

A Case Study: The Nurse Researcher in the Home Setting

Wendy Lovelace Ray

University of Mississippi Medical Center, wlovelace@umc.edu

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Introduction

The state of nursing science and nursing care has significantly changed over the last decade. Caring for patients in the home setting has become more commonplace. Home based care is expected to continue to increase as the “Baby Boomer” population ages (United States Census Bureau, 2010; Organisation for Economic Cooperation and Development [OECD], 2011). The life expectancy of those in developed countries is predicted to continue to climb (CDC, 2010; OECD, 2013). The number of individuals who are living with chronic or terminal illness is also on the rise (National Center for Health Statistics, 2012; World Health Organization Europe, 2012). As a result, these patients require the medical management and nursing care of multiple health problems and/or chronic conditions (Ward, Schiller & Goodman, 2014). Many of these patients are elders and receive home care services (Kirby & Lau, 2010). They are often dependent on others for basic needs and require assistance performing activities of daily living. As a result, conducting nursing research with patients in the home setting can present ethical challenges.

Ethical Issue

What are the key ethical challenges of implementing research in the home setting in the context of role conflict of nurse researchers and therapeutic misconception by participants?

Identification of the Dilemma

Conducting research in the home presents unique ethical challenges (Locher, Bronstein, Robinson, Williams & Ritchie, 2006). Two ethical issues that are well documented in the literature are therapeutic misconception by the participant and researcher role conflict. Therapeutic misconception is described as a situation that results in research participants mistakenly believing they will receive some type of treatment or care (Lidz & Applebaura, 2002). The Declaration of Helsinki document interchanges the terms therapeutic and treatment resulting in the misperception of research as a therapeutic intervention (World Medical Association, 2004). Research conducted in the home is especially vulnerable to the ethical dilemma of therapeutic misconception for several reasons. One involves the manner in which home care participants may be recruited for research. Another reason deals with the home setting as the site in which the research is conducted.

Relying on service providers to facilitate the recruitment of participants of home care services is a common practice. This practice often involves asking those who receive home care services if they will agree to participate in a research study. This method of recruitment may unintentionally result in home care patients feeling obligated to agree to participate in the research study (Stevens & Pletsch, 2002). This is especially true if the offer is given to them by a trusted healthcare provider with a previously established relationship, such as a nurse. In addition, patients of home care services may feel compelled to agree to participate in research due to fear that home care services may be withdrawn if they do not agree (Steinke, 2004).

Some patients who are socially isolated, such as those living in rural areas, may mistakenly view participating in research as a way to obtain access to health care (Ritchie & Dennis, 1999).

Researcher Role Conflict

Research conducted in the home may result in researcher role conflict as a result of acquired knowledge of abuse and/or potential harm to the patient (Lachs & Pillemer, 2004). Should such knowledge come to light, the nurse researcher is legally obligated to report these findings. Doing so may result in the removal of the patient from the home, threatening the patient's autonomy. This particular situation presents an ethical dilemma because research participants agree to participate in research but may not be aware of the legal obligation nurse researchers have to report such findings.

Nurse As Guest

Another example of a situation in which researcher role conflict may occur in research in the home setting involves the role of the nurse as guest. Many times the role of the nurse is described as a 'guest' and the appointment in which home care services are scheduled are referred to as a "visit" (Milton, 2005; Oresland, Maata, Norberg, Winther Jorgensen, & Lutzen, 2008). A qualitative study conducted by Greemen (1999) revealed that nurses view themselves as a "special guest".

Although nurses in the Greemen study identified themselves as guest, it is worth mentioning that none of them alluded to being "hosted" by patients. This author searched the literature for studies that addressed the question of patients feeling obligated to serve as hosts to nurses visiting them in their home. This omission in the literature leads one to wonder about the role reciprocals of guest and host, questioning whether it is possible to have "guests" in the home without assuming the role of "host". If so then a plethora of ethical dilemmas are possible.

Assuming the role of nurse researcher or guest in the home of a research participant may lead to additional ethical dilemmas. As a guest in a home, societal norms and expectations exist. The owner of the home is considered to be the authority in that home (Gremmen, 1999). In the American culture, guests are expected to defer to the home owner and abide by the rules of conduct of the home owner (United States Bureau of Education and Cultural Affairs, 2011). On the other hand, many cultures abide by the social norm of deferring to guests during a visit (Hechter & Opp, 2001). These conflicting societal norms may result in a potential ethical challenge when conducting research in the home setting.

Philosophical Framework

A social construct epistemological framework will be used as a basis to guide the proposed plan addressing the ethical challenges of researcher role conflict and therapeutic misconception in research conducted in the home setting. According to Burr (1995), there are four key premises of the social construct framework. The first premise involves language and the important role language has in the social construction of the identity of self, and relationships between people and society. The second premise deals with how knowledge cannot be taken to be objective truth because humans view the world by using their own concepts of language (Crowe, 1998). For example, when someone refers to their home, they use concepts often associated with the home such as valuable items, family or guests. These ideas influence how one perceives and understands the concept of home. Third, the manner in which one perceives the world is influenced by historical events and is specific to a particular culture (Burr, 1995). Individual roles and positions are created between individuals by determining appropriate behavior based on the context of the situation. The fourth premise proposes there is a connection between the specific knowledge of individuals and the actions of society. Additionally it suggests

that this knowledge is created by social interactions and mutual truth, and is continually debated throughout the process of social construction of role (Crowe, 1998).

Ethical Framework

Two relevant ethical theories, ethics of justice and ethics of care, are proposed as guidelines for conducting research with vulnerable populations in the home setting. Ethics of justice is an ethical theory that focuses on respect for autonomy and rejects intrusiveness and paternalism (Komter, 1995). On the other hand, ethics of care promotes actions that reject indifference to human suffering and encourage actions that relieve distress and pain (Tronto, 1993). Other principles of ethics of care are promoting trust, attentiveness, openness and communication. These two perspectives, justice and care, are frequently viewed as opposites or at odds (Gremmen, 1999). Ethics of care is often viewed as a feminine perspective with lesser status and ethics of justice is regarded as having a masculine viewpoint and a higher position (Clement, 1996). It could be argued that both ethical perspectives are valuable and necessary in order to conduct sensitive and morally considerate research with research participants in the home setting.

A fundamental principle found in the American Nurses Association (ANA) Code of Ethics is the respect for the inherent worth, dignity and human rights of every person (2001). Similar basic ethical principles are provided in federal research guidelines (National Commission for the Protection of Human Subjects of Biomedical & Behavioral Research, 1979). These fundamental principles are respect for person and beneficence. Each of these ethical principles are related to and supported by the ethics of care theoretical framework. Another example of an ethical principle of the ANA Code of Ethics is self-determination (2001). This principle is associated with the federal research guideline of ensuring voluntary informed consent of research

participants. Both principles of self-determination and informed consent are interconnected with the tenets of the ethical theory of justice.

Moral Reasoning as a Strategy to Solve Ethical Dilemmas

According to Liaschenko, (1994) “agency is the capacity to initiate meaningful action” (p. 17). A modification of this definition, used by Peter (2002), is that “ moral agency is a mix of motivation and physical action directed toward some moral end” (p. 66). With that in mind, it is first necessary to confirm that the ethical decisions used to design the research question are appropriate in order to explore moral agency or reasoning in the context of therapeutic misconception and researcher role conflict in home-based research. As mentioned previously, many patients who receive home care services are socially and geographically isolated. These patients often have multiple health conditions that are chronic in nature, and symptoms of chronic illness may result in a life-threatening situation (Coward & Cutler, 1989). Situations such as these may be further complicated if the patient lives in a rural area where access to healthcare is scarce (Nyman, Sen, Chan & Commins 1991), and therefore, these patients may be considered a vulnerable population.

Of course, protection of vulnerable patients is necessary when designing research. There is debate as to whether people with life-threatening illness should be included in research (Kristianson, Hanson & Balneaves, 1994). In fact, de Raeve (1994) argues that research of patients with life-threatening illness is not morally justifiable and provides numerous reasons for this stance. One is the belief that those patients will feel coerced to participate, that their numerous health needs may potentially threaten research results, and that the patients are unlikely to benefit from the research. Of course, this argument substantiates the misconception that research always provides an immediate therapeutic benefit. Opposing views of this argument

can easily be found. One such argument is that ethical principles of research can be applied to homebound patients who have chronic illness (Addington-Hall, 2005). Other authors point out that with appropriate medical and nursing interventions many patients who suffer from chronic illness are capable of making informed decisions (Mount, Cohen, MacDonald, Bruera & Dudgeon, 1995). Keeley argues that the consequence of not conducting research in this population is more detrimental because data suggesting appropriate care measures for providing care to these patients would be unavailable (2008). Others propose that labeling patients as vulnerable disrespects personhood and is a paternalistic viewpoint (Berry, 2004).

These opposing arguments for and against conducting research with chronically ill patients confirm the existence of an ethical dilemma when determining if one should conduct research with elderly and/or homebound patients. The existence of opposing arguments only substantiates the appropriateness of using opposing ethical frameworks of ethics of care and ethics of justice as a guideline when deciding if research should be conducted in this population. The researcher should also ask questions to decide if the research participant burden is justifiable. Ethics of justice framework is appropriate to use when deciding this question. Other questions the researcher should ask when considering research in this population include what strategies will be used to meet the patient's healthcare needs that may arise while conducting the study; and what ethical principles will be used to intervene appropriately. In the research situation with elderly and/or homebound patients, an ethics of care framework is suitable to guide the researcher in the process of moral reasoning. Alternately, ethics of care principles that may be appropriate in this situation are attentiveness, openness, responsibility and communication.

Assuring informed consent is necessary in order to conduct an ethically based research study. Informed consent depends on the patient being provided with sufficient information to understand the risks and benefits of the study (Levine, 2003). Truly informed consent also relies on the capacity of the patient to comprehend the information in order to make a voluntary decision that is devoid of coercion (Ingelfinger, 2003). If research participants experience therapeutic misconception by misunderstanding the benefits of the study and mistakenly believing that the research may yield a therapeutic intervention, then they are unable to truly give informed consent. In this case, an ethics of justice framework should be used to appropriately intervene by re-explaining the objectives of the study and clarifying the difference between research and therapeutic intervention. If the research participant is still unable to understand, it would be necessary to excuse the participant from the research study.

Researchers must continually evaluate and act appropriately to avoid unwarranted intrusion into the lives of participants. It may be appropriate to take an unobtrusive presence while conducting research in the home setting. On the other hand, researchers may need to act decisively in the event a participant begins to show signs and/or symptoms of worsening illness. The potential necessity for researchers to act in opposing positions also substantiates the aptness of proposing the two divergent frameworks, ethics of justice and ethics of care, in order to meet the competing needs of research participants in the home setting.

Case Illustration

Yvonne is a 65 year old widow. She has severe heart failure and lives alone in an old, small, wood frame home. She worked as a laundress but is no longer able to work. She lives in a rural community with the nearest gas station located 10 miles from her home, and the nearest grocery store and medical center

located 20 miles away. She has two adult children and four grandchildren, all of whom live quite a distance away. She relies on church members to help her with obtaining groceries and other necessities. She has difficulty catching her breath with minimal effort, such as walking a few feet or speaking a few sentences.

Yvonne receives home care services through a local home health agency. A home care nurse visits her once a week and a nurse's aide usually comes to her home twice a week. Yvonne enjoys living by herself and has refused efforts by her family to arrange to have her placed in an assisted living facility. She states, "I don't want to live anywhere other than the house my husband and I raised our children in."

The home care nurse recently asked her to participate in a research study being conducted by a graduate nursing student. Her reply to the home care nurse when asked to participate was, "I will do whatever you ask me to do." The graduate student arrived the following week. When she knocked on the door, the participant was slow to answer the door and once the introductions were made the participant stated, "I don't get many visitors. Thank you so much for being my guest." The graduate nurse explained the study and obtained informed consent. The study involves visiting the participant once a week for six weeks. During a visit the following week, Ms. Yvonne began to have severe shortness of breath and had difficulty answering questions. The nurse researcher intervened by assisting Yvonne to an upright position and helped her locate her medication. The nurse researcher also contacted emergency services. As a result, Yvonne was taken to the hospital and was admitted with a diagnosis of heart failure

exacerbation. Consequently, her children who lived out of state decided Yvonne was no longer capable of taking care of herself and arranged for her to be placed into an assisted living home.

Discussion

The first ethical dilemma that should be addressed in the case study is the manner in which Yvonne was asked to participate in the research study. An ethics of justice framework is appropriate to use in this situation in order for the nurse researcher to promote self-determination in the participant. If it were necessary for the nurse to introduce the study, the nurse should have emphasized that participating in the research study was completely voluntary and that Yvonne was not obligated to participate. A better arrangement would have been for the nurse to have introduced the nurse researcher to Yvonne and for the nurse researcher to have introduced the study without the nurse being present. This arrangement would have made it easier for Yvonne to decline to participate in the study if she was not willing to participate.

Another ethical dilemma that should be discussed in the case study involves the statement made by Yvonne, "I don't get many visitors. Thank you so much for being my guest." This statement clearly indicates that Yvonne felt as if the nurse researcher was a guest in her home. An ethics of justice framework is also appropriate to use in this situation in order to avoid intrusiveness, prevent research role conflict, and to assure informed consent. An appropriate action would be for the nurse researcher to again discuss who she is and why she is there. Care should be taken by the nurse researcher to ensure that Yvonne comprehends the role of the researcher and the purpose of the

research as well as assuring continued informed consent. This should be a continuous ongoing process throughout the research study.

Yvonne's desire to live independently is another potential ethical dilemma in this case study. She specifically expresses this in her statement, "I don't want to live anywhere other than the house my husband and I raised our children in." Ethics of care is the appropriate ethical framework to use to for this issue. The nurse researcher should be open and honest while communicating with Yvonne about her desire to live independently. It is also necessary for the nurse researcher to be attentive during interactions with Yvonne and to respect her as an individual person with specific desires and needs.

The last ethical dilemma to be addressed in the case study involves the medical emergency experienced by Yvonne and witnessed by the nurse researcher. The nurse researcher responded appropriately by using the principles of ethics of care to handle the situation. The actions of the nurse researcher resulted in the relief of Yvonne's suffering, distress and pain. However, Yvonne lost her independence and was unable to live in her home after being hospitalized. This results in another ethical dilemma.

Summary

The philosophical framework of social construct theory supports the idea that people use language to construct relationships between people. This premise has been substantiated while exploring the ethical challenges of conducting research in the home of elder adults who have chronic illness and are homebound. The results of this exploration have revealed the uniqueness of the context of the home setting. Therapeutic misconception and researcher role conflict are

ethical dilemmas that which may occur while conducting research in the home. Studies were reviewed found that indicate both patients and nurses view the nurse as a guest while in the home to deliver home care. The role of the nurse researcher as guest in the home may result in an ethical dilemma due to conflicting and opposing demands. For this reason, it is inappropriate to attempt to solve ethical dilemmas that are derived from opposing positions by using one ethical framework. Care must be taken by the researcher to act appropriately when ethical dilemmas occur. Using both an ethics of care and ethics of justice framework provides the researcher a more comprehensive perspective when faced with an ethical dilemma.

Future Research

The nursing literature of research in the home setting has identified several unexplored areas for future research. Prior studies have explored the nurse's role in research in the home setting. More research is needed from the perspective of the patient in the home setting. Research opportunities for all types of research design approaches are needed.

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