Article

Insider Research with Family Members Who Have a Member Living with Rare Cancer

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Abstract
In this article the author explores insider research in relation to family members facing a diagnosis of rare cancer, using her experiences as one such family member undertaking doctoral research into journeys similar to hers. The "insider" issue is explored through three realms: the ethical realm, including issues of "fitness" to undertake the research; the methodological realm, including how data are obtained and used; and the trustworthiness realm, including research rigor. The exploration of her insider experiences includes personal challenges in relation to facing familiar emotionally charged experiences, insights gained as a result of her insider status, and her ability to join with participants in ways that might not be possible for an outsider. In the paper the author challenges taken-for-granted assumptions that trustworthiness can be assured only from the position of "objective" researcher. Rather, this analysis places knowledge gained through the processes and products of research as constituted and contextualized.

Keywords: insider research, research ethics, cancer, social work, qualitative methods

Introduction

In this article I will explore issues raised throughout my insider journey over the years of my doctoral research. In the paper I will first provide an overview of journey into the research that gave rise to consideration of these concerns. I will then give an overview a range of issues relating to insider research and the challenges that the "insider"/"outsider" dichotomy raise. Then I will explore three realms of inquiry that were central to my research journey: ethical issues relating to insider research, methodological issues, and the rigor and trustworthiness of the research.

In my doctoral research I used an insider lens, and this article is contextualized with my experience of rare cancer in my family, which led to my researching family members' experiences of the early stages of rare cancer of an adult loved one. Methodologically, my research is based on van Manen's (1990) hermeneutic phenomenology, seated within an interpretive theoretical frame. Using in-depth semistructured interviews and member checks, I analyzed data using NVivo software as a "sorting chamber" for the data. Thematic analysis was undertaken, from which three central issues emerged around which family members' experience can be understood: expertise and knowledge, being responsibilized yet remaining invisible, and trust amid uncertainty. The focus of this paper is to outline my thinking about my insiderness throughout this research.

My journey

The journey into my research began as an intensely personal experience. When my husband was diagnosed with a rare cancer, the life of our small family changed. Medical concerns were appropriately center stage, yet there was confusion, uncertainty, and a feeling of being swept along in a bewildering round of medical consultations and treatments. The time it took to diagnose the cancer, the understandable prioritizing of the medical, nevertheless meaning that all things personal were relegated to low status, and my frustrated attempts to see social workers all framed this experience. As a professional social worker with more than 20 years' experience, I reflected on the family's interaction with the medical system from a personal perspective previously foreign to me. It became important for me to understand how others experienced their journeys. Researching this area, then, meant interrogating and acknowledging my experience as potentially both informing and intrusive to the research outcomes.

My research

In light of my experiences, I wanted to further understand the phenomenon of the lived experience of family members going through the early days of a rare cancer. My overall research question was thus framed broadly in an attempt to capture a range of possibilities: What are the meaning, structure, and essence of the lived experience of a family member during the early stages of rare cancer in an adult loved one? Recruitment was through "opt-in" approaches using advertising in various Cancer Council publications. Potential participants would contact me, we would discuss their eligibility for the research, and then I would send information sheets and consent forms. Follow-up contact would lead to setting a time for the first research discussion.

Eighteen participants were initially recruited for the study. However, one participant's family member died after the initial interview during the data-gathering months, and on request of the participant, these data were not included in this research. Of the remaining 17 participants, there

were 9 men and 8 women, with ages ranging from 25 to 58 years. The participants were from 14 separate families in New South Wales and southern Queensland in Australia, representing 14 patients with 13 different rare cancers. Three families contributed 2 participants each; 2 families had each parent, and 1 family had 2 adult offspring.

The insider/outsider dichotomy

We can no longer assume that any research is without bias. Gone are the days when quantitative research based on "scientific" method with hypothesis testing, controlling for variables, and statistical analysis was the sole path to understanding social reality. Qualitative research into lived experience defies precise measurement, and claims to universal truth are just that: claims. Although we cannot ignore the influence of positivist notions traditionally emphasizing objectivity in research endeavors (see Brewer, 2003; Gilbert, 2001), within interpretive theoretical and methodological perspectives and qualitative method we are seeking a form of clarity about social phenomena that can be complex and messy.

Concerns linger, however, regarding the level of interpretation that is acceptable within research. In qualitative research there can be an assumption of objectivity, even if this takes the form of a barely noticeable nod toward the scientific method and related truth claims. This nod often brings with it assumptions of distance between the researcher and the researched as the best way to see clearly that which is being researched. Questions remain as to what truth actually is, how to go about finding it, and indeed whether truth is something reasonably sought in the first place.

Therefore, it was with some trepidation that I began my doctoral research; my position as someone who had experienced that on which my research was based made me at first wonder about the potential integrity of my research. Exploring my feelings, attitudes, and knowledges so that they not unduly impinge on the research has been vital to ensuring that my research was oriented toward the experiences of participants. The last thing I wanted my research to be was a mere reflection of my journey.

I take the position that all research is, at least in part, a product of human thought and meaning-making, including that of the researcher. In this article I declare and explore my personal interest in the area I have researched while outlining how the research process adheres to rigorous measures consistent with good practice in qualitative research. I do so by the use of a critical framework that links the personal and the political (Fook, 2002; Mullaly, 2007; Payne, 1997) through using a hermeneutical phenomenological methodological approach (van Manen, 1990) to the inquiry that allows interrogation of the meaning of lived experience. In my PhD research I sought to arrive at a form of negotiated text (Fontana & Frey, 2000) that reflects a mutual understanding of the research conversation between the participants and that has a resonance with the reader.

A note on form: Although I am uncomfortable with the dichotomy created between insider and outsider research, as these are commonly used to describe such concepts, I will continue their use in this article.

The literature refers to four main ways a researcher becomes an insider. A researcher can be described as an insider when she or he has

1. experienced that which is being researched (Farnsworth, 1996),
2. experienced that which is being researched and has a personal relationship with many of the participants (Sherry, 2002),

3.   been part of the community being researched (Bolak, 1995), or
4.   worked with the population under study (Bland 1987; Coglan 2000, cited in Sherry, 2002).

The first position above is relevant to my research. My insider status is similar to that of Farnsworth, who researched what it was like to suffer the death of a child, something she had previously experienced. Although there are considerable differences between Farnsworth's experience and mine, I, like Farnsworth, sought to understand what it might be like generally to experience that which I have specifically experienced. To the research process I brought my own emotions, thoughts, memories, and residual feelings: my assumptions about what it is like to have a loved one diagnosed with a rare cancer.

To more carefully review the insider issues involved in my research, I will use three realms to illustrate my thinking about my position as an insider researcher:

1.   the ethical realm: issues of my fitness to undertake the research,
2.   the methodological realm: how I obtain and use the data, and
3.   the trustworthiness realm: the issue of rigor.

Insider ethics: Am I fit to undertake this research?

The label *insider* implies two mutually exclusive types of researcher, insider and outsider. Such essentialist categories engender simplistic consideration of those who have, versus those who have not, had the experience of a rare cancer in the family. The dichotomy might have arisen due to perceived (and no doubt also experienced) exploitation of minority groups when being researched by those outside those groups (Zinn, 1979), where the outsider is believed to have no right to explain something involving that of which she is not a part (see Rose, 1978). One position holds that the insider is the only one endowed with special insight that cannot be accessed by others; the other holds that knowledge not prejudiced by experience can be accessed only by those who have not had the experience (Merton, 1972, cited in Zinn, 1979).

There can be a tendency to equate outsiderness with "objectivity" and insiderness with a lesser methodological breed in which "truth" becomes the first casualty. How on earth could I ethically continue my research in that case as surely no reasonable information could arise as it would inevitably be tainted with my subjectivity? Life, however, is not that tidy. I am seated as an insider within this research in terms of my experience, but my other personal contexts such as gender, relationships, socioeconomic status, education, race, culture, age, and religious conviction give rise to the complexity of my human existence.

Given this complexity, it is quite possible that I am at once an insider and an outsider, never having had the exact experience of any other. My social work practice over more than two decades has been based on notions of the client being the expert in their situation, and touchstones that exist between us are places where we can briefly meet and share a moment. They do not mean our identities are subsumed one into the other. We remain as others.

The ethical issue becomes one of negotiating this otherness (Thapar-Bjorkert, 1999), where the category of other is not fixed in whether I have had the same experience as my participants, but is negotiable and continuously negotiated. What might be considered by some to be my primary position in relation to the research, my insider status, might be considered by others as less important than my gender or my profession, for example. Who, then, defines what insider is and how it relates to the other? Is there a most important other? Are there degrees of otherness?

To negotiate this delicate terrain, it was ethically important for me to declare my experience at the outset of the research, so the advertisements, letters of invitation, and information sheets for the research all declared that I had a family member with a rare cancer. These documents smoothly negotiated both university and Cancer Council ethics approvals processes. How this knowledge might influence decisions made about opting into the research and subsequent discussions could not be known at that point. In any case, prior to participants' making contact with me and signing the consent forms, they all knew that I had some prior experience of the research question, but just what that meant to each participant would most likely vary.

Essentially what is being discussed here is the notion of understanding and recognizing difference in the research process. Our common experience of rare cancer in our families does provide a basis for understanding that outsiders may not have: those touchstones I mentioned a moment ago. However, we are not united in the totality of our experience by a single identifying characteristic. Rather, I accept that there exists the possibility of a "plurality of experiences" (Tuana, 1993, cited in Olesen, 2000, p. 228) of the family members facing rare cancer. Respecting the difference in others' experiences has been one of the drivers of this research for me as I seek to more fully understand and articulate the nature of the broad experience. The meaning of insider and outsider status thus becomes blurred, shifting according to context and interpretation of both researcher and participants.

Acknowledging the possibility of a multiplicity of positions (Bolak, 1995) leads to appreciating the uniqueness of each individual. Each person, researcher and participant, becomes product and producer of his or her unique place in and experience of the world. No one can fully know the other, no matter what experience we might have in common. We are all outsiders in some senses when we enter the research relationship. I am aware that there might be some important touchstones between me and each participant, but those touchstones cannot be predicted, and they can change with each encounter.

That there exist such touchstones does mean that there can be advantages in having experienced that which we research. As an insider I could use personal reflexivity (Farnsworth, 1996) that could help me to engage more meaningfully with participants. There also exists tacit knowledge (Lincoln & Guba, 1985) through a personal experience that allows researcher to interpret verbal and nonverbal signs throughout the research process. A subjective voice can also capture "information and insight" (Berg, 1998, p. 216) about the research that otherwise might be lost. Having some knowledge about the phenomenon in question, then, might enable deeper understanding of that which is being researched (Gadamer, 1975) and therefore, dare I say, be a requirement of qualitative research (Minichiello, Aroni, Timewell, & Alexander, 1995).

I believe that engagement with my participants was made more meaningful as once they knew of my own situation, participants often told me they felt a connection and would on occasion ask if I experienced the same. They would look knowingly at me at certain points in the conversations when I was able to paraphrase and interpret what they were saying in such a way as to make it clear to them that I really understood. Those "aha" moments were really quite special. Tears would come to their eyes; a pause and a look would illustrate clearly that I actually gotten what they were trying to say. This spurred some to tell me something they had never told anyone before. At times they would say, "I know you will understand when I say . . ." Even long after the data collection stage was finished, when I was letting the participants know of my themes and findings, some would ask about my partner. Connections had truly been made.

Ethically, as an insider, am I fit to undertake this research? Yes, no more and no less than others.

The methodological realm:
The how and what of gathering and using data

One noted methodological advantage of insider research is in gaining access to an otherwise difficult-to-reach, closed, or guarded population (Mitchell, 1998; Sherry, 2002; Zinn, 1979). Some research was with people previously known to me through groups (Sherry, 2002) or the workplace. Access can become methodologically quite easy when the researcher is a member of specific population. I was an insider in terms of my experience, but I did not know the participants, so the issue of access was not determined by my insider status.

Collection and interpretation of the data can be affected by the insider/outsider status of the researcher. Had the participants in my research been interviewed and the data been analyzed by someone who knew the participants personally, the data and their interpretation might have varied from mine. Had someone who had not had a similar experience undertaken the research, the research product might also have differed from mine. The research conversations might have varied due to the researcher's interests and knowledge, resulting in difference in the nature of data collected. We cannot prove any of this, however, as research becomes an interpretive and negotiated process between researcher, participants, and the data. Understanding might require us as researchers to engage our bias, to identify it, and to work with it to enhance the research (Schwandt, 2000).

Neither being an insider, nor simply acknowledging my position, however, excused me from adhering to high standards of research practice. To do so would have meant abdicating my responsibilities to the participants and the phenomenon of family member experience of rare cancer, and would have resulted in methodologically unsound practices. Such research standards include examining what Gadamer (1975) termed prejudices or preunderstandings, those assumptions, knowledges, and biases that we bring to the research. This is achieved through a reflexive approach to the research, where the researcher examines her or his social identity and values as they affect interpretation of the data (Vernon, 1997). Seated as it is within a discussion on insider research, however, I must declare that dealing with preunderstandings is a task for all researchers in all research. It is not just an issue for insider researchers; nor is it just an issue only within qualitative research. If any researcher fails in her or his duty to recognize and deal with preunderstandings, then we risk a research product that is little more than that which we "understood" in the first place (Nystrom & Dahlberg, 2001).

For the purposes of this methodological discussion, I use Nystrom and Dahlberg's (2001) threefold interpretation of Gadamer's (1975) preunderstandings while adding a fourth dimension of my own. In my research I needed to become self-aware, investigate the nature of my preunderstandings, remain open to the phenomenon, and deal with my story and emotional responses during the research.

Becoming self-aware

Self-awareness for Gadamer (1975) relates to an ability to recognize what it is in our history that affects how we think about the issue prior to the research. In other words, we need to consider our "history of effect," or preunderstanding, to truly be self-aware. This meant I needed to delve into my experience of my partner's diagnosis of a rare cancer, to bring this experience to a level of consciousness that I might not otherwise have had. I did this in several ways: I presented a paper at an international psychooncology congress using my experience as a case study, I talked of my experience with small regional cancer support groups, I presented a formal speech to a NSW Cancer Council Daffodil Day service, and I published an article of my experience in a peer-

reviewed journal. In myriad other ways in the normal course of life, I thought about, talked about, and reflected on my experience with my family, friends, and acquaintances. These activities were vehicles I used to further explore and more fully understand what my experience was and how it has shaped my assumptions.

Investigating the nature of my preunderstandings

Next we need to know a little about these assumptions. With an awareness of our history we can look to what it is we think, assume, or believe about the phenomenon. My experience led me to think that rare cancers were filled with more uncertainty than common cancers in terms of diagnosis, treatment options, and prognosis; I believed that rare cancers can take longer to diagnose correctly, thus potentially leading to worse prognoses. My experience was that family members were not considered by health authorities to be emotionally affected by the diagnosis. These experiences were documented in the papers and talks mentioned above. In effect, we are bringing into the forefront of consciousness those things that might have stayed hidden.

Remaining open to the phenomenon

I needed to remain open to other possibilities, however. The methodological question becomes, How does a researcher remain or become open? We begin philosophically, with an awareness that our experience and preunderstandings are but one part of the broader phenomenon. My experience, for instance, questioned the support provided to family members in the early stages, but remaining open meant not making these assumptions for others.

We acknowledge our experience while recognizing that our experience is seated within a larger context; throughout the research process we "toggle" between the two realms, being simultaneously aware of both. This allowed me to see the possible as well as the actual in relation to my research (Kemmis & McTaggart, 2000). Just because I was not offered support through the health system in those early days does not mean that others were ignored, too.

How to remain open is the methodological question here. I am not comfortable with Husserl's (1970) concept of bracketing simply because to totally suspend preunderstandings seems a harsh and impossible task for any researcher. I prefer the Gadamerian (1975) approach of questioning, recognizing that my experience is, like all other experience I was privileged to hear, unique. My research questions were framed with both my specific experience and the possibilities for the general experience simultaneously in mind. Unfortunately, however, each of the participants in my research had a similar experience of not having been offered support for themselves throughout the early uncertain, confusing days of the rare cancer.

The participants' stories were all different from mine in some respects, however. One or two family members related a speedy diagnosis, for instance. My experience, valid as it is, did not prevent me from being open to alternative experiences of rare cancer in a family member, or, in van Manen's (1990) terms, always trying to be oriented toward the phenomenon under study rather than to my issues. I was also encouraged to maintain a balance by Cohen, Kahn, and Steeves's (2000) call that "the goal of the hermeneutic phenomenological researcher is to be able to report things as they appear to be as encountered in the field . . . rather than as the researcher would have them be" (p. 86). Methodologically, continually identifying my responses as I gathered the information allowed me to remain open to other possibilities.

Journaling allowed me to identify any changes or challenges for me throughout the process to the range of issues, feelings, assumptions, and preunderstandings I brought to the research process in

the first instance. In comparing my journal notes with themes developed during the data analysis phase, I could maintain my orientation to the larger phenomenon.

Dealing with my own story and emotional responses during the research

My fourth dimension extends Nystrom and Dahlberg's (2001) interpretation of Gadamer (1975), and relates to needing to deal with our own stories and emotional responses during the research. Rejecting positivist claims to there being one truth, the outcome of hermeneutic phenomenological research is inevitably a subjective, negotiated interpretation of the point-in-time descriptions of the participants. To achieve this, I needed to be a "real" person acknowledging the relationships created through the research process. I provided each participant with research information that included declaring I, too, was a family member of someone with a rare cancer. I therefore had to be emotionally ready and present for the inevitable questions about my experience.

What should I do when questioned? Traditional research techniques would have me somehow dodge the questions participants might ask me, consistent with the view that to give information might tarnish the validity of the data I receive (Oakley, 1981). However, I believe that objectivity is an illusory goal of in-depth qualitative research (Penn, 2001), that it is absurd to perceive a research conversation being one-way (Daly, 1992; Oakley, 1981), and that had I not engaged with participants' questions on my experience, they might not have been as forthcoming with their stories. I could do no more than sit reasonably comfortably with participants' need to hear some of my story as the research relationship developed with each participant.

It was not all easy, though. I found myself, depending on what was happening in my family at the time, feeling more or less emotional when questions were asked of me. At some times I was also able to identify more fully with feelings such as anger or sadness expressed by participants than at other times. On reflection, this seemed to depend on the touchstones with my experience over time. When participants were closer to my age, with children of their own, again my responses were tinged with a different level of detail when the questions came as I reflected on my children's lives before and after their father's diagnosis. Unique relationships were formed with each and every participant, all of it tiring, most of it fulfilling. Regarding what do to with these feelings and emotions, perhaps my professional background as a social worker helped me through that mire.

It was important for me to not simply state my experience but to bring the focus back to the participant and ask how it was for them, clearly declaring my belief in their unique journey. Our journeys are equally real while not the same.

The trustworthiness realm:
The issue of rigor

Berg (1998) asserted that an insider position is unique. Although I agree, I would not go as far as Rose (1978), who suggested that insiders, because of their special position in relation to the experience, do not have to be research methodologists. I believe that insider status merely adds one more dimension to the researcher's position in relation to the research and cannot be considered as a substitute for methodological rigor as it is no more and no less morally superior to the outsider. But what is rigor in qualitative research? I like to think of it not so much in terms of reliability and validity but more in terms of research trustworthiness: Is the analysis a reasonable reflection of the phenomenon as presented by the data?

It has been claimed that an insider status means the researcher must be more conscious than others in issues of rigor (Daly, 1992; Sherry, 2002). Daly believes that for the insider research, there are inherent dangers in subjectively distorting the data due to the unique way in which the insider relates to the data. This would mean the data are no longer trustworthy, leaving the reader unsure as to which voice was being represented in the research findings. I find this argument unsatisfying, particularly in light of historical accounts of research undertaken by outsiders in issues of gender and race, subsequently being accused of misunderstanding and bias by the outsider researcher (Oakley, 1981; Zinn, 1979).

As a researcher I needed to be true to research trustworthiness criteria; of that there is no doubt or argument. However, there is little evidence (indeed little research) to support a claim of an inherent increase in bias of the insider as long as the accepted practices of methodological rigor for all research are undertaken. One such practice was member checks, going back to the participants to ask them whether I had interpreted their stories and developed themes in ways that were comfortable and real for them. Checking for negative cases that run counter to what appears to be the general theme is also a test for trustworthiness. Reflecting on those different experiences challenges us to think more clearly about our story. My insider status perhaps meant my being clearer and more careful about articulating how I attended to elements of the trustworthiness criteria than outsider researchers may be. I would like to hope that all researchers are in fact particular about attending to research trustworthiness criteria.

Conclusion

Qualitative research acknowledges the researcher's role in the development of knowledge (Grbich, 1999). Indeed, in accordance with both van Manen's phenomenology and a critical realist position, "no one can step out of their conceptual world and see if reality 'really exists' or what it 'essentially is,' free of conceptual prejudging" (Danermark, Ekstrom, Jakobsen, & Karlsson, 2002, p. 18). In this article I have explored potential issues in insider research through three conceptual realms: fitness to undertake the research, methodological concerns, and notions of trustworthiness of the research. In directly confronting traditional requirements of objectivity in research, it has been demonstrated that good quality research is not reliant on a distant researcher. Indeed, it is claimed that some understanding of the phenomenon under question can enhance research outcomes. Researchers can be oriented "to the object of study in *a unique and personal way"* (van Manen, 1990, p. 20, emphasis in original) by embracing their experiences to interact with the participants' experiences and the research data. In this way, they can lay claim to the results of research, as it is seated within cultural, historical, personal, social, and professional contexts in which it is developed, as being both worthy and trustworthy.

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