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# Risk and Resilience: Living with a Neurological Condition with a Focus on Health Care Communications

Kerstin Roger and Leslie Penner  
*University of Manitoba  
Canada*

## 1. Introduction

There is little research examining the daily lived experiences of families in which one person is living with a neurological condition. Further, there is no research which examines how patients evolve and adapt in ways that allow them to have their needs met within the complex system of health care provision. This paper explores nine factors that emerged in original, empirical qualitative data, and how these factors are perceived by the participants to contribute towards increasing resilience when communicating with the health care system. The data were collected over a three year period, utilizing focus groups and interviews. Our primary focus in this paper will be on the participants living with Huntington's and Parkinson's, although other participants will be referred to as well.

Communication about care can be shaped by many factors such as a concern about being a burden to others, the proximity of family, family dynamics, personalities, stress related to the illness itself, and, socio-cultural belief systems about health and healthcare (in the example of persons with a collectivist versus more individualistic cultural background). It has become clear (Roger et al., 2010; Roger & Medved, 2010; Zloty et al., 2010) that contradictory and often unspoken expectations of care emerge between professionals, family and individuals. Because of this, errors, poor treatment, and misunderstandings can result, in addition to diminished well-being of caregivers and individuals. Further, the ways in which individuals and family members experience and perceive interactions with health care providers have been shown to affect the level of trust that the patients have in their care providers (Tarrant et al., 2003), and have been demonstrated to impact health care outcomes (Moreau et al., 2006; Safran et al., 1998). These outcomes can result in significant costs to individuals and the health care system. This paper will explore how the nine factors that emerged can contribute towards the development of tools that can be used to facilitate improved communication between patients living with neurological conditions and health care providers.

## 2. Ecological model

Bronfenbrenner's ecological approach (1979) is a suitable framework. His approach identifies how individuals, small groups and larger groups, as well as institutions, interact systemically and bi-directionally to shape relational patterns, norms and values.

Bronfenbrenner (1979) initially described four nested systems: micro-, meso-, exo-, and macrosystems, with family being the primary microsystem within which the individual develops (Bubolz & Sontag, 1993, p. 424). The mesosystem refers to interactions and relationships between the family and other systems where individual learning takes place. This is an important concept in relation to the current study because there is much health care teaching that individuals and their family members are exposed to when interacting with the health care system. Bronfenbrenner suggested that if the connections between families and the environments where learning takes place are healthy and positive, it would affect the individual in a positive way. For example, according to this theory, if individuals and their family members have open and positive connections with their neurologists, the health of these patients will be improved. The exosystem represents environments that adults participate in which, in turn, affect the individual and the family as a whole (e.g. work settings, recreational organizations, volunteer settings). Finally, the macrosystem, which includes cultural beliefs, customs and laws, is the outermost layer of the linked systems – it envelopes and influences the interactions of all system layers. Later in the development of his theory, Bronfenbrenner (1986) added the chronosystem, which refers to the influence of the person's development of changes over time in the context of the environments in which the person interacts. He suggested that life transitions were the simplest form of chronosystem, with the development of an illness being an example. This transition has the potential to affect the development of the individual (and family members) directly, or indirectly by affecting the interactions and functions of the family. The chronosystem includes the cumulative effects of evolving developmental transitions over the life of an individual. This concept is useful when exploring the impact that a chronic, deteriorating neurological illness has on the development of patients and their family members; despite being a difficult transition, it has the potential to instigate developmental change. This systemic approach is particularly useful here since the stories and narratives between couples and care professionals reflect important aspects of Bronfenbrenner's systems approach. The themes that emerged in this study moved from descriptions of very personal responses to situations, to daily communications and interactions among family members, to interactions with the larger network of resources and organizations.

Human beings are inherently social; they do not generally operate independently and in isolation. Therefore, it follows that the behaviour and responses of individuals cannot be fully understood without considering the environment within which they are embedded. Human ecological theory "...is concerned with interaction and interdependence of humans (as individuals, groups, and societies) with the environment" (Bubolz & Sontag, 1993, p. 421). A key concept in this theory is the process of adaptation – the way in which individuals and families attempt to cope with their ever-changing environments. Particular attention is given to communication and the underlying values which guide these decisions (Bubolz & Sontag, 1993). Resilient couples who interact with the health care system on a regular basis can and do find techniques and strategies which ensure effective and creative adaptation to the challenges they face. In this way, Bronfenbrenner's model is a helpful framework for the data to be discussed in this paper.

### 3. Background

The National Health Charities of Canada (NHCC) is an umbrella organization that works with government, researchers and the community to promote and support services and

research to a number of related neurological disease conditions such as neurotrauma (e.g., acquired brain injury and spinal cord injury), neuromuscular disorders (e.g., cerebral palsy, epilepsy and spina bifida), degenerative demyelinating conditions (e.g., multiple sclerosis, Guillian-Barre syndrome), and movement and other neurodegenerative disorders (e.g., Parkinson's Disease, Huntington's Disease, Alzheimer's Disease and Amyotrophic Lateral Sclerosis [ALS]). This study recruited participants from conditions under this umbrella: to be discussed in this paper are participants with Parkinson's Disease (the majority of our sample) and Huntington's.

Huntington's Disease is an inherited neuropsychiatric disorder that causes brain cells to die, resulting in clinical features which present in a triad of movement disorder, cognitive dysfunction and psychiatric or behavioral disturbance (Sturrock & Leavitt, 2010). Because the disease is inherited as an autosomal dominant trait, each child of an affected individual has a 50% chance of inheriting the gene (Aubeeluck & Wilson, 2008). The average age of onset of Huntington's Disease is between 35 and 44 years (Paulsen, Ferneyhough Hoth, Nehl & Stierman, 2005), but it can present anytime between ages 2 to 85 years (Roos, 2010). Huntington's is a rare disease with a prevalence rate that varies between 5-10 per 100,000 in the American population (Nance & Myers, 2001) and 4-8 per 100,000 in the European population (Harper, 1992). There is no cure for Huntington's Disease at this time and patients die, on average, 20 years after onset (Paulsen et al., 2005).

Mild cognitive and personality changes can occur in the early stages of the disease (Sturrock & Leavitt, 2010; Walker, 2007). The early symptoms are often first noticed by family, friends and co-workers and may include disinhibited behavior, fidgetiness, irritability, anhedonia, obsessive behaviors, altered executive function, and slowed processing speed which manifests in decreased productivity (Sturrock & Leavitt, 2010). As the disease progresses, motor disturbances such as chorea, speech and swallowing difficulties, rigidity, bradykinesia and akinesia develop (Roos, 2010). Eventually, mobility is lost (Sturrock & Leavitt, 2010) and oral motor dysfunction leads to incoherence of speech and inability to eat (Sturrock & Leavitt, 2010).

Cognitive deterioration is progressive in Huntington's Disease (Sturrock & Leavitt, 2010). There is a decline in executive functioning that affects judgment, insight, and ability to organize (Roos, 2010; Sturrock & Leavitt, 2010) and there is a progressive deterioration in recall and complex intellectual functioning (Sturrock & Leavitt, 2010). Eventually, cognitive decline becomes global and all aspects of cognition become impaired (Sturrock & Leavitt, 2010). Psychiatric symptoms such as depression and anxiety are often present during the disease trajectory and are relatively independent of the motor and cognitive aspects of the disease (Paulsen, Ready, Hamilton, Mega & Cummings, 2001). As well, although less common, delusions and hallucinations can also emerge during the course of the illness (Paulsen et al., 2001). There is an increase in suicidal ideation in individuals at risk for, and diagnosed with Huntington's Disease, particularly in the period immediately before receiving a diagnosis, and then again in the period where independence begins to diminish (Paulsen et al., 2005).

Parkinson's Disease is the second most common neurodegenerative disorder worldwide, second only to Alzheimer's Disease (de Lau & Breteler, 2006). It is commonly diagnosed in individuals over the age of fifty, with its prevalence affecting approximately three percent of the Canadian population over the age of 65 (Public Health Agency of Canada, 2000). Recent

Canadian research has shown that the prevalence of Parkinson's Disease is increasing, perhaps due to an aging population (Guttman, Slaughter, Theriault, DeBoer, & Naylor, 2003; Lix et al., 2010).

The most common symptoms of Parkinson's Disease are tremor, muscle rigidity and stiffness and psychomotor retardation (bradykinesia) (Clark, 2007; Heisters, 2011). As the disease progresses, postural abnormalities and instability can emerge (Clark, 2007; Nutt, & Wooten, 2005). These symptoms can interfere with ambulation and increase the risk of falls. There is a wide range of non-motor symptoms which pain, dementia, mood disorder, psychosis, apathy, sleep disorder and excessive daytime sleepiness, bowel and bladder dysfunction, excessive sweating, and sexual dysfunction (Clark, 2007; Heisters, 2011). Dementia is common, affecting approximately 30% of patients with Parkinson's Disease (Aarsland & Kurz, 2010). The severity and presentation of Parkinson's related dementia varies between individuals, but common characteristics are impairment in attention, memory, ability to plan, organize and problem solve, and impaired recall, personality changes, behavioral symptoms and hallucinations (Emre, 2003). Because non-motor symptoms affect several domains of functioning, and because they are difficult to treat, the impact on the patient's quality of life can be profound.

Both HD and PD are chronic neurodegenerative and progressive in nature (National Institute of Neurological Disorders and Stroke, 2008; Public Health Agency of Canada, 2000). As well, symptoms can affect all domains of functioning: physical, cognitive and emotional, resulting in complex health care needs.

Although each of these neurological conditions has their own etiology, they share symptoms which can impact everyday activities and the health and well-being of individuals and family members. Shared experiences include disrupted relationships and a reduction in participation in personally meaningful activities (e.g., employment, shared family activities) (Statistics Canada, 2007). While there has been some attention paid to the illness experience (Brody, 1987; Charmaz, 1991), little research was found that examines communication and the daily experiences of persons with neurological conditions in relation to their families and health care providers. The impacts in this context are multi-faceted including multiple changes to couples' roles and responsibilities over years, every day routines, marital relationships and financial status.

#### 4. Methods

This was a qualitative pilot study conducted over three years using interviews and focus groups. Initially, community consultations were held with affiliated staff and organizations (see Table 1) to better understand organizational needs regarding care services to families and couples with long term neurodegenerative conditions (e.g. Huntington's, Alzheimer's, ALS, Multiple Sclerosis, and Parkinson's). This led to a clarification of the need for research on people's daily lived experiences and especially a need to better understand their interactions with the health care system. The research team was then successful in receiving funding to conduct Phase II in 2009. This explored decision-making between couples and care professionals. We received funding for Phase III where we were able to explore in more depth, given the same sample of participants, what had changed for them given their daily lived experiences in the last year. The data to be described in this paper emerged from this last sample in Phase III collected in 2010.



	2007-08	2009	2010
Event	PHASE I: Community-based consultations (3)	PHASE II: Interviews (16)	PHASE III: Follow-up interviews (8) and focus groups (2)

Table 1. Research Phases.

4.1 Ethics approval

The authors prepared an ethics protocol for the most suitable ethics review committee at the local university and this was approved. Components of this protocol included: i. a script for the research assistant to be used when discussing possible recruitment with relevant organizations and a script to be used when discussing the study with potential future participants; ii. a list of the interview questions; iii. a pledge of confidentiality for the research assistant and the transcriber; and, iv. a consent form that described the study, it identified the process that ensured the participant’s confidentiality and how this would be maintained over time. The consent form addressed the treatment of the data once the study was to be completed, how the data will be stored, and when and how the data will be discarded.

4.2 Interview and focus group sample

We aimed for equal representation of individuals in the three proposed categories: the individual with a selected neurological condition, a familial support person, as well as a professional care provider (see Table 2). Fifteen people were interviewed in total over three time periods in the three years. Over the three years, some changes did occur to our sample due to divorce, moves out of province, and a willingness to participate in the study. We held two focus groups once the interviews were conducted and themes were analyzed. They were recruited in the same manner as described below for the individual interviews. The focus groups were comprised of six participants each (not the same persons as the interview sample) who were all formal caregivers working in any one of the affiliated organizations. Diversity for the focus group participation was sought in regards to the type of professional (e.g. nurses, social workers, administrators).

Participants with an interest to participate in the study were eligible if they met the following inclusion criteria:

- i. They understood the primary goal of the study and were able to articulate their thoughts verbally on the topic;
- ii. They fit on of the disease categories;
- iii. They were able to provide consent at the beginning of the study by reading the consent form, asking questions about the study, and signing the consent forms;
- iv. They were able to hold a full conversation in English;
- v. They or a family support was affiliated with one of the selected and recognized institutions. Or, for the focus groups/consultations, they were a staff person in one of the affiliated organizations;
- vi. A primary diagnosis of one of the conditions under the NHCC umbrella had occurred as confirmed by a key familial support person, a physician, social worker, nurse or patient care manager familiar with the participant’s history;

vii. Participants for the interviews had engaged in communications regarding health care involving a person with a selected condition in the last 6 months; viii. Participants had to be over 18 years of age.

	PSEUDONYM	RELATIONSHIP	AGE	PROFESSIONAL BACKGROUND	PROFESSIONAL/ PATIENT WITH CONDITION
1	Neil	Married to 2			PD
2	Flora	*	65	SW	Support
3	Len	Brother to 4	79	Business	PD
4	Frieda	*	83	Secretary	Support
5	Estrella		2003 began	OT with MS	Prof
6	Sophie		1986 began	SW with HD/PD	Prof
7	Daniel	*	55	Welder	Support
8	Doreen		50	Computer analyst	MS
9	Jane	Married to Ken	59		MS
10	Ivan		1997 began	Warden/vol pall care	Prof
11	Leila		1999 began	nurse	Prof
12	Nettie		2005 began	Health care/MS	prof
13	Janelle	Married to 7	54	Bakery manager	PD
14	Margareta	*	81	banker	PD
15	Friederich	Married to 14	83	Power engineer	support

Table 2. Interview Sample.

Individuals for the interviews were asked whether they would provide one key family support person. A person with one of the selected neurological conditions could take part in this study even if they had no key family support person and wanted to select a second health care provider, or their key family support person declined but someone else was willing to be interviewed. The definition of the family support person was quite broad including family members, common law partners, neighbors who provide significant frequent care, or another relative doing the same. This individual would sign a consent form prior to being interviewed. Both the individual and their family support person received an honorarium for their participation. Confidentiality agreements as documented through the consent form applied to each participant. Professionals working in related areas and with populations who fit the criteria were recruited as well.

Once the consent forms were signed by participants, the interviews were held individually at a site selected by the participant, and lasted approximately two hours. A demographic section began the interview process including basic questions about a person’s age, gender, professional affiliation if appropriate and so on. Semi-structured interview questions were then used to investigate the primary objectives of the study. Questions included asking

about the wished for and perceived role of health care providers communicating on their behalf, the wished for and perceived impact of family members making decisions on their behalf, and the perceived changes and role of their own independence as their condition was diagnosed and as it progressed. New probes were developed as data was collected based on the findings in the ongoing interviews. All interviews were audio taped and then transcribed verbatim.

Once the consent forms were signed by the participants, two focus groups were held at locations convenient for the participants and lasted approximately two hours. Themes from the individual interviews had been compiled and were presented to the focus group members. Similarities between the themes and the participant's experiences, identified gaps and differences were discussed. Probes had been developed in the ethics protocol for this purpose. Detailed notes were taken in these two focus groups by a research assistant.

#### 4.3 Analytic process

NVIVO8, a qualitative data management program, was used to code all transcribed interviews. Content analysis was used as a framework (Graneheim & Lundman, 2004) where constant comparison is possible between themes and sub-themes as they emerged. Once the researchers coded the transcripts and assessed the main and sub-themes, selected experts were provided with a sample of transcripts in order to code them. By applying the principles of qualitative content analysis, further exploration of the data was performed to encourage trustworthiness and credibility of the research findings. This approach allowed the researcher to "condense" the data into additional and/or comparative codes, followed by "aggregation" or the progressive interpretive process of thematic abstraction. The themes were then compared and similarities noted while differences will be documented in subsequent papers.

Rigor was determined according to principles set out for conducting qualitative research (Morse et al., 2002). For example, *consistency* was ensured by choosing participants who have experiences with the research topic and a genuine interest in taking part in the interviews. *Transferability* will be fulfilled by making certain that detailed information will be provided in future papers so that readers would be able to identify a similar situation in a similar context. *Credibility* was attained through editing of the interview transcripts as well as integration of field notes in line with what does exist in the literature. Inter-rater reliability throughout all phases of analysis solidified credibility. Results and interpretations were checked by members of the research team who then reviewed the analysis, obtaining consensual validation.

### 5. Findings

Three levels of the Bronfenbrenner ecological model were most apparent in our emerging nine factors: the microsystem, the mesosystem, and the chronosystem. The findings will be presented in two parts – the interview data first and the focus group discussions second.

#### 5.1 Microsystem

Individual and family characteristics were included to represent the microsystem.



1. Manner of Communicating: Ability to Push the System
2. Self-Reflection about Characteristics Prior to Condition
3. Existing Social Supports
4. Education Levels
5. Gender of Primary Caregiver/ Professional

## 5.2 Mesosystem

The mesosystem includes the connections and interactions between the family and other systems where individual learning takes place. Here, the system where learning takes place is the health care system.

1. Health Care Literacy

## 5.3 Chronosystem

Bronfenbrenner's chronosystem is useful for examining the impact that the passage of time has on the individual. For example, the passage of time can impact the individual's physical state (eg. children maturing, individual's with chronic illness deteriorating), and this in turn, can affect the way in which they interact with the environment. As well, the passage of time can allow individuals to gain mastery and experience in coping with a difficult situation, for example. The chronosystem encompasses anything that has to do with the passage of time.

1. Length of Relationship to Primary Caregiver
2. Stage of the Illness
3. Age

## 5.4 Findings from interview data

### 5.4.1 Microsystem

#### 5.4.1.1 Manner of communicating

Resilience research has often sought to understand specific personality traits or characteristics inherent in an individual - qualities which were described as being protective in nature (Earvolino, 2007; Johnson & Wiechelt, 2004; Richardson, 2002). The participants in this sample demonstrate personality traits that reflect their individual abilities regarding communication. For example, communicating about their care needs in a clear and articulate manner was for some a new skill and for others an existing long standing trait. Not being able to communicate well with care professionals in many cases reduced their ability to interact in effective and beneficial ways with the health care system.

It was evident that the manner in which a patient, family or professional caregiver communicated with others shaped how they perceived their care plans developed. Janelle talks about her ability to communicate to 'push' the system:

*Janelle: And the Pharmacare system out here is a lot stricter as well, and at first they weren't gonna cover me for a couple of my main medications. I had to, this is quite funny. Well it's funny but it wasn't. They made me get a letter from my doctor saying that it was absolutely necessary that I have these medications. And I said, well, of course I do, I have Parkinson's. So they said, well, isn't there something else you could use? And I said no, and I had to get a note from my doctor in order to have*

*those two medications covered. (Int.: "So you really had to push the system?") Yes – I really had to work hard to get those medications!*

Janelle described that her ability to be persistent and forthright in her communications with care professionals was a skill she needed to learn, that she had previously been less assertive and unable to express her needs when interacting with professionals in larger institutions or organizations. Her illness 'taught' her this skill. Upon being diagnosed, she learned that her new found ability to 'push' the system by being more assertive was useful when advocating for herself. People are also aware that their ability to communicate on their own behalf will change as their condition progresses. Ironically, participants talked about how important it was to be polite and nice when interacting with health care professionals, to be courteous with care professionals in order to get ones care needs met. However, participants also spoke proudly about their ability to push the system and get what they needed when they were less polite. At times, they enlisted the support of health care professionals to achieve their goals. In cases where a care professional was not able to assist them in successfully 'pushing the system', it was clear that disappointment in the care professional occurred. There was an expectation that when patients had allies in health care, the patients felt better able to communicate within the system. This theme persists throughout the study and becomes important to our broader theme of social support promoting individual resilience. Those who felt supported by a social service professional also expressed higher levels of satisfaction with communications with health care professionals.

Troubling communications with people with neurological conditions are often attributed to the disease itself, while Janelle is articulate in stating that some of her characteristics, which may in another person be seen as a symptom of her condition, are part of her old normal self. Medicalizing personality traits that existed prior to the onset of an illness can lead to mis-understandings and inadequate care plans. In this sense, people's ability to communicate with health care professionals may be interpreted as part of their condition, but in fact, may be describing personal traits and qualities they have always had.

#### **5.4.1.2 Self-reflection about personal characteristics prior to condition**

The participants in this study demonstrated resilience in the example of adaptation and coping with extraordinary circumstances. While these may appear as minor or simple reflections of resilience, they must be understood in the context of challenging and usually complex lives. One approach to resilience research has been to seek out adaptive processes or a means of coping with various adversities and defining these as an opportunity to learn or improve upon an individual's protective qualities (Richardson, 2002). Research in this realm has helped to broaden the predominant mindset of problem-oriented approaches, where one would focus on the importance of prevention, encourage strengths and value human fortitude; ultimately, focusing on the basics of a strength-based lens (Krawlik et al., 2006).

For example, Neil says he has always had an optimistic attitude and that this now serves him well as he begins to live with some of his early limitations. He says it could have been anyone who received this diagnosis, so 'why not me?', and he states that he is fine even though he now has this additional condition in his life. His wife Flora also underlines how optimistic he remains after receiving his diagnosis. Janelle describes herself here:

*Well, for instance, I'm terribly, terribly disorganized and always have been. Now, I don't write things down and I forget my appointments and like it causes everybody a lot of stress because I'm scrambling at the last minute to make arrangements and what have you, and she'll say to me, get a book. I'll buy you a book and write these things down and I'll help you with your appointments. I'll help you arrange them and I'll help you get there, you know, but you've got to make the effort to write them down and take note of them so, you know, we're not doing things at the last minute. And she said, I'm quite willing to take you and do anything you want, but you've got to at least be a little bit more organized. And it's true, like I need a kick in the butt. Its always been that way.*

We know that self-reflection about personal characteristics can fade as disease trajectories of neurological conditions progress. A fading ability to recognize one's own style or interactions with others can lead to challenges for health care professionals with the goal of determining where a person with a neurological condition is at. Certainly, when health care providers have known an individual over years as their condition progresses, they are in a much stronger position to assess how an individual is doing – especially as they become less able to reflect on their own processes.

#### 5.4.1.3 Existing social supports

While this factor (#3) does fit with other levels in the Bronfenbrenner system, it is being placed here as the primary location. Traditional research on resilience was rooted in psychiatric literature and focused primarily on children and adolescents capable of dealing with great difficulty (Garmezy, 1985, 1993; Masten, 1999; Werner, 1990; Werner & Smith, 1977). More current examples reflect essential components of social support when developing qualities associated with that traditional literature on resilience. It appears that social support is highly correlated to resilience and that networks are critical for a positive description of social support. A better understanding of how couples might experience or express resilience can directly and indirectly impact care provision, and a professional's inclination to provide better care for a particular dyad. If social supports result in a more resilient patient, it would be helpful to be able to assess this at intake.

It was clear that participants with strong and reliable family or friendship supports were more able to interact effectively with the health care system. Flora states,

*We have a lot of friends who have Parkinson's, by coincidence, not that we've acquired them later on. A lot of people have Parkinson's. And the Parkinson's community now, we've seen it developed. When Nick was first seeing his doctor for Parkinson's, the specialist, there's one neurologist that was looking after it, it was him. Now you've got the Movement Disorders Clinic.....*

Flora and Neil were among the most resilient couples, expressing satisfaction with each other and their communications with the health care system, stating in no uncertain terms that they were happy and getting their needs met. Their social network within the PD community contributed in particular to their perception of resilience, and this is mirrored in other research as well (Roger, 2007a,b; 2006a,b; Roger et al., 2010; Roger & Medved, 2010).

Jack lives in an intergenerational home that led to more supports than he would otherwise have: his wife's mother was living with him, and as an older senior who was cognitively well was supporting Jack in the care of her daughter (his wife with early onset dementia). Jack's grown daughter, who is now a mother as well, comes regularly to bathe and care for

her own grandmother. This pattern of intergenerational supports clearly reduces the caregiving stress Jack has experienced.

However, alternately, another participant had a very different experience. Margareta, whom her husband described as quite a formidable force, did not find support in her own family. She said:

(Int.: "Do you talk to your kids about it at all?") No...No, they don't want to hear about it...They've got families of their own and they're all busy.

Margareta expressed disappointment that 'one must always do everything for oneself' in regards to her family. She also spoke disparagingly of the health care system as an institution.

Although Len did have a sister who lived near him, he was reluctant to over-rely on her for support. His children did not live in the same province, so when he went for what is typically a day surgery, he demanded extra support from the system to compensate for absent family support:

*If I needed it, I'd damn well go after it...I would insist, as I did with the nurses 4 times a day. I told the doctor and his secretary, look, I don't have anybody. If I had somebody, I might not be here. I don't have nobody to do this for me. When I had my surgery, they want someone to stay with you overnight. You shouldn't be alone. I don't have anybody to stay overnight. No family. No relatives. Nobody that can stay the night. I want to stay in the hospital the first night cause I have nobody at home and that's what I want. (Int.:"And what did they do?") They gave it to me...I told them I want it, that's it.*

It was apparent that when family supports were not available that participants depended much more strongly on the health care system and in this way also, our data suggests that they did not always feel the health care system was providing for them. Perhaps their expectation of imagined family assistance was superimposed onto the health care system in a way that could only disappoint. Furthermore, the health care system utilizes an individualistic approach which often leaves family support people "out of the loop". Over time, the rigid boundary which exists between the health care system and the family many have reinforced the tendency of individuals to over-rely on health care professionals, with expectations that the system should provide supports which are not possible in all circumstances.

#### 5.4.1.4 Education levels

A study by Berkman and Syme (1979) identified that a greater social network and frequency of contact lead to decreased mortality of men and women across all ages, even when controlling for socioeconomic status, health status and health practices. However, interestingly, we found participants stated a perception that education and financial resources in fact would significantly improve their interactions with health care professionals. Neil suggests:

*Yeah, probably. Cause I know how to write a letter. You know, that's the thing, when you're submitting your resume, you put a covering letter. The first 5 sentences determine where you're gonna go. I got good writing letters when I was a department head of science. There are ways of writing a letter of recommendation which are positive, and there are negative ways.*

Later, he describes:

*Well you know when you start speaking with an educated person or an uneducated person, you'll notice things in their conversation, grammatical structures and the like, that are more middle class or upper middle class, if you listen carefully, the subjunctive case if you were. If I were instead of if I was. That's what makes a more educated or less educated conversationalist. Now I don't want to be pedantic, but one, so I do make some really simple conversions, but there's different classes of language in English. If you listen carefully, you can tell a person's grade level.*

Janelle's partner (who became her ex in the course of the study), was a skilled labourer and was intimidated not only of the health care system (as he said) but also by engaging with us as researchers in this study. He initially felt he had nothing important to say, which changed as he began to engage with us in the interviews.

It was apparent that other participants who felt confident about their ability to articulate their needs clearly and those with higher levels of education felt more confident in getting their needs met from the health care system.

#### 5.4.1.5 Gender of primary caregiver/ professional

Upon examining ageing women with MS, Harrison and colleagues (2008) identified that women with higher levels of social support experienced higher levels of positive attitude towards their condition even when measured over a period of seven years. Janelle reflects here on her very close care relationships with her daughter:

*My daughter and I...As close as you can get to a caregiver. (Int. "Okay. So I'm gonna just sort of, like the boys, are they more sort of a peripheral role?") Yes. (Int. "Okay. Okay. But your daughter is the one who is more primary?") Yes, absolutely. (Int. "Okay. Alright. So I'm just curious. Do you think that's a function of her being a woman or a nurse?") Actually I think, it's hard to say, but I'd say as a daughter. More as a daughter.*

Another participant, Margareta, exclaimed in no uncertain terms that her girlfriends were her best supports, and regrettably she added, that may include ruling out her husband. Even Jack reflects on gender when he describes that he did not feel comfortable with the quick advice he received from his younger and male doctors:

*Oh, the males were stereotypic doctors. They knew, they had all the answers and attitude and whatever. And the women were there to find out what was wrong with you.*

Later, Jack says that his son was much less involved and even interested in the kinds of care needs he has with his wife and mother-in-law. Evidently, he thought gender played a role in how caregiving occurred and who was hands on in his household. It appears that the gender of the primary caregiver or the care professional shaped how communication occurred, in the minds of our participants.

### 5.4.2 Mesosystem

#### 5.4.2.1 Health care literacy

Couples who had good 'health care literacy' were most able to effectively get their needs met. The relationship between health care provision and the couples we interviewed was described in particular in relation to the participant's ability to confidently interact with the



system. Couples who were the most familiar with the health care system also appeared to have the most effective tools of communication.

For example, Flora and Neil had several experiences with illnesses (each) before Neil was diagnosed with Parkinson's Disease. This meant that they had had a previous entry into the health care system and how it worked and they were more able to translate this into assistance. In Flora's case, her ability to maneuver within the health care system was compounded by the fact that she had been a Social Worker and had firsthand knowledge of how 'care systems' and institutions operate. She speaks proudly of her high level of health care literacy, acknowledging that this has supported Neil's care plan over the years.

On the other hand, Janelle had not had previous health care concerns or interactions with health care, and so when she was diagnosed, she states in no uncertain terms that she found it very difficult to begin to understand the health care system in a way that provided her with the resources. She stressed that she had been a very independent person prior to being diagnosed, and that this new condition left her feeling more vulnerable and needy than previously. Her husband at the time similarly felt overwhelmed by potential interactions with health care professionals. It appears that being new to 'illness' and 'health care' was an additional challenge (and form of literacy) that some participants were less able to deal with.

In another example, Friedrich had been deaf for years, and that now that his elderly wife Margareta had Parkinson's, he said they just 'carried on as usual'. He said they were already familiar with health concerns and the health care system, they were older and had been married over 50 years, and he felt that they were simply able to step into the system and communicate their needs well within it.

In another similar example, Jack described that one of his parents had had a declining neurological condition and that he had grown up with awareness of this condition and the kinds of care and interactions with care professionals that it required. Now, he was caring for his wife and his mother-in-law. He stated that this gave him some insight and even potentially positive perspectives on how now to deal with his wife's young diagnosis in the context of the health care system.

A study by Wallace and colleagues (2001) suggested that resilience improved among individuals who had a sense of purpose and opportunities for communication particularly during times of personal duress. It was found that providing opportunities for communication could impact a person's compliance to medication, reduce errors in communication, and generally improve the experience of the disease trajectory. Further, those who had previous experience of stressful situations and had a sense of purpose might be better able to maximize previous successful social supports as new situations arose. It was evident that those participants in our study who had experienced previous health crises in their lives, and had already become familiar with the health care system, were much better equipped to handle changes now related to the new diagnosis. Clearly, health care literacy improved participant's interactions with health care providers.

### **5.4.3 Chronosystem**

#### **5.4.3.1 Length of relationship to primary caregiver**

Weak social ties have been shown to be correlated with poor health and premature death (Berkman et al., 2000). This may be due to the fact that healthy support systems encourage

good self-care. For example, men in happy marriages are less likely to have health problems, and both men and women in happy marriages are more likely to access health care services when required (Sandburg et al., 2009). Kiecolt-Glaser and Newton (2001) reviewed evidence from 64 articles published from 1991 to 2001, and concluded that poor marital quality negatively impacts health of individuals both directly and indirectly, through poor health habits and depression.

Papadatou (2009) states that social support shapes well-being between people over time, especially when they are dealing with exceptionally difficult life processes, and these may include: a long time committed and shared trajectory; shared responsibility; reinforcement of communication and involvement between committed partners; continuity in times of uncertainty and distress; and allowing for shared learning throughout the defining life process. Certainly, those participants who could be described as strong in their committed relationships appeared to be more resilient and excelled at interacting with the health care system. Thus, evidence suggests that the bond that couples have with each other can contribute to health-related benefits and improve upon an individual's capacity for resilience.

An important factor was how long couples had been together and whether they were married and had raised children together. It was clear that couples who had raised children together and/or had been married for a longer time, were more resilient in handling the issues that now arose. In fact, one of the younger (in age) couples who had only been together a few years and that we interviewed in the first Phase of the study, were no longer together in the second Phase of the study. It became clear in the second interview in Phase II, when we only interviewed one person in the couple, that the progression of the condition had contributed towards the ending of their relationship. In another case, however, a long time marriage led to a deepened sense of commitment to the husband who had one of the selected conditions.

*I don't have trouble with that really. Well if anything's bothering me, I tell her right out. I don't care how they feel about it. In my mind, my concern is my husband. I don't care what you're doing with anybody else, but my husband, I want him looked after too. And they've been very, very good.*  
(Marlene)

Marlene stresses that she knows her husband well and what his needs are and that this aids her in communicating more effectively with the health care professionals. She acknowledges that the long term care unit her husband is on is chronically lacking enough staff to adequately meet the residents' needs. However, her loyalty and commitment to her husband ensure she advocates for him so that he gets his needs met, despite a lack of resources:

*I don't have trouble with that really. Well if anything's bothering me, I tell her right out. I don't care how they feel about it. In my mind, my concern is my husband. I don't care what you're doing with anybody else, but my husband, I want him looked after too. And they've been very, very good.*  
(Marlene)

Length of time together is an indicator of relationship commitment and loyalty, and even when the patients cannot advocate for themselves, a committed and assertive partner can ensure they have their needs met, even in an overburdened healthcare system.

Margareta and Friedrich also stressed that their 50 + years of marriage had allowed them to grow more resilient as a couple over time in a way that was demonstrated by their ability to now cope. This length of time together, according to Friedrich, has positively impacted their ability to communicate with health care professionals.

#### 5.4.3.2 Stage of the illness

It became evident over the three years of collecting data that the patient's stage of illness in tandem with existing social supports largely contributed to their sense of resilience (or lack thereof) and (in)ability to communicate well with health care professionals. Research has shown a consistent positive relationship between social connectedness, integration and stages of physical health (Cohen, 2004). Janelle became much less able to engage with the health care system after her relationship ended and her condition deteriorated. However, she then made the decision to move to another province where her children were living and this dramatically improved her health – as evidenced in her second interview with us. She felt more able to communicate about her needs, and she certainly had social supports around her.

Flora on the other hand, suggested that you need to prepare for times ahead when you know a condition will be deteriorating:

*I think it's partly communication. Sometimes people just don't know what to ask for even in the beginning. Like you haven't been trained to know what to ask for. You know, people vary. Sometimes they just think, oh I'll just keep managing, or I'll just keep going. They wait until there's a crisis instead of saying, okay, we're on this path anyways now. But this is a chronic illness. What is it's path? What do we expect? You can't predict. You know, you could have Parkinson's and die of a heart attack. You have to start early and prepare for things down the road.*

Other participants reflected on a 'future' when they may not be able to communicate as well as they do now. They were developing an awareness of the kinds of supports they might need to put into place for that point in time. When people are living with a neurological condition, a fact which clearly demarcates them from examples such as cancer, they know that their condition may progress over sixteen or more years. Their ability to consider a distant future means that they have a lot of time to consider changes that might occur to them. This makes their situation unique from other conditions. Their engagement with health care professionals will also remain in a more 'chronic' phase for many years, with room for many discussions about possible later stages. This can both be a strength and a vulnerability where people can prepare and plan, but also may become overwhelmed with realities. Health care professionals must have a clear understanding of this trajectory which includes emotional, cognitive and physical realms.

#### 5.4.3.3 Age

While there were few quotes that specifically explored participant's reflections on age, it was apparent that 'age' was a constant presence in the discussions regarding health care communications. Jack stated how much he did not appreciate 'the younger physicians', who he felt had less experience and fewer insights into situations he might have questions about. Age shone through in another way as well - it was clear that the older couples in

our sample were more resilient than the younger couples and that they were more prepared for eventualities related to neurological decline. They appeared to have more capacity when interacting with and communicating with the health care system as well. It was apparent that younger folk had a much harder time with their diagnosis, such as Janelle. She would not have anticipated this diagnosis at such a young age, and her stories indicate that she was having a harder time in general. Age also intersected with the long term couples to create a bond that promoted not just their social supports developed over time, but also their sense of resilience as individuals and a couple.

### **5.5 Findings from focus group data**

The focus group data consolidated the importance of the nine factors found in the interviews that have been discussed above – bringing together key elements to this study and the emerging data. The above nine factors were presented in summary form to the focus groups to ascertain the extent to which these findings reflected the participant professional's experiences. Each of our focus group participants confirmed that these factors were highly relevant in their experience of intake with new individuals in order to determine how couples were handling difficult situations related to their diagnosis. They stated that the nine factors were central to how well the couples (and families) were doing and thus also how they would benefit from health care communications.

However, focus group participants also expressed concern that there was not a standard form or approach to this kind of intake assessment. Few tools if any existed to refine or better understand these nine factors. They underlined how relevant this information would be if it were being collected and analyzed more effectively by individual organizations / researchers.

One of the key discussions in the focus groups thus revolved around the preparation, implementation and compilation of their organization's intake forms. The participants in our focus groups stated that while intake forms were used to collect information related to the nine factors, the process of collecting information and the forms themselves were limited. For example, there were several different forms to be used at intake. Little training existed in how best to fill out the intake forms and what to do with the information professionals had collected. Further, our focus group participants described that any number of forms developed by their organizations might be used at intake and then filed away without being compiled or analyzed. Therefore, the information being collected was fragmented and lacked a cohesive structure or purpose after collection.

The focus group participants stressed that developing a unified form, and a comprehensive analysis of the data on these forms, could result in an important source of information for developing not only better assessment tools for intake, but also towards improved services for patients. Professionals stated they could better assess couples at risk and also provide more catered and effective care services if this information was made analyzed and compiled and then available to them. However, care professionals in our focus groups stated they had neither the time nor the skills to compile and analyze the data available to them through their own organizational intake forms.

## 6. Discussion

Since we know so little about interactions between family care providers and their loved ones in terms of health communications, and we know equally little about their interactions with health care professionals, it is even more significant that we also know so little about a large group of persons living with neurological decline. Living with a neurological condition is a reality which can affect individuals and their caregivers for well over fifteen years. The unique medical realities associated with the etiology of the neurological conditions encompassed within the mandate of the NHCC must be better understood.

Firstly, the value of social support has emerged in this data as central to the couples interactions with health care professionals, and this in turn, matches what the literature suggests about resilience. Assessing for social support and resilience early on in the intake procedure will benefit a well implemented care plan and improved well-being for all concerned. Social support has been shown to emerge not only through personal family and friendship relationships but also through professionals who have had a continuous relationship with the patient over time. When there is a high turnover and professionals have little education and training in dealing with neurological conditions, patients are impacted with less than optimal care conditions. Compliance to treatment plans and general well-being are affected.

In the context of Bronfenbrenner's ecological model, we can presume that a care professional's ability to communicate clearly with couples in a health care context depends on an understanding of factors that go beyond the medical condition itself. A couple's level of social support appears to be important to building their perception of their own resilience. Likely, social support is critical when we consider communication issues with health care providers as well - potential errors in developing care plans, misjudgment of what is required, and the patient's ability to successfully carry out what has been suggested. If professionals have a good understanding of social factors that surround a patient's daily life, these could be articulated and understood in order to benefit the medical aspects of the treatment. To separate out medical aspects of a condition from daily lived experiences (e.g. social support) may be setting the stage for poor care plans that may not be implemented properly - leading to potential for further crisis and poor health down the road.

The participant narratives demonstrate that the couples' perception of resilience was intertwined with factors associated with social support. Participants who were less able to 'push the system' also appeared to have fewer social supports in their life, they had less familiarity with the health care system, they appeared to have lower levels of education, or, they were simply farther along on the disease trajectory and depended on others to advocate on their behalf. A better understanding of the intersection of these nine factors is imperative.

The goal of this study has been to better understand how couples living with a neurological condition communicate and how they do so in the context of health care communications. In particular, the data discussed in this paper are intended to assist the development of tools that can also assist professionals in improving their understanding of individuals ( e.g. couples and families who provide care) living with neurological conditions. Recommendations towards this goal follow.



7. Recommendations

Several recommendations are highlighted as a result of this study (see Table 3). It was evident that social support can be seen to improve the participant’s sense of their own resilience when communicating about health and with the health care system. Intake could also be improved to assess for levels of social support and resilience in couples. The nine factors found in our sample reflect important aspects of social support and resilience. This information can lead the way to the development of a new tool that would provide more insight into how couples experience resilience and how this can benefit their communication with health care professionals and the health care system. This data leads to the recommendation that the nine factors be used to develop a new form which could be piloted in a selected set of organizations. These organizations could then participate in a second phase where the data collected over a specified period of time be compiled and analyzed with ‘social supports as promoting resilience’ in mind. This would have in mind a third phase with the purpose of establishing improved communication training (e.g. developing new training and education) between professionals and clients.

PILOT NEW FORM	NEW DATA COLLECTION UPON INTAKE	NEW TRAINING FOR PROFESSIONALS AND FAMILY
1. To develop a pilot of a new form that encompasses the nine factors identified here.	2. To collect data on each of the nine factors as these relate to patient intake. To support inhouse compilation and analysis of these data.	3a. This would include training for professionals in order to identify levels of risk and resilience.  3b. Selected mentors, advocates, and/or a buddy system within health care could be created to train family members upon intake.

Table 3. Recommendations for New Research and Organizational Interventions.

8. Conclusion

This paper has discussed original, empirical data highly critical for health service provision given the anticipated increased diagnoses of persons with neurological conditions. Since we know that little research has been found examining the daily lived experience of families, where one person is living with a neurological condition, this study contributes to knowledge in this area. The paper has explored nine factors that emerged from the data. The authors suggest that communication about care, and the many factors that shape it, must be better integrated into our daily health care provision – expanding on what we know about medical aspects of conditions such as Huntington’s and Parkinson’s. Since contradictory and often unspoken expectations of care emerge between professionals, family and individuals, a better understanding of social factors that influence communication might

reduce errors in care, poor treatment, and misunderstandings. These outcomes can result in significant cost savings for the health care system but also improved well-being of families and those affected by neurological conditions.

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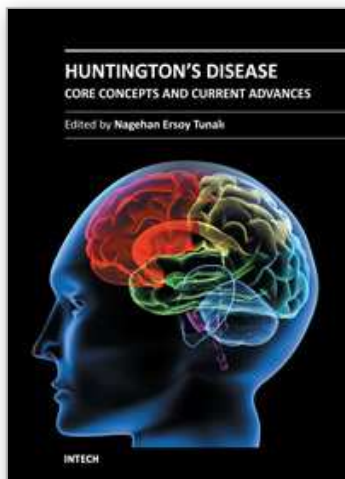
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## **Huntington's Disease - Core Concepts and Current Advances**

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Huntington's Disease is one of the well-studied neurodegenerative conditions, a quite devastating and currently incurable one. It is a brain disorder that causes certain types of neurons to become damaged, causing various parts of the brain to deteriorate and lose their function. This results in uncontrolled movements, loss of intellectual capabilities and behavioural disturbances. Since the identification of the causative mutation, there have been many significant developments in understanding the cellular and molecular perturbations. This book, "Huntington's Disease - Core Concepts and Current Advances", was prepared to serve as a source of up-to-date information on a wide range of issues involved in Huntington's Disease. It will help the clinicians, health care providers, researchers, graduate students and life science readers to increase their understanding of the clinical correlates, genetic aspects, neuropathological findings, cellular and molecular events and potential therapeutic interventions involved in HD. The book not only serves reviewed fundamental information on the disease but also presents original research in several disciplines, which collectively provide comprehensive description of the key issues in the area.

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Phone: +86-21-62489820  
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