Enacting a Theory of Caring to Recruit and Retain Vulnerable Participants for Sensitive Research

Karen Kavanaugh[1,2,*], **Teresa T. Moro**[3,†], **Teresa Savage**[2,‡], and **Ramkrishna Mehendale**[4,§]

[1]Advanced Practice Palliative Care Nurse Training Grant, University of Illinois at Chicago, College of Nursing, Chicago, Illinois

[2]Department of Maternal-Child Nursing, University of Illinois at Chicago College of Nursing, Chicago, Illinois

[3]School of Social Service Administration, University of Chicago, Illinois

[4]University of Illinois at Chicago Medical Center, Chicago, Illinois

Abstract

The recruitment and retention of research participants always presents challenges to researchers. This process is made more complicated when the research being undertaken is socially sensitive and the populations of interest are considered vulnerable. The purpose of this article is to illustrate how Swanson's middle-range theory of caring can be used as a framework for recruitment and retention for studies on sensitive topics that involve vulnerable participants. We provide an overview of the theory as well as illustrations from three separate studies that involved in-depth interviews with vulnerable participants. These studies included parents who had either experienced the death of their infant or were involved in life support decisions because of potentially giving birth to an extremely premature infant (22–25 weeks gestation).

Keywords

neonatal care; recruiting vulnerable populations; Swanson's middle-range theory

Recruiting and retaining vulnerable populations for sensitive research presents ethical challenges for researchers. Three ethical principles should guide research: respect for persons, beneficence, and justice (Thomas, 2005). These principles are particularly salient to recruitment and retention processes with vulnerable participants because of the delicate balance between protecting potential participants from harm and allowing them to make autonomous decisions about participation in research. Efforts to enroll participants are enhanced by anticipating and planning ahead for potential problems (Burr, 1996) and allocating adequate resources towards recruitment (Hogue, Johnson-Leckrone, & Liddle, 1999). When conducting research it is of paramount importance that participants' well-being takes precedence at all times (Burr, 1996; Demi & Warren, 1995; Miranda, Azocar, Organista, Munoz, & Lieberman, 1996; Munhall, 1988).

Correspondence to Karen Kavanaugh PhD, RN, FAAN, Department of Maternal-Child Nursing, University of Illinois at Chicago, 845 South Damen, Room 848, Chicago, IL 60612-7350.
[*]Co-Project Director and Associate Professor.
[†]Doctoral Student.
[‡]Research Assistant Professor.
[§]Research Associate.

There are many strategies that researchers can use when designing and implementing projects that will protect and uphold respect for participants, promote successful recruitment and retention, and maintain the integrity of their research. Strategies that are guided by caring behaviors enable the researcher to convey empathy and warmth, which allows them to establish a positive environment for participants (Dyregrov, 2004; Miranda et al., 1996). Swanson's (1991, 1993, 1999b) middle range theory of caring is one template that nursing researchers can use when conceptualizing and enacting recruitment and retention procedures for vulnerable participants. This theory is appropriate because it focuses on the importance of being mindful of the needs and well-being of participants, and as a middle-range theory, is readily translatable for application to research and practice.

The purpose of this article is to illustrate how Swanson's middle-range theory of caring can be used as a framework for recruitment and retention for studies on sensitive topics that involve vulnerable participants. We will use examples from three of our studies. In the first study, called "Perinatal Loss in Low-Income African American Parents (PLS)," we examined parents' experiences surrounding pregnancy loss and newborn death (Kavanaugh & Hershberger, 2005). In the next study, called "Life Support Decisions for Extremely Premature Infants: A Pilot (LISD-P)," we examined life support decisions surrounding the potential birth of an infant between 22 and 25 weeks of gestation (Kavanaugh, Savage, Kilpatrick, Kimura, & Hershberger, 2005) from the perspectives of parents, physicians, and nurses. The final study, "Life Support Decisions for Extremely Premature Infants (LISD)," is an extension of the LISD-P and is currently on-going. We used qualitative methods for these studies; for the parent participants the mode of data collection consisted of face-to-face interviews.

Sensitive Research and Vulnerable Participants

According to Lee and Renzetti (1990), sensitive research is that which involves topics that may be threatening to participants. Topics may be considered threatening for the following reasons: they are of a deeply personal nature; they impinge on the interests of those being studied; they involve deviance or social control; or they enter the world of that which is personally sacred (Lee & Renzetti). The PLS and LISD studies are considered sensitive research because we examined the deeply personal stories of parents at risk of birthing an extremely premature infant, or parents who had experienced the death of their newborn.

Vulnerability may be conceptualized as a way to identify groups or individuals who are susceptible to or at an increased risk of physiologic or psychosocial harm for a myriad of reasons (Purdy, 2004). Research participants may be considered vulnerable as a result of the group they belong to, the nature of the situation they are in, or the research itself. In our studies, participants are considered vulnerable due to the nature of their experiences, as these parents often experience a range of emotions and feelings and are emotionally vulnerable as they cope with the real or anticipated loss of an infant (Kavanaugh & Wheeler, 2003; Werner-Lin & Moro, 2004).

While the right of researchers to conduct studies that may cause emotional pain has been raised (Rosenblatt, 1995), several investigators have illustrated that participants who are considered vulnerable as a result of illness, loss, or threatened loss of a loved one appreciate the opportunity to tell their story and also give meaning to their experience (Burr, 1996; Dyregrov, 2004; Kavanaugh & Ayres, 1998; Rosenblatt). Despite the importance of sensitive research with vulnerable participants, this area of exploration is often plagued by numerous difficulties that stem from negotiations between the community involved, institutional regulations, and the need for methodological rigor (Chiang, Keatinge, & Williams, 2001). Participants who are vulnerable may also be more difficult to locate and may be less likely to participate in research due to past experiences with exploitation (Flaskerud & Winslow, 1998). In addition,

investigators have found that despite giving consent for research participation, some vulnerable participants may not be fully aware of what they are consenting to (Stenson, Becher, & McIntosh, 2004), or may not realize that participation is optional and can be discontinued at any time (Burgess, Singhal, Amin, McMillan, & Devrome, 2003).

Researchers can be more successful with recruitment of vulnerable participants by gaining a better understanding of those being studied and gathering information and linking with the community of interest when designing the research (Demi & Warren, 1995; Elam & Fenton, 2003; Flaskerud & Winslow, 1998; Hogue et al., 1999; Miranda et al., 1996). Enlisting the help of members within the community or institutions of interest can help alleviate the potential for coercion and the difficulty in locating and recruiting potential participants (Flaskerud & Winslow). This can also increase credibility for the research team and the study (Hogue et al.). Community involvement might include committee work, giving in-services, and hiring a consultant from the community of interest. For example, for the LISD study, the principal investigator (PI; KK) delivered in-services at the clinical sites, and members of our research team attended a total of 33 staff meetings across the three clinical sites.

Swanson's Middle-Range Theory of Caring

Swanson's (1991, 1993, 1999b) middle-range theory of caring is comprised of five caring processes each with multiple subcategories. The caring processes are maintaining belief, knowing, being with, doing for, and enabling. According to Swanson (1991), caring is a "nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility" (pp. 165). In this theory, the ultimate goal of nurse caring is to enable clients to achieve well-being (Swanson, 1993).

This theory was derived from three phenomenological studies conducted in the area of perinatal nursing. Swanson also drew from nursing and non-nursing literature (e.g., philosophy, ethics) to develop this middle-range theory, which contributes to our understanding of the unique dynamics of the phenomena of a caring relationship between an individual and others. Elements of this theory have been supported in a caring-based counseling intervention study with women who had miscarriages (Swanson, 1999a), in a meta-analysis of caring research (Swanson, 1999b), and in studies of perinatal loss (Kavanaugh, 1997; Kavanaugh & Hershberger, 2005; Lemmer, 1991).

Although this middle-range theory is based in nursing research, it presents a way to conceptualize the meaning and components of caring that extend beyond the traditional nurse-patient dynamic (Swanson, 1993). For this paper, we focus on the relationship between nurse researchers and study participants. In the following sections we provide examples from our research on how components of the theory can facilitate recruitment and retention strategies for vulnerable participants.

Maintaining Belief

This process provides the foundation of caring and refers to believing in another person's capacity to work through and find personal meaning in his or her experience regardless of the challenges or conditions faced (Swanson, 1993). Within this process are the subcategories of: believing in, offering a hope-filled attitude, maintaining realistic optimism, helping to find meaning, and going the distance (Swanson, 1999b). By approaching participants from a strengths based perspective and believing in their capacity to make meaning in their experiences, researchers convey a sense of hope and concern that helps to establish trust between the researcher and participants (Elam & Fenton, 2003; Hogue et al., 1999). This approach should inform all aspects of the research because the manner in which information

is presented will impact one's understanding of the research and consequently recruitment (Bosk, 2002).

Recruitment and consent materials are generally participants' first introduction to the research, thus it is important that hope and realistic optimism be conveyed through careful choices in the design, format, and language used in these materials. Because the research experience should be meaningful for participants, it is also important to develop strategies to assess their response to participation in the research (Kavanaugh & Ayres, 1998) to ensure that the research does not cause undue stress and to see if they find it beneficial. Participants may benefit personally from their involvement in the research, if the environment created reinforces the ideas that they are giving more to us than we are to them and that their well-being is paramount.

Examples of conveying hope, maintaining realistic optimism, and finding meaning—When designing all of our visual and written materials (e.g., recruitment literature, the consent forms and the interview guides) in our LISD studies, our goal was to convey a message of hope and realistic optimism. To help us achieve these goals, all of our materials were reviewed by a consultant on our research grant who is the parent of a young adult who was born very prematurely. One very important way we conveyed hope was through the use of respectful language. In both the PLS and LISD studies, we used the term "your baby" as opposed to technical terms (e.g., "fetus") or other or non-person terms, such as "micropreemie" that are commonplace. In addition, while the focus of our LISD study are parents who are at risk of giving birth to an infant before 25 weeks gestation, our logo portrays an image of parents embracing an infant who is depicted abstractly and is not clearly identifiable as an extremely premature infant.

In the parent recruitment letter and consent forms in the LISD studies, we try to convey hope and maintain realistic optimism by clearly outlining why these parents have been identified, yet omitting any mention of adverse pregnancy outcomes, such as newborn death. Once the parents agree to be contacted they are given a letter on pastel stationary hand signed by the PI. The letter acknowledges the difficult time that parents are having and includes: the purpose of the study; the rationale for selecting the parents as potential participants; a brief review of the study procedures; and the PI's background and experience. Even though it is possible that many parents in our study will have adverse pregnancy outcomes, such as stillbirth or newborn death, in the consent forms we did not have any specific mention of this and we tell parents that we will conduct interviews with them prenatally and postnatally. We worked with the Institutional Review Boards to outline acceptable procedures to obtain additional consent from those participants whose infant dies at that later date. Furthermore, by designing our study to include follow-up for all parents regardless of infant outcome, we convey to parents that they are individuals whose story is important, and that we are interested in their story even if their baby is not born between 22 and 25 weeks gestation.

Because the parents in our studies are giving us invaluable information, we strive to make their experience meaningful as well. We conclude every interview by asking parents, "What was it like for you to talk to me today?" By doing this we are alerted to any problems that participation may have caused the parents, and it gives us the opportunity to incorporate any suggestions into the way we continued to approach these or future participants. We have found that most of the parents in the PLS and LISD studies reported that the interview experience was beneficial. In the PLS study parents reported that the interviews helped them to find meaning and they appreciated the opportunity to talk about their experience (Kavanaugh & Hershberger, 2005). Most parents in our LISD studies have indicated that they valued the opportunity to participate in the research because it was beneficial for them and because they could find meaning in helping others by telling their story. As one father in the LISD study said:

> I guess because I like talking to people expressing my opinions and getting other people's opinion. So, it has actually been good for me. Just to sit down and talk to someone and give my opinion and maybe the stuff that I am saying will help someone else to deal with it, someone else may not be able to deal with it like me.

Knowing

Knowing is striving to understand what an experience means from the perspective of the person living it (Swanson, 1993). This includes focusing on understanding what a participant's situation means to him or her, as opposed to what it means to the researcher. The subcategories of knowing are: avoiding assumptions, assessing thoroughly, seeking cues, centering on the one cared for, and engaging the self of both (Swanson, 1999b). This process is essential when working with vulnerable participants because they are allowing researchers into their deeply personal, often painful, worlds. By striving to understand a participant's experience, and its meaning to them, researchers can create a positive and safe environment.

While knowing is facilitated by experiential and scholarly knowledge, researchers also need to avoid making assumptions in order to understand participant's physical, cultural, spiritual, and emotional reality (Swanson, 1993). Knowing is enhanced by the use of a well-prepared, expert staff. When members of the research team are aware of participants' needs, they can tailor the recruitment process to each unique case, instill confidence in the research (Hogue et al.), and facilitate enrollment (Hogue et al., 1999; Miranda et al., 1996). Furthermore, Dyregrov (2004) found that when telling their story it was important to parents that the interviewer was both knowledgeable and inspired confidence.

Examples of seeking cues and centering on the one cared for—In the LISD studies we enlisted the help of expert professionals with specialization in high-risk pregnancy in every aspect of the recruitment and data collection processes. We identified and recruited participants through research specialists who were nurses or fellows specializing in high-risk obstetrical care. These experts were sensitive to both the medical and emotional vulnerability of this group, and only approached parents who were eligible for participation. For all of our studies, the PI, who is a nurse with more than 25 years of neonatal experience and 15 years of experience with bereavement research, performed all contacts and interviews with parents.

Another way we conveyed knowing was through the careful selection of gifts we gave parents as a thank you for their participation in our study. We attempted to convey respect and understanding of participant's situations by giving them personalized gifts at both the prenatal and postnatal interviews. After the prenatal interview in the LISD study, parents receive a card that reads "A special time for caring," mothers receive body lotion and a notebook, and fathers receive a food snack. Because all of the mothers in our studies were hospitalized, a mildly scented body lotion was chosen because it provided a means of self-comfort. We began providing mothers with a journal and matching pen after realizing that parents needed to have pen and paper to write down all of the information they were receiving. Food was given to fathers because often fathers were by their partner's side and may or may not have time to eat. Thus, a quick snack acknowledges the partner in a thoughtful way. At the postnatal interview, if the infant is born alive, parents select either a book on parenting a premature baby or a gift certificate for their infant. In both the PLS and LISD studies, when an infant died, parents received a culturally and spiritually appropriate sympathy card designed for bereaved parents, and they were able to choose from several books on the loss of a baby, or a memory box for their infant's mementoes.

Being With

Being with refers to being authentically present with another person in order to convey that their experiences are important (Swanson, 1993) and includes the subcategories of being with, non-burdening, conveying availability, enduring with, and sharing feelings (Swanson, 1999b). When qualitative methods are used, investigators are often in a unique position to "be with" participants, which allows researchers to assess and understand participant responses during all phases of the study (Kavanaugh & Ayres, 1998; Koenig, Back, & Crawley, 2003; Munhall, 1988; Rosenblatt, 1995). In particular, when the method of data collection is an interview the interviewer has the opportunity to use self as the instrument and display characteristics that are essential to a caring encounter and facilitate authenticity, credibility, and intuitiveness (Rew, Bechtel, & Sapp, 1993).

Researchers can be present with participants by spending extra time with them, sitting quietly alongside them, accepting their emotions, and offering kind words that convey respect. Nonverbal communication such as eye contact, attentive listening and concerned facial expressions can also convey support. While it is important to show support to participants, researchers should avoid assuming a therapeutic role that is outside the boundary of the research (Bosk, 2002; Burr, 1996; Koenig et al., 2003; Munhall, 1988; Rosenblatt, 1995). Potential research participants may not always understand that researchers have a different role with different rules (Bosk) and researchers who are also trained as health care professionals may themselves be tempted to provide services that are not part of the research. However, this is often of no benefit to the participant and can jeopardize the study. Role conflict may be avoided by openly discussing the researcher-collaborator relationship at the recruitment and consent stage of the research (Munhall).

Examples of being with, conveying availability, and enduring with—For the PLS and LISD studies, we preferred to be present with participants as opposed to communicating via the phone. By doing as little as possible over the telephone we demonstrated a willingness to make multiple calls and trips to see the participants. All of the consents and interviews were done in person by the PI at the parent's convenience. This gave the PI a chance to meet the parents, introduce herself, and to show personal interest and an appreciation for their situation.

The PI often spent more time with participants than the data collection interview required. For example, in the PLS study while the interviews were about 2 hours long most meetings lasted 3 or more hours. In the PLS and LISD studies, once interviews were scheduled there were many instances in which they were postponed due to the mother's emotional state. For example, one interview was postponed because in the hour between scheduling the visit and the PI's arrival the mother had become upset after overhearing physicians discuss her infant's condition. The PI sat with the overwhelmed mother instead of conducting the research. While these situations delay the progress of data collection for the study, this action is essential because it shows the participants that they and their situation were important to the researcher. In the PLS and LISD studies when an infant died the PI showed availability by sitting with the parents and looking at the infant's mementoes before beginning the interview, a strategy recommended in bereavement research (Dyregrov, 2004). Despite the intimate nature of the interviews, in particular during those in which an infant died, the PI in these studies attempted to avoid role conflict by clarifying her role as a researcher and not a clinician. In general, we found that most parents just appreciated the opportunity to tell their story to an attentive listener and were not seeking advice.

Doing For

Doing for means doing for others what they would do for themselves if possible (Swanson, 1993). Doing for consists of comforting, performing competently, preserving dignity,

anticipating and protecting (Swanson, 1999b). This process consists of acts as simple as offering to get water, contacting the nurse, or making sure parents are comfortable. This process refers to more than physical tasks; it encompasses using therapeutic communication to help facilitate other's self-healing (Swanson, 1993).

To preserve dignity and protect participants from undue harm, issues of coercion and confidentiality must be addressed (Bosk, 2002; Demi & Warren, 1995; Elam & Fenton, 2003; Golec, Gibbins, Dunn, & Hebert, 2004; Rosenblatt, 1995). As part of the recruitment process, participants must be assured that confidentiality will be maintained, and procedures for doing so should be clearly explained. Depending on the nature of the research, a certificate of confidentiality, which protects the identity of research participants, may be appropriate (Koenig et al., 2003).

Many researchers have called for a re-evaluation of the current consent procedures when conducting sensitive research (Bosk, 2002; Golec et al., 2004; Stenson et al., 2004; Thomas, 2005). It has been suggested that consent be an ongoing process of decision-making (Burr, 1996; Koenig et al., 2003; Munhall, 1988; Rosenblatt, 1995; Stenson et al., 2004). In addition, once potential participants are approached they need adequate time and written information to make informed and autonomous decisions about participation (Bosk, Burgess et al., 2003; Dyregrov, Golec et al., Hogue et al., 1999; Kitson et al., 1996).

Coercion may be avoided by paying careful attention to subtle cues that indicate reluctance to give consent (Demi & Warren, 1995) and by realizing that some participants are too impaired to be able to give consent (Bosk, 2002). Recruitment may need to be deferred in order to explain the study multiple times and fully address participants' questions or concerns (Burgess et al., 2003; Golec et al., 2004; Hogue et al., 1999). For example, when parents are research participants it is often best to approach them for one study at a time and only for studies that are clinically relevant to them or their child (Golec et al., 2004). If possible, investigators in hospitals should consult with nursing staff to avoid recruiting subjects who are too ill to participate (Henderson, Addington-Hall, & Hotopf, 2005), because nurses are often the ones to assure the safety of research participants (Thomas, 2005).

Examples of protecting—For the LISD studies we enacted a number of measures to protect participants by avoiding coercion and maintaining confidentiality. For example, we obtained a certificate of confidentiality due to the potential for a medical malpractice lawsuit. The PI reviewed the measures to maintain confidentiality during the consent process and reintroduced this issue several times throughout the interviews. Because both parents and healthcare professionals (physicians and nurses) are interviewed in the LISD studies we have different members of the research team interview each group of participants to avoid inadvertent disclosure between the two. All of the parent interviews are conducted by the PI, and all of the physician and nurse interviews are conducted by either a co-investigator, who is a nurse researcher, or the project director, who is a licensed social worker.

We used formal and process consent in both PLS and LISD studies. The formal consent process, undertaken in person by the PI, entailed a full review of the consent form that was read verbally, and participants were given a signed copy. Thereafter, process consent was used. Each time parents were interviewed they were asked if they wished to continue participation. The PI also reminded parents that participation was voluntary and that they could choose to selectively answer questions or discontinue the interview at any time.

The PI took additional steps to protect parents by declining to interview impaired participants and by communicating with the nurse caring for the mother or baby before every contact to avoid inconveniencing or upsetting the mother. In instances in which the PI felt that the mother

was too heavily medicated or ill to make an informed decision, the PI always chose to defer recruitment until the mother's condition stabilized. The choices to defer recruitment and postpone interviews greatly increased the time and effort needed to complete data collection. For example, in the LISD-P study an average of 35 contacts were made for each case to parents or their care professionals to complete the parent interviews (Kavanaugh et al., 2005). However, these strategies protected participants from coercion and demonstrated a concern for patients to the hospital staff. These actions subsequently helped generate staff confidence in our research, which has aided in the recruitment and data collect processes for other cases.

Enabling

Enabling refers to assisting others in gaining the tools needed to be able to care for themselves (Swanson, 1993). Enabling includes validating, informing and supporting participants, giving them feedback, and helping them to focus and generate alternatives (Swanson, 1999b).

Several strategies can be carried out to enable participants. For example, researchers can create an environment that stresses partnership as opposed to a hierarchical dynamic. When working with vulnerable participants, in particular those in hospitals, enabling may include giving them some control over their surroundings. While researchers should not change the hospital environment, they can give participants some control over the research process by allowing them to decide when and where to meet (Dyregrov, 2004). Flexibility in scheduling interviews and understanding when parents need to reschedule makes it more convenient for participants to be in research (Hogue et al., 1999). Finally, it is essential, particularly for sensitive research, to provide participants with relevant and reliable resources.

Examples of informing and supporting—Because enabling involves giving participants the tools to help themselves, in the PLS and LISD studies we provided information and support to participants by offering to provide them with a list of local and internet support services and mental health resources. In choosing these resources, we first checked to make sure the groups were still active and that internet resources were reliable. This is an important step because we found that often the local resources change, and many support groups may no longer be active. The mental health resources we provide were researched and have at least one person on staff that specializes in illness and loss or perinatal loss. In an attempt to maintain consistency with the information received from the hospital, before giving parents books on parenting a premature baby we met with the health care professionals at each institution and reviewed the books with them. All of the gifts we provide were endorsed by the health care professionals.

In terms of internet resources, we are very careful before recommending these to parents because many of the resources may be deceptive. Some sites may seem useful or comforting at first glance, but upon deeper inspection may be judgmental, full of false information, and potentially damaging. In the LISD study parents described mixed experiences with the internet. One mother reported becoming upset because the information she found (that infants born at 20 weeks gestation had a 100% survival rate) was inaccurate and contradictory to what she was being told by her health care professionals. Another mother found comfort and very useful advice when she used chat rooms for mothers experiencing a high-risk pregnancy. To assure the resources are reliable, it is therefore important to scrutinize websites thoroughly, this includes searching the site in-depth, finding out what group or individuals created and maintain the site, and checking the links to other resources.

Summary

Participants in sensitive research are generally vulnerable, if for no other reason, than they are participating in research. It is important for us to remember that they are individuals first whose well-being is a priority. Thus, when conducting sensitive research with vulnerable participants

it is important to spend extra time and effort preparing for the recruitment process. This may translate into better retention and serve to help participants feel positive about and gain meaning from their research experience.

In this article we have presented Swanson's middle-range theory of caring as a useful template for conceptualizing and designing recruitment procedures. Middle-range theories are designed to guide empirical inquiry, and components of the theory are meant to be empirically tested (Merton, 1967). Thus, by explicitly drawing from aspects of middle-range theories researchers can both further theoretical knowledge and inform their individual research projects. We have illustrated, through examples from our three studies, ways that researchers can use aspects of a theory to inform their research. We did not illustrate how to use the theory in its entirety, but rather were able to demonstrate the components that were relevant to our study.

While this theory is one of many that can inform research design it is valuable when working with vulnerable participants because it encourages researchers to create an environment that is beneficial to participants. The middle-range theory of caring reminds nurse researchers of the importance of viewing participants as capable individuals, with important stories they should be able to tell in a safe and non-judgmental environment. It also reminds us that research can and should be beneficial for participants, and that by being mindful of the five processes we can facilitate this.

Although this middle-range theory is based in nursing research, it presents a way to conceptualize the meaning and components of caring that extend beyond the traditional nurse-patient dynamic (Swanson, 1993). While this theory and the studies we presented are all rooted in research with perinatal loss, or threatened loss, it can be applied to other sensitive areas. Ideas such as, believing in the capacity of another to make meaning, and the importance of understanding others from their perspectives, should be universal. The concrete ideas presented in this paper, for example, personalizing gifts, enlisting the help of the community of interest, and using respectful and appropriate language, are not new but can be easily forgotten in the rush to launch a project. Swanson's theory calls us to stop and re-evaluate our approach to research. Through our experience with the PLS and LISD studies, this approach has been beneficial for both our participants and the research projects.

Acknowledgments

References

Bosk CL. Obtaining voluntary consent for research in desperately ill patients. Medical Care 2002;40:V64–V68. [PubMed: 12226587]

Burgess E, Singhal N, Amin H, McMillan DD, Devrome H. Consent for clinical research in the neonatal intensive care unit: A retrospective survey and a prospective study. Archives of Disease in Childhood Fetal and Neonatal Edition 2003;88:F280–F286. [PubMed: 12819158]

Burr G. Unfinished business: Interviewing family members of critically ill patients. Nursing Inquiry 1996;3:172–177. [PubMed: 8868731]

Chiang VC, Keatinge D, Williams AK. Challenges of recruiting a vulnerable population in a grounded theory study. Nursing and Health Sciences 2001;3:205–211. [PubMed: 11906629]

Demi AS, Warren NA. Issues in conducting research with vulnerable families. Western Journal of Nursing Research 1995;17:188–202. [PubMed: 7732685]

Dyregrov K. Bereaved parents' experience of research participation. Social Science & Medicine 2004;58:391–400. [PubMed: 14604624]

Elam G, Fenton KA. Researching sensitive issues and ethnicity: Lessons from sexual health. Ethnicity & Health 2003;8:15–27. [PubMed: 12893582]

Flaskerud JH, Winslow BJ. Conceptualizing vulnerable populations health related research. Nursing Research 1998;47:69–78. [PubMed: 9536190]

Golec L, Gibbins S, Dunn MS, Hebert P. Informed consent in the NICU setting: An ethically optimal model for research solicitation. Journal of Perinatology 2004;24:783–791. [PubMed: 15372063]

Henderson M, Addington-Hall JM, Hotopf M. The willingness of palliative care patients to participate in research [Letter to the editor]. Journal of Pain and Symptom Management 2005;29:116–118. [PubMed: 15733802]

Hogue A, Johnson-Leckrone J, Liddle HA. Recruiting high-risk families into family-based prevention and prevention research. Journal of Mental Health Counseling 1999;21:337–351.

Kavanaugh K. The parental experience surrounding the death of a live-born infant weighing less than 500 grams at birth. Journal of Obstetric, Gynecologic, and Neonatal Nursing 1997;26:43–51.

Kavanaugh K, Ayres L. "Not as bad as it could have been": Assessing and mitigating harm during research interviews on sensitive topics. Research in Nursing & Health 1998;21:91–97. [PubMed: 9472241]

Kavanaugh K, Hershberger P. Perinatal loss in low-income African American parents: The lived experience. Journal of Obstetric, Gynecologic, and Neonatal Nursing 2005;34:595–605.

Kavanaugh K, Savage T, Kilpatrick S, Kimura R, Hershberger P. Life support decisions for extremely premature infants. Journal of Pediatric Nursing 2005;20:347–359. [PubMed: 16182094]

Kavanaugh, K.; Wheeler, S. When a baby dies: Caring for bereaved families. In: Kenner, C.; Lott, J., editors. Comprehensive neonatal nursing: A physiologic perspective. 3rd. Philadelphia: Harcourt; 2003. p. 108-126.

Kitson GC, Clark RD, Rushforth NB, Brinich PM, Sudak HS, Zyzanski SJ. Research on difficult family topics: Helping new and experienced researchers cope with research on loss. Family Relations 1996;45:183–188.

Koenig BA, Back AL, Crawley LM. Qualitative methods in end-of-life research: Recommendations to enhance the protection of human subjects. Journal of Pain and Symptom Management 2003;25:S43–S52. [PubMed: 12691696]

Lee RM, Renzetti CM. The problems of researching sensitive topics: An overview and introduction. American Behavioral Scientist 1990;33:510–528.

Lemmer CM. Parental perceptions of caring following perinatal bereavement. Western Journal of Nursing Research 1991;13:475–493. [PubMed: 1897209]

Merton, RK. On theoretical sociology. New York: The Free Press; 1967.

Miranda J, Azocar F, Organista KC, Munoz RF, Lieberman A. Recruiting and retaining low-income Latinos in psychotherapy research. Journal of Consulting and Clinical Psychology 1996;64:868–874. [PubMed: 8916613]

Munhall PL. Ethical considerations in qualitative research. Western Journal of Nursing Research 1988;10:150–162. [PubMed: 3394317]

Purdy IB. Vulnerable: A concept analysis. Nursing Forum 2004;39:25–33. [PubMed: 15700483]

Rew L, Bechtel D, Sapp A. Self-as-instrument in qualitative research. Nursing Research 1993;42:300–301. [PubMed: 8415047]

Rosenblatt PC. Ethics of qualitative interviewing with grieving families. Death Studies 1995;19:139–155. [PubMed: 11652993]

Stenson BJ, Becher JC, McIntosh N. Neonatal research: The parental perspective. Archives of Disease in Childhood Fetal and Neonatal Edition 2004;89:F321–F324. [PubMed: 15210665]

Swanson KM. Empirical development of a middle range theory of caring. Nursing Research 1991;40:161–166. [PubMed: 2030995]

Swanson KM. Nursing as informed caring for the well being of others. Image: Journal of Nursing Scholarship 1993;25:352–357.

Swanson KM. Effects of caring, measurement, and time on miscarriage impact and women's well-being. Nursing Research 1999a;48:288–298. [PubMed: 10571496]

Swanson, KM. What's known about caring in nursing science: A literary meta-analysis. In: Hinshaw, AS.; Feetham, S.; Shaver, J., editors. Handbook of clinical nursing research. Thousand Oaks, CA: Sage; 1999b. p. 31-60.

Thomas KA. Safety: When infants and parents are research subjects. Journal of Perinatal and Neonatal Nursing 2005;19:52–58. [PubMed: 15796425]

Werner-Lin, A.; Moro, T. Unacknowledged and stigmatized loss. In: Walsh, F.; McGoldrick, M., editors. Living beyond loss: Death in the family. 2nd. New York: W.W. Norton; 2004. p. 247-271.