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## Challenges & Strategies for Conducting Qualitative Research with Persons Diagnosed with Rare Movement Disorders

Kori A. LaDonna

Western University, kladonna@uwo.ca

Michael J. Ravenek

Western University, mravenek@uwo.ca

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## Challenges & Strategies for Conducting Qualitative Research with Persons Diagnosed with Rare Movement Disorders

### Abstract

Unique features of Huntington's disease and young-onset Parkinson's disease, both neurodegenerative movement disorders, can pose challenges for conducting qualitative research. From the perspectives of two doctoral candidates conducting research with these groups, a number of challenges are presented and discussed alongside strategies for managing such challenges. Challenges are organized according to physical (e.g., movement), psychological (e.g., cognition) and social (e.g., speech impairment) aspects of these diseases. The strategies presented emphasize the importance of ethical reasoning in situations that can arise, as well as the relationships developed with the research participants. Author transparency and ethical reasoning are both important in conducting quality qualitative research. It is hoped that presenting these challenges and strategies will promote greater dialogue on such issues, and help researchers enable more people with rare movement disorders to participate in qualitative research.

### Keywords

Huntington's Disease, Parkinson's Disease, Young Adults, Interviews, Focus Groups, Qualitative Research Methods

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## Challenges & Strategies for Conducting Qualitative Research with Persons Diagnosed with Rare Movement Disorders

Kori A. LaDonna and Michael J. Ravenek  
 Western University, London, Ontario, Canada

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*Unique features of Huntington's disease and young-onset Parkinson's disease, both neurodegenerative movement disorders, can pose challenges for conducting qualitative research. From the perspectives of two doctoral candidates conducting research with these groups, a number of challenges are presented and discussed alongside strategies for managing such challenges. Challenges are organized according to physical (e.g., movement), psychological (e.g., cognition) and social (e.g., speech impairment) aspects of these diseases. The strategies presented emphasize the importance of ethical reasoning in situations that can arise, as well as the relationships developed with the research participants. Author transparency and ethical reasoning are both important in conducting quality qualitative research. It is hoped that presenting these challenges and strategies will promote greater dialogue on such issues, and help researchers enable more people with rare movement disorders to participate in qualitative research. Keywords: Huntington's Disease, Parkinson's Disease, Young Adults, Interviews, Focus Groups, Qualitative Research Methods*

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Huntington's disease (HD) and young-onset Parkinson's disease (YOPD) are progressive neurological movement disorders that affect both voluntary and involuntary motor control. Both also have associated psychosocial concerns that can add to the disability experienced by those living with these conditions. These conditions may be considered rare or uncommon, given the very low world-wide prevalence rates associated with the conditions. In fact, both conditions are listed as "rare diseases" by Orphanet (2012), a recognized international organization aimed at generating awareness of such conditions. Estimates vary, but HD affects approximately 4-8 per 100,000 worldwide (Harper, 1992). In comparison, YOPD occurs in approximately 12-45 per 100,000 in countries around the world (Muangpaisan, Hori, & Brayne, 2009; Schrag, Ben-Shlomo, & Quinn, 2000; Wickremaratchi et al., 2009; Willis, Schootman, Kung, & Racette, 2012). However, there are a number of issues that make the estimated prevalence of YOPD challenging, which will be discussed in the section on YOPD that follows.

Limited work has explored challenges in conducting qualitative research with either of these populations. However, Williams and Ayres (2007) discussed the importance of rapport building and finding "common ground" for HD care partners when discussing sensitive issues; researchers in Sweden (Hartelius, Jonsson, Rickeberg, & Laasko, 2010) explored communication issues with HD individuals, their family members and professional care providers; and an abstract (Skirton, Soltysiak, & Gardiner, 2007) briefly discussed the challenges of using qualitative methods with individuals with manifest HD. Sheriff and Chenoweth (2003) identified a number of challenges encountered by a multidisciplinary team evaluating an outpatient rehabilitation program for people with PD in Sydney, Australia. Although these authors identified challenges such as poor recruitment support from general practitioners, the perceived vulnerability of the participants and difficulty separating researcher and therapist roles, the majority of their sample was over the age of 60 and thus not specific to YOPD. However, researchers have discussed challenges and strategies for

researching individuals with other neurological impairments including dementia, traumatic brain injury, and stroke (Lloyd, Gatherer, & Kalsy, 2006; Nygard, 2006; Paterson & Scott-Findlay, 2002; Wiersma, 2011). On a broader level, a number of challenges faced by qualitative researchers have started to receive attention in the literature, including challenges like developing rapport, self-disclosure, researcher exhaustion, and exiting the research relationship (e.g., Dickson-Swift, James, Kippen, & Liamputtong, 2007). While helpful, awareness of these general challenges do not address specific issues that may arise while conducting research with persons with uncommon movement disorders, such as HD and YOPD.

## Purpose

The purpose of this article is to discuss some of the *challenges* and *strategies* of using qualitative research methods to explore HD and YOPD, based on our own experiences conducting qualitative research with these groups. Our hope is that this article will encourage and assist researchers to use qualitative research methods to explore individuals with a variety of health conditions, and particularly those with unique challenges that might complicate their ability to participate in research. For example, individuals with impaired cognition or speech difficulties may sometimes be unfairly excluded from participating in research studies. Moreover, alternate paradigms of qualitative inquiry, such as constructivism, are capable of empowering participants and achieving social justice (Denzin & Giardina, 2009). Social justice may result by identifying challenges and strategies for conducting research with vulnerable populations thus facilitating the participation and contribution of individuals who might not otherwise have an opportunity to voice their experiences. Therefore, thinking critically about challenges encountered during the research process, and being transparent about these challenges, are both integral to conducting quality qualitative research (Ravenek & Laliberte Rudman, 2013; Tracy, 2010). Furthermore, discussing strategies for managing these challenges with other researchers is a means to promote ethical qualitative research with these populations, especially in terms of *situational and relational ethics*. That is, ethics involving relationships and interactions with research participants and specific situations that occur during the research process (Tracy, 2010).

## Huntington's Disease

Huntington's disease is an autosomal dominant genetic disorder in which each child of an affected parent has a 50% chance of inheriting HD. The gene was located and described in 1993 (The Huntington's Disease Collaborative Research Group), and genetic testing is available. HD can strike at any life stage, and the current literature suggests that diagnosis can be made anytime from age 2 to 80. While there is a juvenile form of the condition, symptoms of HD most commonly manifest between the ages of 30 and 50 (Shoulson & Young, 2011). As such, there are a host of social, financial, and familial implications that impact affected individuals. For example, individuals may have already had children prior to diagnosis, and/or they may have to leave the work force during their prime wage earning years. HD is characterized by motor, cognitive, and psychiatric symptoms. The primary motor symptom is chorea (involuntary writhing movements), but affected individuals may also experience vocal and other tics, parkinsonism, and problems with voluntary and fine movements (Roos, 2010; Sturrock & Leavitt, 2010).

HD has a variable disease course (Kremer, 2002), and affected individuals may look quite different from each other, even for affected individuals within the same family. While motor symptoms are often the primary endpoint for clinical research they are often the least

troublesome symptom for patients who may not notice their motor impairments (Bonelli & Hofmann, 2004; Kremer, 2002). Instead, the cognitive and psychiatric symptoms are far more troubling for affected individuals and their care partners (Gudesblatt & Tarsy, 2011; Snowden, Craufurd, Griffiths, Thompson, & Neary, 2001). Depression and anxiety are common, and individuals may experience increasing problems with irritability, apathy, aggression, disinhibition, substance abuse, psychosis, and suicidality (Paulsen, Ready, Hamilton, Mega, & Cummings, 2001). Death typically occurs approximately 15-20 years following diagnosis (Shoulson & Young, 2011), and the most common causes of death are pneumonia and suicide (Roos, 2010). In fact, the suicide rate for HD is higher than in the general US population (DiMaio et al., 1993), and the risk increases prior to receiving the diagnosis and when manifest individuals begin to lose their independence (Paulsen, Ferneyhough Hoth, Nehl, Stierman, & Group, 2005). Arguably, the numerous social, physical and emotional implications of HD raise several issues that can be explored via qualitative inquiry.

### **Young-Onset Parkinson's Disease**

Parkinson's disease is characterized by the presence of four cardinal motor symptoms: bradykinesia (slowness of movement), muscle rigidity (stiffness), postural instability and resting tremor; as well as a number of non-motor symptoms including depression, pain, sleeping problems and cognitive changes (Gelb, Oliver, & Gilman, 1999; Jankovic, 2008). However, similar to HD, the experience of PD is very individual and can vary from case to case with few or many of these symptoms being present (Jankovic & Kapadia, 2001; Politis et al., 2010). Although PD typically affects those ages 55 and over, PD does occur in younger adults as well, where it is referred to as young-onset Parkinson's disease (YOPD). There are varying definitions of what age a person has to be before it actually constitutes a diagnosis of YOPD, which poses a challenge for conducting research with this population, including the estimation of prevalence and incidence. Although variations exist, generally, it is agreed that if a diagnosis is made between the age of 21 and 55, a person has YOPD and not the "older-onset" or "juvenile-onset" forms of the disease (Quinn, Critchley, & Marsden, 1987; Rana, Siddiqui, & Yousuf, 2012; Selikhova et al., 2009).

Apart from age of onset, few differences exist between YOPD and the older-onset form of PD in terms of disease presentation; however, the differences that do exist are significant and important to highlight. For example, people diagnosed with PD at a younger age tend to have greater rates of motor complications, such as dyskinesia (involuntary writhing movement similar to chorea) which is a side effect of dopaminergic medication, as well as an increased rates of employment disruption, marital dissatisfaction, and depression (Schrage, Hovris, Morley, Quinn, & Jahanshahi, 2003). Combined, these factors contribute to a greater decline in quality of life compared to both the general population and those diagnosed with PD at an older age (Schrage, et al., 2003; Schrage, Jahanshahi, & Quinn, 2000). Many of these, and related factors, will be considered later in the paper when we discuss challenges and suggestions for conducting qualitative research with people diagnosed with YOPD.

### **Introduction of Authors**

We (KAL and MJR) are both PhD candidates in the Health and Rehabilitation Sciences program at Western University in Ontario, Canada, and we are both using grounded theory (Charmaz, 2006) to explore HD (KAL) and YOPD (MJR). Individual interviews (KAL and MJR), focus groups (MJR), and on-line discussions (MJR) were the primary

methods for data collection. In addition to our research experiences, we both have extensive community volunteer experience working with people affected by these conditions. We will briefly review our personal and research experiences in order to better situate the challenges and strategies we discuss. Our research studies have been approved by the Western University Research Ethics Board.

Using interviews, KAL is exploring motivations for clinic attendance and health care expectations for individuals with one of two neurological conditions (HD and myotonic dystrophy) for which there are few symptomatic treatments and nothing available to slow or reverse neurodegeneration. In short, why do individuals with few treatment options continue to regularly attend an outpatient neurology clinic, what are their health care expectations, and do their reasons and expectations change over time? To date, 9 individuals with HD have been interviewed. KAL comes to this research with a long history working with individuals with chronic neurological diseases in a variety of positions including as a board member of a Huntington's Disease Society of America chapter; a support group facilitator for individuals with HD and YOPD; a clinical trials coordinator; and now as a PhD candidate/researcher using qualitative methods to explore chronic neurological conditions.

MJR is investigating the role of knowledge and information about PD in the lives of those with YOPD. Given that PD is typically associated with older age, much of the materials and resources available are not geared towards younger people with the disease. How then do younger people with PD learn about their condition, and how does this process of acquiring knowledge impact their lives? How does this process change over time? MJR is using a variety of methods to collect data and assemble a theoretical model to better understand these questions, including interviews, focus groups, and a private online discussion board. Sixteen individuals with YOPD participated in interviews, and five focus groups were completed. The impetus for this work stems from earlier research that MJR completed on PD during his academic career, as well as his involvement in exercise and support programs for individuals with PD. MJR also volunteers extensively with the Parkinson Society Southwestern Ontario, with an emphasis on enhancing opportunities and resources for those with YOPD.

### **Challenges and Strategies**

We have organized the challenges we encountered during data collection, and the strategies we used in trying to overcome these challenges, according to three broad categories:

- a) physical;
- b) psychological; and
- c) social aspects of HD and YOPD.

Throughout the discussion, we will consider situational and relational ethical challenges, and describe strategies for enacting social justice with research participants.

### **Physical Aspects of HD and YOPD**

#### **Motor impairments**

Given that both HD and YOPD are classified as “movement disorders,” it is not surprising that certain challenges for qualitative research exist related to the participants' motor impairments. With respect to HD, the chorea experienced by some individuals can make it difficult for a person to walk or sit still for a prolonged period of time, and the

choreic movements may intensify when the individual feels stressed (Kremer, 2002). This may pose a challenge to individuals who participate in lengthy individual interviews, particularly when sensitive topics are discussed. Similarly, some of those with YOPD will experience dyskinesia and tremor (Schrag & Quinn, 2000). Chorea, dyskinesia, and tremor have the potential to create difficulty collecting data in a situational sense and a relational sense.

In a situational sense, an individual experiencing dyskinesia, tremor or chorea may hit the table where the digital recorder is positioned with parts of his or her body. While interviewing participants, both MJR and KAL encountered situations where this occurred. Fortunately, this did not cause a problem with the quality of the recordings, other than producing loud noises on the recordings that were apparent during transcription. It is, nonetheless, important to consider digital recorder placement when research participants experience these types of movements so as to prevent potential damage to the recording device or possible disruption of the recording itself.

In a relational sense, choreic and dyskinetic movements can become distracting for researchers, especially if they are not used to being around people who experience these types of movements. It may be difficult to focus attention on an individual's words and experiences, and maintain eye contact with participants when the movement abnormalities are pronounced. As qualitative researchers, maintaining eye contact with participants is an important non-verbal cue that can indicate how engaged we are with our participants. When involuntary movements take away the ability to focus on a participant's words and maintain eye-contact during interactions with participants, the attention of both parties can potentially be affected.

In addition to the hyperkinetic symptoms of HD and medication side-effects in YOPD, those with YOPD also experience hypokinetic movement difficulties that can impact qualitative data collection. For example, some individuals with YOPD may appear expressionless, often referred to as a "masked face." Similar to maintaining eye-contact, we look for non-verbal cues in the expression of others while we interact with them. These cues let us know if we are being understood, if a person is happy or sad, if a person is joking or being serious, all of which are necessary to collect qualitative data. Postural instability and muscle rigidity, also hypokinetic symptoms of YOPD, can make sitting for long periods of time a challenge for participants. Qualitative interviews and focus groups conducted by MJR have been as long as 120 minutes in duration, making it uncomfortable and potentially painful for a person if they are experiencing either of these symptoms. To maintain the comfort of participants, and to facilitate mutual understanding of participants' experiences, there are a number of strategies that qualitative researchers can employ during data collection. In turn, these strategies emphasize situational and relational ethics that facilitate research participation for individuals with physical and emotional challenges.

### **Strategies for movement challenges**

With respect to involuntary movements (chorea, tremor, and dyskinesia), it is important to consider that individuals with HD and YOPD may not always be aware of their movements (Craufurd & Snowden, 2002; Vitale et al., 2001). Therefore, it may be inappropriate to specifically address these motor impairments unless the participant broaches the subject first. Often, a general question such as, "If you notice symptoms [or side effects], what do you notice?" is helpful and then you can guide the conversation based on the participant's response; it is important to normalize the movements in your interaction with the participant by talking about it and then proceeding on with the direction of the interview. If the participant does not have awareness of his/her involuntary movements, however, it may

not be wise to push this area of inquiry (unless it happens to be the specific focus of the research). Instead, researchers will have to use other strategies to circumvent difficulties with their own understanding, or their interactions with the participant, that may be caused by the involuntary movements. Such strategies may include those discussed below in relation to other movement challenges encountered in HD and YOPD. In particular, these strategies are sensitive to the research situation and to the researchers' relationship with study participants.

In situations where participants have difficulty with non-verbal expression, such as when experiencing a "masked face" in YOPD, asking more expressive questions such as, "How does this make you feel?" may be helpful. In other words, asking questions to clarify the experiences of your participants can help to overcome difficulties related to altered or absent non-verbal information. Although this can add to the length of interviews, it is important to take this time so that your understandings of your participants' experiences are not impacted. It is essential to remember that developing a trusting and respectful relationship with research participants is of the utmost importance. If data collection sessions do occur over extended lengths of time, however, other strategies should be used to ensure the comfort of the participants.

In terms of the organization of data collection sessions, a number of strategies can be used to help to ensure the comfort of participants and uphold situational and relational ethics. First, data collection can be conducted over a number of sessions rather than attempting to collect all of your data in one extended session. MJR used this strategy within his own research where three interview sessions were conducted with each participant. This allowed him not only time to develop better rapport with participants, but also meant that individual sessions did not have to be several hours and he could gear the length of each session to the comfort of each participant. Also, make sure that participants are aware that they can ask for a break at any time they need one, as the safety and comfort of participants are always of utmost concern when collecting data. On a related note, it may be necessary to ask when participants need to take medication so that they do not miss a dosage by participating in the interview. Both of these strategies, however, may be limited to some degree by factors outside of your control, such as time and space available to you to conduct data collection and the availability of your participants. It is, therefore, important to think about these strategies when designing your data collection protocol so that any barriers in implementing these strategies can be managed ahead of time.

A third strategy for ensuring the comfort of participants is related to the setting where data collection will take place. If the data collection is being conducted in a formal setting, as in a clinic where KAL completed her data collection, it is important to seat participants in a stationary chair without wheels and to have a stable surface available for the participants to use for balance. In some cases, it may also be necessary to re-arrange the setting to accommodate for wheelchairs or other mobility aids. If conducting data collection in the homes of participants, where MJR completed his interviews, ask the participants where they are the most comfortable sitting. For example, one of MJR's participants with severe dyskinesia always chose to sit in a rocking chair in her living room, which not only helped her stay comfortable but also reduced the impact her dyskinesia had on their interactions. If researchers offer refreshments during interviews or focus groups, be mindful of only filling cups halfway to avoid embarrassment from spills. Again, owing to the great variability in motor symptoms among participants, reflecting on researchers' relationship with participants and the data collection environment are important prior to and throughout interactions with participants.



## **Psychological Aspects of HD and YOPD**

### **Cognitive impairment**

Although cognitive impairment is a potential non-motor symptom of YOPD, in the study conducted by MJR cognitive impairment was not measured as it was not a means of including or excluding participants. When participants spoke of “cognitive changes” they had perceived to experience themselves, it was often related to slowed thinking, needing more time to process information (bradyphrenia), and short-term memory problems. Both bradyphrenia and memory difficulties are documented problems that can occur in individuals with PD (Dubois & Pillon, 1996). Although this information was pertinent to an overall discussion of how a person’s life had been affected by YOPD over time, it also provided insight into individual differences between his participants that he would need to consider during data collection sessions.

The biggest challenge that MJR experienced during data collection related to cognitive changes occurred when a participant’s ability to focus his/her attention had been impacted. Attentional difficulties are a documented change that can occur in YOPD (Dubois & Pillon, 1996). Such was the case with one participant who required constant re-direction during interviews to stay on-topic. Although by positioning himself within a constructivist paradigm, MJR values the inherent nature of conversational flow that face-to-face data collection permits, there are limits to how far conversation can flow from the topic of the research. To give an example of how this participant’s attention difficulties created a challenge for data collection, it took MJR close to 2 hours to review the study and obtain consent before the first interview even began. These 2 hours were filled with stories about people that the participant knew (unrelated to the study) and his opinions of various physicians he has encountered in his experience with YOPD. The average time that it took with other participants in MJR’s study to accomplish the same tasks was less than 30 minutes.

Cognition was also not formally evaluated during KAL’s study; instead, the referring health care provider only approached participants who either had no cognitive impairment, or who were mildly affected but were deemed able to consent and participate in research. However, even the mild cognitive impairment experienced by individuals with HD may make individual interviews problematic. HD affected individuals may have difficulty participating in conversations due to their slowed thought processes and word-finding difficulties (Skirton, Soltysiak, & Gardiner, 2007) In KAL’s experience, individuals with HD may forget the question posed, confuse information that was presented to them by the researcher, or have difficulty re-calling information about their health history. It is not unusual for HD affected individuals to take a long time to answer questions, and long silences and irritation due to word finding difficulties should be anticipated. For example, one individual remained silent for a prolonged period of time, frequently asked for questions to be repeated, and then became frustrated because he was having difficulty maintaining the conversation and initiating responses. Further, another individual mixed up information discussed prior to the interview, and several individuals relied on their care partners to answer questions about their health history. Including care partners can be a strategy used to overcome particular challenges encountered during data collection.

## **Strategies for cognitive impairment**

Similar to challenges related to involuntary movements encountered in some of our participants with HD and YOPD, specific strategies were helpful in overcoming difficulties we encountered when a person's cognition had been impacted by the disease process. These strategies foreground situational and relational ethics, and have helped us to facilitate the participation of those in our studies by providing a means to bridge the cognitive difficulties experienced by individual participants.

Within our own work, we found that when participants experienced short-term memory problems and/or slowed thinking it was necessary to change the way we asked questions. More specifically, we would repeat or re-word questions whenever participants had difficulty remembering or understanding them. Complicated language or asking multiple questions at once should also be avoided. If necessary, asking concrete (Nygard, 2006) or simple yes/no questions first, and then asking for clarification may be a useful strategy for individuals who have difficulty synthesizing their thoughts. If care partners are present, they can be helpful in re-directing their loved one by re-stating the question in a manner better suited for the cognitive needs of the participant. They may also provide the participant with relevant examples that might encourage or enable him or her to delve more deeply into the question or to "find the right words." This strategy values not only the relationship between the researcher and the participant, but also that of participant and his or her carer in helping to shape his or her story. While this may be a valuable strategy, it is important to be aware if and how the care partner imparts his or her own perspective or experiences into the conversation (Nygard, 2006).

Pre-interviewing participants (Paterson & Scott-Findlay, 2002) to determine their ability to participate in data collection, or providing participants with rough interview guides ahead of the planned interview may help participants formulate ideas that can be discussed in detail during the actual interview session. This strategy may not only be beneficial for memory and word-finding problems, but may also be beneficial when participants have difficulty focusing their attention during interviews.

With attentional problems, we would also reduce the number of questions we asked a participant leaving the topic of discussion broader, and we allotted more time to complete interviews. Allowing a participant to go "off-topic" for a few minutes, but then asking questions to steer the conversation back to information relevant to the topic under study was a necessary, and sometimes valuable, strategy. To overcome problems related to attention or thought production, some participants needed to form their thoughts tangentially to provide the "background" to a point before they could describe an experience or answer a question. Nonetheless, individual differences need to be accounted for, and patience and understanding is required when conducting data collection with individuals. It may also be necessary to be flexible to the timing of the interview (i.e., if a participant is more awake or aware at a certain time of day) and to re-schedule interviews if participants become overwhelmed or fatigued (Paterson & Scott-Findlay, 2002). It is also essential that the informed consent process be revisited throughout the research process to ensure understanding (Nygard, 2006). With each of these strategies we continue to emphasize the unique research setting and the importance of relationships with participants.

## **Psychiatric manifestations**

Individuals with HD may experience a number of psychiatric problems including depression, anxiety, apathy, and impulsiveness. Irritability, potentially coupled with aggression, is a common HD symptom that may be associated with underlying issues like

depression, discomfort, or difficulty communicating (Anderson & Marder, 2001; Craufurd & Snowden, 2002). Individuals with HD may also become irritable if they feel “cognitively overwhelmed” (Craufurd & Snowden, 2002). Suicidal ideation and suicide were first noted by George Huntington (1872) in his original description of the condition and may result from HD-related mental illness and not as a reaction to the disease (Craufurd & Snowden, 2002). Psychiatric symptoms, particularly suicidality, should be anticipated when discussing sensitive issues with HD individuals during an in-depth interview.

Some of KAL’s participants expressed anger at having HD, and several care partners described that their loved ones had mood and behavioral problems. While no one became aggressive during an interview, several individuals became quite sad or irritable when describing the impact of HD on their lives, and one participant expressed suicidal ideation. Toward the end of the interview, the conversation regarding the study deteriorated and the individual with HD and her care partner became quite tearful and distressed. The following is a passage from this specific interview:

*Person with HD:* I’d rather have any disease, MS, cancer, anything than this. I just feel really ripped off that I got this thing. It’s just Huntington’s is the worst f’ing nightmare in the world to me, like it really is. . . . I just would rather have anything than this because to watch somebody just deteriorate non-stop. Like my family and friends, I see them watching me non-stop and it freaks me out that they’re doing it. And I know every day that I get up, I just hope I can get up and keep walking and doing what I can do. But it’s very, very depressing to me. . . . And I have suicidal thoughts all the time because I can’t deal with this.

One of the most common comorbidities associated with YOPD is depression; however, the origin of the depression, either a reaction to the diagnosis or part of the disease process, remains to be fully elucidated (Schrag, et al., 2003; Willis, et al., 2012). Many of the participants MJR interviewed reported having periods of depression, some lasting several years before finding reprieve and some were still experiencing symptoms of depression at the time he interviewed them. Although not formally assessed as part of MJR’s study, it was clear from the descriptions of his participants that the severity of the depression varied between each of them and at different times in their lives. In a few cases, participants spoke of thinking that they would “end it all” or commit suicide if their functioning ever deteriorated past a particular point. This point usually related to the degree to which they had become dependent on others, or perceived themselves to be a “burden” to their loved ones. The following is a passage from one such interview:

*Person with YOPD:* Well, one issue that we had to deal with was the change in my standard of living. And there are things to me that are very important that I will not accept to lose as a standard of living. And if I come to lose that, then there’s no point of living, so I will get suicidal. . . . To some people their standard of living of being in a wheelchair half comatose, drooling all day long is acceptable to stay alive to do that. Well, that’s not my standard of living. So when I get to a point where the standard of living is so compromised that I cannot live with it, then I will just give everybody a break and myself a break I think.

If research involves human subjects, especially where depression and suicidality are a possibility, it is important to be prepared and know how to handle difficult situations if and

when they arise. The strategies discussed below emphasize the relational and situational ethical responsibilities of researchers when difficult situations arise during data collection.

### **Strategies for psychiatric manifestations**

Given the complex and often sad issues that can be discussed during interviews, it is important to be aware of strategies to protect the well-being of both the participants and the researcher. One strategy, which should always be included in research discussing sensitive issues, is to include contact information for a social worker, nurse, or other health care professional in the consent form so that participants are aware that staff members are available for consultation should they experience distress during or after their interview. A second useful strategy, related to the design of the study, is to incorporate means for ongoing communication with the participants. For example, in MJR's study, he provided the participants the option to consent to periodic telephone calls and an online discussion board, and also encouraged participants to call or email him if they had any questions or additional things they wanted to discuss. This proved to be valuable for one participant who became very emotional during their first interview together. As she had consented to follow-up calls, after MJR returned home from the interview he called her to ask how she was feeling. The participant was comforted by this as it showed her that he truly cared about her feelings and her experiences, and allowed him to make sure that she was safe.

Any time that suicide is mentioned by a participant during an interview (or other means of data collection), the first thing you need to do is to make sure they do not have an active plan to carry out an intention to end their own life. Be aware of the warning signs for suicide, and when active plans are in place be sure to get help for the participant immediately (Rudd et al., 2006). Fortunately, when suicide was mentioned by participants in MJR's study, none of the participants had an active plan. In the instance where the HD participant and the care partner became distressed during the interview with KAL, it was necessary for her to page the individual's attending physician to come to the research room to evaluate the situation. The physician had a long conversation with the individuals and helped the researcher diffuse the situation. The individuals were calm when they left the research room. However, with the participant's permission, the physician and KAL ensured that the HD clinic social worker was made aware of the problem, and they asked him to follow up with the participants within the week to ensure that the participants' distress had resolved. It may be important to include a statement in the consent form saying that confidentiality may not be maintained if the participant is a danger to him/herself or others. The Research Ethics Board was also notified about this event.

In addition to protecting the well-being of participants, we also need to be concerned about our own well-being when conducting research with people where sensitive issues and topics can arise. As discussed by Dickson-Swift et al. (2007), it is important for qualitative researchers to build in support mechanisms for themselves when difficult issues are discussed while collecting data. Debriefing with either health care providers who have experience working with HD and/or YOPD families, an academic advisor, peers, or writing in a reflexive journal are all ways to protect a researcher's well-being and can also advance data collection and analysis. Both of us have found these strategies useful throughout the research process but especially when difficult topics, such as suicide, were discussed with our participants. If you do not use strategies to manage your feelings and protect your own well-being, it is possible to develop "researcher fatigue" and "exhaustion" (Dickson-Swift et al., 2007). In cases where this has been documented, researchers may have difficulty focusing on participants' responses and/or asking appropriate follow-up questions (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007). To prevent fatigue from occurring, identify

strategies and resources that you can use within your own setting during the planning stages of your project. While concern for the well-being of participants is paramount, we must also not neglect our own well-being during the research process. Researcher self-care is an important part of upholding situational and relational ethics with research participants.

## **Social Aspects of HD and YOPD**

### **Participation**

Sometimes the actual act of participating in data collection sessions can be made difficult for individuals with HD and YOPD for a variety of psychosocial and physical reasons. Given the cognitive and mobility issues of HD affected individuals, many are often unable to drive or to coordinate their own transportation to clinic or study visits. This is complicated by the fact that the local HD clinic where KAL conducted her research supports a wide catchment area and patients may live several hours away from the clinic and research site. Thus, sometimes participants either declined participation due to transportation issues, or they had to ask their care partner to take time off of work to drive them.

Driving can also be a concern for those with YOPD, with several involved in MJR's research noting that they had self-limited their own driving because of concerns they had, and because of concerns that were brought to their attention by others (family, friends, and/or co-workers). People with YOPD may also continue to work for years after their diagnosis, as was the case with several participants involved in MJR's research, which can pose a challenge for arranging times for them to participate in data collection sessions. This is especially true when they have familial responsibilities above and beyond employment responsibilities. Despite these barriers, there are strategies that can be used to facilitate the participation of those with HD and YOPD while emphasizing the consideration of relationships and the research setting.

### **Strategies to enable participation in data collection**

Being flexible and creative with ways to collect your data can often go a long way in helping participants who might otherwise have trouble taking part in data collection. In addition to helping protect the well-being of participants as discussed in a previous section of this paper, providing a number of options for participants to take part in a study is also a way to enable their participation. While conducting two pilot focus groups at the outset of his research, MJR explicitly asked 15 participants with YOPD how he should collect his data for the larger study he was planning. The resounding answer was that there should be a variety of ways that people can participate, so as not to limit those who are still working or have family or other obligations. As a result of this insight, he setup his study with four means by which participants could consent to participate: interviews, focus groups, online discussion board and/or follow-up phone calls. MJR also gave participants the option of conducting interviews over the phone, if there were factors that limited getting together face-to-face. Similarly, participants were given the option to choose the location of the interviews. All 16 of MJR's interview participants chose to have the interviews conducted in their homes where they felt comfortable and did not have to travel. Conversely, due to the unpredictable behavioral aspects of HD, KAL's academic advisor preferred interviews to be conducted in a clinical setting so that health care providers were readily available should an emergency arise. Strategies and training to deal with situations would, therefore, be imperative if researchers were to consider conducting research with people with HD in their homes.

A strategy that both KAL and MJR found useful for facilitating participation was to coordinate group data collection with pre-planned events like clinic visits, conferences, or workshops. For example, KAL amended her ethics protocol to facilitate recruitment at the Huntington's disease clinic. The original protocol asked for the attending neurologist to make first contact with potential participants about the study. By recruiting directly at clinic, the physician was able to screen patients and approach them about the study during their appointment; some participants agreed to participate in an interview the same day. This facilitated the participation of individuals living out of town, and/or for those who had already taken time off from work to come to their clinic appointment. Finally, conducting the visit in the clinic ensured the safety of both the researcher and the participant(s) by having health care providers on-site should participants become upset during the interview.

In conducting his focus groups with individuals with YOPD, MJR coordinated their time and location with conferences and workshops that were being hosted by the Parkinson Society Southwestern Ontario. MJR was very fortunate that the Society was willing to support his research this way, providing a meeting place and room to conduct focus groups on several different occasions. He had already developed a rapport with the Society by volunteering with them on past occasions, and we highly recommend that researchers connect with community organizations. Conducting focus groups at the Society's events meant that MJR's participants were able to participate in research and connect with the services provided by the Parkinson Society Southwestern Ontario.

### **Speech impairments**

Speech impairments can create challenges for the individuals who participate in research projects as well as for the researchers collecting qualitative data because they have the potential to impact the relationship between the researcher and the participant. Individuals with speech impairments or communication difficulties may be stigmatized by society (Lloyd, 2006) and consequently, may be unfairly excluded from research. Individuals with manifest HD may experience slurred speech or difficulty pronouncing or enunciating words (dysarthria), and individuals may become mute in the late stages of the disease (Kremer, 2002). Interviewing patients with pronounced speech impairment was perhaps the most challenging aspect of conducting qualitative research with individuals with HD. It was sometimes difficult for KAL to conduct the interview due to difficulty understanding the participant, and the professional transcriptionist had difficulty accurately transcribing the recordings. Skirton, Sotysiak, and Gardiner (2007) experienced similar challenges during their research with individuals with HD. Interestingly, the referring physician was so familiar with the individual that he did not perceive difficulty understanding the participant's speech.

In a study by Hartelius, Jonsson, Rickeberg, and Laasko (2010), 11 individuals with HD acknowledged that their communication difficulties included word-finding problems, losing their train of thought during conversations, and the fatigue of participating in conversations. Their ability to participate in conversations was also negatively impacted if their conversation partner spoke too quickly (Hartelius et al., 2010). In KAL's study, some participants spoke in short phrases with little elaboration, and it was difficult to determine whether or not this was a result of speech impairment, cognitive impairment, or both. Some participants expressed forgetfulness and/or needed questions clarified or repeated. In several cases, the HD individual deferred answers to their care partner.

Speech impairment can also occur in YOPD, especially in the form of reduced speech volume or hypophonia (Jankovic, 2008). This can pose a challenge for data collection and transcription depending on the severity of the hypophonia and the setting in which data collection is taking place. In MJR's research, hypophonia had only become an issue when

trying to collect data in focus groups. With one-on-one interviews, he was able to position himself and the recording device relatively close to his participants. With focus groups, however, participants are positioned further from each other, and further from the recording device(s). When one or more of the participants have hypophonia, this can make it challenging to collect your data clearly enough that it can be transcribed and can also cause problems for participants to be able to engage actively in the discussion.

### **Strategies for speech impairments**

Individuals with HD and their family members noted that communication for those with HD improved when they felt safe with their communication partner and when they were given time to synthesize their thoughts and formulate responses (Hartelius et al., 2010). It may be important to engage the participant in informal conversation prior to initiating the consent process and beginning the interview. Not only does this build rapport with individuals, but Hartelius, Jonsson, Rikeburg, and Laasko (2010), found that individuals with HD perceived that they were able to communicate more effectively if they had the opportunity to speak for an extended period of time. KAL would engage participants in “small talk” prior to the consent process. KAL also made it clear when the audio recorder was turned on to mark a clear delineation between friendly conversation and the beginning of the research interview. Given the sensitive topics that may be discussed during an interview with HD individuals, the goal was to provide a safe space where participants were sufficiently “warmed up” while ethically ensuring that participants were able to differentiate between friendly conversation and “data.” Often, KAL would bring the interview back to something that was discussed prior to turning on the recorder if it was related to the research topic. Another strategy may be to use innovative methodologies to facilitate participation by those with physical, intellectual, or emotional challenges. For example, photovoice which uses the visual image to augment traditional interviews (Wang & Burris, 1994), was used successfully with individuals with HD (LaDonna, Landry, Johnson, & Hyson, 2009). As mentioned previously, MJR completed interviews with participants over three sessions, thus allowing time for the development of rapport, as well as a level of comfort for the participants and a familiarity with their speech (including volume and accent) to be established. Thus, for both KAL and MJR, providing ways to facilitate relationships with participants was important for helping to overcome speech challenges during data collection.

Specific strategies related to recording equipment are also helpful when participants have speech impairment, which can make transcription easier and more accurate. First, the use of multiple (high-quality) recording devices is always a good idea. High quality devices (multiple microphones, high rate recordings) are worth the extra expense and often come with software that allows for easy transfer between the device and a computer. Within focus groups, multiple recorders can be placed closer to individual participants who have a speech impairment to create as clear a recording as possible. Limiting the size of focus group to 5-6 people and reviewing “talking rules” with the group can also be useful in ensuring accurate recordings and preventing people from talking over one another on the recordings. In both interviews and focus groups, the use of multiple recording devices provides a safety-net if one of the recording devices was ever to stop working. This strategy emphasizes the importance of taking into account the unique aspects of the research setting when conducting research with those living with HD and YOPD.

Another useful strategy that can be used if you are having trouble understanding a participant is to ask them to repeat themselves and/or repeat the participants’ words back to them. This can aid the researcher in being able to ask thoughtful follow-up questions, ensure that the researcher’s understanding of the participant was correct, and it can assist the

transcriptionist in making sure the transcript accurately reflects what was said during the session. Both KAL and MJR took extra care while reviewing the audio-recordings to ensure that the transcripts were accurate and that whenever possible, portions of the transcript labeled “inaudible” were resolved.

In cases where a participant’s speech is more severely affected, as was the case for some of KAL’s participants, drawing on the knowledge and experience of care partners can be an invaluable resource for facilitating study participation. Not only are care partners instrumental for transporting affected individuals to study visits, but they can interpret their loved one’s meaning if speech is impaired and/or fill in details about health history or past experiences. Carlsson et al. (2007) argue that proxies can be “gatekeepers” (p. 1364), and they may be sampled to accurately depict the experiences of individuals with communication difficulties. For example, with her son’s permission, one HD care partner served as a self-identified “translator” and translated her son’s words for the researcher. Again, within the research setting, relationships between participants, researchers, and carers help to uphold ethics and achieve success within the research setting.

### **Conclusion**

Conducting qualitative research with individuals living with uncommon movement disorders, including HD and YOPD, poses a number of unique challenges that raise important situational and relational ethical concerns. Some of these challenges stem from specific impairments that can result from the disease processes or from side effects of treatments, including motor, cognitive, and speech impairments. Other challenges, including potential psychiatric manifestations and more practical concerns related directly to participants’ ability to take part in data collection sessions all need careful consideration when working with these groups. Overcoming these challenges is possible with a number of thoughtful and pre-planned strategies. As constructivists, we (MJR and KAL) believe that the voices of our participants should be heard, and that their participation in research should not be limited because of challenges that can be overcome or minimized.

Among a number of other factors, quality qualitative research is marked by both the transparency of researchers and the use of ethical reasoning (Ravenek & Laliberte Rudman, 2013; Tracy, 2010). In discussing the challenges we have encountered conducting qualitative research with people who have HD and YOPD, we have striven to be transparent. Likewise, the strategies we have used in our own work, and recommend that other researchers consider, are aimed to promote situational and relational ethics. That is, strategies that consider the unique situations and relationships that may be encountered while conducting research with those who have HD or YOPD. We hope that presenting these challenges and strategies will help other researchers, promote dialogue about managing these challenges, and encourage researchers to investigate important and sensitive issues in the lives of those with uncommon movement disorders.



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### Author Note

Kori A. LaDonna, PhD(c) is a doctoral candidate in the Health & Rehabilitation Sciences Program at Western University, London, Ontario, Canada. Email: [kladonna@uwo.ca](mailto:kladonna@uwo.ca)

Michael J. Ravenek, PhD(c) is a doctoral candidate in the Health & Rehabilitation Sciences Program at Western University, London, Ontario, Canada. Email: [mravenek@uwo.ca](mailto:mravenek@uwo.ca)

All correspondence can be made to Kori A. LaDonna at the following: Western University, Elborn College, Health & Rehabilitation Sciences, 1201 Western Rd., London, ON N6G 1H1 Canada; Email: [kladonna@uwo.ca](mailto:kladonna@uwo.ca)

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