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CONCEPTUAL AND DESIGN ISSUES IN INSTRUMENT DEVELOPMENT FOR RESEARCH WITH BEREAVED PARENTS*

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Abstract

Many childhood deaths in the United States occur in pediatric intensive care units (PICUs) and parents have special needs in this death context. As an interdisciplinary research team, we discuss conceptual and design issues encountered in creating a new instrument, the *Bereaved Parent Needs Assessment–PICU,* for assessing parents' needs in this setting. Using a qualitative approach, our team previously explored how the culture and related ways of providing care in one urban Midwestern children's hospital PICU affected parents' bereavement needs and experiences. We describe using this qualitative foundation in the development of a new quantitative instrument to more widely validate and measure bereaved parents' needs around the time of a child's death across multiple PICUs. We highlight a series of issues that warrant consideration in designing a research instrument for this vulnerable population including setting and context, format and content, temporality, recruitment, and content expertise.

The death of a child often results in tremendous suffering and life disruption for parents (Christ, Bonanno, Malkinson, & Rubin, 2003; Hendrickson, 2009; Murphy, 2008). Parental needs and experiences before, during, and after a child's death are shaped, in part, by the particular setting in which the death occurs. Of the 53,000 child deaths that occur in the United States each year, 56% occur in hospitals (Field & Behrman, 2003; Heron, Hoyert, Murphy, Xu, Kochanek, & Tejada-Vera, 2009). Of these, over 80% occur in intensive care settings (Angus, Barnato, Linde-Zwirble, Weissfeld, Watson, & Rickert, 2004). Whereas the pediatric intensive care unit (PICU) is a high-tech setting focused on restoring health to critically-ill children, it must also be studied as a special context for child death. The purpose of this article is to describe the processes and issues involved in using qualitative data previously collected to develop an instrument to measure parents' needs around the time of their child's death in the PICU.

Both conceptual and design issues must be addressed as part of instrument development. Numerous sources cover the fundamental steps of instrument development (Bernard, 2006; DeVellis, 2003; Dillman, 2007; Polit & Beck, 2008). Some key principles include determining what data needs to be collected, identifying if existing instruments are available, planning for reliability and validity assessments, designing new instrument format and content, establishing pre-testing protocols, and evaluating pilot data. These issues apply to making bereavement research instruments whether they arise primarily from the research participants and content experts, and/or are developed mainly from the published literature.

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CONCEPTUAL ISSUES

In the Parkes and Weiss (1983) classic definition, bereavement encompasses the entire experience of anticipating a death, the death itself, and the subsequent adjustment to living. We therefore conceptualize parents' bereavement needs as those needs that arise at any point during this process. This broad definition of bereavement allows a more comprehensive exploration of needs over time— including the periods while the child is dying in the PICU as well as after the death has occurred there. The PICU literature highlights many parental needs such as communication (Meert, Eggly, Pollack, Anand, Zimmerman, & Carcillo, et al., 2008; Meyer, Ritholz, Griffith, & Truog, 2006), decision-making (Meert, Thurston, & Sarnaik, 2000; Meyer, Burns, Griffith, & Truog, 2002), parental presence (Robinson, Thiel, Backus, & Meyer, 2006; Smith, Hefley, & Anand, 2007), spirituality (Meert, Thurston, & Briller, 2005; Robinson et al., 2006), and bereavement care (Cook, White, & Ross-Russell, 2002; McDonald, Liben, Carnevale, Rannick, Wolf, Meloche, et al., 2005; Meert, Eggly, et al., 2007).

Both the individual experiences of parents and the context of the child's death are important to understanding parental bereavement. One recent model suggests that parents facing life-threatening illness in their child are at risk for traumatic stress responses (Kazak, Kassam-Adams, Schneider, Zelikovsky, Alderfer, & Rourke, 2006). According to Kazak's *Model of Pediatric Medical Traumatic Stress*, parents' stress responses depend heavily on their subjective experiences of the child's medical events; and interventions for traumatic stress are best considered in light of the individual family's circumstances. When the medical event results in a child's death, parents' subjective needs and experiences are often very intense, producing vivid and lasting memories that can impact their long-term adjustment. Kazak's model is complemented by our work focusing on the personal and cultural making of the PICU as an end-of-life context. In our prior qualitative research, we described how the culture and related ways of providing care in an urban Midwestern children's hospital PICU greatly influenced parents' needs and experiences (Meert, Briller, Schim, Thurston, & Kabel, 2009). The next step in our program of research was to develop an instrument, the *Bereaved Parent Needs Assessment–PICU*, which can be used to more widely validate and measure bereaved parents' needs in various PICU settings.

Our instrument development process began with careful review and comparison of existing instruments for assessing: a) the needs of parents of hospitalized children, b) the needs of family members of critically- and/or terminally-ill patients, and c) the nature and intensity of grief among bereaved persons. In the literature on the development of questionnaires about parents' needs during their child's hospitalization, researchers often excluded parents of children who had a poor prognosis. For example, the *Needs of Parents Questionnaire* was developed and has been primarily used with study samples that excluded parents of children with cancer and those hospitalized in PICUs (Kristjánsdóttir, 1991, 1995; Shields, Hunter, & Hall, 2004; Shields, Young, & McCann, 2008). Instruments to assess the needs of families of critically- and or terminally-ill patients have been developed mainly with study samples that excluded families of pediatric patients. For example, the *Needs Met Inventory*, designed to measure the met and unmet needs of families in adult ICUs (Warren, 1993), has only recently been tested with families in PICUs; however, those families were not necessarily experiencing their child's death (Sturdivant & Warren, 2009). Many tools purport to measure the construct of grief among adults (Tomita & Kitamura, 2002); however, those developed to specifically assess grief among bereaved parents have been limited to certain types of loss. For example, the *Perinatal Grief Scale* (Toedter, Lasker, & Alhadeff, 1988) and the *Perinatal Bereavement Grief Scale* (Ritsher & Neugebauer, 2002) are focused on miscarriage, fetal death, and/or neonatal loss. No instruments were identified that adequately address the specific needs of parents whose children die in PICU. This observation further supported our belief that a new instrument is necessary for both research and practice.

We also examined the literature for psychometrically sound tools that could be used to support validity evaluation for the new instrument. We selected the *Inventory of Complicated Grief* (ICG) (Prigerson, Maciejewski, Reynolds, Bierhals, Newsom, Fasiczka, et al., 1995), the short *World Health Organization Quality of Life* tool (WHOQOL-BREF) (WHOQOL Group, 1998a) and four items from the WHOQOL-100 pertaining to personal beliefs (WHOQOL Group, 1998b) for inclusion in the packet of instruments with the *Bereaved Parent Needs Assessment–PICU*. The ICG is an instrument designed to assess complicated grief with higher scores indicating more symptoms. Complicated grief is defined by separation distress and traumatic distress that persist for more than 6 months; complicated grief is associated with adverse health outcomes (Prigerson, Vanderwerker, & Maciejewski, 2008). Multicenter PICU research by the Collaborative Pediatric Critical Care Research Network (2007) showed that 59% of bereaved parents had ICG scores ≥ 30; scores of this magnitude are highly suggestive of complicated grief (Shear, Frank, Houck, & Reynolds, 2008). Other researchers have similarly found high ICG scores among bereaved parents (Dyregrov, Norganger, & Dyregrov, 2003). Perceived circumstances of death and preparedness for death have been associated with complicated grief (Barry, Kasl, & Prigerson, 2002). We plan to correlate fulfillment of parent needs with ICG scores as an assessment of construct validity. A higher degree of need fulfillment is expected to be inversely correlated with ICG scores. The WHOQOL-BREF and personal belief items are designed to assess quality of life. Higher scores indicate better quality of life. We plan to correlate the scores regarding need fulfillment from our new tool with WHOQOL scores as an additional assessment of construct validity, expecting that a higher degree of needs fulfilled will positively correlate with better quality of life.

INSTRUMENT DESIGN ISSUES

Whereas research methodologists have discussed how qualitative and quantitative designs can be used together to enhance understandings of complex phenomena (Bernard, 2006; Elliott, 2005; National Institutes of Health, 1999; Polit & Beck, 2008) few have provided concrete examples of how to do this as an interdisciplinary team in the bereavement domain. When our team began to investigate parental needs around the time of a child’s death in the PICU, the research domain was understudied. Therefore, we used a phenomenological approach to explore a range of physical, emotional, social, informational, and spiritual needs that parents experienced before, during and after their child’s death in this setting (Meert, Briller, Schim, & Thurston, 2008; Meert et al., 2005). From this initial qualitative work using in-depth interviews, focus groups with bereaved parents, and focus groups with hospital chaplains who worked with bereaved parents, we generated a detailed listing of categories and themes (Meert et al., 2009). Using a rigorous process and multiple types of triangulation, important concepts were brought forward from the *emic* (insider) voices of the bereaved parents and those who work closely with them in the PICU (Briller, Meert, Schim, Thurston, & Kabel, 2008). As a result of our ongoing engagement as an interdisciplinary team we better understand the research domain, the complexities of working with bereaved parents, and the need to generate findings that can inform research and practice.

The challenge, as we engaged in debate over how to bridge between our ongoing qualitative work and the quantitative work being proposed, was how to move into the quantitative phase while maintaining qualitative sensibilities that are so important in the bereavement domain. For example, in the qualitative paradigm, it is easily recognized that researchers participate actively in the “making” of the data and that the co-created process influences the production of findings. As we thought about new instrument development, we carried forward a heightened awareness of ways in which we, as researchers, influence measurement through the process, structure, and content of the new tool.

Ethical concerns must be weighed carefully when balancing the valuable resource of parental insights with the potential toll of this type of emotionally-taxing data collection. In an earlier paper on special considerations in conducting bereavement focus groups, we articulated some key ethical issues that must be carefully addressed such as choice of research method, the data collection experience for participants, and the importance of maximizing data gained from vulnerable participants (Briller, Schim, Meert, & Thurston, 2007–2008). In thinking about what we are asking of bereaved parents, we strove to be mindful of what it would be like for them to complete a lengthy pen-and-paper questionnaire on such a difficult emotional topic.

Considering Setting and Context

Some bereaved parents who had previously participated in survey research told us that although they were willing to fill out mailed questionnaires, they found it difficult to begin and to complete the task in their home settings. We considered what issues might arise for participants who would likely be filling out this new instrument at home. Whereas previously we were concerned with how parents might feel about sharing their needs in an interview context, either with researchers and/or other bereaved parents, and how to best address emotional and privacy issues; our concerns in instrument development were different. We now worried about what it would be like for a bereaved parent to attempt to complete this instrument and revisit thinking about their needs away from a research context with established supports. For example, in our focus groups we had a chaplain and nurse present and specifically tasked with monitoring and responding to emotional needs that might arise, whereas such in-person professional support is not available with a mailed questionnaire. With our mailed questionnaire we are including information on bereavement support services and contact information for the research team members, with an invitation to call as needed.

Additionally, we worried about the shift from a conversation about the loss experience that occurs in a one-time interview or focus group session versus the potentially less-structured undertaking of completing the instrument at home. Whereas the participants at home may be in a more familiar environment and do not have to travel to a different setting (as did those who came to the children’s hospital for interviews in our qualitative studies), arranging time and finding emotional strength to sit down and work on this task alone could be daunting. In interviews and focus groups the concept of social validation for research participation (Dillman, 2007) is supported in ways that are not as clear with a mailed questionnaire. We attempted to address the issue of social validation by including language in our cover letter and instrument instructions thanking parents for considering participation, indicating that other parents have shared information about this difficult topic, and stating that the research is intended to help other parents and families in the future. Further, after receiving completed questionnaires from parents, we send a personal thank you note acknowledging the importance and value of their research contribution, again highlighting how their participation can help others.

Formatting the Instrument

We next turned our attention to considering the overall format as well as what domains would be included in the new instrument. In researching the existing tools from closely-related areas, we found some with features that served as good models for our new instrument. For example, Kristjánsdóttir’s *Needs of Parents Questionnaire* (1995) has a format in which a need is stated and then parents are asked to rank the need on three scales.

Importance is scored with a 5-point Likert scale from *does not concern me* to *very important. Fulfillment* is scored on a 3-point Likert scale with options of *fully met, partially met,* or *not met. Independence* is defined as whether parents could meet the need independently in the hospital environment and requests a *Yes/No* response. We decided that for bereaved parents it would be better to reduce the number of questions relating to each specific need to minimize respondent burden in completing the instrument. Accordingly, we re-examined our earlier extensive qualitative data and observed that during the highly stressful period of their child's dying, parents were more concerned that their needs be met rather than that the needs be met independently. Consequently, we determined that the key elements for assessment among bereaved parents were the *importance* of the need and *fulfillment* or the degree to which the need was met. In order to make the response sets easier to navigate and to maximize potential response variability, we opted to use consistent 5-point Likert responses for both scales.

Creating Item Content

Since our qualitative interview data were so rich, we were concerned with creating short items that could capture the essence of the needs that parents had so eloquently expressed in interviews. This concern resulted in an initial drafting of a long list of items that we thought could potentially be scored on both importance and fulfillment. We relied on the detailed coding scheme and extensive notes from our qualitative phase to ensure that no important concepts were left out for which individual items should be created.

Once we had developed a complete first pool of specific need items we consulted with our statistical methodologist to go over the draft and get further feedback about the length, format, content, and ordering of the items. Our team discussed the benefits of a shorter instrument including only the most salient items and reiterated our major concern that for this particular vulnerable population we minimize burden on the participants. We discussed pros and cons of blending some items where there was conceptual overlap so as to reduce the overall number. This process proved difficult as we considered ways to combine like items without violating the intent and meaning we got directly from bereaved parents in our previous work. For example, it may seem logical to combine the *need for family nearby at the time of a child's death* with the *need for friends nearby* into a stem about the *need for family and friends nearby*. We made this combined item, however, acutely aware of the distinctions some parents in our prior work made about how family and friends are needed at different points in the process of a child's death and how family and friends may offer different types of support. We were also concerned about combining needs such as family and friends and the desire to avoid "double barreled" item stems that have negative conceptual and methodological implications (Dillman, 2007). In spite of these concerns about potential loss of meaning, our choice was to focus on mitigation of respondent burden by reducing the number of items even if this meant a loss of specificity in some cases. We were able to come to this particular trade off for now, knowing that for the quantitative part of our research we need to develop an instrument that will be manageable for parents.

As we reexamined the pool of items and looked for ways to combine, clarify, and reduce the number of items, we constantly returned to the original transcripts and analysis of material directly obtained from bereaved parents in our initial work. The need to balance the number of items with the necessary clarity and specificity while being true to the emic perspective of bereaved parents led to many hours of dialogue and debate which eventually yielded a set of 101 items for the next version of the new instrument.

Following these conversations, both the more quantitatively- and qualitatively-oriented members of our team could accept necessary tough trade-offs. From the quantitatively-oriented we have accepted the idea that the instrument's measurement properties will be strengthened by having fewer items, potentially less missing data, and better overall response rates. From the qualitative members of the team we are more comfortable knowing that it will be possible to later return to qualitative analysis to gain in-depth understandings of the patterns revealed by the new instrument’s testing results.

Considering Temporal Issues

Temporal elements are also highly relevant for avoiding undue respondent burden. In our qualitative work, it was clear that parents moved back and forth in time in recalling their child’s death experience and their needs around that time and afterwards. In some cases, as soon as parents were asked to tell about their loss experiences, they were immediately “back in the moment” telling their stories in a vivid way that emphasized the power of memory and emotion even when years had passed since the child’s death. Whereas, qualitative research formats can easily accommodate discussions that circle through various points in time and non-linear narratives that reflect the natural flow of participant thought, this issue is more challenging in quantitative research. For a pen-and-paper questionnaire, the order of items matters greatly as it sets up for the participant a particular temporal flow. Although it is possible for participants to answer questions in whatever order they choose, it is most common for items to be addressed in the order in which they are presented.

Some of the parental needs that emerged in our qualitative work were time specific while others transcended time. For example the need for privacy was most salient at the time of death for many parents, but others spoke of the need for privacy being highly relevant at other times both before and after the child died—the need transcended time. The need to bathe and dress their child’s body soon after the death, in contrast, was more time specific. As these needs were translated into survey items, we struggled with item ordering because, to the extent possible, we wanted to avoid making parents go back over similar difficult topics as they proceed through the new instrument.

General ordering of the items that were categorized as most relevant to the times before, during, and after the child’s death was consistent with our definitional concept of bereavement as encompassing all these periods (Parkes & Weiss, 1983). We also saw this conceptual scheme as a way to logically order the items and thereby ease the cognitive burden of responding as suggested by Dillman (2007). Potential order effects among items and the temporal journey we are asking of parent participants was the subject of intense dialogue among the research team members and remains a critical issue as the new instrument moves through pilot testing.

Another important temporal element we considered was verb tense. Given our prior findings that parents clearly recall their needs and experiences with a sense of immediacy regardless of the length of time since the death, we struggled with whether questionnaire items should be phrased in the present or past tenses. Are we asking parents to “think back to the time your child died” and say what they felt? Or are we asking what they are feeling now about that time? We settled on the following instructions to frame the questions temporally: *Listed below are needs that some parents have around the time of their child’s death in a Pediatric Intensive Care Unit (PICU). Think back to the time around your child’s death. For each of the needs listed, please answer two questions: (a) How important was the need for you?, and (b) To what degree was the need met?* We chose the past tense because we anticipate that one of the new instrument’s primary uses will be retrospective assessment of whether meeting parents’ needs around the time of their child’s death affects their grief experiences and subsequent quality of life. Such research is necessary for informing clinicians about the creation of a PICU death context that supports rather than further hinders parental adjustment to loss.

We also discussed the temporal issue of the order of the various survey instruments that would be included in the packet sent to bereaved parents. Our decision on ordering of instruments was informed once again by what we feel are critical temporal issues and our desire to mitigate respondent burden. We chose to begin the packet with demographic questions about the deceased child in keeping with Dillman's recommendation to begin with the most salient items for the respondent (2007) and to set up the context for the immediately subsequent items in our new questionnaire (*Bereaved Parent Needs Assessment–PICU*). We then added the ICG (Prigerson et al., 1995), the short WHOQOL-BREF tool (WHOQOL Group, 1998a), and four items from the WHOQOL-100 (WHOQOL Group, 1998b) pertaining to personal beliefs. We finished with demographic items related to the parents themselves. Tools included in the pilot packet are described in Table 1. This ordering allows the parents to address many of the potentially most taxing items early in their completion of the packet materials and to finish with somewhat easier and less emotionally-laden items. The effectiveness of this ordering is being evaluated as part of our current pilot work.

Considering Recruitment Issues in Instrument Design

While response rates are a classic concern in survey research, this problem is heightened in working with bereaved parents who often find this activity daunting, even when they very much want to participate. From prior experience, our team was aware that only some (and possibly a relatively small percentage) of bereaved parents would likely complete the mailed questionnaire without a more personal contact. In another study which involved mailing questionnaires to bereaved PICU parents our response rate was increased by contacting parents and offering them the opportunity to complete the questionnaire by telephone (Meert, Thurston, & Thomas, 2001). Therefore, we agreed on making provisions for telephone administration of the new instrument. Specifically, we designed questionnaire instructions, items, and response formats that could be easily understood in writing and/or over the telephone in order to minimize concerns over bias introduced by multiple data collection methods.

USE OF CONTENT EXPERTS

Both qualitatively-oriented and quantitatively-oriented researchers can appreciate why using content experts in the complex domain of parental bereavement research is potentially very helpful. Although bereavement universally occurs, it is individually and collectively experienced differently in people's lives. Bereavement and related needs are each complex and dynamic constructs that change over time. Ways in which to adequately capture and frame these constructs is important for those working in both research traditions and how to effectively utilize content experts merits serious consideration.

Qualitatively-oriented researchers are characteristically concerned with how to emically understand and contextualize bereavement experiences as well as employ strategies to stay close to participants' language and meaning. Content experts can assist with checking that the participants' language and meanings have been interpreted appropriately. Additionally, since qualitative researchers are very aware of their own role in the "making" of the data, using content experts can shed light on how these co-created processes may have shaped the production of findings in important ways. Given the special design considerations highlighted earlier, the content experts may be able to provide further insight into how the framing and ordering of items may have profound implications for data-gathering.

Quantitatively-oriented researchers typically emphasize the use of content experts who are able to evaluate the measurement properties of individual survey items and the instrument as a whole. In a classic article focusing on quantitative methods and the use of content experts in the development of new measurement tools, Grant and Davis discuss the value as well as the process for selecting experts who can assist in the “judgment-quantification stage of content validation of instruments” (1997, p. 269). What becomes clear through their description of this key stage of instrument development is that individuals with professional expertise in the domain of interest (e.g., history of publications in refereed journals, national presentations, or clinical practice experience) are required for assessing content validity. After detailing the selection criteria and roles for professional experts, Grant and Davis also briefly mention that “… instrument review by a sample of subjects drawn from the target population is another important component of content validation” (p. 273). However, this concept is not given the same weight or centrality in their article as the role of professional experts. What does it mean when professionals are labeled as “content experts” and research participants with lived experiences (e.g., bereaved parents) simply as “a sample of subjects”?

With all of this in mind, our team discussed how we would use content experts at this stage of our instrument development process. We felt that the priority on professionals, academics, and clinicians as the most desired experts to perform content review, in keeping with the traditional quantitative paradigm, was somewhat at odds with our team’s orientation. Although these types of experts are essential for assessing the measurement properties of the new instrument, we saw bereaved parents as equally valuable experts to refine the instrument based on their direct personal knowledge. We ultimately proceeded with instrument review using a variety of content experts including bereaved parents, health professionals who work with bereaved parents, and health researchers capable of judging measurement properties. In several instances, the selected content experts fit into more than one of these categories. Table 2 includes a brief description of the content experts who participated in development of the *Bereaved Parent Needs Assessment–PICU*.

Once the *Bereaved Parent Needs Assessment–PICU* was drafted, we sent it, along with an instrument evaluation form, to our content experts and requested that they do the following activities: (a) rate the relevance and clarity of individual items, (b) suggest items for elimination that they perceived as redundant, and (c) comment on individual items and overall format of the instrument. In addition, professional experts were sent the domain definitions from our qualitative work so that they could assess the degree to which each item related to a specific domain. Using the feedback from all of our content experts we were able to edit some items for clarity and reduce the number of items to 68. The final instrument that was prepared for pilot testing consists of these 68 items rated on two parallel 5-point Likert scales: (a) How important was the need? 1 = *not at all important* to 5 = *very important,* and (b) Was the need met? 1 = *not at all met* to 5 = *completely met*. The instrument also includes additional open-ended items asking what other needs the participant might have had that we did not ask about and what further comments they might want to share.

Some of the most powerful feedback we received was from the content experts who were bereaved parents. Such feedback involved their reactions to the specific wording and meaning of items and explanations given for why some items were emphasized over others. For example, one bereaved father ranked the item “For hospital staff to acknowledge my child’s death as a special moment” as highly relevant. He commented that this was the “best question and that the statement needs to be sensitive and respectful” (Content Expert H). Whereas, this parent also scored other items highly, he chose to call attention to this item as especially salient in the PICU, where creating a proper atmosphere for death can be particularly challenging.

One bereaved mother expressed how the item “to be told that my child was likely to die” encapsulated her experience of realizing that her child’s death was imminent. She wrote about how the item evoked a powerful memory of what that moment was like for her.

> This question really hit me hard. I cried five minutes and it changed my emotions for the rest of the questionnaire. All of the other questions up to here were more about hospital supports and my needs and were not directly about the actual “death”. Seeing the word “die” all of a sudden felt harsh. Maybe it would help to divide the questionnaire into three sections: 1) while my child was ill, 2) the time around the death and 3) the time (or months) following the death. Each section could be introduced by one or two sentences saying what the section is about to emotionally prepare the respondent for what’s coming. (Content Expert K)

Such sensitive and meaningful input from the parent content experts suggested that we had created items that accurately reflected what we had heard in the qualitative interviews upon which this new instrument is based. This type of feedback also helped to confirm our ideas about item ordering and the relationship between this ordering and respondent burden for bereaved parents. Another parent spoke to the issue of respondent burden when he gave his overall impression of the experience of completing the instrument. He wrote “Difficult. I revisited the experience of my daughter’s death. I hope this helps others” (Content Expert J).

CURRENT PILOT TESTING

The newly-developed *Bereaved Parent Needs Assessment–PICU* is now being pilot tested in partnership with five large children’s hospitals across the country. We plan to enroll 250 parents by contacting them 6 months after the death of their child. With the assistance of our biostatistician, we estimated that a sample of this size is reasonable for factor analysis and, while challenging, should be possible to obtain over the period of our grant funding. Each of the PICU sites has between 40 and 80 deaths per year depending on unit size. Therefore the number of deaths expected across the five sites should allow us to obtain the pilot sample within the study period even with a relatively low response rate. Including parents from multiple PICUs will also help to increase generalizability of findings.

We are now sending bereaved parents a mailing that includes a sensitive cover letter expressing condolences and inviting participation, a IRB approved research information sheet, and the instrument packet titled *Needs of Bereaved Parents Survey* that contains the study instruments which are listed in Table 1. Presentation of the whole packet including page layouts, format of items, and use of graphics and white space was guided by Dillman’s recommendations (2007). Additionally, we relied on team members’ prior experience with research packet design for bereaved parents in selecting suitable features from the cover to the end. The instrument packet is 13 pages including a cover page, a page of information and instructions, and 11 pages of items. Responses from this pilot test will allow psychometric testing of the new instrument and estimates of reliability and validity as well as providing a test of the feasibility of our quantitative methods. Parents’ comments to open-ended questions will be analyzed qualitatively to better understand patterns observed in the quantitative analysis, explore any unexpected findings, and to illuminate areas in need of further study.

CONCLUSION

In this article we have focused on some of the special conceptual and design issues in developing a new instrument for use with parents who have experienced a child’s death in the PICU. As we have described some of the considerations in developing a new instrument, we have highlighted issues such as setting and context, format and content, temporality, recruitment, and content expertise. In our research process, we are committed to bringing forward the voices of bereaved parents, employing rigorous methods to yield sound findings, and integrating qualitative and quantitative research paradigms to more fully understand the bereavement experiences of parents in PICUs. We offer here what we have learned from qualitatively exploring in-depth parental needs around the time of a child's death in a specific PICU and designing an instrument so that some of the issues could be explored quantitatively across a wider range of PICU contexts. Our work has also shown that it is very important not to consider findings devoid of understanding the research process in this domain.

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Table 1

Elements of Instrument Packet Being Pilot Tested

Section	**Description**	**Items**	**Source**
About Your Child	Child-related demographics	7 items Gender, date of birth, date of death, cause of death, length of stay in PICU, # hospital admissions, # PICU admissions	Investigator developed
Bereaved Parent Needs Assessment–PICU	Items about specific needs that parents had around the time of their child's death in the PICU	68 items Two 5-point Likert scales —Importance/Fulfillment 2 open-ended items	Investigator developed — NEW TOOL
Inventory of Complicated Grief	Series of first-person items about feelings regarding the child who died	19 items 5-point Likert scale rating frequency of feeling	Prigerson et al. (1995)
WHO-QOLBREF	Item stems regarding overall quality of life and health status including physical and mental health	26 items 5-point Likert scale	WHOQOL Group (1998)
WHO-QOL 100 selected items	Items regarding personal beliefs and meaning	4 items 5-point Likert scale	WHOQOL Group (1998)
About Yourself	Personal parent demographics	7 items Gender, date of birth, relation to child, race, ethnicity, education, other children died (Y/N), # living children, marital status	Investigator developed
Survey Experience	Feedback on survey experience	3 items Ease of answering questions, amount of time to complete, additional comments	Investigator developed

Table 2

Characteristics of Expert Reviewers for BPNA-PICU

Expert	Description
A	Pediatric critical care physician in a large community medical center (male)
B	Pediatric critical care and palliative care physician in an urban academic medical center (female)
C	Director of family-centered care, hospital administrator in an urban academic children’s hospital, parent of a child with chronic illness experiencing many hospitalizations (female)
D	Chaplain with experience at an urban academic children’s hospital and at a community hospice (male)
E	Nursing professor, medical anthropologist, parent of an adult child who died suddenly in an intensive care unit (female)
F	Statistician with expertise in instrument development and psychometrics, parent of a child with chronic illness (male)
G	Parent of premature infant with chronic encephalopathy who died in early childhood after many PICU hospitalizations (female)
H	Parent of an adolescent who died of an acute neurologic condition during a PICU admission (male)
I	Parent of an adolescent who died of an acute neurologic condition during a PICU admission (female)
J	Parent of an infant with congenital heart disease who died after multiple PICU admissions (male)
K	Parent of an infant with congenital heart disease who died after multiple PICU admissions (female)