Caregivers’ Lived Experience of Participating Biweekly in a Year-long Interview Process

Submitted by
Heidi M. Pitzen-Osswald

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Major Advisor
Linda Pierce, Ph.D., R.N.

Academic Advisory Committee
Victoria Steiner, Ph.D.
Elizabeth Grothaus, M.S.N., R.N.

Dean, College of Nursing
Jeri A. Milstead, Ph.D., R.N., FAAN

Dean, College of Graduate Studies
Keith K. Schlender, Ph.D.
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Heidi M. Pitzen-Osswald

Medical University of Ohio at Toledo

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DEDICATION

This thesis is dedicated to my mom, Harriet, for her advocacy, perseverance, love, and daily care of my dad, Ken, since his stroke. It also is dedicated to my dad, whose example taught me how to cherish a hard day’s work and a good laugh. Finally, this thesis is dedicated to all caregivers of persons with stroke; in the middle of this “tough row to hoe,” may they cherish the hard days’ work and the good laughs.
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CHAPTER 1

Introduction

Interviews are frequently used as a method for collecting research data (Lowes & Prowse, 2001; Speziale & Carpenter, 2003). “The purpose of the interview is to understand the worldview of the interviewee on the theme of the research” (Hiller & DiLuzio, 2004, p.6). The interview process provides an opportunity for the participant to not only discuss their thoughts but also to reflect (Hiller & DiLuzio). The reliance on interviews to produce narrative experience reflects and reinforces the United States as an interview society (Fontana & Frey, 2000).

However, research interviews can have effects on the participants that have more to do with the interview process during data collection than the topics discussed during interviews, which should be taken into consideration for both research and ethical reasons (Shamai, 2003). Put another way, “hearing the voice of the participant is not the same as understanding how the interviewee perceives the research process” (Fontana & Frey, 2000, p. 4).

In order to protect study participants the particular risks of taking part in interviews for the purposes of any research are normally scrutinized by institutional review boards (IRBs) (Hutchinson, Wilson, & Wilson, 1994). Yet the benefits to the interviewee have not been examined as in depth; indeed, discussions of the benefits of the research interview have generally been “limited to the potential for generating knowledge” (Hutchinson et al., p. 164). The research interview is usually discussed from the perspective of the researcher and the objectives of the research project rather than the perspective of the person being interviewed (Gibson, 1998; Hiller & DiLuzio, 2004).
It has been suggested that therapeutic effects can emerge from participation in research interviews (Colbourne & Sque, 2005; Gale, 1992; Hutchinson et al., 1994; Shamai, 2003). In this regard, the research interview begins to resemble the therapeutic interview, with similar effects on the participants, such as greater self-awareness or venting repressed emotions (Colbourne & Sque).

During a one-time interview, the current study asked caregivers of persons with stroke about their participation in a National Institutes of Health (NIH) sponsored study. The NIH study used a year-long interview process with the caregivers to collect data on their experiences. Research about caregivers is crucial because people are increasingly finding themselves in this role. Eighty percent of persons who survive a stroke return to their community and rely on family caregivers for assistance (Anderson, Linto, & Stewart-Wynne, 1995; Grant, Elliot, Weaver, Bartolucci, & Giger, 2002). Caregivers can be thrust into the caregiving role abruptly (Kerr & Smith, 2001), and caregivers experience high levels of burden (Scholte op Reimer, de Haan, Rjinders, Limburg, & van den Bos, 1998). For these reasons, the experiences of caregivers participating in interviews for the purpose of research is significant to nurses and researchers who work with caregivers and persons with stroke.

The phenomena of the lived experience of caregivers participating in a year-long interview process is introduced in this chapter. The conceptual framework and research question are identified. Conceptual and orientational definitions, assumptions, and limitations are included. A discussion of the significance of the study concludes this chapter.
Statement of the Problem

This study examined the lived experience of caregivers who were interviewed bimonthly as part of a year-long NIH research study. These caregivers were interviewed for the purpose of collecting data. Data collection using interviews is fundamental to health research in order to help understand the human response to illness or particular situations (Hutchinson et al., 1994, p. 161). Yet references to the therapeutic effects of interviews are scarce (Kahn, 1994; Shamai, 2003). Further, little research has been published describing the telephone interview process and its impact on the caregiving experience (Salfi, Ploeg, & Black, 2005). While, risks to the participants of research interviews have been the focus of much attention in scientific literature, the benefits of participating in research interviews have generally been limited to the potential for knowledge generation (Hutchinson, et al.). “There has been remarkably little attention given to the meaning of the research interview from the perspective of the interviewee” (Hiller & DiLuzio, 2004, p. 2). The implication for nurses and researchers is to recognize that interviews are not neutral or non-interactive and that it is potentially acceptable for interviewees to derive therapeutic benefits from their participation (Colbourne & Sque, 2005; Gale, 1992; Hiller & DiLuzio, 2004; Hutchinson et al., 1994; Shamai, 2003). Findings regarding the year-long caregiver telephone interview process can have implications for the caregiver population as well as the telephone interview process that go beyond the purposes of the research.

Statement of the Purpose

This study is a descriptive exploration of the lived experience of caregivers who were interviewed bimonthly via the telephone during a year-long NIH research study,
with the goal of uncovering the patterns, features, attributes, and meaning of this lived experience.

Conceptual Framework

Phenomenology was used to conceptualize this study. Phenomenology is considered both a philosophy, or way of thinking, as well as a research method (Burns & Grove, 2005). “Phenomenology is portrayed as the study of essences (Merleau-Ponty, 1964), the study of phenomena (van Manen, 1997) and the exploration of human experience (Polkinghorne, 1989)” (Racher, 2003, p. 62). Speziale and Carpenter (2003) explained that phenomenology says that people can only know their world and selves through their perceptions. This is because humans exist in a world that is always already there (Merleau-Ponty). Phenomenology searches to give a description of lived experience as it is, without causal explanations of why it should be so. Its purpose is to describe the appearance of things as lived experience (Merleau-Ponty). As such, phenomenology is concerned with uncovering “essences” or themes that represent basic units of common understanding about a phenomenon (Speziale & Carpenter). Because nursing practice is enmeshed in life experience, phenomenology is useful for investigating phenomena important to nursing (Speziale & Carpenter).

Research Question

What is the lived experience of caregivers who were interviewed bimonthly via the telephone during a year-long NIH research study?

Conceptual and Orientational Definitions

The following conceptual and orientational definitions were used in this study. Burns & Grove (2005) explained that a “concept” is a term that “abstractly describes and
names an object, phenomenon, or idea” (p. 122). A conceptual definition gives a concept an identity through connotative meaning. This meaning may be abstract, comprehensive, or theoretical. Further, conceptual definitions are established through “concept analysis, derivation, or synthesis” (p. 731). An orientational definition describes the specific way a concept is to be observed in a study (Burns & Grove).

**Lived Experience**

*Conceptual definition.* The perception by an individual of his or her own reality. Experience is “something personally encountered, undergone, or lived through” (Merriam-Webster, 2005). “Relation to the world is a living and nonirreducible impulse that is understandable only as a unified experience” (Munhall & Boyd, 2001, p. 96). This unified experience is unique to the individual and can be viewed and understood as a phenomenon. It gives meaning to and is influenced by everything internal and external to the individual to whom it belongs (Speziale & Carpenter, 2003).

*Orientational definition.* The experiences of the caregivers while participating in the year-long interview process as part of an NIH research study on caregivers of persons with stroke.

**Interview**

*Conceptual definition.* Interviews are an interchange of views between two people on a mutual theme of interest with the purpose of unearthing the meaning of people’s experiences (Kvale, 1996). Interviewing is a method used to elicit high quality data through conversation with a participant (Burns & Grove, 2005). Interviewing as a skill requires development before being used to collect data in a study (Burns & Grove).
**Orientational definition.** A year-long telephone interview process for an NIH research study that took place between an interviewer and a caregiver. These conversations occurred bimonthly, usually between the same interviewer and caregiver, on the topic of caring for someone who has had a stroke.

**Caregivers**

**Conceptual definition.** Caregivers are individuals engaged in “watching over, providing for, and looking after a person or thing” (Orem, 2001, p. 514). According to Orem, when an individual’s therapeutic self-care demand exceeds his or her self-care agency (ability to care for self), a self-care deficit exists. The self-care deficit indicates that a person must have help. Caregivers provide this help. For example, a caregiver is defined as the individual who takes action, on behalf of the person with stroke for whom he or she is providing care, in order to overcome self-care deficit(s). Likewise, since caregivers are persons in their own right, they also have the task of overcoming any of their own self-care deficits (Orem).

**Orientational definition.** The individuals performing activities on behalf of their loved-one with stroke. These individuals were the participants in the interview process for the NIH research study on caregivers of persons with stroke.

**Assumptions**

Assumptions are “statements that are taken for granted or are considered true even though they have not been scientifically tested” and “uncovering them requires introspection” (Burns and Grove, 2005, p. 39). The following assumptions made here related to caregiving are as follows: caregiving is important to the individual being cared-for and to society in general; caregiving is difficult; caregiving requires the caregiver to
develop internal and external resources; caregivers often seek and benefit from help with
development of their dependent-care agencies (ability to provide care for another);
caregiving has economic value; and caregiving requires commitment (Orem, 2001).

Assumptions related to the individuals being cared for are many (not all): require
assistance to meet their self-care requisites; desire to have a caregiver assist them with the
developing their self-care agencies; and experience bouts of self-reluctance and resistance
in developing their self-care agencies. An assumption related to nursing is that
interventions to assist caregivers in the development of their dependent-care agencies are
beneficial to the caregiver, the person for whom the caregiver is providing care, the
economy, and the quality of life in communities (Orem). An assumption related to the
interview process is that people generally want to talk to an interested listener.

Assumptions related to participants in research is that they have undertaken participation
of their own accord, for personal reasons that may or may not be different from the
purpose of the research; they want to present the truth as they perceive it; and that their
participation in this research has impacted them in some way that would not have
occurred if they had not participated (Hiller & DiLuzio, Shamai).

Limitations

Limitations are restrictions that may decrease the transferability of a study’s
findings (Burns & Grove, 2005). One limitation is related to the numerous philosophers
from whom phenomenology derives, such as Heidegger, Husserl, Marcel, and Merleau-
Ponty; all who have different positions, and these positions are very different from those
common in nursing and healthcare (e.g. the scientific method) (Burns & Grove;
Speigelberg, 1972). Second, the in-depth view of the “lived experience” of an individual
in a phenomenological study is only useful to nursing research if it can be transferred to a larger population than a single individual. A third limitation is related to the question of rigor, which is defined for qualitative research as openness, adherence to a philosophical perspective, thoroughness of data, and consideration of all data (Burns & Grove).

Significance

Caregivers are important contributors to the quality of life of their loved ones, as well as to the economy and the community. Research on caregivers is important because of the increasing number of people finding themselves in this role. Because caregivers often are thrust into the role suddenly, many need support and to develop resources in order to provide care. Nursing is professionally poised to provide interventions to assist caregivers in developing their dependent-care agencies in order to make them effective helpers to their loved-ones. Nursing is obligated to look at the phenomenon of caregiving, since nurses frequently work with caregivers in their professional practices. Findings from research on the experiences of caregivers participating in an interview process can have the potential to inform health-care researchers about the therapeutic benefits for participants of research. Nursing can further use this research to develop effective interventions caregivers for evidence-based clinical application.

Summary

The phenomena of the lived experience of caregivers participating in a year-long interview process was introduced in this chapter. The conceptual framework and research question were identified. Conceptual and orientational definitions, assumptions, and limitations were also included. A discussion of the significance of the study concludes the chapter.
CHAPTER II

Literature Review

A discussion of the framework being used to conceptualize this study about the lived experience of caregivers who participated bimonthly in a year-long interview process is provided in this chapter. Additionally, a review of the existing relevant research is presented. A summary ends the chapter.

Conceptual Framework

Phenomenology was used to conceptualize this study (Figure 1). Phenomenology is considered both a philosophy, or way of thinking, as well as a research method (Burns & Grove, 2005). On the concrete level, caregiver and NIH interviewer intersected at the point of the telephone interviews, which were conducted every two weeks during the course of a year. This bimonthly interaction generated a lived experience for the caregiver. On the abstract/conceptual level, phenomenology was employed to examine this lived experience. The phenomenological question, “what is the lived experience of caregivers who participated bimonthly in a year-long interview process?” was used to gather the data for this study via a one-time telephone interview with the caregiver. On the applied level, the findings from the caregivers’ responses were used to garner the themes that were the essences of the caregivers’ lived experience.

Hebert Spiegelberg, considered the historian of the phenomenological movement (Speziale & Carpenter, 2003), defined descriptive phenomenology as “an attempt to intuit, analyze, and describe the data of direct experience in a fresh and systematic manner” (Spiegelberg, 1972, p. xxix). Therefore, “existence can be approached
Figure 1

Study concepts related to phenomenology.
phenomenologically and studied as one phenomenon among others in essential structures” (p. xxix). “Phenomenology is portrayed as the study of essences (Merleau-Ponty, 1964), the study of phenomena (van Manen, 1997) and the exploration of human experience (Polkinghorne, 1989)” (Racher, 2003, p. 62). Speziale and Carpenter explained that phenomenology says people can only know their world and selves through their perceptions. This is because humans exist in a world that is always already there (Merleau-Ponty). Phenomenology searches to give a description of experience as it is. Its purpose is to describe phenomena, or the appearance of things, as lived experience (Merleau-Ponty).

As such, phenomenology is concerned with uncovering “essences” or themes that represent basic units of common understanding about a phenomena, i.e. lived experience (Speziale & Carpenter). “Relation to the world is a living and nonirreducible impulse that is understandable only as a unified experience” (Boyd, 2001, p. 96). Because nursing practice is enmeshed in life experience, phenomenology is well suited to the investigation of phenomena important to nursing (Speziale & Carpenter).

Lowes and Prowse (2001) suggested that excluding researcher preconceptions in phenomenological nursing research in the pursuit of rigor is impractical and not necessary in order to achieve researcher objectivity, as long as researchers fully explain their preconceptions and their contributions to the interview process. Researchers engaged in phenomenology should consider the assumptions of their chosen method of inquiry, consider whether those assumptions are consistent with their own views, ensure the study methods reflect those assumptions, and that they account for those assumptions in the conduct of the research (Lowes & Prowse). Edmund Husserl, one of the prominent
leaders of the phenomenological movement, believed that preconceptions and beliefs of the researcher must be examined, acknowledged, and then put to one side or “bracketed” (Lowes & Prowse). Bracketing is separating out of consciousness what the researcher knows or believes about a topic (Speziale & Carpenter). Bracketing begins the process of recovering original awareness (Boyd).

Although phenomenology is considered a philosophical approach, it is also considered a research method. Speziale and Carpenter explained that Spiegelberg identified a three-step process for descriptive phenomenology: 1) intuiting, 2) analyzing, and 3) describing. ‘Intuiting,’ or uncovering the accurate interpretation of what is meant in the description of the phenomenon being studied (Speziale & Carpenter), requires first dwelling with the data. According to Munhall and Boyd (2001), ‘dwelling with the data’ requires time, commitment to authenticity and to the participants. ‘Analyzing’ requires identifying the essence of the phenomenon and how the data are presented (Speziale & Carpenter). The researcher as “instrument” contemplates, over a period of time, the meaning the participant was trying to convey, and after a certain amount of time has passed, the researcher becomes aware of similarities and differences and writes about them, while holding the individual as the focus for meaning (Munhall & Boyd). This ‘describing’ is communicating, in verbal and written form, the distinct elements of the phenomenon (Speziale & Carpenter). Munhall and Boyd suggested steps to guide the researcher through a phenomenological inquiry. These were: 1) immersion, 2) coming to the phenomenological aim of inquiry, 3) phenomenological contextual processing, 4) analysis of interpretive interaction, 5) writing the phenomenological narrative, 6) writing a narrative on the meaning of the study, and 7) phenomenological contextual processing.
Reading and thinking through each of these steps guides a novice researcher through a beginning understanding of phenomenology in process, and revisiting this guide gives a researcher an opportunity to gauge progress in that understanding.

Review of Literature

A discussion of selected studies about conducting interviews is in the following review of literature. In addition, the experiences of caregivers as well as how telephone contact has been used both to gather data and as an intervention, is also included. The majority of the studies gathered for this literature review are qualitative in nature. An expectation of qualitative studies is that they involve a smaller numbers of subjects who provide a characteristic depth and richness of data not usually visible in quantitative studies. The review of literature is presented here under the headings of interviews, telephone interviews as a method for data collection, and caregivers and caring.

Interviews

“The in-depth, open-ended formal interview is a mainstay of qualitative nursing research” (Robinson, 2000, p. 18). The research interview is “a purposeful data-generating activity, characterized and defined by the particular philosophical position adopted by the researcher” (Lowes & Prowse, 2001, p. 471). Robinson provided a broad template for the interview process consisting of introducing and personalizing, reminiscing and contextualizing, and closing and reciprocating. Introducing and personalizing consists of introductory remarks made by the researcher regarding himself or herself and the study. Reminiscing and contextualizing is allowing respondents time to share life episodes and stories, which may be more or less relevant to the reason for the interview and question(s) asked. Closing and reciprocating consists of tying up loose
ends or matters of business, or answering questions for the respondent as far as the researcher is able, within the limits of his or her researching role. The practical implementation of these ‘phases’ of the interview may result in a broader or narrower definition of each phase consistent with the particular research study (Lowes & Prowse).

“An interview guide consists of general questions or topical outline, and is used early in the encounter to provide structure, particularly for the novice [interviewer]” (Robinson, 2000, p. 18). In a phenomenological study, the question “what is it like?” can begin an interview, leading to a description of the experience (Munhall & Boyd, 2001). Further questions such as “how were you feeling? thinking? and other variations can lead to the meaning of the experience” (Munhall & Boyd, p. 147). The “meaning of things to individuals” (p. 148) is what is being sought through the interview.

When an interviewer helps the interviewee tell his or her story, the process allows individuals to translate their experiences into words (Egan, 2002; Hutchinson et al., 1994). The data from research interviews is often collected into transcribed text. Within these texts are expressions of meaning (Munhall & Boyd, 2001). Throughout the material, the researcher can highlight expressions conveyed as words. These expressions can be “emotions, thoughts, desires, questions, wishes, hopes and complaints” (Munhall & Boyd, p. 150). The research interview is similar to the therapeutic interview as both the researcher and the therapist “listen, demonstrate empathy and respect, seek clarification, and confront the interviewee with new thoughts” (Hiller & DiLuzio, 2004, p. 4). Hiller and DiLuzio present characteristics that distinguish the research interview from normal conversation:
While an interview is a dialogue between individuals, the structure is weighted toward the purpose of listening to the interviewee on a specific topic, and the interviewee understands through the informed consent process that he or she is an informant to the research and does not expect to converse with the interviewer in a normal conversation (p. 5).

The research interviewer must instill trust in the participant, before the participant will feel comfortable revealing information, which is accomplished by conveying a sense of interest and concern for the participant (Speziale & Carpenter, 2003). In a study by Schubert, Mulvey, Lidz, Gardner, and Skeem (2005) that conducted weekly interviews with high-risk participants, it was found that there was internal conflict for the researchers between the role of interviewer and the empathic desire to intervene. “We asked interviewers to walk a fine line, build rapport, and obtain information without offering advice to the participant that might alter the course of events that would occur in his or her life without involvement in the study” (Schubert et al., p. 639). Interviewers had to determine how rigidly they adhered to the research role (Schubert et al.).

Participants in research interviews are likely telling some things, but not all things, or they may think there is a “correct” response to give (Munhall & Boyd, 2001). In a study by Robinson (2000) with the elderly, one of the difficulties was artificial responses caused by a desire to be socially acceptable. “If you ascertain that the participant’s comfort level is being disrupted for any reason at all, you need to attend to it and respect the participant’s wishes at the time” (Munhall & Boyd, p. 153).

Interviews conducted for the purposes of data collection often have therapeutic effects for the participants (Colbourne & Sque, 2005; Gale, 1992; Hutchinson et al.,
Shamai suggested that it was possible for therapeutic effects to emerge when clients reconstructed the experience of medical treatment through qualitative interviews. “Although these therapeutic effects are not planned and do not have clinical or research purposes, their consequences should be taken into consideration from both ethical and research perspectives” (Shamai, p. 465). These therapeutic effects come from three areas, “the content of the interview, the context in which the interview takes place, and the interviewer-interviewee relationship” (p. 455). A variety of benefits for the participants have been associated with research interviews such as catharsis and healing, validation, intellectual stimulation, insight, self-awareness, and empowerment (Hutchinson et al.; Robinson, 2000).

Studies that provided participants a chance to reflect on daily experiences have been shown beneficial. In a phenomenological study that included repeat interviews with nursing home carers discussing videos of themselves caring for dementia clients (Hanesbo & Kihlgren, 2001), improvement was found in carers’ ability to verbalize their reflections, and in their awareness and knowledge about their own influence on quality of care. Over time, the interviews helped the carers’ reflect and gain a better understanding of the motives for their actions (Hanesbo & Kihlgren, 2001).

A qualitative study by Dowswell, Lawler, Forster, and Hearn (1997) interviewed stroke patients about their participation in a study of a nurse-intervention program in which they were contacted multiple times over the course of a year. Two themes were found: 1) the benefits of simple friendliness and 2) knowing someone was interested in them. Participants also appreciated the convenience of using the telephone with the nurse. Although the control group in this study received phone call interviews, they did not
receive the benefits of information, advice, and support as interventions. These were described as unmet needs that caused frustration for the patients (Dowswell et al.).

**Telephone Interviews as a Method for Data Collection**

A study by Goldstein and associates (2002) found that telephone interviews had limited validity because of the high proportion of missing data from the participants who refused to answer one or more questions. In this study, participants were asked to respond to a structured survey of closed-ended questions. This contrasts with several qualitative studies employing telephone interviews using open-ended questions (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; Chang, Nitta, Carter, & Markham, 2004; Grant, et al., 2002; Salfi et al., 2005; Walsh, Estrada, & Hogan, 2004). Open-ended interview formats contained results with a rich depth of data that may not be possible with a structured survey, because structured surveys do not allow for respondents to guide the conversation (Gibson, 1998). “This was supported by respondents who said that they could tell the researcher everything they wished to with unstructured interviewing” (Gibson, p. 476). A survey can pigeonhole individuals, while open-ended questions allow the personal interpretation of a unique reality, resulting in more in-depth data (Gibson).

**Caregivers and Caring**

Researchers generally agreed upon the definition of caregiver. Kerr and Smith (2001) defined a caregiver as “the primary, unwaged person providing physical, social, and/or emotional support” (p. 429). In a study of caregivers for cancer patients, Walsh and associates (2001) defined a caregiver as “someone who had close ties to the patient and was expected to provide care to the patient” (p. 182). Secrest (2000) referred to a
caregiver as the “Primary Support Persons (PSPs) of stroke survivors who help reintegrate the stroke survivor’s life, as well as their own” (p. 93).

Researchers agreed that caregivers of stroke often find themselves thrust into their role unexpectedly and abruptly, without much time to acclimate to their new role and develop caregiving skills (Kerr & Smith, 2001). Walsh et al. (2004) found that they feel resentment. “They never planned or expected to be in the role of caregiver. Suddenly they were faced with new responsibilities and did not feel prepared” (Walsh et al., p. 184).

While most caregivers for persons with stroke are caring for aged persons, they are as likely themselves to be older. In a study about using Internet-based support for rural caregivers, Pierce, Steiner, Govoni, Hicks, Cervantez-Thompson, and Friedemann (2004) found that the study sample of caregivers ranged in age from 51 to 72 and these people were caring for stroke patients age 54 to 87 years of age. Walsh et al. (2004) reported that the caregivers in their study were all over 45 years of age. Secrest (2000) included subjects age 40 to 72 years. While one study included a participant as young as eight (a secondary caregiver in a study by Eaves (2002) about rural African-American caregivers), the majority of participants were older adults receiving or giving care.

Perhaps the most difficult aspect of being a caregiver is the unrelenting nature of caring. Caregivers were functioning in the role 7 days a week, 12 hours a day (Kerr & Smith, 2001).

In a study of male caregivers for women with stroke, Pierce and Steiner (2004) found that, contrary to the myth that men are emotionally detached, the men in this study were enmeshed in the caring experience. They felt that the stroke event brought them, their wives, and their families closer together. Yet, this closeness can become a source of
stress for the caregiver. In a study looking at the difference between stroke patient and
caregiver perceptions of stroke survivor behavior, Williams and Dahl (2002) found that
caregivers perceived stroke survivors as more impaired than the survivors considered
themselves. “Because the caregiver and patient must deal with the sequelae of stroke,
they are, in a sense, both ‘stroke survivors’ and are thus placed into a mutual and
interdependent relationship” (Williams & Dahl, p. 23). Constantly negotiating this new
relationship is a difficult process, which is a common theme in the caregiving literature
(Kerr & Smith, 2001; Williams & Dahl).

In trying to adjust to the new role as a caregiver for a person with stroke,
caregivers frequently had needs for information and education. Kerr and Smith (2001)
found that “carers reported discussing issues and problems and receiving advice from
someone who was viewed as an expert on stroke made a significant difference to them in
the early weeks and months following their relative’s discharge from [the] hospital” (p.
434). Educating themselves about stroke is one way caregivers try to take back control of
a situation that seems quite beyond control, in order to improve their coping abilities
(Pierce & Steiner, 2004).

However, while stroke education has been recommended as a key service after a
stroke event, stroke patients and their caregivers need more than just information for a
nursing intervention to have meaningful impact (Forster, Smith, Young, Knapp, House,
& Wright, 2001). In a 2001 literature search conducted by the Cochrane Stroke Group
Specialised Trials Register, Forster and associates found that the provision of information
alone had no effect on mood, perceived health status or quality of life for patients or
carers. Additionally, a study by Bakas et al. (2002) showed that although caregivers may
indicate a need for information, information provision is not a cure-all, because
caregivers often require help in providing emotional support and managing behavioral
problems of the stroke survivor. They needed help with physical care, help with
instrumental care (i.e. finances, transportation, etc.), and “managing personal responses to
the caregiving situation” (p. 250).

A study by Secrest (2000) focused on the meaning of being a primary support
person (PSP) of a person with stroke. Secrest investigated the complex shifting that takes
place in the new caregiver/stroke patient relationship. Secrest reported that caregivers
experienced a heightened awareness of the fragility of life. “This awareness enhanced
their vigilance, which in turn increased their sense of loss and its concomitant
responsibility… the balance of the relationship shifted and roles changed” (p. 97). Secrest
provided a poignant explanation of how caregiver burden (and exhaustion) developed.
PSPs experienced vigilance as they monitored the stroke survivor. Despite the different
ways in which a PSP implemented the responsibility of vigilance for the stroke patient,
they still felt overburdened. Feelings of vigilance did not seem to decrease over time,
contributing to caregiver burnout (Secrest). Finally, in a qualitative study by Walsh et al.
(2004), common caregiving themes found were “bearing the burden, distressing feelings,
learning to cope, conditional well-being, and feeling abandoned” (p. 183).

Summary

A discussion of phenomenology was provided, as it was used to conceptualize
this study about the lived experience of caregivers who participated bimonthly in a year-
long telephone interview process for an NIH research study. Additionally, a review of the
existing relevant literature was presented. A summary of ended the chapter.
CHAPTER III

Method

The purpose of this qualitative research study was to describe the lived experience of caregivers who participated bimonthly in an interview process during a year-long NIH research study. An explanation of the study design, the method for data collection, selection of participants, and the procedure followed to protect participants’ rights is explained in this chapter. A description of the materials used and the method for data analysis are also included.

Design

A phenomenological research design was chosen for this study in order to gain a better understanding of the lived experience of caregivers who participated in an interview process as part of a larger, year-long NIH study.

Data Collection

Using a one-time telephone interview with an open-ended question format, this study investigated the lived experience of being a participant in a year-long NIH research study with caregivers of persons with stroke. “The purpose of the interview is to understand the worldview of the interviewee on the theme of the research” (Hiller & DiLuzio, 2004, p.6). Interviews are a common data-collection strategy for many qualitative studies and in phenomenological research, data are often gathered via unstructured interviews (Platt, 2002). “Often in an unstructured interview format a grand tour question such as “Tell me about…” is used to begin an interview and specific prompts and probes follow to clarify and expand understanding of the participant’s answer (Norwood, 2000). Further, Norwood explained that the setting for the interview
should be private, free from interruptions, and in as natural a setting as possible, such as the participant’s home. For these reasons, the individual participants were contacted at the telephone numbers that they provided to the larger NIH study, in order for the one-time interview to be a comfortable and private experience. With IRB approval (see Appendix A), a research team member with training and experience in interviewing techniques, interviewed participants once by telephone in order to answer the research question: What is the lived experience of caregivers who were interviewed bimonthly via the telephone during a year-long NIH research study?

To obtain consent, the research team member asked the caregivers over the telephone if they would be willing to speak during a one-time interview about the experience of participating in the year-long NIH study’s telephone interview process. If the caregiver verbally consented to participate, the research team member further arranged a date and time to conduct the one-time interview. However, if the caregiver was prepared to be interviewed at the time of this first telephone call, the research team member continued with the questions in the interview protocol (see Appendix B). Page one, which included the participant’s name, telephone number, and assigned identification (ID) number, was used only to make initial contact with the participant at the time of the interview. It was then separated from the rest of the form and destroyed. Pages two through four contained the ID without further identifying information. On page two it was recorded whether the caregiver was willing to be interviewed, which was kept as a record of consent. On pages three and four of the protocol, the research team member recorded the answers to the questions asked during the interview. These two
pages were given to the graduate nursing student who was responsible for analyzing the data.

During the course of the larger NIH study, these caregivers received telephone calls from an interviewer bimonthly for one year and were asked about their experiences in caregiving. For the purposes of the current study, participants were asked to describe what it was like to have an interviewer telephone them every two weeks over the course of a year. Additional questions, probes, and requests for examples from the participants were used to promote detailed and expanded descriptions of their experiences. Probing by the interviewer invites the participant to be more accurate and precise (Hiller & DiLuzio, 2004).

Participants

In phenomenology, the strategy of the researcher is to be the data collection instrument, gathering individual narratives from the small, intentionally selected sample (Norwood, 2000). Sample size is often small, with as few as “six to ten participants” (p. 47). For the current study, a research team member interviewed subjects from the control group of a larger NIH study with caregivers of persons with stroke. Purposive sampling, which is a conscious selection of subjects by a researcher based on the characteristics they desire supported by rationale for selection (Burns & Grove, 2005), was used in order to obtain the data for the study. Only the control subjects who had never before spoken with the research team member who conducted this one-time interview were selected. This was important to prevent any bias from an interviewer and participant who had extensive contact during the year-long NIH study.
Using purposive sampling, 21 participants met this criteria and 14 agreed to participate. Of the seven who did not participate, two telephones had been disconnected and five subjects were called three times, however, they were never available to talk with the research team member or did not return messages.

The 14 participants met the criteria for inclusion in the larger NIH study:

1. He/she was a caregiver of a person with a new diagnosis of stroke.
2. He/she was a caregiver of a care recipient who had completed in-patient rehabilitation treatment and discharged home.
3. Caregiver was the primary person responsible for providing day-to-day care.
4. Caregiver lived in an urban setting in northern Ohio or southeastern Michigan.
5. Caregiver was able to read, write, and understand English.
6. Caregiver had a telephone.

Further, during the year-long NIH study, the interviewer invited the participant to comment only upon his or her caregiving experiences. The interviewer provided no advice or interventions to the participant. If the participant had questions or problems, referral to his or her primary healthcare provider was suggested.

For the current study, then, the caregiver had completely finished his/her participation in the larger NIH study before the one-time interview.

Protection of Human Subjects

For the current study, the anonymity of the participants was respected and protected, and participation in this one-time interview was on a voluntary basis. The participants were free to refuse or end the interview at any time. An ID number was assigned to the participants’ responses in order to keep their identities anonymous. The graduate nursing
student who analyzed the data had no knowledge of which number was assigned to a participant, or access to the participants’ contact information. Therefore, the graduate nursing student was not able to contact the participants.

Limitations

This work posed no physical risks, however, certain psychological risks can be associated with the research interview. For example, an interviewer’s attempt to understand and clarify details may force participants to deal more directly with what he or she is saying, by admitting or confronting things never before verbalized (Hiller & DiLuzio, 2004). This can be cathartic and a relief for some (Hutchinson et al., 1994) but it can also be uncomfortable. However, Hutchinson et al., found that people who cannot tolerate talking about a topic will not. They will find a way to avoid it, “sometimes by directly refusing, sometimes by not finding a convenient time, sometimes by not appearing for an interview” (Hutchinson et al., p. 161). Participants in this study were free to refuse or end the interview at any time. Since “the interviewer controls the direction, length, and focus of the interview” (Hiller & DiLuzio, p. 20), there is also the potential that an interview will end before a participant is psychologically ready to stop, which could be upsetting. This can be mitigated by an experienced interviewer who is sensitive and has skills in “empathic listening” (Egan, 2002). The research team member conducting the interviews in this study had experience with interviewing caregivers from her involvement in the larger NIH study. She was able to conduct the interviews in a respectful and sensitive way in order to preserve the participants’ psychological integrity. Other risks of participating in research interviews include that they are burdensome and
time-consuming (Hutchinson et al.). Since this interview was a one-time event, usually lasting less than one hour, the burden and time commitment was limited.

A limitation of this study was that the graduate nursing student who analyzed the data was not the same person conducting the telephone interviews with the participants and could not return to the participants for clarification of their responses. However, it was considered a larger benefit to employ the expertise of the research team member since she had been contacting participants in the larger, year-long NIH study and understood the telephone interview process. Finally, it was assumed that the one-time telephone interview for the current study was of sufficient length to allow the participants to express their thoughts and ideas. However, that may not be true.

Materials

Predetermined open-ended questions were used with the participants during the one-time telephone interview for this study. Open-ended questions were appropriate, because they require more than a simple yes or no answer (Egan, 2002). The goal of this approach was to elicit rich, detailed data rather than superficial yes or no answers. The research team member who conducted the one-time interview had the opportunity to contribute input to the interview protocol. She made it clearer by adding an introduction about the graduate nursing student who analyzed the data, as well as an explanation of why the participants were being asked to be interviewed. No additional changes were made to the interview protocol and the final version is displayed in Appendix B.

The interview protocol consisted of four main questions beginning with “Can you describe what it was like being interviewed by telephone every two weeks for the year of the stroke study? Please tell me about that.” Second, the participant was asked “Can you
tell me what it was like for you on a day when you received a call from your interviewer? What were you thinking or feeling?” If the participant was not forthcoming, the interviewer added, “just before the call? / just after the call?” Third, the participant was asked “Can you tell me what it was like for you on a day when you did not receive a call from your interviewer? What were you thinking or feeling?” And last, “Is there anything more that you would like to tell me about your telephone interview experience that we haven’t talked about?” The interviewer also had a list of seven probes from which to choose in order to interject and encourage the participant to continue the conversation, such as “Please tell me more about…” and “Can you give me some examples?” The research team member had the discretion to use prompts like “I see”, “sure”, and other verbal affirmations, as well as any appropriate probes. The goal of prompts and probes was to keep the story going without influencing content (Norwood, 2000).

Data Analysis

Colaizzi’s (1978) method for qualitative analysis was used to allow themes to emerge from the data, with the goal of uncovering patterns, features, attributes, and meaning of this particular lived experience. The analysis of transcribed telephone interviews followed protocols for rigorous data analysis incorporated in Colaizzi’s method. Colaizzi’s steps for data analysis are:

1. Read the entire descriptions to obtain a sense for the whole.
2. Extract significant statements and phrases pertaining directly to the phenomenon, (in this case the experience of caregivers participating in a year-long interview process for the larger NIH study).
3. Formulate meanings from the significant statements and phrases.
4. Cluster meanings into themes.

5. Integrate results into an exhaustive description of the phenomenon.

6. Formulate the exhaustive description into a statement of identification.

The analysis of the transcribed interview data was completed using only the information that was communicated by the participants without allowing the graduate nursing student’s preconceived ideas bias the information. In order to prevent bias associated with preconceived ideas about the caregivers participating in the larger NIH study’s interview process, phenomenological reduction and bracketing were used. In fact, both the research team member who conducted the one-time interview, as well as the graduate nursing student who analyzed the data, used bracketing prior to data collection to identify self-assumptions and set them aside in order to isolate pure phenomena free from preconceived notions. The aim of bracketing was to examine prejudices and commitments on the part of the researchers and “bracket” them out so that the lived experience of the caregivers could be seen as it is and not as reflected through preconceptions (Cohen, 1987; Munhall & Boyd, 2001).

The research team member and the graduate nursing student bracketed the following beliefs: being interviewed about the caregiving experience is therapeutic and beneficial; caregiving is valuable and appreciated by the individual being cared for and society in general; caregiving is difficult, has economic value and requires commitment; and people participating in research genuinely desire to participate with honesty and openness. Bracketing allowed the research team member to conduct the interviews and the graduate nursing student to analyze the caregivers’ responses, without allowing personal beliefs bias the information.
In order to ‘immerse’ herself in the data, the graduate nursing student read all verbatim transcripts of the telephone interview data in their entirety to establish a baseline impression of the whole dialogue. Then the graduate nursing student reread the transcripts and extracted significant statements relating to the participants’ experience of the year-long NIH study’s interview process. By repeatedly reading the transcripts, significant statements were clustered into themes. Throughout the process, differences in coding or categorizing the data were considered until no further new information was gathered from the process. An audit trail was constructed in order to provide transparency such that other individuals could reasonably expect a similar result, if they followed the same process of data collection and analysis.

Summary

The method used in the design of the current study was presented in this chapter. Phenomenology was used to explore themes in order to describe the lived experience of caregivers who participated bimonthly in a year-long interview process for a larger NIH study. This chapter contained the study design and methods, as well as Colaizzi’s (1978) method for data analysis.
CHAPTER IV

Results

The purpose of this qualitative research study was to describe the lived experience of caregivers who participated bimonthly in an interview process during a year-long NIH research study. The participants in this study and the themes along with narrative data from which the themes emerged are described. This chapter ends with a summary.

Sample

The 14 participants (see Table 1) included 3 men (age 58 to 72 years), and 11 women (age 33 to 74 years), who had completed the year-long NIH research study with caregivers of persons with stroke. All three men were of White, non-Hispanic origin and were caring for their wives. Only one man had completed high school. One man worked full-time, while the other men were retired. Eight women in the study were providing care for their husbands, two were providing care for a parent, and one woman was caring for her sister. Most of the women were of White, non-Hispanic origin and were not employed. Four women worked full-time and had completed high school or beyond.

Findings

Five themes emerged from the data related to the lived experience of participating in a year-long interview process for a study with caregivers of persons with stroke. These were: looking forward to talking with someone; feeling helped and connected; being busy caregiving and taking care of business; helping others; and being ambivalent or negative about the interview process. Fictional names were used to protect participants’ privacy.

Theme One: Looking Forward to Talking with Someone

Participants expressed how welcome it was to have someone listen to them, and
Table 1.

*Participants' demographic characteristics (n = 14).*

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<td>21</td>
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<td>12 (high school graduate)</td>
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<td>29</td>
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<td>13-15 (college)</td>
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<tr>
<td>16 (college graduate)</td>
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</tr>
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</table>
that they looked forward to the telephone calls. Glen, a 72-year-old caring for his wife, stated, “When I was having a bad day, I looked forward to the call. When I was at my breaking point, it was something for me to look forward to.” Corrine, a 74-year-old caring for her husband, agreed: “I looked forward to talking to her when she called.” Linda, a 65-year-old full-time teacher caring for her husband, referred to anticipating the calls: “I looked forward to talking to somebody. Sometimes I wished she would call because it was nice having someone to talk to.”

Helen, a 55-year-old caring for her husband, explained what the interviews provided her. “It gave me a sounding board. I didn't have a lot of people to talk to. It is tough to be alone taking care of someone.” The interviewer also became someone on whom Corrine felt she could talk to without burdening friends or family. Corrine stated, “I appreciated someone who wasn’t close to us to talk to. You really don’t want to complain to people you know. She let me talk and I didn’t have to feel bad for it.”

**Theme Two: Feeling Helped and Staying Connected**

The participants in this study knew that they were in the control group, and some felt disappointed about not being placed in the intervention group. However, after the year-long study had ended, they believed that they had derived some benefit from their participation after all. Alice, a 54-year-old caring for her husband, said, “I was skeptical but it helped me get through some tough times. I felt down [on days] I didn’t get calls because they really helped.”

Ellie, a 60-year-old caring for her husband, explained that the interviews were helpful because they gave her a chance to reflect on her experience. They gave her a chance to build an awareness of what she was doing and why she was doing it: “It really
made me think about what was going on. I think it made me more aware of how my husband was doing and what I was really doing. I think it was good for me to do it. It was helpful for me.”

Talking with the interviewer made both Linda and Alice simply feel better. Linda said, “a lot of times I felt better. If I were feeling depressed or frustrated she would talk with me about why and I would feel better.” Alice characterized this benefit as a feeling of relief: “I felt much better. I felt relief after the call.” Linda went on to characterize the main benefit she felt from participating in the interviews as reassurance. “I definitely felt more confident and reassured after talking to her,” Linda said. Noralynn, a 33-year-old caring for her mother, also mentioned reassurance as a benefit of the interviews, going so far as to call the interaction therapeutic. “Looking back on it, it was sometimes nice to verbalize what I was going through with my mom. It was almost therapeutic. She did offer me reassurance.”

Helen, stressed how the interviewers made her feel less alone: “The interviewer helped me understand that I was not alone and there are lots of other people out there who were in the same situation.” This feeling of connection was something that several caregivers mentioned. Alice said, “I liked the phone interview because I felt like it kept me connected to someone and kept me abreast of what was going on. I didn’t feel like I was alone.” Melanie, a 47-year-old caregiver, also felt better because of the sense of connection with those sharing the same experience. “I felt better because she let me know that other people were going through the same thing.”

Corrine expressed a feeling of contact with the interviewer and a sense of loss associated with the end of her participation in the year-long interview process.”I didn’t
mind [the interviews]. It was a contact. In fact, I miss her.” Linda’s one to one interaction with her telephone interviewer generated a sense of friendship for her.

**Theme Three: Being Busy Caregiving and Taking Care of Business**

A number of caregivers focused on their caregiving experience as demanding and hectic, leaving little time to contemplate any effects that the telephone interviews may or may not have had. Noralynn, a full-time graphic designer, recalled, “to be honest she’d call and I’d say ‘has it really been two weeks already?’ I was so busy that I wouldn’t have known if it was one week or three months in between phone calls.” Barbara, a 72-year-old caring for her husband, explained, “Sometimes I forgot about you calling, I just waited until you called and answered your questions the best I could. I was too busy taking care of [my husband] to worry about it. I tried to give you the answers you wanted to hear.” Glen, who was retired from factory work and farming, put it plainly: “I was too occupied with taking care of my wife to give any thought to what day it was or if someone would be calling.”

**Theme Four: Helping Others**

Two of the three male caregivers in this study expressed that one motivation for their participation was altruism. Glen spoke of his participation this way: “It was ok. I took the time to do it. I was busy but I wanted to help get what they needed.” Jack felt that he had been able to make a contribution through his participation in the interviews: “I think I added to the study and it was productive. I like being able to help. Maybe somebody can learn something from the things I dealt with.”
Theme Five: Being Ambivalent or Negative about the Interview Process

Some of the caregivers expressed ambivalence about their participation in the study. Fran, a 59-year-old caring for her mother, said “it was nice when she called, but it really didn’t do anything for me.” Jack, a 70-year-old caring for his wife, said, “I don’t think it made me feel any better or worse about what was going on.” Kathy, a 61-year-old caring for her husband expressed that the interview process had not made any significant impact on her situation: “I didn’t think about the interview. It wasn’t that important.”

Some caregivers who wanted to be in the intervention group, but were selected for the control group instead, expressed that they felt they had missed out on opportunities. Melanie explained her ambivalence: “I did enjoy the study but I had so many questions and I wanted to research things [on the Internet], but I wouldn’t because I said I wouldn’t [go on the Internet while participating in the study].”

Not all the caregivers who participated in the interview process found it beneficial. Barbara stated, “it was different, but not enlightening. Nothing monumental was said.” Irvin, a 58-year-old caring for his wife, also felt he didn’t get anything out of the calls: “I was frustrated over the condition of my wife. I didn’t look forward to the calls and I wouldn’t have cared if nobody called.”

When asked to comment on their experiences, a few caregivers took the opportunity to evaluate it and suggested ways to “improve” the study. Corrine said, “it was too routine because the questions were always the same and you could answer them without being asked. They didn’t make you think about anything else.” Noralynn, expressing her belief that caregivers need support, responded:
We were in the control group. I was a little annoyed by that because we could have really used the help. Mom made good progress. If she hadn’t, I don’t know that I would have stayed in it. People should have been moved out of the control group if they didn’t have a lot of support. Hospitals should have an outreach program to do periodic checks to make sure people have what they need.

Summary

This chapter presented the findings of the phenomenological study on the lived experience of participating in a year-long interview process for an NIH study with caregivers of persons with stroke. Colaizzi’s (1978) method was used to analyze the data. After examination of the interview transcripts, five themes emerged. Significant statements were extracted and presented in order to support each theme.
CHAPTER V

Discussion

The purpose of this qualitative research study was to describe the lived experience of caregivers who participated bimonthly in a year-long interview process for an NIH study with caregivers of persons with stroke, in order to help nurses and researchers develop a greater understanding of the impact of the research telephone interview on the interviewee. In this chapter the findings of this phenomenological study are discussed and linked to Orem’s (2001) self-care deficit nursing theory. Conclusions follow this discussion, along with limitations of the study, implications for nursing, and recommendations for future research.

Findings

Phenomenology

Phenomenology was used to conceptualize this study in which a one-time interview was conducted with 14 caregivers of persons with stroke about their experiences of participating in a year-long interview process for a larger NIH study. Phenomenology is considered a philosophy as well as a research method (Burns & Grove, 2005). Because nursing practice is enmeshed in life experience, phenomenology is well suited to the investigation of phenomena important to nursing (Speziale & Carpenter, 2003). It is “an attempt to intuit, analyze, and describe the data of direct experience in a fresh and systematic manner” (Spiegelberg, 1972, p. xxix).

Phenomenology is also considered a research method which provides a means to explore human experience and derive essences, or themes, of that experience. On the concrete level (Figure 2), caregiver and interviewer intersect at the point of the year-long
Figure 2

*Concepts related to phenomenology and Orem’s (2001) self-care deficit nursing theory.*
telephone interview process for the NIH study. This interaction generated a lived experience for the caregiver. On the abstract/conceptual level, phenomenology as philosophy was employed to examine this lived experience. For the current study, the phenomenological question, “what is the lived experience of caregivers who were interviewed bimonthly via the telephone during a year-long NIH research study” was used to gather the data during the one-time telephone interview between the research team member and each participant. On the applied level, the findings from the participants’ responses were used to garner the themes that were the essences of the caregivers’ lived experience. Colaizzi’s (1978) method was used to analyze the phenomenological data, from which five themes emerged:

Theme one: Looking forward to talking with someone.
Theme Two: Feeling helped and staying connected.
Theme three: Being busy caregiving and taking care of business.
Theme four: Helping others.
Theme five: Being ambivalent or negative about the interview process.

These themes were then envisioned at the conceptual level using Orem’s (2001) self-care deficit nursing theory, in order to reflect further upon this experience within an established nursing theory.

Orem’s (2001) Self-care Deficit Nursing Theory

Orem’s (2001) self-care deficit nursing theory was used in order to reflect upon the themes within the realm of nursing. The self-care deficit nursing theory focuses on self-care ability or agency. Orem defined caregiving as “watching over, providing for, and looking after a person or thing, performed by a responsible individual or group”
Caregiving is performed by a caregiver, or in Orem’s language, a dependent care agent. Dependent care consists of the learned, goal-oriented actions performed by a responsible adult on behalf of another individual who cannot meet his or her therapeutic self-care demands. Therapeutic self-care demands are the actions required for a specific amount of time in order to meet self-care requisites. In this study, caregivers performed these actions on behalf of the person with stroke for whom they provided care.

While dependent care agents are engaged in meeting others’ self-care requisites, at the same time they must meet their own. According to Orem (2001) there are three types of self-care requisites; universal, developmental, and health-deviation. Requisites must be met in order to maintain “life, healthful functioning, continuing personal development and well-being” (p. 523). Universal self-care requisites consist of those for air, food, water, elimination, activity and rest, solitude and social interaction, normalcy, and preventing hazards. Developmental requisites are concerned with specific stages during the human life cycle. Health deviation requisites are those that must be met for a person who is ill or injured in order to return to health. When an individual’s therapeutic self-care demand exceeds his or her self-care agency, a self-care deficit exists (Orem). Orem’s self-care deficit nursing theory provides a means for discussion of caregivers’ experiences in terms of their own self-care agencies (capacity and ability to care for self) and their dependent-care agencies (capacity and ability to provide care for another).

Theme one: Looking forward to talking with someone. The caregivers in the study were asked to comment on their own experiences. Their responses came out of a reflection upon their own conditions and not necessarily the conditions of their loved
ones. Looking forward to talking with someone came from a need to meet Orem’s (2001) universal self-care requisite of a balance between solitude and social interaction. Melanie illustrated this plainly when she said: “they listened and that was what I needed because I couldn’t talk to anyone else.”

While the participants in this study were not receiving the telephone call as an intervention, another study which did use telephone calls as an intervention with caregivers found that caregivers for cancer patients were enthusiastic and looked forward to the calls (Walsh et al., 2004). “This reliance on another person to take the initiative, to offer nonconditional support, to call at the scheduled time with no changes, and to keep the caregiver welfare as the primary focus appeared to be the major advantage felt by caregivers during a time when there was little stability in their lives. Many caregivers said that they began to care for their own health as a result” (p. 186). The discussion of the types of benefits continues under the next theme.

Theme two: Feeling helped and staying connected. The participants met Orem’s (2001) self-care requisite of balance between solitude and social interaction (i.e. staying connected), but this theme goes a bit further to explain why a caregiver wanted to be connected. This is because the sense of connection helped them in some way. Some of the ways the caregivers characterized the help that they felt was relief, reassurance, confidence, therapeutic, a sense of friendship, and knowledge that their condition is one that is shared by many people.

A study by Kerr and Smith (2001) reported that caregivers said “discussing issues and problems and receiving advice from someone viewed as an expert on stroke made a significant difference” (p. 434). In Secrest’s (2000) study, caregivers saw the interview
process of sharing experiences as therapeutic in and of itself. “Both the researcher and the therapist are taught to listen, demonstrate empathy and respect, seek clarification, and confront the other with new thoughts” (Hiller & DiLuzio, 2004, p. 4). The interview process for research has the potential to become like a therapeutic interview because of these shared characteristics. Indeed, the participants’ responses in this study indicated that they, too, felt a therapeutic benefit during their participation.

What comes to mind, then, is how were the caregivers receiving “help” that was not explicitly given? The research interviews were not intended to be therapeutic, they were for data collection purposes only and the interviewer was to remain neutral. The interviews were conducted with the control group who received no intervention. Yet, several caregivers clearly indicated feelings of having been helped. It has been suggested that therapeutic effects can emerge from participation in interviews (Colbourne & Sque, 2005; Gale, 1992; Hutchinson et al., 1994; Shamai, 2003). An interviewer helps an interviewee translate his or her experiences into words (Egan, 2002; Hutchinson et al.). In this regard, the research interview begins to resemble the therapeutic interview, with similar effects on the participants, such as greater self-awareness or venting repressed emotions (Colbourne & Sque). Shamai suggested that therapeutic effects come from three areas, the content of the interview, the context in which the interview takes place, and the interviewer-interviewee relationship. For example, Linda indicated that she had experienced positive interaction in the interviewer-interviewee relationship when she said “we sort of became friends, even though I knew I would never meet her.”

A study by Boter, Rinkel, and de Haan (2004) developed a nurse outreach care program consisting of three telephone calls over the course of six months, and one home-
visit, with 173 stroke patients and their 148 carers. The nurses either used interventions themselves or referred patients to a resource. It was found that of 874 interventions the nurses applied to the patients, the most frequent intervention the nurses chose was "supportive listening," which was used over half the time. The nurses also used supportive listening with caregivers about 50% of the time. This seems to indicate that the act of listening is a potent and frequently used intervention by nurses.

*Theme three: Being busy caregiving and taking care of business.* A number of caregivers focused on how hectic and demanding caregiving is. Consequently, they did not give much thought to the interview process, because they were too inundated with the responsibilities of caregiving, or as Orem (2001) describes, being a dependent-care agent. Kathy said, “I was usually too busy so I didn’t think about [the interview]. I had to get my husband to bed after we hung up.” Some felt more confident than others did with the development of their caregiving skills, or, in Orem’s terms, their dependent-care agencies. For example, Jack said, “I was busy, but I kind of knew what I was doing. I took care of Marie’s dad, and Marie before the stroke, so it wasn’t anything new.”

Caregivers experience high levels of burden (Scholte op Reimer et al., 1998). The nature of caregiving is such that it is easy to burn out. Secrest’s (2000) implications for nursing were replete with suggestions for how nursing’s knowledge of the experience of caregiving can help caregivers as dependent care agents (Orem, 2001) develop stronger dependent-care agency. For example, nurses can help caregivers mitigate the wearying vigilance through discussion and find joy in day-to-day accomplishments (Secrest).

*Theme four: Helping others.* For some participants, the study met a developmental requisite (Orem, 2001) consistent with the adult stage of life. Helping
others often is an outgrowth of a belief in altruism, which, according to Merriam-Webster (2005), is “the belief that acting for the benefit of others is right and good.” Caregivers felt like they could give back to their communities through their participation in the scientific study of their experiences. As Jack said, “I like being able to help. Maybe somebody can learn something from the things I dealt with.” Munhall (1988) wrote that for a participant, being part of research can afford “individuals the opportunities of contributing to society, of being of service and perhaps advancing a cause of their own” (p.155).

**Theme five: Being ambivalent or negative about the interview process.** These responses indicated that these caregivers had needs, or as Orem (2001) described, self-care requisites, that the interview process was not able to meet for them. Jack said “It was ok to talk to somebody… but I don’t think it made me feel any better or worse about what was going on.” For some, the interviews may have been more a burden than a help. For example, Irvin, said “I didn’t look forward to the calls and wouldn’t have care if nobody called.”

Some participants took the opportunity to suggest ways they believed their self-care needs could have been met. For example, Fran indicated she wished she’d been placed in the intervention group instead of the control group “because we could have really used the help.” However, Fran did not specifically indicate what she thought she would have received through participation in the intervention group that would have been of benefit to her. Fran may be describing a phenomenon that would be consistent with the results Salfi et al. (2005) found in a study on caregivers of dementia patients, which
suggested caregivers sometimes use a request for help as a portal to obtain a sense of connectedness and companionship through conversation.

Conclusions

“We all think we know how to ask questions and talk to people… Yet to learn about people we must treat them as people, and they will work with us to help us create accounts of their lives” (Fontana & Frey, 2000, p. 668). The participants in the NIH study with caregivers of persons with stroke experienced the rhythm of bimonthly interviews. This rhythm influenced their time-space relationships as they organized their own reality through making decisions and forming opinions and values about what was transpiring. Through no inherently deliberate effort or evidence of flaws in data collection design, the interview was transformed via participant perception into a new reality in which what the interviewers intended (i.e. the collection of data) became interpreted more meaningfully. This was evidenced by the participant’s themes in this study.

An effective therapist builds good rapport with a client, and this plays a part in eliciting a therapeutic response. This response is potentially independent of the specific type of therapy in which the therapist and individual are engaged. Similarly, the effective interviewer often establishes rapport with the interviewee, which can elicit therapeutic effects independent of the topic being discussed. The therapeutic benefits from participation in an interview process for the purpose of gathering research data should not be overlooked or prevented. Instead, it can be considered a positive byproduct of this particular type of research. While not everyone derives benefits from their participation in interviews for research, many do. In this study, such therapeutic benefits ranged from
having someone to talk to, to feeling helped and connected, to feeling able to make a
collection.

Limitations

A limitation of this study is the inability to obtain true saturation because of the
small sample size of 14 participants. A larger sample may have clarified themes with
common responses found between more than two individuals. Further, the graduate
student was not able to return to the participants to validate their responses with them.
Theoretical limitations were also found in Orem’s (2001) theory as there were no clear
means for conceptualizing the idea of a lived experience.

Implications for Nursing

Nurses can assess and are expected to provide interventions for caregivers in a
manner specifically tailored to the individual. The telephone is a communication tool that
can be utilized. Dowswell and colleagues (1997), in their study about nurse support for
stroke patients and caregivers, found that the accessibility of the nurses by telephone was
appreciated as much as face-to-face visits. As one participant succinctly put it “…It’s
contact – I need the contact” (p. 298). Nurses have “specialized knowledge, experience,
understanding, and credibility, combined with the ability to develop and maintain helpful
relationships, and can guide caregivers and patients through a complex [healthcare]
system, without creating dependency” (Dowswell et al., p. 299).

Therefore, the implication for nursing researchers is to recognize that interviews
for data collection are not neutral or non-interactive and that it is potentially acceptable
for interviewees to derive therapeutic benefits from their participation (Colbourne &
“Why should we [researchers] deny the reality that our research, besides enriching our knowledge about helping procedures, satisfying our egocentric curiosity, and promoting our academic careers, is also contributing to the health and welfare of those people who are helping us reach our goals?” (Shamai, 2003, p. 465).

The implication for nursing practice is to research and apply new interventions based on the research interview process for use with caregivers in order to help them develop their dependent care agencies and succeed in their caregiving role. “As nurses strive to situate themselves in the everyday world of their clients, they are integral in the development and application of new research methods” (Racher, 2003, p. 69).

Interviewing is a potent skill that nurses can employ to elicit therapeutic effects in caregivers. These effects have a wide range and benefit the caregiver and the patient if they result in improved caregiver self-care agency (Orem, 2001) and improved dependent-care agency (Orem). This study showed that the control group of a larger NIH study with caregivers derived a benefit from the simple act of talking with someone. This would imply that nurses can employ a simple telephone interview, without a complicated protocol, as an intervention and still reasonably expect to elicit a therapeutic result in the caregiver.

In short, telephone interviews with open-ended questions are useful in research for gathering data because they allow for an interviewee to elaborate on their responses and provide valuable information the researcher may not have anticipated. The telephone interview is a valuable data collection method that should continue to be utilized. Second, therapeutic results from research interviews are a beneficial byproduct of the process that does not need to be avoided. Third, the caregivers in this study needed to feel connected.
To that end, nurses can refer clients to resources, such as church and community organizations, support groups, family members, friends and neighbors to provide this connection. For example, a caregiver to caregiver support groups would include people that have a better understanding of what it is like to be a caregiver. Fourth, caregivers appreciated the interviewer being responsible for making the call. This suggests there is potential for beneficial nursing interventions in which nurses take the responsibility for making calls to clients. For example, nursing telephone support or counseling lines that include calling out to clients, opposed to the client being responsible for making the telephone call into the nurse, could be applied with busy caregivers. Fifth, the caregiving role is hard work and a nurse can recommend adding respite, sitters, and day-away programs to provide breaks to caregivers. Last, negativity and ambivalence can be symptoms of unmet needs. Astute nurses can assess these symptoms in caregivers in order to better meet their needs.

Recommendations for Further Research

This was a small qualitative study and it could be reproduced to ask larger groups of people, and more diverse samples, about their interview experiences to see if they felt helped during their participation in the interview process. The findings could be used to help design future studies using interviews with caregivers and others, bearing in mind interviews have therapeutic potential. Further, ways to measure the effects of therapeutic interventions could be researched in order to develop better interviewing methods. For example, quantitative methods for evaluating caregiver burden, coping mechanisms, and self-esteem could be implemented before and after interviews to determine their therapeutic effect.
Another topic would be to compare the responses between men and women who participate in research. It is interesting to note that two of the three men in this study said they liked being able to help with the study (altruism), yet none of the women did. It would be interesting to research whether the men derived a sense of self-esteem through their participation that the women did not experience. Another topic that would be interesting to study is how significant is it that the interviewer just listened; they did not judge, offer advice, or request the interviewee take any action.

Moreover, research on the experience of being interviewed can build a body of knowledge that nurses and others can draw upon to develop best practices in the clinical setting. The findings could be used to help develop effective nursing interventions with caregivers, based on the telephone interview process. For example, simply taking time to listen to caregivers may help reduce burnout and improve the caregiver experience, or in Alice’s words, “When I was at my breaking point, it was something for me to look forward to.” Better experiences between caregivers and nurses characterized by feelings of care and concern can potentially improve the caregiving experience. A small action such as giving a caregiver time to answer an open-ended question can provide him or her a sense of being heard.

Summary

Researching interventions that assist caregivers with improving their caregiving experiences to develop their dependent-care agencies, can result in the persons they care for remaining at home with their loved ones. Further, research to develop an effective interview with a caregiver can help a nurse better understand the patient’s needs, and both the nurse and caregiver can benefit from pursing this understanding. The findings of
the study were discussed and related to the literature and Orem’s self-care deficit nursing theory. Limitations of the study were described and implications for nursing practice were clarified. Recommendations for further research were suggested and the chapter ended with a summary.
REFERENCES


Appendix A: Institutional Review Board Approval

Medical University of Ohio at Toledo
INSTITUTIONAL REVIEW BOARD
Department for Human Research Protections
Center for Creative Education Building – Room 0106
3023 Arlington Avenue, Toledo, Ohio 43614-2570
Phone: 419-383-6796  Fax: 419-383-3248
(PWA00007382)

TO: Linda Pierce, Ph.D., R.N.
   MUOT Department of School of Nursing

FROM: Connie Roth-Sautter, Ph.D., R.N., Vice Chair
       MUOT Institutional Review Board

DATE: June 30, 2005


Your amendment (Add Erin Nofziger B.S., Rosalyn Pawlak B.S., R.N., Heidi Havens B.S., R.N., Heidi Pitzen-Oswald B.S., and Kevin Weber and delete Kimberly Drummond and Judy Dawson-Weiss as study personnel; add secondary data analyses to be done by Nofziger, Pawlak, Havens, and Weber; and add an additional phone interview (data collection tool for phone survey included) and analysis of de-identified information from the interview by Pitzen-Oswald) to the above protocol was reviewed and approved by the Vice Chair of the Institutional Review Board. This does not change the previous determination that this research meets the criteria for Consent/Authorization for Use and Disclosure of Protected Health Information to be waived. It was determined that this waiver will not adversely affect the rights or welfare of the participants. This action will be reported to the committee at its meeting on 08/18/2005. Thank you for your notification.


It is the Principal Investigator’s (P.I.’s) responsibility to:

1. Abide by all federal, state, and local laws and regulations; the MUOT federal assurance and institutional policies for human subject research and protection of individually identifiable health information including those related to record keeping and be sure that all members of your research team have completed the required education in these areas.

2. Comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and institutional policy regarding the accounting and tracking of uses and disclosures of protected health information and security of protected health information.

3. Promptly notify the MUOT IRB at (419) 383-6796 of any untoward incidents or unanticipated adverse events that develop in the course of your research. Please complete and submit RGA Form 317 for ALL SUCH REPORTS for this protocol. The Principal Investigator is also responsible for submitting to the MUOT IRB reports of adverse events that occur at other sites conducting this study and for maintaining an up-to-date cumulative table of adverse events (RGA Form 316) and submitting it to the MUOT IRB for each research project. The Principal Investigator is responsible for reporting adverse events to the appropriate federal agencies and the sponsor (when one exists).

4. Report promptly to the MUOT IRB any deviations or violations from the MUOT IRB approved protocol in accordance with the procedures outlined in RGA Form 309. In your report include the protocol number and title, the subject’s initials/specimen identifier (as appropriate) and study I.D. number, date of the event, a brief description of the occurrence and a description of any corrective actions taken. The Principal Investigator is responsible for reporting deviations, violations and participant non-compliance to the appropriate federal agencies and the sponsor (when one exists) in accordance with federal regulations, institutional policy and any other legal agreements with these organizations.

5. Obtain prior MUOT IRB review and approval for changes in study personnel and for any and all changes/new information that may require additional information be provided to participants.

6. Report promptly to the MUOT IRB, sponsor (if this research is sponsored) and all other required federal and state agencies all new information affecting the risk/benefit ratio and obtain prior MUOT IRB approval for any changes in the study documents that may be required by the new information.

7. Obtain prior MUOT IRB review and approval for all modified and/or added incentives going to the P.I., study coordinator, other study personnel, and/or the institution. These incentives may be in the form of money or other
items of value, including, but not limited to, equipment, such as computers, and intangibles, such as frequent flyer miles.

8. **Promptly** notify the MUOT IRB; other required MUOT committees, departments or individuals; the sponsor (if this research is sponsored); and all other required federal and state agencies of all potential conflicts of interest before beginning this research and, during the course of this research, any changes that may affect conflict of interest for any of the study personnel. **Prior MUOT IRB approval** must be obtained for any changes in the study documents that may be required by information related to conflict of interest or any changes in this information during the course of the research.

9. **Promptly** notify the MUOT IRB of any changes in contracts, budgets, grants or other agreements with sponsors, agencies or individuals regarding the conduct of this research **before** initiating these changes. The IRB reserves the right to review these study related documents and changes to them to verify accuracy and consistency with regard to the research protocol in order to protect the rights and welfare of the study subjects. Changes in these documents that have the potential to affect the rights, welfare or willingness of the study subjects to participate in or continue to participate in this research and changes in subject documents (such as informed consent, assent or authorization for use and disclosure of protected health information forms, etc.) that are a result of these changes **must** be reviewed and approved by the MUOT IRB **prior** to being instituted.

**Additional Information:**

- **Other Required Review(s) or Approval(s)**
  Review or approval by the MUOT Institutional Review Board does not take the place of any other review or approval required by the Medical University of Ohio at Toledo, non-MUOT performance sites, the government and/or the study sponsor.

- **Required Procedure to Request Review and Approval for Changes/Updates to MUOT IRB Approved Research:**
  Please complete and submit the Request for Amendment/Changes/Updates (RGA Form 314 found at <http://www.medunohio.edu/research/rga_frms/rga314.doc>) with a copy of all materials relevant to the requested change (including consent/assent/authorization for use and disclosure of protected health information forms if applicable) with the changes underlined. If you are requesting review and approval of consent/assent/authorization for use and disclosure of protected health information forms, please attach a clean copy of the revised forms for the MUOT IRB to stamp. Please remember that all changes and correspondence submitted to the MUOT IRB (regardless if they are generated by a sponsor, the P.I. or requested by the MUOT IRB) must be **in writing, signed and dated by the Principal Investigator**.

- **Federally Mandated Continuing Review:**
  MUOT IRB protocols must be reviewed and reapproved not less than once per year. The Institutional Review Board will try to remind you when reapproval is due. However, it is the responsibility of the Principal Investigator to have his/her own reminder system in place to initiate the re-approval process at least a month prior to the expiration date shown above. Please note that Federal Regulations prohibit the extension of this expiration date. Please see the Application for Continuing Review (RGA Form 319 found at <http://www.medunohio.edu/research/rga_frms/rga319.doc>) for items required for continuing review.

- **Required Final Report Upon Termination of Research:**
  When you decide to stop this research, you are responsible for completing and submitting a Final Report (RGA Form 320 found at <http://www.medunohio.edu/research/rga_frms/rga320.doc>) to the MUOT IRB for review.
Appendix B: Interview Protocol

ID # ______________

THE LIVED EXPERIENCE OF PARTICIPATING BIMONTHLY IN
A YEAR-LONG INTERVIEW PROCESS

[FOR NON-WEB USERS ONLY]

TO BE COMPLETED BY THE INTERVIEWER BEFORE THE CALL:

Caregiver's Study Name ________________________________________

Telephone Number _________________________

* DISCARD THIS PAGE AFTER THE TELEPHONE INTERVIEW
HAS BEEN CONDUCTED AND AN IDENTIFICATION NUMBER
ASSIGNED.
ID # ______________

TELEPHONE INTERVIEW PROTOCOL: ______________

Hello, may I speak to [CAREGIVER STUDY NAME]?  
My name is [INTERVIEWER].  
I'm an interviewer from the MUO study with caregivers of persons with stroke.

We are working with a graduate nursing student, Heidi Pitzen-Osswald, who is interested in how you felt about participating in the interview process for this study. Would you be willing to answer some questions for us? It should only take about 10 minutes of your time.

NO _____ IF NO, THANK THE PERSON AND END THE CALL.

YES _____ IF YES, CONTINUE.

Is this a good time for you to talk with me?

NO _____ IF NO, SET A DATE AND TIME TO TALK WITH CAREGIVER.

What day would be best for you? DATE ___________________

What time? TIME ______________AM or PM

YES _____ IF YES, CONTINUE ON TO THE NEXT PAGE.
1. Can you describe what it was like being interviewed by telephone every two weeks for the year of the stroke study. Please tell me about that.

2. Can you tell me what it was like for you on a day when you received a call from your interviewer? What were you thinking or feeling?

IF NECESSARY ASK:

a. Just before the call?

b. Just after the call?

3. Can you tell me what it was like for you on a day when you did NOT receive a call from your interviewer? What were you thinking or feeling?
4. Is there anything more that you would like to tell me about your telephone interview experience that we haven’t talked about?

Thank you for your time.

Helpful probes to use when appropriate:

1. Can you explain more about that?
2. Can you give me some examples?
3. How did that make you feel?
4. What did you feel when she said that?
5. Please tell me more about..........?
6. When you say ............... what does that mean?
7. What did you think when she said that?
ABSTRACT

Caregivers of persons with stroke participated in a bimonthly interview process for a year-long NIH study. The current study described that lived experience for these caregivers. Phenomenology was used as a conceptual framework and method of data collection. Data were gathered from telephone interviews with 14 participants (n=3 men, n=11 women) from the control group of the NIH study. Most subjects were white Americans, aged 33 to 74 years, caring for their spouses. Using Colaizzi's (1978) method for data analysis allowed the following themes to emerge from the interviews: (a) looking forward to talking with someone; (b) feeling helped and staying connected; (c) being busy caregiving and taking care of business; (d) helping others; and (e) being ambivalent or negative about the interview process. Orem's (2001) self-care deficit nursing theory was used to reflect upon the themes to suggest research and interventions to help caregivers develop their dependent care agencies.