

*Article*

## **Divining for Water: Considerations for Methodology**

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### **Abstract**

The authors explore the steps between conceptualizing a qualitative study based on Charmaz's definition of grounded theory and carrying it out in the field. We reflect on how the reality of the vulnerable population to be studied (individuals living with a condition that involves neurological decline) required us to shift our original conceptualization, not only of the research question but of the recruitment and interview process as well. Other factors such as organizational gatekeeping, clinical procedures, university regulations as well as recruitment strategies are discussed. The authors reflect on the study of persons who are living with chronic conditions and end-of-life realities for whom research is not considered a priority. We discuss the sequential steps that had been envisioned for the study and the real - world conditions that required revisions to conduct the study. Recommendations emerge that will assist students and researchers alike when studying a similar vulnerable population.

**Keywords:** neurological decline, MMSE, end-of-life, grounded theory, recruitment, interviewing

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## **Introduction**

In this paper we will elucidate how a research process evolved by describing the initial study design and then highlighting how the design had to be reconsidered and then altered with regard to recruitment processes and interview structure. The study in question was designed to explore communication between individuals with a terminal medical neurological condition (in the example of Alzheimer's, Huntington's, Parkinson's disease, or multiple sclerosis), a key support person, and paid health care providers. Little research was found on this topic, yet clinicians verify how important more information on this topic could be for their practice. Engaging in the "real world" of recruitment and data collection can lead to essential revisions to the original design when problems begin to emerge. As a diviner does when seeking water with a rod, in this paper we aim to describe the sometimes magical yet ultimately outcome-oriented process that occurs in research; namely, finding a core category through the tender process of recruiting and interviewing vulnerable populations.

## **Background**

Alzheimer's disease (AD) is a term commonly used to encompass a range of conditions marked by irreversible cognitive decline at end of life, often including changes in personality, mood, and behavior (Alzheimer's Society of Canada, 2008). Currently 1 in 13 Canadians over age 65, and 1 in 3 over age 85, have Alzheimer's or a related disease (Alzheimer's Society of Canada, 2008). Second, Huntington's disease (HD) is a genetic neurological disorder resulting from an affected gene passed on from one parent to a child. Approximately 1 in every 10,000 Canadians has HD, but one in every 1,000 is affected by it (Huntington Society of Canada, 2008). The age of onset for this disease is most commonly between 30 and 55 years of age. The degeneration caused by HD leads to impaired cognitive functioning, emotional disturbances, and altered motor movements (National Institute of Neurological Disorders and Stroke, 2008). Currently there are no treatments to slow the progression or cure this disease. Third, Parkinson's disease is commonly diagnosed in individuals over the age of 50, with its prevalence affecting approximately 3% of the Canadian population over the age of 65 (Public Health Agency of Canada, 2000). The cardinal symptoms of Parkinson's disease include resting tremor, cogwheel rigidity, bradykinesia/akinesia, and postural reflex impairment (Michigan Parkinson Foundation, 2003). Parkinson's disease carries similarities to both Alzheimer's and Huntington disease as all three conditions are chronic neurodegenerative and progressive in nature (Alzheimer's Society of Canada, 2008; National Institute of Neurological Disorders and Stroke, 2008; Public Health Agency of Canada, 2000). Finally, multiple sclerosis (MS) is a complex and incurable disease of the central nervous system. MS is most often diagnosed in young adults although it is seen in children as well. The disease process damages the protective myelin sheath of the nervous system, and in its most common form, there are periods of active disease followed by periods of partial, remission or complete recovery. The course of the disease is unpredictable, and can affect hearing, balance, vision, cognitive function, and mobility (Multiple Sclerosis Society of Canada, 2009). MS is more common in countries that are farther away from the equator, so, not surprisingly, Canada has one of the highest rates of MS in the world with 55,000 to 75,000 Canadians being affected. Prevalence rates across the country range from 1 in 500 to 1 in 1000 people (Multiple Sclerosis Society of Canada, 2009).

Each of the selected conditions involves neurological deterioration, each frequently includes depression, and each has no cure (National Institute of Neurological Disorders and Stroke, 2008). Another commonality is that individuals diagnosed with these progressive neurological diseases require individualized support and care, not only to maintain their health but also to maintain their sense of self-sufficiency and their overall sense of well-being over many years. Furthermore, any

one of the conditions can include memory loss and/or dementia. In this vein, memory loss as a possible experience is important because authors such as St. John and Montgomery (2002) have documented that memory loss not only can affect one's ability to share in reminiscence with others but can lead to social isolation and threats to self.

Given that each of these conditions can include memory loss, it is important to briefly address why we chose not to clinically assess for memory impairment as eligibility criteria for participation in the research reported here. Competency or mental capacity is commonly assessed for research (and clinical) purposes utilizing the Mini Mental Status Evaluation (MMSE) or the short MMSE (SMMSE) (Molloy, 1999). Yet, caution in the use of these tools is warranted as education level, culture, language ability, and familiarity of this tool influence the ability of one to be accurately assessed (Molloy, Darzins, & Strang, 1999). Furthermore, no widely accepted standardized instruments exist for competency assessment for the purposes of research (Marson, Schmitt, Ingram, & Harrell, 1994). In the course of doing qualitative research with a focus on social aspects of a condition, most researchers will agree that knowing an MMSE score is not always helpful in determining whether a person can participate in an interview process. Because many ethics review boards still use this score as a gold standard for inclusion criteria for research purposes, it is important to recognize that the inclusion criteria in this study did not require this score.

Developing a better understanding of the person in question, rather than just paying attention to the diagnostic score, is becoming more common as managers and health care practitioners work to develop effective care strategies for this population. This suits a qualitative methodology in particular. Kitwood's (1997) seminal work explores the concept of personhood. He suggested that it is essential to look beyond a diagnosis of dementia to see the whole person, including his or her history and personality. Various key features of personhood have been described by Coker (1998) and include wholeness, contentment, self-worth, self-esteem, purposefulness, peacefulness, and spirituality. Social being, interaction, and relationships are constructs in which the essence of personhood is established and maintained (O'Connor et al., 2007). Keady, a scientist internationally renowned for his research with people with dementia, has suggested that the task of communicating with individuals with a neurological condition is one in which we must develop the capacity for people to be seen as contributors to these relationships, where we learn to accommodate various communication styles for the purpose of engaging these individuals in the communication process (Keady, 2005; Keady, Gilliard, Evers, & Milton, 1999).

Wilkinson (2002), in asking people with dementia about their role in research, has stated that people with dementia have not felt that they have valuable experiences worth sharing and they have not wanted to come forward and disclose their experiences of this condition. Roger (2006, 2007), similarly, has documented that people with dementia can provide useful insights into their experience as research participants. Work by Medved and Brockmeier (2008) found that individuals with brain disorders maintain self-continuity amid the chaos in their lives. Utilizing narratives provides evidence for participants' experience of memory loss, but also important is that evidence exists for their psychological and psychosocial well-being despite memory losses.

Finally, because the selected conditions have some significant social similarities, they are often linked in the development and provision of community services, the expertise required regarding treatment and health care, and the concerns that arise when communicating about and making decisions regarding an individual's daily care and as they approach the end of life. Stigma and increasing social isolation occur for any one of these individuals even though we often see the

same individuals living a long time in the community. The objective of this study was to better understand social aspects of the experience of a population that has received little attention in social science research.

### **Methods design**

Given the need for empirical work in this area, the research team intended to create an exploratory design based on the tenets of grounded theory. Grounded theory allows for the investigation of interactions between people, how they understand those interactions, and the context and history within which those relationships occur. It is a method whereby data collection, analysis, and theory stand in reciprocal relationship with each other (Strauss & Corbin, 1990). Thus, this method allows for a systematic and ongoing analysis of the data as it is being collected, and its intention is to lead to the development of theory. In this study, narrative approaches to data analysis also complemented the primary framework selected for data collection of grounded theory: The dynamics of communication, the description of social influence, and how language is used play an important role in our understanding and analysis of the phenomenon of interest.

Initially we designed the pilot study to involve up to 30 participants and aimed for equal representation of individuals in triads: individuals with a diagnosis ( $n = 10$ ); key support persons ( $n = 10$ ); and, physicians and health care providers ( $n = 10$ ). Our decisions were based on the criteria of Denzin and Lincoln (2005), who suggested that 10 participants are necessary to achieve theoretical saturation. The researchers involved in this study recruited individuals living in larger cities from a specific Canadian prairie province through two primary methods: (a) a recruitment notice for newsletters was created describing the study, and these were placed in established and well-known settings and in newspapers likely to recruit desirable participants; and (b) members of the research team gave oral presentations of the study in suitable professional and community-based meetings. Existing affiliations existed with the Alzheimer's Society, the Parkinson's Society, and the local Huntington's Resource Centre, as well as senior centers, other health care centers, and local hospitals, and these affiliations were instrumental in the success of the recruitment process. Notices provided a contact number, and individuals interested in participating in the study called the research assistant and asked questions about the study.

Front-line staff persons in the designated organizations were central in assisting the research team in determining which potential participants fit the eligibility criteria set out in our protocol, based on their professional expertise and experience with particular individuals. The definition of a key support person was quite broad, including family members, common-law partners, neighbors who provide significant frequent care, or another relative doing the same. Both the individual and their support person received an honorarium if they participated. In the original study design conceptualization, we asked the individual with a diagnosis to select a significant health care provider, including possibly a physician, nurse, social worker, or other health provider primarily involved in their care. All participants must have engaged in communications regarding health care involving a person with one of the selected conditions (AD, HD, PD or MS) in the previous 6 months.

The recruitment process resulted in an ongoing need to be flexible as we learned to match our real-world situations. Throughout the recruitment and then the interviewing phase, we were aware that we had recruited high-functioning individuals. When asked to produce a key support person to fulfill the triad, one person with HD did eventually decline participation because she did not like the idea of another person she knew talking about her. The researcher was well-known and trusted in this woman's community, and this had facilitated recruitment. A significant amount of

time had gone into addressing her concerns over a number of phone calls. In the end, it became apparent that anxiety and concern about what others might say about her could not be calmed, and she resigned from eventual participation in this study.

There were a few other participants who similarly contacted the recruiter but did not proceed to the interview process. Although they were never interviewed, these “missing” participants provided interesting information regarding what might motivate individuals to participate in the research process and about the fit between the participant and the research method. The experience reminded us that as researchers we must remain cognizant of how our participants are referred to us and if this process might cause individuals to feel pressure to participate. We later interviewed one health care provider of those living with Huntington’s who informed us at that time that the research questions would have been too difficult for some participants to answer because their disease process significantly affected their abstract reasoning skills, and in some cases we surmised that the diagnosis was still too new to discuss openly. We also knew from previous studies that interviews were possible and the study was important to do. During the time taken to apply for and then successfully receive funding, prepare an ethics protocol, and then recruit, which can be a year, some potential participants might have experienced significant decline.

Another reality of the recruitment phase was that those who seemed to have profound grief and loneliness (e.g., they would not have a key support person to identify for the study), or those who let us know that there were very grave conflicts in their family lives eventually declined participation. This was not our initial intent but became a reality of the study. In one case, we were informed by a key staff person in an organization that her community-based people would be more willing to participate in medical research on a “cure” than our study on social aspects of the condition, in part, because too many researchers had come by, and they were now streamlining research participation. Recruitment for research studies might be easier for those that promise hope for a cure rather than reality of decline. Care providers also acted as gatekeepers when a too many researchers had been conducting studies.

Such concerns and gatekeeping required us to reconsider the initial eligibility criteria that we had laid out in our funding proposal. We had originally intended to specifically study participants who were living independently in the community with some cognitive limitations to see how families and professionals communicated with them. Based on our now increasingly limited sample, we proceeded to expand our sample criteria to other neurological conditions that might not specifically include cognitive decline. Thus, we began to recruit people with multiple sclerosis, stroke, and frontotemporal dementia, all of which include neurological decline and no cure. In the end, none of the participants appeared to have noticeable memory impairments or reported an MMSE score (diagnostic score for memory limitations).

Another change to our terminology occurred in discussion with participants. Initially we had used the term *family support* for the ethics protocol with reference to the key support people. Given further consideration, this was revised to *key support person*, which was considered to be more inclusive of persons who might not be blood relatives but could be ex-spouses, friends and siblings, family, and neighbors. However, even the allocation of the term *key support person* was limited, as one participant stated: She was a “wife” first and had many years of history with her husband, who now had Parkinson’s. She was not just a “care provider” or a “key support person.” She stated that she made care decisions in the context of her marriage, and the narratives highlight this reality. The concept that communication about health care is unidirectional in these care relationships proved to be false, so finding a term that did not indicate a one-way care path and that reflected this mutuality became a challenge.

One of the initial questions that arose as we began to recruit for triads was the question of having “real” triads, where each person to be interviewed knew the others. We had discussed this with a number of other health care researchers who said they also were trying to recruit real triads for their research, and although it was challenging, they were able to recruit. However, this became a challenge for us regarding the professionals who either did not know the individuals we were interviewing or had privacy restrictions regarding discussing their cases for the purposes of research. The issue of professional privacy had not been queried by the ethics review board at the university level, so our design of the original triad did not reflect this reality. We decided to recruit professionals who worked with the specified populations but might not have worked with the actual individuals or couples we were interviewing. This resulted in excellent data from the professional group of participants, but it did not result in our initial “real” triads.

We had at least eight sites representing each neurological condition through which we would recruit. Our first announcement for recruitment went out through the Parkinson’s newsletter, and an influx of calls resulted in our first five eligible participants having Parkinson’s. These interviews were conducted immediately. Because newsletters for other organizations went out at intervals suitable to those organizations, and this sometimes meant a month or two later, our timelines for the study had to be revisited by the time new potential participants from new groups called us into Month 3. This changed the distribution in favor of participants with Parkinson’s. We also realized that we did not have enough participants responding to our recruitment who were living with Alzheimer’s, and although we had not considered people with MS in our initial criteria, we did end up expanding the study to be able to recruit from that population in a way that complied with our ethics protocol. Although we faced challenges in recruiting, theoretical sampling was possible and is being discussed in subsequent papers when we present the findings. Ultimately, we recruited 16 people in total (5 individuals, 6 key support persons, and 5 formal care providers) with no participants who had Huntington’s or Alzheimer’s. In this sense, we as researchers came to feel a bit like diviners seeking water with a rod, researchers seeking participants in a somewhat arid context, and despite the knowledge that success would come to be ours, the path to water was not always immediately visible. As the study continued, amendments to the ethics protocol were made as required. Generally, the ethics protocol allowed for flexibility given the changes that are discussed here.

### **The interview**

Our university REB approved our original ethics protocol, and no subsequent amendments were submitted because the protocol, as it was prepared, allowed for flexibility as we are describing here. The interview questions were based on an interpretation that communication occurs as a relational process between individuals, family and health care providers and that traditionally held notions of autonomy and self-sufficiency might be limiting in this context. As is common with qualitative research, we allowed for the development of new probes based on the findings in the initial interviews. All interviews were to be tape-recorded and transcribed verbatim.

Prior to approval, the ethics review board quite appropriately expressed concern regarding the skill and experience of the individual conducting the interviews. The graduate student who was hired was recruited specifically because she had 16 years of professional experience as a psychiatric nurse with well established counseling skills. In particular, she had experience working with people who had the selected conditions and thus would have high theoretical sensitivity. Her ability to tune in to the possible symptoms of a condition from a medical perspective but with a strong focus on the social experience was critical for the successful completion of these interviews. The interviewer used several interview techniques that had been well honed, given her years of nursing practice. These included establishing rapport, providing

nonverbal cues, using probes, and providing a sense of safety for participants, strategies designed to encourage expression and sharing by those who were being interviewed. These techniques were particularly crucial for the interviewer to employ when interviewing more introverted and/or anxious participants, as this approach allowed these individuals to find their voices. It is probable that these techniques contributed to the richness of the data collected and that the interviewer was like the diviner seeking the “water,” or stories of the participants. Being able to establish a good relationship with the participants was a key to the data we uncovered.

Some participants seemed eager to contribute to “anything that will help people with this horrid condition,” and others clearly appreciated the opportunity to speak about their isolating and often troubling experiences. Two of the participants who wanted to participate to contribute to others’ knowledge about their illness had been former teachers. In essence, by participating, they were continuing on in their vocation as teacher. These particular participants had accepted their situations and were in a place where they could give back to others, and this seemed to give them much peace and satisfaction. It is likely that not all individuals reach this point of acceptance and ability to contribute.

The overlap between collecting data for research and what might be called an intervention identifies the extent to which research affects the participants involved. Participants enjoyed being listened to, and some stated that they found the process therapeutic. One participant in particular, an individual with PD, was motivated to participate in the study along with her husband because she felt “he needed someone to talk to.” This concept, that the research process might have some therapeutic benefit for participants, has been explored previously. For example, in their study on workplace abuse of psychiatric nurses, Lanza, Zeiss, and Rierdan (2006) suggested that nurses might receive direct benefit from the process of the research, a concept termed sensitive research. That is, the opportunity for individuals to have access to a forum to discuss difficult experiences and to have their voices heard has the potential to provide positive psychological benefit to participants. Although this was not part of the design, it would be an important endeavor to develop a follow-up study in which the researchers asked the same participants a few months later whether the discussions that occurred in the interview process had any bearing on how they thought about their own communication, or those of their spouse or the care professionals in their lives.

It was evident that there were varying levels of enthusiasm regarding participation in the study. Due to the fact that we were initially attempting to recruit triads, the persons who were most motivated seemed to be those who initially contacted the recruiter; this included both participants with the condition and their caregivers. Predominantly, however, persons with the condition were the group most highly motivated to participate in our study. During interviews, participants communicated enthusiasm for the process by openly and freely sharing information and maintaining good eye contact and open body language.

One individual was particularly enthusiastic and made great efforts to come from another city to the interview appointment at the university. As the interview with that participant unfolded, the initial impression regarding her motivation was proven wrong. She disclosed that she wanted to participate to provide her husband with a chance to speak about their situation. When they both arrived at the interview, he opted to be interviewed first. He was very communicative during the interviews and eloquently spoke about their life together, his role as the primary caregiver, and his feelings of sadness and loss. During the interview, his wife knocked on the door and seemed very anxious to leave. She later told the interviewer that she felt anxious and a bit angry because he had spoken so long. She was very upset, and they decided to leave and come back at a different time. When we interviewed her a few weeks later, she had come to a place where she

viewed her feelings about her husband's participation in the interview as irrational, and she openly and willingly shared her own experiences. She also stated that the interview had been very helpful to her husband and, ultimately, for their own discussions as a couple.

Resistance to the interview process and specific questions was more evident in those who did not self-refer. It was evident that individuals were reluctant when they failed to elaborate on responses despite prompts, were persistently evasive with particular questions, folded their arms and legs, and avoided eye contact. Although such participation is rich in its nonverbal cues and could provide important data for us, we were not able to verbally uncover the emotions underneath some of those communications. There was one particularly resistant participant. His wife asked that he participate in the interview as he provided the perspective of a family caregiver. It appeared that perhaps within their marital relationship he had less power. He had his arms folded and legs crossed through the entire interview, and his responses were brief. He required much encouragement to elaborate on his comments, and it took a great deal of effort to have him completely answer questions. Despite this, he was very pleasant and friendly, but the interviewer had the sense he might be participating only because he felt this was his responsibility. His reasons for being reticent were unclear. As the interviewer was leaving his home, he stated, "I don't really like to talk much about these things." This certainly highlights the fact that consent is a complicated concept, especially given that we are recruiting pairs or triads for our studies. Consent is clouded by power discrepancies and relationship obligations in these cases. During these interviews where resistance is evident, it is difficult to know how much to persist when asking questions.

Resistance toward certain questions can provide evidence about how the individuals cope with their circumstances. For example, one participant, a man who has PD, made it clear in the initial telephone conversation that he did not want to dwell on his illness but, rather, wanted to talk about his hobbies and activities. During that interview, he frequently deviated from the interview questions, talked at length about his hobbies, and shared various stories about his life. This avoidance was possibly a reflection of how he coped in general with his life circumstance. He was thriving and living life to the fullest of his ability, and he refused to dwell on his limitations. This seemed to serve him very well and reminded us that an illness lens or disease focus did not necessarily dominate all aspects of the individuals' lives. Although this actually was the focus of our questions, his interview was rich for the resistance he offered to our focus. Sometimes even the diviner finds water where least expected.

Conversely, another participant was reluctant to elaborate on questions about her illness other than saying, "I'm mad." She could not explain what in particular made her angry, and, in fact, she experienced very few limitations as a consequence of her illness. All the same, she seemed to be having great difficulty accepting her diagnosis. It was certainly evident that the level of disability does not directly correspond with well-being, but, rather, personality structure and attitude are essential components regarding how well people cope. This further underlines the value of doing qualitative research on this population.

A few participants had difficulty answering questions and needed much clarification and reassurance. We found it interesting that these participants had agreed to participate after being encouraged by persons that they would have perceived as having more power than themselves. This difficulty did not seem to be because they did not want to participate but, rather, seemed to come from a lack of confidence that they were going to answer the questions "correctly." The interviewer needed to provide these participants with a lot of reassurance and explanation. It is not clear if their performance anxiety was related to the fact that the people who suggested they participate were symbolically present, if they were reacting to the interviewer as someone who

was perceived to be assessing or judging their performance, or if having their responses recorded created an unknown audience. Perhaps they lacked confidence in their lives for other reasons as well. The process of doing interviews with this particular vulnerable population proved to be a bit like a diviner seeking water with a rod that appeared to be magical and outcomes mysterious, yet water was the ultimate outcome, as the rich interview data showed us.

### *Data analysis*

Grounded theory principles provided the basis for analysis, which includes developing initial themes and categories found in the first interviews that might encompass overarching themes and what is known from the literature on this topic. NVivo was used to create an audit trail, and field notes were taken throughout the interviews. All interviews were read in hard copy first with the themes that were emerging noted on paper. The initial themes were generated in relation to our main research question and what emerged as key for each participant: We noted the primary and secondary themes for each interview. Once the initial themes from first interviews had then been coded through NVivo, discussion occurred with other experts and colleagues about the themes that were emerging. NVivo acted to aid the organization of our three levels of coding, from primary themes to subthemes and deviant cases within that.

This process then included asking one expert and one graduate student to code the data for main themes in selected transcripts to confirm an overlap or contradiction given the themes detected by the researchers. Not all themes found by the researchers and the external reviewers were similar. Differences had to be integrated, left as deviant themes for a paper discussion, or left out if seen as irrelevant to the research question or redundant to existing literature. As the interviews continued, the researchers went back to coding old interviews for new themes that had emerged in subsequent interviews. As well, the primary themes in the literature and the research question were kept in mind in order to establish themes in the data that were not repetitive but were a new contribution to the field. Theoretical saturation was ultimately achieved as we continued throughout the interview process.

On completion of the interview process as well as engaging in the analytic process, Bronfenbrenner's ecological approach (1979) began to emerge as a suitable framework for the broader themes in the data. These themes clearly moved from descriptions of personal responses to the conditions and daily communications, to interactions with couples/dyads and small family groups, to interactions with the larger network of resources and organizations. Finally, almost all participants described a sense of meaning and value, resulting in a tiered level of interactions as described in the ecological approach by Bronfenbrenner. Although this theoretical framework became a kind of holding tank for the themes in general, as the writing process began, the data began to reveal new possibilities for theorizing. This is being discussed in other papers.

Currently, new models regarding key issues in communication are emerging as the data continue to be analyzed and the content papers are being prepared. For example, one specific paper on the construction of consent between couples is already producing a new model or lens through which to view communication in this context. In another paper, which is emerging based on the themes that arose, we examine the networks within families and professionals that participants rely on. In this manner, their narratives are allowed to speak within a variety of rich and diverse models, which reflects the richness and diversity inherent to the participant lives.

## **Conclusion**

The participants in this research project hold a rich body of knowledge regarding the experiences we inquired about, but the research process itself has also shifted over time, requiring the researchers to be flexible regarding their initial research objectives and recruitment / interview criteria. Qualitative researchers can never conduct research “on” people, and this study has demonstrated how unique this process is: It must be constantly interactive with the people we want to engage. It is essential to hear what potential participants and participants are communicating at every stage of the research process, from recruitment to analysis. In this study, it was important to hear what people were “saying” when they were not responding to the recruitment efforts. It was also important to ask “why” when it became apparent that some individuals were reluctant to include others in their triad of care, and to allow individuals to respond to the interview questions and tell their stories as they felt they needed to rather than forcing the research agenda. This flexibility allowed for rich data, and it was our intention also to communicate our respect to those who had so generously offered their time.

## **Recommendations**

In the following discussion we explain five particular recommendations that emerge from this experience.

### **Privacy restrictions**

Members of review committees for ethics protocols in university settings might not always understand the privacy regulations that institutions or organizations in the community need to uphold. It is recommended that such privacy restrictions, as in the example of a professional who may not discuss the case of an individual patient in any great detail (thus making the examination of real triads extremely difficult), be settled in advance of developing an ethics protocol. At times this restriction renders qualitative research undoable as it can significantly restrict the amount of information a professional may share about a specific patient. This can limit the data to the point where it is not detailed or rich enough to be usable. Communication back to the ethics review committee should occur when these privacy legislations create a barrier to research.

### **The Mini Mental Status Examination**

The MMSE is being questioned more and more as a reliable standard to assess someone’s ability to communicate in an interview setting for a wide range of research purposes (e.g., we know people with dementia who can and should be interviewed for the purpose of research). For example, if an individual was determined to have apparent difficulty with memory and/or was known to have a low MMSE or SMMSE (Molloy, 1999) score prior to signing the consent form (e.g., between 18 and 24 is considered low but functional, whereas below 18 is considered below average), but they remained very interested to be part of the study, they were still declined as participants for a study. We did not ask for access to medical files, trusting that staff members assisting us in recruitment were following our ethics protocol guidelines regarding a participant’s MMSE diagnosis. In our case, we did agree to interview some individuals with a lower MMSE and had made provisions for such in our ethics protocol. This inclusion was also decided on, given previous ethic protocols, to ensure that no person who was interested in the study but not deemed eligible due to the MMSE was then rejected. In particular, because of the increasing

isolation and stigma experienced by many people with each of these conditions, it was seen as a sign of respect and dignity to interview them regardless of eligibility rating according to the MMSE. All eligible participants would then be asked to sign the prepared consent form.

### **Eligible participants**

Who is actually available in a selected recruitment site can change from time to time, and this can alter the nature of the initial focus or research question, indicating that even key objectives that drive a study might require revision. Although in one given year recruitment from one local organization was very fruitful, the following year our contact persons for this organization informed us that because of the overwhelming numbers of studies being conducted, the organization was not providing access to new recruitment by researchers. It is recommended that a selected population of interest is known, as much as possible, to be available prior to designing the objectives of research, that a research objective be flexible (as ours was) to revisions, or that researchers allot the time and money to expand their recruitment sites beyond the initial geographic boundaries. This is particularly true for smaller communities where many researchers might be trying to access the same population for their research. Communication with relevant health professionals in advance of designing a protocol can be useful for this purpose. As well, researchers must craft ethics protocols in a way that builds flexibility into the research process so that emerging changes can be addressed without stalling the process.

### **Value of research participation**

Research can have a positive effect on your participants in the example of the interviews. Some participants felt they were providing a useful contribution for others who might be experiencing the same issues, and several participants actually stated that this contribution increased their own sense of well-being. They felt valuable as persons that they could help others through this process, clearly working against the isolation and stigma some of them felt in their daily lives. Research participation was not a neutral process for them. As well, participants felt that the interview process itself meant that they were being listened to and heard. The research experience, in fact, can be a therapeutic process and can lead to changes in how individuals articulate or feel about their situation. Considering this, we recommend that a given study might integrate a follow-up aspect in the design so that the first interview might be seen as an intervention and the second interview reflect on the value of the first. A subsequent interview process might ask participants what has changed since their first interview in their understanding and actions given sensitive topics. This could allow for another paper where researchers can evaluate and describe their potential therapeutic impact on the participants.

### **Who is conducting the interviews?**

Although students often do their own interviews, researchers frequently hire others to do their interviews for them. The benefit to being in the interview is that many nonverbal communications and cues occur that provide researchers with a clearer understanding of the issues. In qualitative research and certainly grounded theory, this interaction is vital, demanding excellent communication between the person doing the interviews and the researcher. The researcher needs to sense, as a diviner does with his rod, what has actually occurred in the interview. The tendency in recent times is to rely heavily on e-mail communication (for example, between the interviewer and the researcher), but this form of communication can be one-dimensional and can impede creative, dynamic thought. In this study, frequent phone calls between the interviewer and the

researcher right after an interview allowed for debriefing and therefore a more dynamic communication of what occurred in the interview. This allowed the researcher to see and hear what had just occurred in the interview, a benefit for the subsequent data analysis.

### Sample size

In this study, our sequence of who was first recruited ultimately biased our sample toward those recruits who called us earlier in the study. Furthermore, interviews took longer (from 1.5 in the budget to 2 to 2.5 hours) than we had anticipated, and this affected not only the timing of the interviews but also the budget that was available overall. We therefore recommend that researchers develop a keen sense of how long recruitment might take if they are truly seeking a diverse sample. If flexibility in the sample is possible in the eligibility criteria, this can be positive. If it is not, researchers must employ other methods of recruiting, with an amendment made to ethics. In this study more persons with Parkinson's called right after they saw the announcement, and this dominated and influenced the eventual sample.

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