personal experiences or sacred beliefs (Lee & Renzetti, 1998), is an ongoing challenge for investigators. Recruiting bereaved parents after the death of their infant in a neonatal intensive care unit (NICU) is extremely challenging due to the devastating nature of the loss, risk for complicated grief, and parental feelings of profound self-blame, guilt, and shame which may last throughout their lives (Duncan & Cacciatore, 2015; Meert et al., 2010). As a result, investigators may avoid recruiting bereaved parents for research because of

the perceived risk for emotional and psychological distress. However, bereaved parents may provide valuable insights for developing new interventions to benefit other parents during the bereavement process, and given appropriate human subject protections, should be included in research efforts (Currie et al., 2016).

Regulatory procedures in research to ensure the ethical treatment and protection of human subjects, especially for vulnerable groups such as bereaved parents, can be traced to the 1979 publication of the Belmont Report (Belmont Report, 1979). According to the report, three guiding principles of ethical research are: (1) respect for persons, (2) beneficence and (3) justice. The impetus for the Belmont Report resulted from a history of exploitation of vulnerable subjects during participation in research such as occurred with the Tuskegee Syphilis Study of disadvantaged African American men who were infected with syphilis but were not told about the true nature of the study and did not receive treatment for syphilis even though it was available at the time. The legacy of Tuskegee includes fear, suspicion, and distrust of research, especially among African Americans in the South (Brandt, 1978). Applying these principles in a study of bereaved parents requires the utmost sensitivity and attention to appropriate research procedures – especially during recruitment (Kavanaugh, Moro, Savage, & Mehendale, 2006). However, there is little published literature detailing specific strategies for recruiting bereaved parents for grief research,

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especially reporting the strategies for contacting parents about sensitive topics and those factors affecting participation (Akard et al., 2014).

The purpose of this paper is to describe the process of recruiting bereaved parents into a qualitative research study exploring parental NICU experiences and grief responses following infant death. We describe a successful recruitment plan that led to the enrollment of bereaved parents and other difficult to recruit participants such as fathers, individuals representing minorities, and those from lower socioeconomic (SES) groups.

2. Background: study purpose and design

The aims of this descriptive qualitative study were to describe: (a) bereaved parent experiences related to their infant's NICU hospitalization, end-of-life care, and pediatric palliative care consultation, and (b) parents' grief experiences after infant death and is reported elsewhere (Currie et al., 2016). The study was approved by Children's of Alabama Hospital and the University of Alabama at Birmingham institutional review board (IRB) and Health Insurance Portability and Accountability Act (HIPAA) authorization was granted. The study was conducted at a Level-III NICU at a private not-for-profit teaching hospital in the Southeastern U.S. The study principal investigator (PI) completed all recruitment and data collection activities including conducting all in-depth qualitative face-to-face interviews with bereaved parent participants. All data collection took place in a variety of locations that were convenient for the participants. After informed consent, enrolled bereaved parent participants completed a demographic questionnaire and an individual, in-depth semi-structured interview that ranged from 24 minutes to 136 minutes in duration. The detailed interview script may be accessed in a published report of the study findings (Currie et al., 2016).

Recruitment of bereaved parents and data collection took seven months. The PI reviewed parent contact information (parent names, phone number, mailing address, infant name, infant date of birth, date of death, infant diagnosis, parent permission to re-contact after infant death) provided by the NICU bereavement program from infant deaths occurring 2009–2011. The list was reviewed using the following inclusion criteria for parent participants in this study: (a) over the age of 19, (b) English-speaking, (c) previously had an infant hospitalized in the NICU, and (d) experienced infant death at least 15-months prior to study enrollment. To conform to the existing policy within the NICU bereavement program at the study setting, bereaved parents were contacted 15-months post-infant death for possible recruitment into the study corresponding to the time interval specified by the hospital bereavement support program. Parents were excluded from the study if they selected "no" to receiving any additional/follow-up materials from the NICU at time of discharge or infant death. Parents who selected "no" were not contacted in any way for research study recruitment.

A total of 181 infant decedents were identified that met the inclusion criteria for their bereaved parents to participate in the study. Study packets were mailed in batches of 10 because data collection occurred simultaneously with recruitment. For example, interested bereaved parents were interviewed, and the interviews were analyzed before moving on to additional recruitment. This was done to assess for data saturation before unnecessarily contacting additional bereaved parents for participation. Similar to other grief research studies (Brooten et al., 2015; Youngblut, Brooten, Cantwell, Del Moral, & Totapally, 2013), a two-phase recruitment process was pursued. In the first phase, the following materials were mailed in an 8-by-11 inch envelope: (a) an introductory letter, (b) a form indicating participant interest in the study and preferred contact information with pre-paid postage return envelope, (c) PI contact information, (d) the informed consent document and HIPAA authorization form, and (e) a demographic questionnaire. During the second phase, a phone call using an IRB approved script was made to each potential participant by the PI two weeks after the initial recruitment letters were mailed. The purpose of the phone call was to

determine if the bereaved parent received the information, to answer questions about the study and to assess the level of interest in study participation. The letters and phone calls to bereaved parents were carefully timed to avoid difficult grief days such as the infant's birth and death anniversary.

Bereaved parents ($N = 10$) were recruited as research participants and interviewed from December 2013 to June 2014. Demographic characteristics of the sample are further described elsewhere (Currie et al., 2016). A total of seven mothers (24 to 41 years; mean age 30 years) and three fathers (29 to 43 years; mean age 35 years) were recruited for the sample, all of whom were the biological parents of the deceased infant. The majority of participants were Caucasian ($n = 7$), married ($n = 6$), and educated with at least a two-year college degree ($n = 7$). It is notable that half of the participants reported an annual household income of less than \$10,000. Six parents received pediatric palliative care consultation while their infant was hospitalized in the NICU. While ten parents participated, two married couples were recruited and interviewed separately; therefore, the final sample was comprised of 10 parents of eight infants who participated in this study. For the majority of infants ($n = 6$), cause of death was due to congenital anomalies, while prematurity complications accounted for the remaining two infant deaths. At the time of the parent interviews, the average time since infant death was 50 months or approximately 4 years.

A total of 181 packets of information were mailed to potential participants. However, only 78 potential participants could be reached due to invalid addresses and phone numbers obtained from the hospital. The PI started recruiting parents who experienced infant death closer to the February 2009 cut-off date before recruiting parents with more recent infant deaths. This time delay may explain the inability to contact many of the potential participants. Of the 78 parents, the PI was able to establish contact either by phone or returned inquiry forms for 30 parents. Thus, 38% of bereaved parents responded to recruitment efforts in this study. Of those parents who declined participation ($n = 20$), 10 potential participants discussed the study with the PI and were possibly interested, but did not re-contact the PI to schedule an interview. The remaining 10 parents responded that they did not want to participate most often due to time constraints and competing life demands (See Table 1). Ten parents agreed to participate resulting in a 13% accrual rate. In a seminal study by McMillan and Weitzner (2003), adult hospice patients were recruited for a federally-funded clinical trial on quality of life and resulted in a 5% accrual rate. Historically, recruiting participants for end-of-life research is complicated by the deteriorating health of patients and the high caregiving burden on families (McMillan & Weitzner, 2003).

3. Recruitment strategies and lessons learned

We used the following recruitment strategies to minimize potential psychological risk during recruitment of bereaved parents. These were essential to recruiting an adequate sample. Specific recruitment strategies included: (a) considering the risk-to-benefit ratio for the bereaved parent participants in the study, (b) exploring what it was like for the bereaved parent to participate in a research study, (c) timing of recruitment to avoid difficult grief days, (d) developing recruitment materials with carefully selected, sensitive language, (e) connecting participants with familiar healthcare providers, (f) emphasizing reassuring investigator attributes such as those that have the potential to build trust between the

Table 1
Potential participants' reasons for non-participation ($n = 10$).

Number of respondents	Reason for non-participation
1	Unsure of which child was hospitalized
1	Pregnant and need to avoid additional stress
2	Scheduling difficulties
2	Currently another infant hospitalized in NICU
4	No desire to participate due to research topic

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