
Article

**Using Phenomenology to Examine the Experiences of Family Caregivers
of Patients with Advanced Head and Neck Cancer:
Reflections of a Novice Researcher**

Jamie L. Penner, RN, BN, BPE
University of Manitoba
Winnipeg, Manitoba, Canada

Susan E. McClement, RN, PhD
University of Manitoba
Manitoba Palliative Care Research Unit CancerCare Manitoba
Winnipeg, Manitoba, Canada

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Abstract

Faced with a number of research methods, astute researchers carefully choose the method of research most appropriate for their inquiry. Even when there is a goodness of fit between the research design selected to conduct the study and the topic of interest, all designs pose challenges for investigators that need to be considered and addressed. This paper represents the reflections of a novice researcher regarding the issues and decisions made in the course of selecting a phenomenological approach to conduct research examining family caregivers' experiences caring for tube feeding-dependent patients with advanced head and neck cancer. As such, the article is aimed at sensitizing other novice investigators about things to consider in selecting a phenomenological perspective to answer their own research questions.

Keywords: phenomenology; reflexivity, qualitative methods, novice researcher

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Introduction

A number of research methods have been developed to answer questions within the realm of nursing and the health sciences. One such approach is that of phenomenology. The many different and sometimes conflicting perspectives within phenomenology can be confusing for investigators who are not well versed in qualitative research methods or are just beginning a career in research. This underscores the importance of researchers' ensuring a good fit between the research design selected to conduct the study and the phenomenon of interest to be examined.

In the following article, we provide some reflections by a novice researcher concerning issues that must be considered in selecting a phenomenological approach to qualitative inquiry. The first author is currently conducting a study examining the area of family caregivers' experiences caring for patients with advanced head and neck cancer that will be used to provide exemplars of these issues. The meanings imbued in being a family caregiver to a loved one with advanced head and neck cancer receiving tube feeding is the phenomenon of interest. The following discussion is not merely a justification for the use of phenomenology. Rather, we are attempting to highlight the considerations that must be brought to bear in selecting a phenomenological perspective to guide one's research. In so doing, other novice researchers will be provided with food for thought as they consider the myriad of approaches available within a qualitative researcher's tool kit and make decisions about the design they will use to guide their work.

The purpose of a phenomenological approach

In a broad sense, the purpose of phenomenology is to describe particular phenomena, or the appearance of things, as lived experience (Speziale & Carpenter, 2007). Lived experiences involve the immediate consciousness of life's events prior to reflection and without interpretation, and are influenced by those things that are internal or external to them. It is the lived experience that gives meaning to each individual's perception of a particular phenomenon and thus presents to the individual what is true or real in his or her life (Giorgi, 1997).

A phenomenological analysis does not aim to explain or discover causes. Instead, its goal is to clarify the meanings of phenomena from lived experiences. As such, phenomenology offers an important shift from a positivist cause-effect focus to one of human subjectivity and discovering the meaning of actions (Giorgi, 2005). Phenomenology practiced within a human science perspective can thus result in valuable knowledge about individuals' experiences.

The selection of a phenomenological approach

Families of individuals with advanced head and neck cancer bear vicarious witness to and are deeply affected by the patient's illness and the side effects of treatments (Baghi et al., 2007). Families play an essential role in the care of patients with cancer (Northouse, 2005) and frequently undertake caregiving responsibilities for their loved ones, including the care of patients discharged from the hospital. Although family caregiving can be rewarding, it is not without stress and anxiety (Payne, Smith, & Dean, 1999). In a comparative study by Vickery, Latchford, Hewison, Bellew, and Feber (2003), partners of patients with head and neck cancer were found to have significantly higher levels of anxiety than the patients themselves ($p = .001$) and showed levels of anxiety that exceeded those of the general population. Stress and anxiety may be caused in part by the new skills and unique knowledge that family caregivers must acquire related to monitoring the ill family member and managing illness related symptoms. These caregiving responsibilities must be carried out while simultaneously responding to emergency care needs, making care decisions, and providing emotional care and support. Accordingly, family members frequently report feeling ill prepared to assume care responsibilities for patients with advanced disease (Ross, MacLean, Cain, Sellick, & Fisher, 2001).

The public health care system emphasizes home-based care in an effort to contain costs. As a result, an increasing number of Canadians, including those with advanced head and neck cancer, are dying at home (Dunbrack, 2005). However, an assumption underlying home care is that informal caregivers will provide the very services that allow the seriously ill and those at the end of life to remain in their homes (Keating, Fast, Frederick, Cranswick, & Perrier, 1999). Moreover, an assumption on the part of governments and policymakers in Canada is that informal caregivers are both willing and able to assume caregiving responsibilities. As such, understanding the role of the informal caregiver and identifying the specific needs of those who provide care to the ill person are essential if health care providers are to be able to support these individuals as they strive to provide quality end-of-life care.

Twenty percent of spouses of patients who receive treatment for head and neck cancer demonstrate clinically significant levels of emotional distress measured by the Hospital Anxiety and Depression Scale (Verdonck-de Leeuw et al., 2007). Emotional distress in spouses is related to the presence of a feeding tube in patients; a passive coping style characterized by pessimism, becoming withdrawn, and the inability to address difficult situations effectively; and a disruption in daily routines as a result of caregiving activities (Verdonck-de Leeuw et al., 2007). Caregiving responsibilities are accompanied by a number of ongoing stressors. To cope with these demands, informal caregivers require psychological support from health care providers (Baghi et al., 2007).

Although these quantitative findings are instructive, however, they do not provide an empirical understanding of the nature or essence of the caregiving experience per se. Given that the ability of the health care team to support family members is contingent on a clear understanding of the experiences of family caregivers, this gap in our clinical knowledge is problematic and warrants further study. A phenomenological approach to inquiry involves a search for the meaning of the caregiving experience for these individuals and thus provides a foundation from which to build an essential understanding of what it is like to be a family caregiver for a patient who has advanced head and neck cancer and is receiving tube feeding.

Applying a phenomenological approach

Perhaps the most explicit challenge in applying a phenomenological approach to examining the experiences of family caregivers of patients with advanced head and cancer receiving tube feeding is determining which method of phenomenology is most appropriate. Phenomenology, which examines subjective human experience, has evolved as a philosophical context for nursing science inquiry and as a research method. However, it is associated with the writings of a number of phenomenologists from various philosophical perspectives. In addition, each of the philosophical traditions also includes a number of methodological interpretations that have been developed to arrive at the essential meaning or general structure of the phenomenon of interest. As a result, research findings generated will depend on which phenomenological approach is used.

In the nursing literature the two main phenomenological frameworks are descriptive (Husserlian) and interpretive (Heideggerian) phenomenology (Lopez & Willis, 2004). Each of these approaches results in knowledge that reflects insights into the meaning of the phenomena under study; however, they differ in their aim. In both the interpretive and descriptive methods, the researcher assumes a readiness to listen to the descriptions of the lived experiences as described by the participants. In the interpretive method, the researcher uses his or her prior knowledge and insights to interpret and uncover hidden meanings with the goal of producing a vivid textual representation of the phenomenon described (Kleiman, 2004). In so doing, interpretive frameworks are used to search out the relationships and meanings that knowledge and context have for each other.

In contrast, in the descriptive method the researcher makes no interpretations. Rather, he or she analyzes the descriptions given by participants and divides them into meaning-laden statements, gathering those meanings that are essential to the construct of the phenomenon being studied. Consequently, the researcher is able to bring to written description the structure of the phenomenon of interest. A descriptive phenomenological approach is used when little is known about an issue and the aim of the study is to make clear and understand the most essential meaning of a phenomenon of interest from the perspective of those directly involved in it (Giorgi, 1997).

In view of the aims underlying each of the major phenomenological approaches, the use of a descriptive phenomenological approach is better suited to examining the experiences of family caregivers of patients with advanced head and neck cancer receiving tube feeding. This approach is especially appropriate considering the paucity of research examining this particular cohort of caregivers and the need for a fundamental understanding of their lived experience. However, it is important to note that there are numerous methodological approaches within descriptive phenomenology that can be used to conduct the study. The methodological guidelines chosen should reflect the descriptive phenomenological approach determined as appropriate for this type of study. Spiegelberg (1975), an American philosopher whose work was largely influenced by Husserl's philosophical perspective of descriptive phenomenology, offered one of many methodological interpretations of this approach. Specifically, he identified three steps for carrying out descriptive phenomenology: (a) intuiting, (b) analyzing, and (c) describing. Therefore, a descriptive phenomenological approach that is informed by both the philosophical views proposed in the phenomenological work of Husserl and the methodological interpretations developed by Spiegelberg would accurately serve to examine the caregiving experiences of family members who have loved ones with advanced head and neck cancer receiving tube feeding.

To gain an in-depth understanding of the philosophy and method specific to a particular phenomenological approach, it is imperative that researchers return to the original work of those

philosophers whose views influenced and shaped it. Examining the philosophical underpinnings of a method prior to its implementation and identifying the procedural interpretation being used will result in research that is clear in its purpose, structure, and findings.

Phenomenological reduction

An element of phenomenology that is important for researchers to consider is that of personal biases. Within interpretive phenomenology the researcher's personal experiences and prejudices are acknowledged as exerting a profound influence on the understanding of phenomena and are thus important to interpretation (Dowling, 2004). As such, the researcher invests personal involvement with the phenomenon of interest, and interpretation pervades every stage of the research process. On the other hand, descriptive phenomenology calls on the fundamental strategy of phenomenological reduction to "reduce" the world from how it is perceived naturally, that is where knowledge is held with judgment, to a world of pure phenomena (Dowling, 2007). Through phenomenological reduction the inherent biases and preconceptions of the researcher are held in abeyance so that they do not influence the object of study (Lopez & Willis, 2004). In so doing, the researcher reduces the world to that of a purely phenomenal realm, and thus the essence of the phenomena is allowed to emerge.

Recognizing that an examination of the experiences of family caregivers of tube feeding-dependent patients with advanced head and neck cancer would best be addressed using a descriptive phenomenological approach, the researcher is challenged with the notion of putting aside any biases and preconceived knowledge to induce a pure description of the family caregivers' experiences. This concept may be especially difficult to exercise for researchers whose clinical expertise lies in the area of head and neck oncology. Aside from personal biases inherent in the human experience, researchers with clinical expertise in head and neck oncology carry with them professional knowledge and presumptions related to caring for these patients that might affect their ability to discover the pure essence or meaning of the caregiving experience for family members. To set aside their preconceptions and presuppositions, investigators must first make them overt and render them as clear as possible. Bracketing is a specific technique proposed by descriptive phenomenologists to achieve this (Dowling, 2007). Gearing (2004) has outlined six distinct types of bracketing and suggested that descriptive bracketing represents the refinement of the technique's earliest Husserlian conceptualization into a more pragmatic form. As such, bracketing involves the researcher's setting aside preconceptions and personal knowledge when listening to and reflecting on the lived experiences of those being studied. Unfortunately, there are few clear guidelines for carrying out bracketing.

Wall, Glenn, Mitchinson, and Poole (2004) have devised a reflective framework to guide the research process and demonstrated how using a reflective diary can be an effective tool for developing bracketing skills. Visual imagery, practicing neutral nonverbal behavior, and honing active listening skills facilitate bracketing in preparation for research. Throughout data collection and analysis the researcher is required to acknowledge and set aside biases during the process and about the process through the use of a reflective diary and conversations with mentors (Wall et al., 2004). As such, bracketing is a continuous process that is used to facilitate the clear emergence of the phenomenon under investigation.

In using a descriptive phenomenological approach to examine the experiences of family caregivers, every effort is made to set aside personal biases and previous clinical knowledge. Preconceptions about the family caregiving experience were documented prior to the onset of the study and will be compared to what was observed and heard in the study. For example, the

assumption that family members are ill prepared to assume care for patients and therefore have specific needs related to their caregiving responsibilities was made explicit. Setting aside biases is facilitated by the use of a reflective diary and open, honest conversations with thesis committee members. In addition, the participants' own words will be used throughout the process of data analysis and phenomenological description. The process of bracketing is ongoing and will be employed throughout the course of the study.

Considerations in data collection

Using purposive sampling, researchers select individuals for study participation based on their particular knowledge of a phenomenon for the purpose of sharing that knowledge (Speziale & Carpenter, 2007). This is an appropriate method to select the participants for a study using a descriptive phenomenological approach because the aim is to understand and describe a particular phenomenon from the perspective of those who have experienced it. Sample sizes of 10 to 15 are adequate provided participants are able to provide rich descriptions of the phenomenon (Speziale & Carpenter, 2007).

To arrive at a description of the meanings permeated in being a family caregiver to a loved one with advanced head and neck cancer receiving tube feeding, purposive sampling is being used to select individuals who have knowledge of such a caregiving experience and are willing and able to share that knowledge. For inclusion in the study, family caregivers must be 18 years of age or older, able to speak, read, and write English, and involved in the care of the patient with advanced head and neck cancer who is receiving tube feeding and must consent to participate in the project. Family caregivers are broadly defined to include those individuals identified by patients who provide patients with unpaid help in relation to their physical care or coping with disease. These individuals are not restricted to biological kin but reflect a more inclusive definition of *family member* as perceived by the patient. Although blood relatives are frequently the main caregivers for patients with advanced disease who are cared for at home (Emanuel et al., 1999), individuals other than biological kin often provide daily care or emotional support to these patients. As such, it is important to look beyond the borders of the nuclear family and define *family members* as those individuals that the patient identifies as important to them (McClement & Woodgate, 1998). To capture a range of caregiving experiences, attempts are being made to recruit both male and female family caregivers.

To gain a more accurate picture of the phenomenon in question, the use of more than one data collection strategy is often used in a phenomenological approach. Collecting data from multiple sources, known as triangulation, provides breadth and depth to a study by ensuring complete and thorough findings (Speziale & Carpenter, 2007). As such, data will be collected from a number of sources to ensure a true description of what it means to be a family caregiver of a loved one with advanced head and neck cancer receiving tube feeding.

In phenomenological research data are commonly collected through face-to-face interviews to gain insights into the experiences of the participants. Open-ended interviews facilitate the collection of rich data by providing the participants with the opportunity to describe their experience fully. A minimal number of broad, data-generating questions are asked to initiate the interview process. Probes are used as needed to clarify the meaning of responses and encourage in-depth descriptions. Face-to-face interviews with family members will be used to explore their caregiving experiences. The interviews will be initiated with a broad, open-ended question aimed at generating responses that describe the experience the participants are having caring for their ill family member. The face-to-face nature of the interview allows for immediate clarification or

expansion of the participants' thoughts and access to nonverbal cues such as gestures and facial expressions (Speziale & Carpenter, 2007).

Although using face-to-face interviews for data collection is beneficial to arrive at detailed descriptions of the participants' experience, it also poses a challenge to researchers exploring the experiences of family caregivers in the complex realm of advanced head and neck cancer. Individuals with these cancers experience a multitude of challenges as they respond to their illness. The specific and considerable needs of these patients are beyond those of most patients diagnosed with other types of cancer because of the functional disability and disfigurement associated with cancer treatments. As such, the experiences and caregiving responsibilities assumed by families of these individuals also have the potential to be multifarious. Because of this inherent complexity, the researcher needs to have astute interviewing skills to respect the caregivers' opportunity to describe their experience while maintaining a focus around a specific phenomenon of interest.

In addition to interviews, data are recorded in the form of field notes and demographic information is collected. The researcher will take brief field notes during the interviews and expand on these notes following the completion of each of the interviews to ensure complete and thorough findings. The context of the interview will be described in the field notes as well as any factors that might have influenced the data collection process. For example, the environment in which the interview takes place, observations regarding the demeanor of the participant, and the dynamics of the interview will be described. Demographic data are also collected to describe the characteristics of the sample. Family caregivers will be asked to fill out a short information sheet at the time of the interview that will reflect their demographic characteristics, the extent of their caregiving involvement, and their prior experience with similar caregiving responsibilities. Patient charts will be reviewed to collect data related to their diagnosis and demographic characteristics. Collecting data from multiple sources will provide breadth and depth to the study findings and facilitate a thorough description of what it means to be a family caregiver of a patient with advanced head and neck cancer receiving tube feeding.

Considerations in data analysis

Generally speaking, in a descriptive phenomenological study the researcher analyzes the descriptions given by participants and divides them into meaning-laden statements. Those meanings that are essential to the construct of the phenomenon being studied are then gathered allowing the researcher to bring to written description the structure of the phenomenon of interest (Giorgi, 1997).

Because of the nature of phenomenological data analysis, researchers who use a descriptive phenomenological approach to examine the experiences of family caregivers of patients with advanced head and neck cancer benefit from immersion in the data collected through face-to-face interviews. Through the interview process, the researcher listens to the participants' descriptions and then repeatedly reviews and studies the data as they were transcribed (Spiegelberg, 1975). In so doing, the researcher begins to know about family caregivers' experiences.

By dwelling with the data, the researcher begins to recognize the emergence of universal essences, or eidetic structures, in relation to the experience of caring for a tube feeding-dependent loved one with advanced head and neck cancer. The researcher is then able to intentionally alter in his or her mind different aspects of the experience by either taking from or adding to the proposed alteration through a process called imaginative variation (Spiegelberg, 1982). This

process allows the researcher to verify whether a particular essence essentially belongs to the caring experience and lends to a representation of the true nature of being a family caregiver.

Finally, the researcher is able to bring to written description the distinct, critical elements of the family caregiving experience in the realm of advanced head and neck cancer (Spiegelberg, 1975). Description involves organizing and describing the critical elements of the family members' experience of providing care for a loved one individually and then within the context of their relationship to one another. As such, a comprehensive description of the experiences can be made.

Strategies for data analysis in studies using a phenomenological approach are dependent on the methodological interpretation chosen within a particular philosophical perspective. There are variations in the procedural approaches that have been developed by various phenomenologists. As such, we emphasize again that researchers should return to the original work of those philosophers whose views were influential in developing the particular phenomenological approach chosen for their study.

Ethical considerations

Employing a phenomenological approach to inquiry also requires attention to ethical considerations. Speaking about the experiences of being a family caregiver to a relative with advanced head and neck cancer might evoke feelings and emotions in participants. Indeed, these individuals might express various emotions overtly during the course of recounting their experiences. This reaction might cause discomfort for researchers or render them uncertain as to how to proceed. In the event that a family member becomes upset during an interview, the investigator should stop the interview, provide emotional support to the person, and pursue psychosocial follow-up as necessary. The participant should be given the option of stopping the interview and rescheduling for another time. Although the emotional aspect of speaking about the experience of being a family caregiver might be challenging to researchers and participants alike, family members are also frequently appreciative of having the opportunity to share their stories, with someone who is genuinely interested in what they have to say. As such, face-to-face interviews within the context of a phenomenological approach facilitate the opportunity for such discourse.

Implications for practice

An explicit benefit of using a phenomenological approach to examine the experience of family caregivers of tube feeding-dependent patients with advanced head and neck cancer is that the experience is captured from the family caregivers' perspective. As a result, clinicians are better able to support family caregivers and deliver interventions that are most meaningful to these individuals. In light of ideologies around patient-centered care, it seems logical that interventions geared toward supporting family caregivers would be free of paternalism and grounded in knowledge emerging from the caregivers themselves.

Currently, the lack of empirical literature related to the experiences of family caregivers of patients with advanced head and neck cancer offers little to clinicians on which to base their support of these individuals. A rigorous, critical, systematic method of a phenomenological approach will yield findings that can provide empirically based guidance to clinicians. Moreover, the knowledge generated by a phenomenological study offers a foundation for future

psychosocial/educational intervention studies involving family caregivers of these patients that will enhance the evidence based knowledge available to clinicians to effectively support these individuals.

Conclusion

A phenomenological approach is well suited to examining the experiences of family caregivers. More specifically, the use of descriptive phenomenology allows the researcher to directly explore and analyze this particular phenomenon to arrive at a description of the lived, or subjective, experiences of the family caregivers (Speziale & Carpenter, 2007). Examining this particular cohort of individuals using a phenomenological perspective has inherent challenges for the researcher, albeit an appropriate methodological fit with explicit benefits. Eliciting a thorough understanding of the method and philosophical underpinnings of phenomenology, as well as gaining an awareness of and addressing its potential challenges and benefits is essential. In so doing, a rigorous process of inquiry will ensue resulting in sound empirical findings that will guide clinicians in supporting family caregivers of patients with advanced head and neck cancer.

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