Humanistic reflections of a research nurse in a longitudinal study: A personal essay

By Michelle Lobchuk

Abstract

The purpose of this paper, first, is to share my 'lived experience' as a research nurse, in a longitudinal survey design study, who followed lung cancer patients and their family caregivers throughout the illness duration. I embraced an overarching 'humanistic' philosophy to 'come to terms' with my intra- and interpersonal reactions arising from my role as a human research tool. These reactions were best captured by Paterson and Zderad's (1976) humanistic concepts of authenticity, vulnerability, relating, disclosure and enclosure, and presence. Second, I will describe how I dealt with these concepts within the context of a research nurse role.

Paterson and Zderad (1976) identified the importance in true humanistic convention of accepting, embracing and articulating our uniquely perceived but commonly shared conditions in nursing practice. Therefore, one goal of this paper is to serve as a means of communicating my 'lived experience' as a research nurse who followed patients and family members in the community as they coped with the diagnosis of lung cancer. Paterson and Zderad conceptualized a theory of humanistic nursing practice that was beneficial in helping me to describe my intra- and interpersonal experiences with research participants. Furthermore, longitudinal designs of scientific inquiry sometimes present fieldworkers with role and relationship dilemmas that require substantial effort and commitment from the entire investigative team. Therefore, I will also offer strategies to deal with dilemmas as a nurse in dual clinical and research roles.

Longitudinal studies are limited in nursing due to the widely acknowledged realities of time, effort and money that serve as deterrents to collecting data from the same group of people at different points in time (LoBiondo-Wood & Haber, 1998). Authors have described methodologies to overcome issues in longitudinal research such as people's reluctance to participate, loss of interest, loss due to address changes, significant family changes, and/or situational stressors such as exacerbation of illness, that arise primarily because of the nature of human subjects (Given, Keilman, Collins & Given, 1990; Ryan & Hayman, 1996; Weinert & Burman, 1996). However, less attention has focused on the intra- and interpersonal effects on the fieldworker of a longitudinal research design that tends to blur two distinct roles of the nurse and the researcher (Clinton, Beck, Radjenovic, Taylor, Westlake & Wilson, 1986; Demi & Warren, 1995; Robinson & Thorne, 1988).

Paterson and Zderad's (1976) humanistic nursing practice theory guided me in my analysis of the role I played and the issues I faced as a research nurse. Humanistic nursing is described as

"nurses [who] consciously and deliberately approach nursing as an existential experience" (Paterson & Zderad, p.3). This means that nurses in their awareness of themselves and others reflect on and describe their lived experiences and what they have come to know in the nursing situation. The nursing situation discussed within this paper stems from a quantitative-survey design study with a protocol of operation that involved home visits occurring at six-week time intervals ($\pm$ two weeks) since time of diagnosis until the patient's death. A total of 826 home visits occurred simultaneously with both the lung cancer patient and his or her family caregiver. As the research nurse, I conducted an average of five visits (range of one to 14 visits) with each patient-family caregiver dyad ($n=157$) prior to the patient's death. A single bereavement visit with the family caregiver occurred three months after the patient's death.

Authenticity

An overarching theme to humanistic nursing practice theory is an "authenticity with the self" that means to allow one's existing mixed, varied, struggling responses, motives and alternatives into self-awareness (Paterson & Zderad, 1976, p.63). Over the course of my mounting exposure to intense family ordeals in dealing with cancer, I found myself experiencing a mixture of automatic, obtrusive and unresolved reactions (e.g., sadness, guilt and uncertainty). However, in the process of keeping personal field notes I allotted myself an appropriate time and space to reflect on the patients' bigger picture, so as not to pass immediate value judgments based on my unyielding experience of emotions. As advocated by McIntyre (1997), personal notes or a diary can allow the interviewer to move "beyond initial reactions" (p.20) that are perhaps biased by one's knowing capacity as a nurse.

Covey (1994) similarly advised that "the more aware we are of our basic paradigms, maps or assumptions, and the extent to which we have been influenced by our experience, the more we can... listen to others and be open to their perceptions, thereby getting a larger picture and a far more objective view" (p.181). Lock and Lella (1986) believed that this reflective process is conducive to the development of empathy and a flexible stance in relationships with patients. Ultimately, 'getting in touch' with our own human responses as fieldworkers serves as an attempt to free ourselves from encumbrances that may pose threats to the study, such as loss of objectivity, burn-out due to ongoing diligent attention to data collection, or over-identification with respondents.

ABRÉGÉ

ESSAI PERSONNEL: RÉFLEXIONS HUMANISTES D'UNE INFIRMIÈRE CHERCHEUSE DANS LE CADRE D'UNE ÉTUDE LONGITUDINALE

En premier lieu, cet article a pour but de décrire l'expérience que j'ai vécue à titre d'infirmière chercheuse qui, dans le cadre d'une étude de conception d'une enquête longitudinale, assurait le suivi de patients atteints du cancer du poumon et de leurs soignants naturels tout au long de la maladie. J'ai épousé une philosophie globalement "humaniste" pour essayer de comprendre mes réactions intra et interpersonnelles liées à mon rôle d'instrument de recherche humain. Ce sont les concepts humanistes d'authenticité, de vulnérabilité, de relation, de communication et de repli, et de présence, présentés par Paterson et Zderad (1976) qui ont rendu le plus fidèlement mes réactions. En second lieu, cet article précise comment j'ai abordé ces concepts dans le contexte de mon rôle d'infirmière chercheuse.

Michelle Lobchuk

Michelle M. Lobchuk, RN, MN, is a full-time student in the University of Manitoba, Faculty of Graduate Studies, Interdisciplinary Doctoral Program. She is also a Research Student of the National Cancer Institute of Canada supported with funds provided by the Canadian Cancer Society.

Vulnerability

Daniel (1998) described "vulnerability" as an inherent human trait that is key to authenticity in the nurse-patient relationship. Dictionary meanings of vulnerability describe it as the state of being susceptible or "able to be physically or emotionally hurt" or "easily influenced or tempted" (Gilmour et al., 1995). However, vulnerability has the connotation of a human inclination to avoid such a state. Thus, there is a risk to not being authentic with ourselves (listening to our inner negative and positive desires) when we choose to avoid serving as a witness to others' suffering or recognizing others' vulnerability as we see it in ourselves (Daniel). The ability to maintain the integrity of a longitudinal study is also jeopardized if research nurses deny themselves the opportunity to participate in mutual vulnerability. For example, the interviewer may decrease efforts at encouraging ongoing participation or may restrict attempts to recruit participants.

In patients' homes, I believed myself to be a privileged but somewhat captive witness to strangers' accounts of intimate feelings and fears (Lobchuk, 1995). At times, patients and family members directed negativity towards me. I represented a health care system that had failed them in their perception, because it would not promise a cure or was slow in diagnosing the cancer. I often could not escape the feelings of guilt I had as a result of being a catalyst for the eruption of participants' raw expressions of distress. For some participants, questionnaire items stimulated them to reveal feelings beyond the study requirements that may have exceeded their perceived level of comfortable disclosure. Subsequently, I could never really predict whether they would be willing to continue their participation in the study.

Data collectors need opportunities to discuss the feelings and emotions arising from their own vulnerability. They also need supervisors to assess if they are disillusioned by the study because disillusionment can affect interaction with and recruitment of participants (Moriarty & Cotroneo, 1993). A key action for me was to consult with trusted and sympathetic colleagues who were willing to witness my release of emotional tension, reassure me in my actions, and validate my perspectives. Regular bimonthly debriefing sessions with the principal investigator - who encouraged me to voice my frustrations, clarify the research protocol, and validate decisions - were valuable in relieving recurrent conflicts I had between meeting the needs of the research protocol and those of the participants.

Relating

"Relating" or an ability to empathize with others is an important part of humanistic nursing (Paterson & Zderad, 1976). These authors described how, in nursing events, there are numerous possibilities for distinct types and degrees of relationships. Positivistic methodology espouses a one-way relation between the human subject (or patient) who can be objectified or understood intellectually and the transcendent researcher (or research nurse or nurse scientist) who is distanced somewhat from the immediate patient situation. This objective stance is valued as a means of assisting the research nurse or nurse scientist in analyzing and reflecting on the phenomenon in focus (Paterson & Zderad). However a climate of reciprocal openness decreases the distance between, in particular, the nurse interviewer and the participant, and fosters the development of empathic relations especially during peak life events, such as death and dying (Paterson & Zderad; Ramos, 1989).

With the duality of research and clinical roles, I experienced an undeniable tension between the need for objectivity in data collection and my inherent urge to relate, understand, and reveal my subjectivity over the course of developing a long-term relationship with the participants. Paterson and Zderad (1976) might interpret this experience as an unfolding of my new empathic relation with participants that involved a "turning to the other, offering the other authentic presence, allowing the authentic presence of the other with the self, and maintaining one's capacity to question" (p.49). These authors argued that the objective scientific relationship and the intersubjective

transactional reality of conducting longitudinal research in the real world of human subjects are not conflicting, but intrinsic to the nurse's way of knowing the world. Furthermore, while empathic relationships may pose certain risks to the subjective-objective distance required in traditional scientific inquiry, they are essential in fostering continued informant participation in longitudinal studies.

Another part of "relating" is strategic self-presentation to establish our identity as nurses in our respective research roles (Kasch, 1985). Although identifying myself as a nurse afforded me some advantages in terms of access to and credibility in the field, I was put at a certain disadvantage by "the social role that participants expect of a nurse in the research context" (Robinson & Thorne, 1988, p.67). One issue arising from the public's misconception of the nurse in the research role is the potential for the nurse interviewer, because of a specialized knowledge and a professional/personal ethical stance, to alter the course of life events if he or she intervenes, thereby impacting the study's validity (Ramos, 1989; Speedling, 1983).

A type of pseudotherapeutic relationship may develop in which the research nurse may be perceived as a friend or therapist. Repeated contacts with participants increase the research nurse's sense of responsibility for participants' welfare. Subsequently, the nurse may experience difficulty and frustration in adhering to research protocols that were established to reduce interviewer bias and promote non-intervention (Clinton et al., 1986; Glazer, 1982). However, the lay public is generally unaware of the distinction between the clinical and research roles of the nurse. In addition, there is a lack of understanding that the research protocol may restrict the nurse's involvement with participants (Clinton et al., 1986).

Ramos (1989) suggested that the interviewer ought to emphasize the boundaries of his or her research role at every opportunity. However, if the research nurse is asked to change the behaviour of participants, Speedling (1983) advised that the research nurse remain sympathetic but neutral. When questions arose about the care patients received, I often referred families to available resources, rather than actively intervening. Additionally, I advised them to take a primary role in addressing their concerns with their health care team.

Lofland and Lofland (1995) advised that in situations where interviewers experience some conflict over participants' expectations of them, then they should keep in contact with principal investigators and colleagues who can discern, place in context, and weigh the problem to determine what compromises are reasonable without jeopardizing the study. Although directives were not developed for myself as the research nurse, Clinton et al. (1986) suggested that at the onset of time-series studies guidelines can be established to direct the fieldworker in deciding how and when to intervene on the participants' behalf.

A final note touches on the issue of equitable *quid pro quo* or 'trade-offs' that arises when participants ask the question, "What do I get in return for helping you in this study?" I believe that we tend to downplay or even underestimate the importance of such events to people. However, trade-off events, such as agreeing to drive participants to medical appointments, can appeal to a research nurse's ethical and altruistic sense of being (Lofland & Lofland, 1995). In my experience, ephemeral trade-offs or less concrete assistance were more common, such as making the time to 'truly listen' to a person talk about something she or he wants to talk about. This was likely a rare opportunity for the patient and the family caregiver, as 'cancer' is still synonymous with death and arouses a level of fear in others and avoidance of the patient and his or her family (Berrenberg, 1989).

Disclosure and enclosure

Both the research nurse and participants have the capacity to "disclose" or openly share and "enclose" or hold back information (Paterson & Zderad, 1976). In field research, the participants are on their home turf. The balance of power is shifted more favourably towards the participant who now has considerable autonomy to make choices about disclosure and enclosure (Ramos, 1989). However, the

research nurse does have some freedom to limit or guide the responses of participants to research questions. One disadvantage in playing the "conversation cop", or one who keeps tangential participants within reasonable limits of the timeframe allotted for the home visit, is that this role demands considerable patience and energy from the research nurse.

Even though I expected a certain degree of openness from the participants, I, on the other hand, felt myself 'holding back'. I was hesitant to share more of myself. Yet, where should the research nurse draw the line of professionalism? How much should one disclose of oneself when one hopes to develop an open and trusting relationship with a patient? Depending on the level of trust and comfort I developed with the family, I relied on my intuition to give in to a willingness to share more of myself. The more generous patients and family caregivers were in their candid attitudes of disclosure, the more of myself I tended to disclose. However, fostering reciprocal openness and rapport with virtual strangers (without feeling threatened oneself as the interviewer) requires a certain maturity and skill. The interviewer's own life journey in having served as a witness to others' suffering in both private and professional realms must provide that maturity and skill.

Presence

A final aspect of humanistic nursing is the concept of presence (Paterson & Zderad, 1976). In order to understand the meaning of presence, I compared my present research role with my previous clinical experience in the hospital setting.

Despite my physical presence at the patient's bedside in the hospital setting, there was no guarantee of my genuine relatedness to the patient as a living presence rather than as an object. As a general duty registered nurse in the hospital setting, I believed that it was more important for me to do than to be there for the patient. This belief arose from my socialization as a nurse in a hospital environment where rules, protocols, time constraints, and even the

attitudes of fellow workers served as powerful influences on my attitude towards patients.

I now appreciate that genuine presence holds a certain spontaneity that is not characterized by routinized tasks and selective communication or hearing of patients. Although physical care wasn't a part of my research role, I found that my genuine presence with participants was relayed through the simple but primary act of unhurried listening. In turn, this act communicated that I, as a frequent visitor, would be receptive and available to them. By respecting the participants' need to expand on or clarify their forced-choice answers to survey questions, I believe the study benefitted in several ways. First, the quality, accuracy, and completeness of responses collected were enhanced because of the increased likelihood of having established a trusting relationship (Given et al., 1990). Second, field notes on details arising from participants' storytelling may serve as a valid source of clarification when principal investigators interpret participants' responses.

Conclusion

The purpose of this paper was to make more explicit the challenges that confront the humanistic nurse practising in the role of the fieldworker in longitudinal scientific inquiry. Guided by Paterson and Zderad's (1976) theory of humanistic nursing practice, I raised major issues concerning the impact of the humanity, personality, ethical stance, and emotion of the research nurse on study validity. This paper illustrates that confronting one's prejudices, feelings and assumptions can serve to safeguard a study from the nature of a human research tool who can influence a study's outcomes, e.g., response rates and retention effects. It is hoped that investigators and fieldworkers will be sensitized to not overlooking human issues. Instead, they must take steps to strengthen study designs that are dependent on the interaction between the personal-humanistic characteristics of the fieldworker and the product of longitudinal endeavours.

References

- Berrenberg, J.L. (1989). Attitudes towards cancer as a function of experience with the disease: A test of three models. **Psychology and Health**, 3, 233-243.
- Clinton, J., Beck, R., Radjenovic, D., Taylor, L., Westlake, S., Wilson, S.E. (1986). Time-series designs in clinical nursing research: Human issues. **Nursing Research**, 35(3), 188-191.
- Covey, S.R. (1994). **Daily reflections for highly effective people: Living the 7 habits of highly effective people everyday**. NY: Simon & Schuster.
- Daniel, L.E. (1998). Vulnerability as a key to authenticity. **Image: Journal of Nursing Scholarship**, 30(2), 191-192.
- Demi, A.S., Warren, N.A. (1995). Issues in conducting research with vulnerable families. **Western Journal of Nursing Research**, 17(2), 188-202.
- Gilmour, L., et al. (1995). **Collins concise dictionary and thesaurus**. (2nd ed.). Glasgow, Great Britain: HarperCollins.
- Given, B.A., Keilman, L.J., Collins, C., Given, C.W. (1990). Strategies to minimize attrition in longitudinal studies. **Nursing Research**, 39(3), 184-186.
- Glazer, M. (1982). The threat of the stranger: Vulnerability, reciprocity, and fieldwork. In J.E. Sieber (Ed.), **The ethics of social research: Fieldwork, regulation and publication** (pp. 49-70). New York: Springer-Verlag.
- Kasch, C.R. (1985). Toward a theory of nursing action: Skills and competence in nurse-patient interaction. **Nursing Research**, 35(4), 226-230.
- Lobchuk, M.M. (1995). A lived dialogue with myself, the nurse. **Pflege**, 2, 120-126.
- LoBiondo-Wood, G., Haber, J. (1998). **Nursing research: Methods, critical appraisal and utilization**. (4th Ed.). Chicago: Mosby.
- Lock, M., Lella, J. (1986). Reforming medical education: Towards a broadening of attitude. In S. McHugh & T.M. Vallis (Eds.), **Illness behavior: A multidisciplinary model** (pp.47-58). New York: Plenus Press.
- Lofland, J., Lofland, L.H. (1995). **Analyzing social settings: A guide to qualitative observation and analysis**. Belmont, CA: Wadsworth Publishing.
- McIntyre, M.R. (1997). Understanding living with dying. **The Canadian Nurse**, 93(1), 19-25.
- Moriarty, H.J., Cotroneo, M. (1993). Sampling issues and family research: Recruitment and sampling strategies. In S.B. Feetham, J.M. Meister, G.L. Bell & G.L. Gilliss (Eds.), **The nursing of families: Theory, research, education, practice** (pp. 79-89). Newbury Park, CA: Sage.
- Paterson, J.G., Zderad, L.T. (1976). **Humanistic nursing**. New York: John Wiley & Sons.
- Ramos, M.C. (1989). Some ethical implications of qualitative research. **Research in Nursing & Health**, 12, 57-63.
- Robinson, C.A., Thorne, S.E. (1988). Dilemmas of ethics and validity in qualitative nursing research. **The Canadian Journal of Nursing Research**, 20(1), 65-76.
- Ryan, E.A., Hayman, L.L. (1996). The role of the family coordinator in longitudinal research: Strategies to recruit and retain families. **Journal of Family Nursing**, 2(3), 325-335.
- Speedling, E.J. (1983). Fieldwork in clinical and home settings. **Journal of Psychosocial Oncology**, 1(3), 73-81.
- Weinert, C., Burman, M. (1996). Nurturing longitudinal samples. **Western Journal of Nursing Research**, 18(3), 360-364.