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Managing Uncertainty in Young-Onset Parkinson's Disease

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A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy

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MANAGING UNCERTAINTY IN YOUNG-ONSET PARKINSON’S DISEASE

Monograph

by

Michael J. Ravenek

Graduate Program in Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

The School of Graduate and Postdoctoral Studies
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Abstract

Typically considered a disease of old-age, Parkinson’s disease can affect those younger in life, i.e., before the age of 55, when it is referred to as young-onset Parkinson’s disease (YOPD). Using constructionist grounded theory, this research sought to understand how, and why, individuals with YOPD became informed about their disease over time. A total of 39 individuals, who self-identified as living with YOPD, took part in this study which was organized according to four cycles of data collection. These cycles utilized focus groups, in-depth interviews and a private online discussion board, supplemented by 14 autobiographies written by individuals living with YOPD.

As the research progressed, it became apparent the process of becoming informed about YOPD was entangled within larger processes of adjusting to, and building resilience to, uncertainty resulting from the disease; this uncertainty was rooted in one’s identity and in one’s ability to function. Resulting from this uncertainty was a perception of having lost control over one’s body and one’s life. The adjustment process described by individuals was categorized according to an initial level of logical adjustment followed by a second level of emotional adjustment that continued throughout one’s experience with the disease. Health information seeking was one of several resilience strategies used by individuals with YOPD to manage the uncertainty they experienced, in an attempt to restore the control they perceived they had lost.

Health information was acquired through extant and elicited sources of information, differing primarily in the degree of interaction each afforded. Early after their diagnoses, individuals sought general information related to the disease, primarily from extant sources. Over time, as one adjusted to the disease, the information sought became more specific to the difficulties experienced by each person, and were acquired primarily through elicited sources. Knowledge accumulated from sources over time was filtered through one’s bodily experience with the disease to make the knowledge more personally relevant, while also influencing subsequent information seeking. The results of this research can help health care professionals provide care to those living with YOPD, and can also help in the design of patient education programs.
Keywords

Parkinson’s disease, young-onset, grounded theory, constructionist, uncertainty, identity, functioning, adjustment, resilience, perceived control, acceptance, denial, health information seeking, experiential learning
Co-Authorship Statement

Select sections of one published paper that I have co-authored with Dr. Debbie Laliberte Rudman (M. J. Ravenek & Laliberte Rudman, 2013), are included in different chapters of this dissertation. For this review paper, I, Michael J. Ravenek, was responsible for collecting and analyzing the literature included, as well as the subsequent writing of the paper. The contribution of Dr. Laliberte Rudman was primarily through guidance in navigating the literature, dialogue around the synthesis of the content of the paper, and edits to the content that I had written.
Acknowledgments

In writing an acknowledgments section, you are reminded very quickly that undertaking a PhD is not a solitary task. A well-known quote from Sir Isaac Newton is helpful in starting such a section, where he has said “If I have seen further, it is by standing upon the shoulders of giants.” Within my own life, and this research - If I have done justice to this research topic, and advanced our understanding beyond what it was before I started, it was only because I was supported by an amazing group of people. Without the contribution of each person and group I name below, and the many others who gave me opportunities to develop my research interests throughout my education, this project would not have been as successful as it was in the end.

First and foremost, I am indebted to the 39 people living with young-onset Parkinson’s disease who took part in this project, dedicating hours of their own time, inviting me into their lives and sharing their wisdom with me for others to read. In some cases, no older than I am now when they were first diagnosed, the lessons I have learned from them extend beyond the pages of this dissertation and flow over into my own life. Most notably, we all live with some uncertainty in our lives, whether we consciously acknowledge it or not, and as such, it is important to take advantage of the present; of today, given the uncertainty of tomorrow.

My doctoral advisory committee, consisting of Dr. Sandi Spaulding, Dr. Mary Jenkins and Dr. Debbie Laliberte Rudman were instrumental in providing feedback on my research as it progressed from an idea to the product you are now reading. Each of them helped me in different ways throughout this process, becoming friends in addition to my advisors. Beyond helping me to develop skills in university teaching, Dr. Spaulding reminded me that a PhD is more comparable to “a marathon than a sprint;” words that couldn’t have been any more true. Her knowledge of Parkinson’s disease, combined with her willingness to make herself available for both formal and impromptu meetings, and always asking “what can I do to help?,“ made completing this marathon a manageable task. As a movement disorder specialist, Dr. Jenkins also helped me to push my knowledge of Parkinson’s disease and my thinking about clinical encounters. Her feedback and reassurance of the importance of this work in caring for those with YOPD was a source of motivation from our first to our last
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Chapter 1

1 Introduction

From birth, individuals are socialized into society and come to learn what is accepted, or what is normal, by interacting with those around them (Berger & Luckmann, 1966). Within many parts of the world, Parkinson’s disease is viewed as a disease of older age, with occurrence younger in life being rare (Muangpaisan, Mathews, Hori, & Seidel, 2011). For those who develop young-onset Parkinson’s disease, however, a number of unique psychosocial issues can make one’s experience with the disease challenging in ways that differ from those who experience onset later in life (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2003). In a sociocultural context emphasizing consumerism, empowerment and personal responsibility for health (Harris, Wathen, & Wyatt, 2010), a common way of managing with these issues is to seek out health information. As such, this thesis sought to understand how individuals living with young-onset Parkinson’s disease acquired health information related to their disease over time.

In this chapter I attend to background and contextual information that helps to situate this thesis. I present an overview of the demographics of Parkinson’s disease in Canada, and in the province of Ontario, which is where this research was conducted. In addition, I overview the main symptomology associated with Parkinson’s disease and, in doing so, I describe differences between young-onset and late-onset subgroups of the disease. Through this description, I illustrate the particular circumstances of being diagnosed with the disease earlier in life. After this overview I situate myself within the research, describing the experiences that have led me to develop an interest in young-onset Parkinson’s disease and health information seeking; and I also describe the qualitative paradigm, i.e., social constructionism, in which I locate myself and this research, and provide an outline for this dissertation. Given the importance of context in understanding social processes, I then turn
my attention to the rise of the health consumerism culture in Western countries\(^1\), and research on patient education, before moving to my review of the literature on health information seeking.

### 1.1 Parkinson’s Disease in Canada and Ontario

Since 2003, it has been recognized that approximately 100,000 Canadians live with Parkinson’s disease (Parkinson Society Canada, 2003). In Ontario, which has close to 40% of Canada’s population (Statistics Canada, 2013), the most current prevalence rates for the province (Guttman, Slaughter, Theriault, DeBoer, & Naylor, 2003) would suggest that more than 48,000 people currently live with the disease. Of those affected by Parkinson’s, the vast majority are between 62 and 70 years of age, with incidence peaking between 70 and 79 years (Muangpaisan et al., 2011). With respect to gender differences, there is a slightly greater rate of Parkinson’s disease in men compared to women (Allyson Jones, Wayne Martin, Wieler, King-Jesso, & Voaklander, 2012; Guttman et al., 2003; Van Den Eeden et al., 2003). In the next 15 years, the worldwide prevalence of Parkinson’s disease is expected to reach upwards of nine million people, which represents a doubling in prevalence of the disease between 2005 and 2030 (Dorsey et al., 2007). This is cause for concern, especially in Ontario, given the financial costs associated with caring for those living with the disease (Canadian Institute for Health Information, 2007; Guttman et al., 2003). Mortality rates for those with Parkinson’s are also higher than the general population (Allyson Jones et al., 2012), especially for those living with dementia and Parkinson’s disease (Xu, Gong, Man, & Fan, 2014). A report by the World Health Organization [WHO] (2006) describes how governments around the world are not prepared to manage with the burden that will result from the increasing number of people living with neurological disease. This increase has

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\(^{1}\) Within this dissertation, “Western countries” are defined by a set of cultural qualities that characterise dominant beliefs within these countries. These qualities, or ‘isms,’ as defined by Eckersley (2001) include: consumerism or materialism, “characterized by the acquisition and consumption of goods and services produced in the market economy” (p. 57); individualism, which “places the individual, rather than the community or group, at the centre of a framework of values, norms and beliefs” (p.57); economism, which “view[s] human society as an economic system, and believe[s] that choice is, or should be, based primarily on economic considerations” (p.57); and postmodernism, which “is marked by the loss of grand narratives, universal truths and unifying creeds … [and] meaning in life is no longer a social given, but is individually chosen, or constructed, from a proliferation of options” (p.57).
been caused by the ageing population and a rise in life expectancy. More specifically, the WHO believes that “unless immediate action is taken globally, the neurological burden is expected to become an even more serious and unmanageable threat to public health” (p. 177). Related more specifically to Parkinson’s disease, the WHO report identified education, awareness and the development of knowledge about the disease as important gaps that need to be addressed. These gaps are considered in relation to other neurological diseases with lower prevalence rates. Such development would help prepare health care providers to better manage the care of individuals living with Parkinson’s disease in the future.

In response to the WHO (2006) report, the Canadian Institute for Health Information [CIHI] (2007) sought to identify the exact nature of the burden of neurological disease in Canada. One of the measures used by the CIHI to identify this burden was disability adjusted life years (DALYs), which considers the impact of the mortality and morbidity resulting from a condition. In terms of DALYs, Parkinson’s disease is third among all neurological diseases in Canada, behind stroke and Alzheimer’s disease, with much of the DALY score for Parkinson’s attributed to disability resulting from the disease. Subsequent to the WHO and CIHI reports, the Public Health Agency of Canada and the Neurological Health Charities Canada have worked to secure federal funding to support research on neurological conditions (Caesar-Chavannes & MacDonald, 2013). Most notably, this collaboration has resulted in the National Population Health Study of Neurological Conditions which will provide a review of the scope, impact, risk factors and health service gaps for those living with neurological conditions in Canada. The results of this study are anticipated later in 2014, which should provide a more accurate picture of Parkinson’s in Canada given that current disease estimates are more than a decade old (Guttman et al., 2003; Parkinson Society Canada, 2003).

1.2 What is Parkinson’s Disease?

Parkinson’s disease is diagnosed through a clinical examination based on the presence of cardinal motor symptoms, including bradykinesia (slowed movement), muscle rigidity, postural instability and resting tremor (Jankovic, 2008). Secondary motor symptoms, including shuffling gait and micrographia, as well as non-motor symptoms, including depression, pain and sleeping problems, help to further differentiate Parkinson’s disease from other neurological conditions (Jankovic, 2008; Ziemssen & Reichmann, 2007). Greater
progression of the disease is associated with a greater decline in quality of life, with non-motor symptoms playing a significant role in this decline (Martinez-Martin, Rodriguez-Blazquez, Kurtis, & Chaudhuri, 2011; Politis et al., 2010; Rahman, Griffin, Quinn, & Jahanshahi, 2008; Weintraub, Moberg, Duda, Katz, & Stern, 2004). However, the experience of the disease is very individualized, varying from case to case in terms of progression and the presentation of symptoms (Jankovic & Kapadia, 2001; Politis et al., 2010).

There is currently no cure for Parkinson’s and, as such, the focus of treatment is on disease management. Most commonly, symptoms are managed pharmacologically by dopaminergic therapy to replace the dopamine lost in the midbrain which is the root cause of the disease (Kostić, 2009; Martin & Wieler, 2003). Various surgical strategies, such as deep brain stimulation, have shown a number of benefits in motor symptoms and are becoming more commonly used in advanced stages of the disease (Benabid, Chabardes, Mitrofanis, & Pollak, 2009; Fasano, Daniele, & Albanese, 2012). In addition to available pharmacological and surgical treatments, an individual with Parkinson’s may benefit from nursing, counseling and rehabilitation interventions (e.g., occupational therapy, physical therapy, speech language pathology), to help with adjustment and maintain their level of functioning over time as the disease progresses (Swann, 2005). As discussed by Martin and Wieler (2003), these adjuncts to traditional treatments make for a well-rounded and holistic treatment program for individuals with Parkinson’s disease.

A review of the “lived experience” literature on Parkinson’s disease conducted by Holmes, Lutz, Ravenek, Laliberte Rudman, and Johnson (2013) identified a number of salient psychosocial issues that coincide with the difficulties in physical function and progression of the disease. More specifically, Holmes et al. describe how the unpredictable nature of the disease, including side effects from medication, can create a preoccupation with daily scheduling in a way to try and maximize function and independence. The progression of the disease, marked by the presentation of visible symptoms and side effects, and perceived changes in physical appearance, can also cause social embarrassment leading to limited interpersonal relationships. Through these experiences, as Holmes et al. describe, individuals living with Parkinson’s often encounter emotional difficulties, including frustration, anger and depression, combined with ambivalence toward receiving help from close family and friends. This review also illustrated how the lived experience can be quite variable from
person to person. The heterogeneity of the disease has prompted some researchers to suggest different subgroups of the disease, of which younger individuals living with Parkinson’s is one of these groupings (Lewis et al., 2005; Post, Speelman, & de Haan, 2008; Selikhova et al., 2009; van Rooden et al., 2010).

1.3 What is Young-Onset Parkinson’s Disease?

Although PD typically affects those ages 55 and over, it does occur in younger adults as well where it is referred to as young-onset Parkinson’s disease (YOPD). Parkinson’s disease is rare before the age of 50 (Muangpaisan et al., 2011), with an estimated 20% of those living with Parkinson’s in Canada diagnosed before the age of 50 (Parkinson Society Canada, 2010). 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, as well as 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 the disease; however, the differences that do exist are significant. Schrag and colleagues (2006; 1998; 2003; 2000; 2004), in the United Kingdom, have done a great deal of work highlighting important issues, and differences, for those with YOPD compared to regular, or later-onset Parkinson’s. In a survey comparing the clinical and psychosocial data of 75 individuals with YOPD and 66 patients with regular Parkinson’s, Schrag et al. (2003) found a number of key differences. With respect to psychosocial health, they found those with YOPD had higher rates of: employment and family life disruptions, including marital dissatisfaction and retiring from the workforce early; perceived stigmatization, which the authors attribute to age-related societal norms; and depression, which was found in 40% of the YOPD sample compared to 17% of the later-onset sample. With respect to clinical data collected, they found those with YOPD had higher rates of dyskinesia (a side effect of dopaminergic medication), especially for those who had lived with the disease more than ten years (Schrag et al., 1998). Given the increased risk of dyskinesia in YOPD greater care is urged in the use of these medications (Kostić, 2009; Kostić, Przedborski, Flaster, & Sternic, 1991). YOPD
has also been described as slower progressing compared to the later-onset subtype of the disease (Jankovic & Kapadia, 2001; Selikhova et al., 2009; van Rooij et al., 2010), which means that individuals will live with these psychosocial disruptions and increasing disability for many years after their diagnosis.

Related to disruptions in family life, the impact of YOPD extends beyond marital satisfaction, as it can also be difficult for adolescent and adult children (Blanchard, Hodgson, Lamson, & Dosser, 2009; Schrag et al., 2004). Sexual and relationship dissatisfaction have also been reported in those with YOPD by other researchers, and correlated with increased depression scores and unemployment status (Jacobs, Vieregge, & Vieregge, 2000; Wielinski, Varpness, Erickson-Davis, Paraschos, & Parashos, 2010). Case studies of women with YOPD who became pregnant illustrate a mixed understanding of pregnancy and the disease process, sometimes resulting in the worsening of motor symptoms (Golbe, 1987; Robottom, Mullins, & Shulman, 2008; Shulman, Minagar, & Weiner, 2000) and sometimes not causing any change in the disease (Hagell, Odin, & Vinge, 1998; Scott & Chowdhury, 2005).

With respect to employment, a number of studies have investigated the impact of Parkinson’s on years of employment lost to the disease. On average, individuals with Parkinson’s disease retire from the workforce four to six years earlier than the general population, with almost all individuals leaving the workforce within ten years after diagnosis (Martikainen, Luukkaala, & Marttila, 2006; Murphy, Tubridy, Kevelighan, & O’Riordan, 2013; Schrag & Banks, 2006). These rates tend to be higher for those diagnosed before 45 years of age (Schrag & Banks, 2006), and for those with greater disease progression and cognitive difficulties (Jasinska-Myga et al., 2012). Combined, these physical and psychosocial factors contribute to a greater decline in quality of life for those with YOPD compared to both the general population and those diagnosed with Parkinson’s disease at an older age (Knipe, Wickremaratchi, Wyatt-Haines, Morris, & Ben-Shlomo, 2011; Schrag et al., 2003; Schrag et al., 2000). Additionally, individuals with YOPD may be reluctant to participate in research because of their adjustment to the illness, i.e., denying the diagnosis, fear of stigma and workplace discrimination, a belief in needing to conceal their symptoms, and fatigue resulting in time and energy restrictions to participate in research (Fontenla & Gould, 2003). Such considerations are important for participant recruitment, and were incorporated into the design of this research.
This review of Parkinson’s disease, and YOPD, illustrates the unique difficulties with which individuals are sometimes faced when diagnosed younger in life. Although the disease tends to be slower progressing in those with YOPD, the time of life in which individuals are diagnosed can make employment and family life more complicated. Increased rates of dyskinesia, perceived stigmatization, and depression can further impact on all areas of an individual’s life, as represented by studies illustrating significant declines in quality of life. As discussed in the WHO (2006) report, there is a need to develop a better understanding of Parkinson’s disease so that health care providers can better care for those living with the disease. With the increases in neurological disease that have been predicted for the coming years, it will be important not to neglect the unique needs of this smaller segment of individuals living with the disease. In describing how this research has sought to improve our understanding of Parkinson’s disease, and more specifically of YOPD, I will first situate myself within this research.

1.4 Location of the Researcher

Situating myself within this research is a practice in reflexivity, which Charmaz (2006) has defined as a researcher’s “scrutiny of his or her research experience, decisions, and interpretations” (p.188). The ability to scrutinize and examine oneself is not an easy task, and takes practice in order to be able to do well (Finlay, 2002). Once the skill is developed, it “informs how the researcher conducts his or her research, relates to the research participants, and represents them in written reports” (Charmaz, 2006, p. 189). Reflexivity has been discussed as a means for qualitative researchers to enhance the quality of their work by openly acknowledging their a priori views and understanding of their research topic (Cutcliffe, 2000; Morrow, 2005). In this way, the reader is able to “assess how and to what extent the researcher’s interests, positions, and assumptions influenced [the] inquiry” (Charmaz, 2006, p. 188). Reflexivity is, thus, not only important to engage in prior to starting the research but remains important throughout the entire research process (Finlay, 2002; Mruck & Mey, 2007). In this section, I provide the reader with an understanding of how I came to be involved in this research topic, and how I came to understand the importance of paradigmatic position in qualitative research. I return to conversations about reflexivity when presenting the methodology and methods (chapter three) and in the discussion (chapter six), in relation to the research I have conducted.
1.4.1 Research Topic and Related Experience

During my time at Wilfrid Laurier University (WLU) as an undergraduate, I had the opportunity to work at the Movement Disorders Research and Rehabilitation Centre (MDRC). Although I did not know it at the time, this experience would profoundly influence my future directions. While at the MDRC, I had the opportunity to complete a qualitative thesis investigating issues surrounding physical activity participation for middle-aged adults with Parkinson’s disease (M. J. Ravenek & Schneider, 2009). Although the sample for my undergraduate thesis was chosen based on an assumption that experiences with physical activity would be different if individuals were older, I came to understand that this was really only part of larger differences. It was through this research that I started to gain an appreciation for the difficulties these individuals experienced at work, at home and in their communities more generally. Furthermore, informational support was one of the types of support that I identified in my analysis in 2009, as being part of what facilitated participation in physical activity. My participants in 2009 used information they received from others, along with other types of support, to try and increase their perceived control over their disease through participating in physical activity. Thus, my interest in YOPD and information needs can, in part, be seen as stemming from this initial research that I conducted as an undergraduate. The importance of perceived control is something that was also raised by participants in my doctoral work, as will be discussed.

In deciding between a clinical path and a research path for my future, I came to Western University and completed a master’s degree in occupational therapy (OT). In comparison to other clinical professions, I was drawn to OT because of its core values and holistic beliefs about health, the person and the environment, and the therapist’s role in enabling individuals using these values and beliefs (Townsend, 2002; Townsend & Polatajko, 2007). Instead of working as a therapist at the end of my degree, my experience in the OT program only deepened my desire to pursue research situated in the experiences of adults living with chronic illness, and more specifically Parkinson’s disease. While in the OT program at Western I became familiar with the Interdisciplinary Movement Disorders Laboratory (IMDL), and spoke with Drs. Sandi Spaulding and Mary Jenkins about the research that had interested me. Subsequently, I became enrolled in the Health and Rehabilitation Sciences program at Western as a doctoral student.
Through a tour of the IMDL taken by staff of the Parkinson Society Southwestern Ontario (PSSO), I met Mrs. Tracey Jones who at the time was the Manager of Programs and Services for the PSSO. Mrs. Jones had expressed to me that more needed to be done for those with YOPD in Southwestern Ontario, so after discussing my research ideas with her we made an immediate partnership. Through my partnership with Mrs. Jones, and the PSSO, I volunteered to help organize conferences and workshops for the Society’s stakeholders, including those with YOPD. I was able to use some of these venues to carry out focus groups that were part of my methods, which I will discuss later. At the same time, I also worked for the PSSO for a number of months under Mrs. Jones’ supervision and fielded calls to the Society from individuals with Parkinson’s, their friends and family members. Although I had some previous experience working with individuals living with Parkinson’s prior to this time at the MDRC, this opportunity was invaluable. Those at the MDRC were accessing a community service and participating in research. However, those calling in to the PSSO were sometimes just newly diagnosed or had identified a need for which they thought the Society could help. A number of those who I spoke to in this position had been diagnosed with YOPD, albeit a minority. Thus, this opportunity sensitized me to some of the issues that individuals with YOPD faced, such as employment concerns, as well as who was seeking information from the Society and what information they were seeking. In many ways, it wasn’t just informational support being sought and provided by the Society, but emotional support as well. I will return to talk about my experience at the PSSO in relation to my results later in the dissertation.

1.4.2 Paradigmatic Position of the Researcher

During my first year in the PhD program at Western, I took a qualitative methodology course taught by Dr. Laliberte Rudman. It was through this course that I began to understand the importance of ontological and epistemological beliefs as a researcher; and the implications of these beliefs for methodological considerations in working towards high quality research. As

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2 Parts of this section have been previously published (M. J. Ravenek & Laliberte Rudman, 2013). The content is included with permission of the publisher, as the authors retain the right to subsequent publication of the material after its initial publication in the journal, i.e., the International Journal of Qualitative Methods.
a graduate student being introduced to qualitative methodology, it was only natural for me to strive for an understanding of how to do work that would be held to a high degree and respected by others; not only in meeting the requirements of my degree but in the uptake of my research by others both within and outside of the academy. Perhaps it is a consequence of many consecutive years in undergraduate and graduate education, where evaluation takes the form of reaching certain standards, but it is important for me to know that I am doing “quality” work. Is it not a responsibility of researchers to our participants, among other stakeholders, to ensure that we are reaching for quality? Working with Dr. Laliberte Rudman, and taking her course, gave me the opportunity to think critically about what quality in qualitative research means, and to have discussions with her on how this has changed over time. The result of these discussions was a publication on different approaches to quality in qualitative research which we placed in relation to changing socio-politics (M. J. Ravenek & Laliberte Rudman, 2013).

Guba and Lincoln (1994) define a paradigm as “basic belief systems based on ontological, epistemological, and methodological assumptions” (p. 107). Paradigms have been defined and organized in other ways (e.g., Creswell, 2007; Kuhn, 1996; Ponterotto, 2005), but this philosophical debate is set aside to focus on considerations related to quality and the position from which I conducted this research. To prevent misunderstanding, my discussion focuses on research paradigms as distinct from Kuhnian paradigms which reflect historical transitions or “revolutions” within disciplines. Lincoln and Guba have presented five different paradigms: positivist, post-positivist, constructivist, critical theory, and participatory (Guba & Lincoln, 1994; Lincoln & Guba, 2003, 2005; Lincoln, Lynham, & Guba, 2011). Figure 1.1 presents a continuum of the research paradigms discussed by Lincoln and Guba, showing points of difference in relation to ontology, epistemology, and methodology that will be the focus of the paragraph to follow.
Among the most fundamental characteristics defining the paradigms is the belief in the nature of reality, i.e., ontology. Generally, a realist position holds that there is a true, real, and single reality of a phenomenon in the world, whereas relativists contend that multiple, equally valid and useful, views of a phenomenon exist. Positivists, post-positivists, and critical theorists are all considered realists, but in varying ways. Those working within constructivism and the participatory paradigm, on the other hand, are considered relativists. More specifically, they believe in a context-dependent created, or co-constructed, reality. Thus, the reality they seek to understand lies at the intersection between the researcher’s personal biography and the biographies of the research participants.

Paradigms also differ epistemologically, that is, in relation to views regarding the nature of knowledge and how things can best be known. Paradigms span from objectivist to subjectivist epistemological stances. Although the term objectivity can be ambiguous (Kvale & Brinkmann, 2009), in general, objectivist epistemology holds that true knowledge exists apart from, and can be understood separate from, a researcher’s values and beliefs. In turn, methodologically, this leads to a focus on techniques to eliminate or control the influence of a researcher, and other potential contaminants, in the knowledge generation process.

Objectivist epistemology is most typical of the ‘traditional,’ positivist and post-positivist, paradigms. Subjectivist epistemology, characteristic of the constructivist and other ‘alternative paradigms,’ emphasizes that knowledge is always generated from, and exists within, a particular perspective and holds that people act in the world on the basis of their subjective knowledge. Methodologically, instead of guarding against researcher influence, a
focus is placed on understanding how participants understand their worlds and also how knowledge is generated through interactions with the participants.

Some confusion often occurs when discussing the constructivist paradigm with respect to differences between the terms constructivism and constructionism. Crotty (1998) provides a useful way of thinking about these terms to distinguish them, i.e., as a continuum from more individual meaning-making to more collectively held meanings. More specifically, he “reserve[s] the term constructivism for epistemological considerations focusing exclusively on the ‘meaning-making activity of the individual mind’ and … constructionism where the focus includes the ‘collective generation [and transmission] of meaning’” (Crotty, 1998, p. 58). As my focus within this research is understanding the experiences of those living with YOPD as a collective, I locate myself more on the constructionist end of this continuum. Crotty adds that constructionists emphasize the power of culture in shaping collective meanings. A more detailed description of the constructionist position, and the way in which I have positioned quality within this research, is provided in the methodology and methods chapter. For now, however, I will turn to the specific aspects of the healthcare culture within which this research took place.

1.5 Contextualizing the Research

In developing a stronger knowledge base related to Parkinson’s disease, as recommended in the 2006 WHO report, and working within the constructionist paradigm, it is important to consider the cultural context of health care and health utilized by the population being studied. For Western countries, as will be described, in the past several decades there has been a growing emphasis on health consumerism. However, there is a growing body of research that illustrates the problems with identifying patients, and those seeking health information, as consumers. Evidence from patient education research is also presented that further problematizes such a conceptualization and supports the need for additional research on understanding how individuals, and more specifically those with YOPD, become informed about their disease over time.
1.5.1 The Rise of Health Consumerism

In presenting health consumerism as increasingly common in Western culture, Beisecker and Beisecker (1993) contrasted beliefs associated with consumerism and paternalism, traditionally associated with the doctor-patient relationship. Within this dichotomy, paternalistic medicine emphasizes the expertise of the physician in making decisions, where the patient cooperates to obtain the mutual goal of benefiting the health of the patient. The patient doesn’t hold the physician accountable for negative outcomes because of the belief that they did what they could to help. Thus, “the doctor, based on his or her professional training and experience and because of his or her more objective view of the medical situation, can better determine the appropriate medical course of action” (p. 46). The outcome, good or bad, is seen as being in control of the physician, and even if a treatment decision contradicts the wishes of the patient they should follow the instructions provided. This stands in stark contrast to health consumerism, which Beisecker and Beisecker believe emerged with changes in broader social policy from the 1960s related to consumer rights more generally. With this change in social policy emerged a growing number of medical specialties, and an increasing number of health insurance companies, where medicine became seen as an industry and physicians became seen as service providers. As such, health consumerism is presented as having a focus on patient rights, with the physician providing information, the patient seeking health information and, ultimately, the patient making final decisions. This occurs in conjunction with a greater emphasis on physician accountability, where the physician and patient engage in a contractual relationship, often represented through informed consent forms. The patient is a buyer, or a ‘consumer,’ and can consult a number of health care providers to ‘shop’ for the best care, resulting in a theoretical equaling of the power between patient and provider.

Others, such as N. S. Lee (2007) and Johnson and Case (2012), also point to the consumer rights movement of the 1960s as being a turning point in the uptake in the description of patients as health consumers. More specifically, the Kennedy Consumer Bill of Rights and the rights “to choose freely, to be heard, to be informed, [and] to be safe” (N. S. Lee, 2007, p. 163) were foundational to challenging the traditional paternalistic nature of medicine and promoting greater patient autonomy. In her historical textual analysis of print media, primarily mainstream health magazines from 1930 to 2006, N. S. Lee describes this transition
from paternalism to consumerism as being less dramatic than how it is often described. More specifically, her analysis showed that in many ways patients still acted as health consumers from the 1930s up to the 1960s, and there was also a large amount of health information to be consumed in print media during this time. Much of this media provided evidence of the paternalistic nature of medicine from the 1930s up to the 1960s, as there was a great deal of material discussing how individuals could be a ‘good patient’ and how they needed to ‘trust their doctor.’ This literature, however, didn’t explicitly describe patients as being ‘consumers’ until the rights movements of the 1960s. Since the 1970s, N. S. Lee describes how being a health consumer has become increasingly more complex, in part because of the corporatization of health care.

Beyond the consumer rights movement, Johnson and Case (2012) also point to a number of other broad health trends that have supported the rise of the consumer metaphor, and the corresponding increase in health information seeking (HIS) and research on the topic. These trends include the growth of technology, especially the Internet, which has made health information more readily available for individuals. Citing that more than one million articles related to health are published online each year, Johnson and Case believe this has made it impossible for physicians to stay current with all of the evidence and has forced a “decentralization of responsibilities” (p. 19). More specifically, if individuals want to receive the most current treatment, they need to take on the responsibility of finding this information for themselves. In many ways, this increased responsibility can be an added burden for those confronted by a serious health issue, where an individual’s resources and the emotional nature of the situation can make it difficult to seek out health information. Bella (2010) describes how, in the United States, United Kingdom and Canada, governments have continued to utilize the consumer metaphor as rhetoric to “disguise the reality that significant work has been downloaded to individuals and families” (p. 28) and away from public responsibility.

Other trends cited by Johnson and Case (2012) that have contributed to increased HIS include shortages of health professionals, the ageing population with increased health care costs, the rise in chronic illness, and a desire for personalized medical care. Such trends have similarly been discussed by Fafard (2006) in the context of Canadian health policy, where generational differences between the ageing baby boomers and their parents have contributed
to the use of the consumer metaphor. Baby boomers are those who were born after World War II, between 1946 and 1964, and grew up during the rights movements. Fafard describes how such consumer qualities have become embedded within their desire for healthcare, demanding choice of traditional and alternative treatments, quality and timely access to care, and a greater role in making decisions about their care. Supporting these demands, and the baby boomers’ indifference to authority compared to previous generations, have been higher rates of education and access to technology to conduct personal health research.

Together, these trends and the description of HIS as being an added burden for some individuals, provide further support for the complex nature of HIS and in viewing patients as health consumers. Thus, although describing patients as consumers may be convenient because of its association with having certain ‘rights’ and greater autonomy in their own health, does it reflect the nature of how health care is delivered or desired by individuals? Salander and Moynihan (2010) believe it is time to start asking these types of questions, moving beyond a focus on autonomy and pre-conceived needs, and using more inductive methods to find out what patients actually need. A Toronto, Ontario based study conducted by Deber, Kraetschmer, Urowitz, and Sharpe (2007) also supports the need to question health consumerist beliefs, given that in a sample of more than 2,700 hospital outpatients 78% of them preferred to share medical decisions with their physicians as opposed to be in an autonomous or passive role.

1.5.2 Health Consumerism and Logics of Choice and Care

Although public health policy of Western governments, such as those in Canada and the United Kingdom, encourages citizens to take personal responsibility for their own health, such as seeking out health information, this policy often fails to reflect existing health care practice (Harris et al., 2010; Henwood, Harris, & Spoel, 2011; Henwood, Wyatt, Hart, & Smith, 2003). Henwood et al. (2003), for example, found that health care providers were often reluctant to take on additional responsibilities associated with reviewing and incorporating health information found by their patients. Additionally, limits of health information literacy, and a preference for such information to come from physicians, can place limits on the extent to which individuals take up the idea of being an ‘informed patient.’ Subsequently, Henwood et al. (2011) framed this disconnect in differences between
the *logic of choice* and the *logic of care* in healthcare, drawing on the work of Annemarie Mol.

Working with individuals living with diabetes in the Netherlands, Mol (2008) illustrates the differences between the logics of choice and care in the context of Western “clichés” (p. 2) about patient autonomy and choice in healthcare. According to Mol, within the logic of choice, individuals are seen as customers or consumers of healthcare where information and/or a product or service are provided and paid for, which then ends the encounter. In this way, individuals use what they ‘purchase,’ either directly or through taxation, to try and maintain ‘control’ over their bodies and a sense of ‘normality.’ However, Mol describes how this logic does not reflect the realities of individuals where decisions are complex, outcomes are unpredictable, and in some cases individuals are not capable of making their own choices. Thus, within a logic of choice, individuals are seen as separate from one another, instead of being part of a collective. In contrast, within a logic of care, individuals work and act together with their care providers, as a collective, to develop health strategies that accommodate for the complexities of personal situations. Thus, their interactions are ongoing and not limited to a product, service or specific number of encounters. In this way, the unpredictable nature of illness becomes integral to care and respecting the idiosyncratic nature of an individual’s biography. Apart from the collective between the individual and the health providers, Mol describes how the patient is also part of many other collectives, or groups of people within their lives, that also impact care. That is, healthcare is not an individual’s personal responsibility.

In evaluating the beliefs of Canadian and United Kingdom citizens about healthy living, Henwood et al. (2011) sought to understand how differences in these two logics, i.e., choice and care, are negotiated in everyday life. They found that the logic of choice, and belief in personal responsibility for health, was apparent in the lives of participants. That is, individuals perceived such messages to exist in their lives. However, achieving such an ideal for healthy living was difficult because of the absence of, and desire for greater, support and care. Such additional support and care would mean providing health information in a way that considers the emotional needs and personal situation of each person. That is, there is a need to “inform with care” (p.2030). Related to HIS, Henwood et al. describe how it is not a rational, linear process; instead, it is a:
“much messier, more emotional and uneasy process that often involves uncertainty, anxiety, and self-doubt, along with a need for interdependence with others who have shared similar experiences and for support and expressions of kindness from help/service providers” (p.2032).

Henwood et al. believe that public health policy should better reflect the need for both choice/information and care, instead of wrongfully assuming that choice and care are synonymous. Further evidence of a tension between logics of choice and care can be found by looking at the patient education literature where programs have been designed with the purpose of ‘informing’ patients to achieve positive health outcomes.

1.5.3 Evidence in Relation to Patient Education Programs

Coulter and Ellins (2007) published a review of 129 systematic reviews related to patient education programs for various health conditions aimed at informing patients and involving them in their care. They organized the reviews according to four broad categories, namely programs aimed at improving: 1) health literacy; 2) clinical decision making; 3) self-care; or 4) patient safety. These reviews were then evaluated based on their effects on patient knowledge, patient experience, use of health services and health behaviour and health status. Overall, Coulter and Ellins found that most of the reviews supported the adoption of such programs to involve and educate patients, yielding positive outcomes. Despite this conclusion made by the authors, it is important to note that many of the reviews also reported either mixed or negative outcomes in the areas they were evaluated. More specifically, across the four categories of systematic reviews, five reviews provided either mixed (n=4) or negative (n=1) results in terms of improving patient knowledge; 29 reviews provided mixed (n=22) or negative (n=7) results for improving the patients’ experience; 21 reviews provided mixed (n=16) or negative (n=5) results for improving the use of health services; and 45 of the reviews provided mixed (n=31) or negative results (n=14) for improving the health behaviour or health status of patients. Although most of the evidence supported a recommendation of continuing, and incorporating such education programs in the care of patients, was such a broad recommendation warranted? If health information is supposed to be beneficial for individuals then why doesn’t everyone benefit from it? And why, in some cases, can it
actually result in negative outcomes? Aren’t health consumers supposed to benefit from health information?

1.5.3.1 Patient Education Programs in Parkinson’s Disease

Related more specifically to Parkinson’s disease, a number of patient education programs have been developed and evaluated. Similar to the review by Coulter and Ellins (2007), evidence that these education programs are effective is relatively weak, and in at least one study the program resulted in negative outcomes for individuals (see Table 1.1). Furthermore, these programs did not consider that the needs for younger individuals living with Parkinson’s might be different for those diagnosed later in life, i.e. after 50 years of age. Based on the age range of the samples in these studies, younger and older individuals living with Parkinson’s were combined into the education groups with the vast majority of the participants across the studies being 65 years or older. A brief description of each of these studies is provided in the sections below.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Country</th>
<th>Type of Study</th>
<th>Parkinson’s Sample</th>
<th>Intervention Outcomes</th>
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<td>Age Range (Mean)</td>
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<td>Positive Change</td>
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<tr>
<td>A’Campo et al. (2010)</td>
<td>Holland</td>
<td>Randomized Controlled Trial</td>
<td>35 IG 48-83 (65)</td>
<td>Mood</td>
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<td>QOL, Psychosocial Health, Depression</td>
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<td>29 CG 45-80 (64)</td>
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<td>Simons et al. (2006)</td>
<td>United Kingdom</td>
<td>Pre-Post Tests</td>
<td>16 50-77 (65)</td>
<td>Mood</td>
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<td>Sunvission et al. (2001)</td>
<td>Sweden</td>
<td>Pre-Post with Follow-Up (3 months)</td>
<td>43 53-85 (75)</td>
<td>QOL, Motor Performance, UPDRS - ADL</td>
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<td>UPDRS – ME, UPDRS – H&amp;Y</td>
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<td>Lindskov et al. (2007)</td>
<td>Sweden</td>
<td>Controlled Trial with Follow-Up (1 month)</td>
<td>48 IG 49-82 (69)</td>
<td>Levodopa Usage, Physical Health Status, Mental Health Status</td>
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<td>Montgomery et al. (1994)</td>
<td>United States</td>
<td>Randomized Controlled Trial</td>
<td>140 IG NP (61)</td>
<td>Exercise participation, ‘off’ score, physician visits, self-efficacy</td>
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<td>Medication use, sick days, hospital days, global assessment of Parkinson’s, global assessment of QOL</td>
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<td>150 CG NP (71)</td>
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<td>Shimbo et al. (2004)</td>
<td>Japan</td>
<td>Mailed Questionnaire (Randomized)</td>
<td>762 58-76 (67)</td>
<td>QOL (in relation to information satisfaction)</td>
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<td>Ward et al. (2004)</td>
<td>United Kingdom</td>
<td>Randomized Controlled Trial with Follow-Up (1 year)</td>
<td>27 IG with PD 29-89 (63) for entire sample</td>
<td>ADL Score, Health Service Utilization, Well-Being</td>
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<td>Self-Reported Falls, Self-Reported Skin Sores</td>
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<td>26 CG with PD 22-86 (65) for entire sample</td>
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**Abbreviations:** ADL – Activities of Daily Living; CG – Control Group; H&Y – Hoehn & Yahr Score; IG – Intervention Group; ME – Motor Examination Score; NP – Not Provided; QOL – Quality of Life; UPDRS – Unified Parkinson’s Disease Rating Scale.
A standardized patient and caregiver education program for Parkinson’s was developed by a group of seven European countries, called the EduPark program or the Patient Education Program Parkinson, consisting of eight weekly 90 minute sessions on a variety of topics related to the disease, and has since been evaluated by teams within the consortium (A’Campo, Wekking, Spliethoff-Kamminga, Le Cessie, & Roos, 2010; Simons, Thompson, & Smith Pasqualini, 2006). Simons et al. (2006) conducted an initial evaluation of the program in the United Kingdom using a sample of 24 individuals with Parkinson’s (and 12 caregivers). However, data from only 10 caregivers and 16 individuals with Parkinson’s were included in the analysis because the others had not completed enough of the program. The authors found that the mood of both patients and caregivers improved after each session, but measures of quality of life, psychosocial health and depression did not show any improvements from the start to the end of the program. Using the same standardized program, A’Campo et al. (2010) conducted a randomized control trial comparing the program to usual care for 64 individuals with Parkinson’s (and 46 caregivers) receiving care in Holland. The authors found the caregivers improved their psychosocial health, and that the mood of both patients and caregivers improved after each session. However, very similar to the results of Simons et al., on the other measures evaluated, patients did not do any better than those in the control group with respect to scores for depression, quality of life or psychosocial health. Despite the lack of evidence, the researchers believe the education program provides promise for empowering individuals affected by Parkinson’s disease.

Similar to the EduPark program, a Swedish multidisciplinary education program for individuals living with Parkinson’s disease, consisting of ten 120 minutes sessions over a period of five weeks, has also been evaluated in the research setting (Lindskov, Westergren, & Hagell, 2007; Sunvisson, Ekman, Hagberg, & Lökk, 2001). Sunvisson et al. (2001) assessed the improvement of 43 participants on a number of measures, including three sections of the Unified Parkinson’s Disease Rating Scale (UPDRS) and assessments of motor performance and quality of life. The UPDRS and motor performance assessment were evaluated at the end of the program, and again three months later. However, the quality of life assessment was only assessment at the three-month follow-up period in comparison to baselines measures. The team found that the program resulted in significant improvements in motor performance scores at the end of the program, which lasted through to the follow up
period. However, only the activities of daily living component of the UPDRS was found to improve at the three-month follow-up. There were also significant increases in quality of life scores three-month after the end of the program. Lindskov et al. (2007) completed a controlled trial evaluating a program based on that designed by Sunvission et al., which involved 96 individuals with Parkinson’s disease, 48 in the control group and 48 in the intervention group. They evaluated the outcome of the program using a measure for levodopa usage and a short health questionnaire, with health status broken down into physical and mental components. Lindskov et al. found that there was no difference in any of these outcomes, between the intervention and control groups, at the four-week follow-up. In contrasting their findings with Sunvission et al., the researchers believe that Sunvission et al.’s positive results may be misleading for a number of reasons, including the lack of a control group and the type of statistical analysis used by the authors.

Montgomery Jr, Lieberman, Singh, and Fries (1994) completed a randomized controlled trial to assess the effectiveness of a mail-based patient education and health promotion program for individuals living with Parkinson’s disease. The sample included 290 individuals, with 140 part of the intervention group and 150 part of the control group. The intervention was a six-month program where participants completed questionnaires every two months, and were then provided educational materials and health promotion recommendations based on their age, disease severity and other items collected on the questionnaires. Reports generated for each participant were also shared with his/her physician with additional recommendations for the physician to consider with respect to treatment. By the end of the program, participants showed improvements in exercise participation, time spent ‘off’ of medication, physician visits and self-efficacy related to symptoms, function and management. However, differences between the groups were not found for medication use, sick days, time spent in hospital, a global assessment of participants’ experience with Parkinson’s, or a global assessment of quality of life.

Shimbo et al. (2004) assessed the extent to which patient education influenced health-related quality of life in a sample of 762 individuals living with Parkinson’s disease using questionnaires. Although the results suggest that there is a positive relationship between patient education and health-related quality of life, the results should be interpreted with caution. More specifically, the questionnaire assessed individuals’ satisfaction with
information related to Parkinson’s on a number of broad areas (e.g., pathophysiology, drug therapy, financial and social resources and rehabilitation). Thus, the results do not indicate patient education resulted in greater quality of life, but rather that there is a positive relationship between one’s satisfaction with the information they received and their quality of life. Another important feature of this study to point out is that it was conducted in Japan using members of the Japan Association of Patients with Parkinson’s. Given the difference in culture between Japan and Western countries, the applicability of these findings within Western countries would likely be limited. In China, Guo, Jiang, Yatsuya, Yoshida, and Sakamoto (2009) completed a controlled trial of patient education for individuals with Parkinson’s and their caregivers. The study did find improvements in health-related quality of life for the intervention group, but the specific impact of the education program is unclear because it was combined with an individually tailored rehabilitation program.

Ward et al. (2004) completed a controlled trial to evaluate the effectiveness of a home-based education program for individuals living with a variety of neurological conditions, including Parkinson’s disease. Their primary outcome measures were self-reported falls and skin sores, which was assessed again one year after the end of the program. Fifty-seven individuals were randomized to either the education group or the control group, for a total of 114. Fifty-three individuals with Parkinson’s and 45 with multiple sclerosis took part in the study from the United Kingdom (England). The remaining 16 participants had a variety of other neurological diseases. The trial provided evidence that patient education can sometimes have negative outcomes, as those in the education group actually had significantly more falls and skin sores compared to the control group, at the end of the program and at one year follow-up. Furthermore, there was no change found in activities of daily living score, service utilization or well-being. Ward et al. describe how their findings “challenge the assumption that person-centered education is inevitably beneficial: in some circumstances it may even be harmful” (p.723), as was the case for their program.

The evidence from the patient education literature suggests a more complex picture than what would be expected using a logic of choice and seeing patients as rational health consumers. More specifically, being provided with health information in a formal education program didn’t always results in improvements for participants, in important areas like quality of life, depression, psychosocial health, well-being, service utilization, etc.
Furthermore, the results from Ward et al. (2004) suggest that sometimes providing health information can even result in negative outcomes for participants. This evidence provides further support for a tension between the logics of choice and care, and that simply providing health information doesn’t always meet the needs of those living with illness.

1.6 Purpose

While individuals within Western healthcare, political and cultural contexts are encouraged to act as consumers and take greater personal responsibility for their health, through activities such as HIS to become ‘informed,’ there may be a tension between this logic and the needs of individuals with respect to their health care. Furthermore, education programs aimed at informing patients do not necessarily benefit those who take part in them, and in some cases can actually be detrimental to their health. At the same time, these programs have not taken into account that younger and older individuals living with Parkinson’s disease may have different information needs. For individuals living with YOPD, who have unique needs and concerns as adults living with a progressive neurological condition, the purpose of this research is to understand their experiences in becoming informed about their disease. That is, this research seeks to understand the HIS behavior of individuals diagnosed with Parkinson’s disease younger in life, in a culture of health consumerism and a prevailing logic of choice. With a better understanding of this process, programs and services can be developed to better meet the needs of those living with YOPD.

1.7 Organization of the Dissertation

In the introduction, I have provided a brief overview of Parkinson’s disease in general, and some of the unique issues and concerns of those living with YOPD. I have also positioned myself in relation to the research topic and the paradigmatic position from which I locate myself and have conducted this research. Contextualizing this research, in terms of its significance and purpose, I have discussed the rise of the patient as a ‘consumer’ metaphor and its associated ‘logic of choice.’ Evidence from the patient education literature, however, supports that idea that this metaphor and logic may not actually reflect the needs and experiences of those in Western cultures. This disconnect, combined with a greater need for knowledge about those living with YOPD to help care providers, has provided the grounds
on which to base an investigation to understand how individuals become informed about their disease.

In chapter two, I take a closer look at the HIS literature outlining the existing theories and gaps, and the specific questions that this research sought to address. It will start with an overview of the HIS literature generally, and then narrow in on literature done with those living with neurological diseases, including Parkinson’s disease.

In chapter three, the methodology and methods used to conduct this research are presented. More specifically, the tenets of grounded theory, and constructionist grounded theory, are described in detail. Following presentation of the methodology, I outline the strategies used in collecting and analyzing the data across the cycles of this research. Working within the constructionist paradigm, I also present the framework through which I sought to achieve quality within this research.

In chapters four and five, I present the grounded theory resulting from my research. More specifically, in chapter four I provide an overview of the participants who took part in this project and the extant texts I used in gathering additional data. The remaining sections of chapter four provide an overview of the theory and outline the core category, managing uncertainty, around which the theory is built. In chapter five, I present the different processes used by individuals in managing with the uncertainty they experienced, including processes of adjustment and building resilience. The abductive and emergent nature of grounded theory methodology led me to broaden my focus beyond HIS specifically, so that I could come to better understand how it fit within the experiences of those living with YOPD in this study.

In chapter six, I discuss the theory I developed in relation to existing literature, expanding my focus beyond the HIS and patient education literature into other literature related to chronic illness adjustment and resilience. I also return to the framework for quality assessment I employed to discuss the different ways that I worked to achieve quality within this research. I conclude the dissertation by summarizing the research, and drawing implications for those who provide care to those living with YOPD as well as for future research.
Chapter 2

2 Literature Review

The health information seeking (HIS) literature is vast to say the least, as much work has been done in this area, given Western cultural beliefs around being informed health consumers. I turn to literature reviews by Lambert and Loiselle (2007) and Anker, Reinhart, and Feeley (2011) that help to situate the focus of research in HIS as it grew as a field over the last 30 years, and point to areas where additional research is still needed. Johnson and Case (2012) and Case (2012) help to differentiate between models and theories related to HIS, and provide an overview of the different types of both that have appeared in the literature. Given the focus of this dissertation on YOPD, an overview of literature related to HIS in neurological populations is also presented. Before presenting specific literature from this body of research, I situate the place of the literature review in a grounded theory study. Although I have yet to describe grounded theory methodology in detail (see chapter three), the place of the literature review is a topic of much debate. Therefore, it is important to discuss my approach to this part of the research process in the context of the methodology that I have used.

2.1 The Literature Review in Grounded Theory

Just as there are different approaches to grounded theory methodology, there are differences in opinion about the place of the literature review (Bryant & Charmaz, 2007b; Charmaz, 2006, 2014). Much of this debate stems from descriptions of the grounded theory process by Glaser and Strauss (1967), who were the original creators of the methodology. For example, they describe how “an effective strategy is, at first, literally to ignore the literature of theory and fact on the area under study, in order to assure that the emergence of categories will not be contaminated by concepts more suited to different areas” (p.37). That is, because a grounded theory seeks to develop a theory that is ‘grounded’ in the data collected, Glaser and Strauss thought it would be unwise to develop preconceptions about a topic fearing that it would influence the development of the theory. According to Glaser and Strauss, developing such a base of knowledge before starting the research “increases the probability of brutally destroying one's potentialities as a theorist” (p.253).
Even among contemporary grounded theorists there are many criticisms of a complete ignorance of the literature (Bryant & Charmaz, 2007b; Charmaz, 2006, 2014), not the least of which points to the differences in existing knowledge between novice and more advanced researchers. More specifically, in making such a claim, it was believed that Glaser and Strauss didn’t need to consult the existing literature because of their vast knowledge about their topic area, developed through extensive research experience (Wiener, 2007). Novice researchers, conversely, do not have the luxury of such an expanse of existing knowledge. Furthermore, and important in taking a constructionist approach, the interest in a specific topic usually implies some understanding of the area, and that researchers will come to the research setting with certain beliefs or perspectives about the topic (Bryant & Charmaz, 2007b; Charmaz, 2006, 2014). Thus, as a constructionist, it is important to make these beliefs and perspectives explicit, as I have done in chapter one in locating myself in the research and which I continue to do in other chapters of this dissertation. Not unlike other research methodologies, Charmaz (2006, 2014) further discussed how the literature review is needed to position the importance of the research, identify gaps and discuss how the theory developed contributes to the body of research. Thus, the literature is not just drawn on at the beginning of the research process but continues to play a role as the theory emerges over time.

To summarize, the literature review in a grounded theory is a delicate balance between accounting for previous work, placing the researcher in relation to this work, and being cognizant of the role of existing research in the development of the grounded theory. As a constructionist, my goal in developing a theory is not to test or evaluate previous research, but to construct a theory within the context of the research setting. The emergent nature of the grounded theory process makes a review of all of the potential literature difficult at the outset, so additional literature from areas relevant to the developing theory may need to be incorporated over time. As the research purpose, as originally conceived, focused on the process of HIS in those living with YOPD, this chapter provides a broad overview of the HIS literature and details some of the specific work done related to HIS and those living with neurological conditions.
2.2 Health Information Seeking

In reviewing the concept of HIS behavior, Lambert and Loiselle (2007) reviewed studies and books published on the topic between 1982 and 2006. Although definitions varied in the sources they analyzed, Lambert and Loiselle described HIS as an overt behavior whereby a person makes a conscious choice to obtain information on a health-related topic. Their review identified the main dimensions and contexts in which HIS behaviour research had been completed up to the time of their review. With respect to dimensions, Lambert and Losielle described an information dimension, referring to the content and depth of information sought, and a method dimension, referring to strategies and sources used to obtain the information. With respect to context, their review identified three main areas where studies on HIS have been concentrated, which include HIS as a: 1) response to a threat perceived in one’s health; 2) means of participating in medical decisions; and 3) means of health promotion. However, Lambert and Loiselle also acknowledged that health information can also be acquired passively, where information was obtained without the conscious effort to do so. In distinguishing HIS behavior from this more passive process, they deferred to Case’s (2002) description of information behavior which includes active and passive means of acquiring health information as well as avoidance behaviors.

Although the focus of the review by Lambert and Loiselle (2007) was to situate HIS behavior as a concept in the literature, their findings with respect to the dimensions of HIS are corroborated by Anker et al. (2011). Anker et al. detailed the increasing amount of research in the area of HIS leading up to 2010, reviewing studies published between 1978 and 2010. Although their review was not framed along dimensions of information and method, they still found that research had focused primarily on information content and search characteristics, such as time spent engaging in information seeking, i.e., information dimension, and the information sources used, i.e., method dimension. Anker et al. recommended that greater work was needed to help understand the role of HIS in health management, associated health behaviors and the function of HIS, especially with groups living with chronic health conditions using novel methods.

More specific to chronic illness, Ayers and Kronenfeld (2007) point out the need for additional research on specific chronic health conditions, and how and why HIS takes place. These recommendations are shared by Lambert and Loiselle (2007) who describe how much
of the HIS literature has focused on specific illnesses, especially cancer, HIV and heart disease, calling for more research on different stages of health and illness, different age groups, and patterns over time. Anker et al. excluded qualitative studies from their review, and Lambert and Loiselle found only a small number of qualitative studies which primarily focused on preferences for information types and sources. However, qualitative methodologies, especially grounded theory, are well-suited to study how and why, or process, questions (Charmaz, 2006, 2014). Indeed, Lambert and Loiselle (2007) emphasize the important role that qualitative research can play in HIS research, which they describe as the approach they are using within their own HIS research on different cancer types.

2.2.1 Health Information & Health Knowledge

Just as there are varying definitions of HIS, there are also varying definitions of information and knowledge. Although these two terms are sometimes used synonymously, it is an important distinction to make with respect to HIS research. In describing the problems that arise in defining information, and distinguishing it from other terms like knowledge, Case (2012) describes information as being “tangible” and knowledge as being a “phenomenon of the human mind” (p.73). Thus, a process of learning or constructing knowledge based on interpretation of the information is implied. Furthermore, Case describes how information can be perceived “in your environment or within yourself” (p.4), acknowledging that, beyond what is typically thought of as information, the body can also be a source of information. This distinction between information and knowledge provided by Case will be how the two terms are operationalized within this dissertation.

Within one’s environment, health information can come from a variety of sources including various types of print and broadcast media, including television shows, commercials, newspapers, magazines and the radio, for example (Brodie et al., 2001; Brodie, Kjellson, Hoff, & Parker, 1999; Case, 2012). Family members, friends and, not surprisingly, health-care providers are also commonly reported sources of health information (Brodie et al., 1999; Case, 2012; Cotten & Gupta, 2004; S. Fox & Jones, 2009). The landscape of HIS research started to change in the 1990s, however, with the broad availability of the Internet and home computers (Leiner et al., 1997).
2.2.2 The Growth of Health Information Technology

As described by Ferguson (1997) and Bischoff and Kelley (1999), the growth of online health information created a ‘paradigm shift’ away from health care providers being the ones to distribute, interpret and filter health information. This shift in beliefs toward patients becoming ‘consumers’ of health information has caused important changes in the patient-health provider relationship. More specifically, some health providers are working with patients to navigate the information or even ‘prescribing’ specific resources, while other providers have become threatened by this change (Malone et al., 2004; McMullan, 2006; Murray et al., 2003). The Internet has become recognized as a readily accessible, up-to-date and anonymous tool for seeking out health information (Bischoff & Kelley, 1999; Cotten, 2001; S. Fox & Rainie, 2000); especially for those living with chronic illness (Ayers & Kronenfeld, 2007). In addition to health information, individuals with health issues also seek out emotional support from others virtually, in chat rooms and discussion boards (Burrows, Nettleton, Pleace, Loader, & Muncer, 2000; Colineau & Paris, 2010; Cotten, 2001).

Reports by S. Fox and Rainie (2000) and S. Fox and Jones (2009) from the Pew Internet and American Life Project, and Underhill and McKeown (2008) from Statistics Canada, have helped to illustrate the extent to which the Internet is being used to collect health information. More specifically, 61% of American (S. Fox & Jones, 2009) and 58% of Canadian (Underhill & McKeown, 2008) Internet users, 18 years of age or older, used the Internet as a means to find health information. Across these reports, the most common reasons for seeking out health information online was to find information about a specific health condition and associated treatments, which is then used to make decisions regarding treatment. However, the ability of individuals to find appropriate and relevant health information on the Internet can sometimes be hampered by reliance on the order of search engine results (Eysenbach & Köhler, 2002; Pan et al., 2007) which may have commercial and biomedical biases (McTavish, Harris, & Wathen, 2011).

In addition, individuals may be unsure of the credibility and their ability to assess the information found (S. Fox & Jones, 2009; Murray et al., 2003). Research on Internet-based HIS has also illustrated a “digital divide” where younger individuals with higher education and higher incomes are more likely to seek out health information online (Anker et al., 2011; Ayers & Kronenfeld, 2007; Brodie et al., 2001; Cotten, 2001; Cotten & Gupta, 2004).
Although much focus within the HIS literature has been placed on online seeking, there is also a recognition that this information is integrated with other ‘offline’ information sources, an area where additional research is required (Sillence, Briggs, Harris, & Fishwick, 2007).

2.2.3 Models and Theories Related to Health Information Seeking

Before presenting an overview of models and theories related to HIS, it is important to first distinguish between a model and a theory. As described by Case (2012), a model is typically more specific than a theory and, in describing a phenomenon, may draw on a number of different theories. Models vary in complexity and are often presented visually, to illustrate main components thought to be part of the phenomenon of interest. Models also differ according to the type of information behavior they seek to understand, e.g., active seeking or exposure to information, as well as their structure, purpose and testability. In contrast, a theory is much broader in focus, and harder to define, but make statements about, or hypothesizes, the nature of relationships between different concepts.

Unfortunately, in a lot of HIS research, the specific theory informing the research is not always described (Lambert & Loiselle, 2007). In helping to organize the great variety of theories that have influenced information behaviour research, Case (2012) has organized them according to paradigms, conceived in a way somewhat similar to the qualitative paradigms that have been discussed in chapter one. More specifically, he discussed two broad categories of theories: those with objectivist origins and those with more subjectivist or interpretivist origins. As I have described already, this research is situated within social constructionism, and in particular within the work of Berger and Luckmann (1966), as a subjectivist theory which I will discuss in detail in chapter three.

In trying to categorize the great number of models that have been developed related to HIS, Johnson and Case (2012) organized them into four broad categories, including flow models, domain models, risk and processing models, and comprehensive models.

- **Flow models:** These models represent HIS as a mechanistic, linear, flow-chart like, process, with a series of yes or no decisions. These types of models are primarily used for the development of computerized information systems, requiring such binary decisions, and limit their focus to “surface” issues possibly overlooking deeper issues that may influence the search process, such as health beliefs.
Furthermore, they don’t take into account that health information can be received from other, non-authoritative sources, that there can be simultaneous searches for health information that may or may not be related to one another, or that need for information can change throughout the search process. In essence, these types of models are too simple and not representative of how HIS takes place in the “real world,” lacking feedback loops to illustrate the complex and dynamic nature of HIS.

- **Domain models**: These models present major components in the information seeking process, such as variables that affect HIS, types of information acquisition and outcomes of the process, without illustrating connections between the components; thus, these types of models are limited to particular “domains” of interest.

- **Risk and processing models**: These models are described as “sophisticated flow models” (p. 110) but are much more intricate in detailing the factors contributing to the need to seek out information. In representing this process, risk and processing models have borrowed concepts from theories, such as the theory of planned behavior, to explain different parts of the HIS process. The need to carry out information seeking is seen as being influenced by personal characteristics, social norms, one’s response to perceived risk in a given situation, one’s beliefs in different sources to provide desired information as well as one’s own ability to obtain the information from those sources.

- **Comprehensive models**: In distinguishing comprehensive models from the other categories, Johnson and Case use the Comprehensive Model of Information Seeking developed by Johnson. This comprehensive model places greater emphasis on communication, and motivations for using specific information, in an effort to make up for the shortcoming of the other categories of models. Given its focus in trying to be comprehensive, it tries to explain actions related to HIS generally as opposed to single issues prompting the need for information. In this manner, the model takes into consideration different antecedents, or factors that influence the need to seek health information, and characteristics related to beliefs about the ability of different sources to provide the desired information. It is described as working best in situations where the sources, or channels, are authoritative figures like doctors for which there is a defined purpose to seek information from, i.e., a medical concern.
Johnson and Case (2012) recognize the need for additional work to improve the ‘comprehensive’ nature of this model. Of particular note, it is described how additional work is needed to better illustrate the role of social context in different information seeking variables. Elsewhere, Case (2012) has also drawn attention to the rather simplistic diagram of the comprehensive model provided by Johnson to describe such a complex process.

I present these categories as part of the existing HIS literature, however, the goal of this research is not to try and identify the process of HIS in those living with YOPD within, or across, these categories. Instead, using constructionist grounded theory, the goal of this research is to develop a theory about the role of HIS in the context of the collective experiences of those living with YOPD who participated in this study. Had this research been positioned within the post-positivist paradigm, it is likely the research would have tried to use elements of models from these different categories to generate the theory. Thus, in taking a social constructionist position, I emphasize the importance of contextualized knowledge, instead of attempting to develop theory imbued with existing conceptualizations of the HIS process. With this important paradigmatic difference noted, I now move away from HIS in general and turn to the specific segment of this literature most relevant to my research. More specifically, I will provide a review of HIS research that has been completed with individuals who live with neurological conditions.

2.3 Health Information Seeking in Neurological Conditions

Although much of the HIS literature has been done with individuals living with cancer, HIV and heart disease, as described by Lambert and Loiselle (2007), some research has also focused on individuals living with neurological conditions. HIS, especially online seeking, is commonly used by those with neurological conditions (Avitzur, 2003). A study by Liang, Xue, and Chase (2011), for example, recruited participants with a variety of neurological conditions from social networking sites like Facebook and disease-specific forums to complete a questionnaire about their online information seeking behavior. Three hundred and sixty-nine individuals responded to the questionnaire, with more than 35 different neurological diseases represented including, for example, Parkinson’s disease, amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), stroke and muscular dystrophy. Broadly speaking, Liang et al. found that as an individual’s self-reported disability score increased, so too did their intention to seek out online health information. However, the authors did not
collect data on how long participants had lived with their disease, i.e., if they were newly diagnosed or many years post-diagnosis, acknowledging that this likely played an important role in addition to disability level. Furthermore, the study found that greater rates of information seeking did not necessarily mean that the information was used for disease management, as both perceived usefulness and perceived risk influenced whether or not the information was used by individuals. In addition to this broad categorization of neurological conditions, research within the HIS literature has also focused on specific conditions, including MS, ALS and Parkinson’s disease.

2.3.1 Multiple Sclerosis (MS)

Baker (1994, 1996) has conducted work on the HIS behavior of women living with MS, primarily drawing upon psychology literature and the Miller Behavioral Style Scale (MBSS) to categorize her participants as monitors or blunters of health information. During times of stress, monitors seek out information whereas blunters avoid information as a means of coping with the stress. Baker’s dichotomy implies that information behavior is more of a trait rather than a state characteristic. Her premise in drawing on this literature was that MS caused individuals to experience stress because of the uncertainty that is part of living with the disease. In Baker’s (1994) first study, she had 160 women with MS complete the MBSS, grouped according to three time frames post-diagnosis, i.e., 0-1 year, 2-3 years, 5-7 years, to see if there was a difference in preferences for information on MS between monitors and blunters. Her results illustrated that monitors were interested in information earlier after the diagnosis, while blunters desired more information only after having lived with the disease for a number of years. However, both groups desired at least some information about MS throughout their experience with the disease.

Baker’s (1996) second study focused specifically on women who were described as actively coping with the disease, categorizing them according to three groups based on time from diagnosis, i.e. 0-1 year, 1-2 years, 2-3 years. The purpose of this study was to try and further differentiate between the information preferences of a group of 46 monitors and 47 blunters, categorized according to the MBSS, using pre-constructed information pamphlets. The pamphlets contained either general information, or specific and more detailed information, about fatigue or managing with acute attacks. Her results indicated that, regardless of time
post-diagnosis, blunters preferred the general information pamphlets, whereas monitors preferred the information regardless of it being general or specific.

A third study by Baker (1998) focused on information preferences during a period of symptom exacerbation, interviewing 10 women and three men with MS. Interviews were analyzed according to information ‘gaps’ experienced by participants, in terms of physical symptoms, emotions and information about medications. Related to physical symptoms, the onset of new or unusual symptoms, or the perceived worsening of symptoms, produced information gaps. However, having a gap did not always predict that individuals sought out information on the topic for one of two reasons: 1) the emotional nature of the exacerbation; or 2) satisfaction with existing knowledge. More specifically, participants experienced periods of depression, fear and grief, related to the uncertainty of the exacerbation and its impact on their functioning, which limited information seeking. Information seeking was also absent, however, if individuals were satisfied with their existing knowledge related to their exacerbation. Baker concludes by calling for more research on the nature and format of information preferences of individuals living with chronic illness in general, during times of stress. Hepworth, Harrison, and James (2003) have also discussed the complex nature of information needs of those living with MS, which can be highly individual, change over time, and related to physical and psychological factors in each person’s experience living with the disease.

Marrie, Salter, Tyry, Fox, and Cutter (2013) conducted a large North American survey on HIS completed by over 8,500 individuals living with MS. Close to 90% of the respondents reported seeking health information related to MS, with the Internet by far being the most common source first consulted. There was also a high level of frustration in finding desired content, and almost 40% of respondents questioned the quality of the content they found. Younger respondents were more likely to use the Internet and to trust the information they found online than older individuals living with MS who completed the survey. Of all of the information sources used, physicians were perceived to be the most trusted. Previous research conducted by Hay, Strathmann, Lieber, Wick, and Giesser (2008) also described the importance of online HIS for those living with MS, with 80% of their sample reporting that they had sought out information online prior to an initial appointment with a neurologist. What is interesting is that close to two-thirds of these individuals did not discuss the
information they found on the Internet with their physician because of a belief that it would negatively impact the interaction. The authors encourage neurologists to discuss information seeking with patients to open this dialog and ensure questions are answered, with additional research needed to deepen an understanding of such behaviour.

2.3.2 Amyotrophic Lateral Sclerosis (ALS)

M. R. O'Brien (2004) interviewed seven individuals diagnosed with ALS to understand their experiences with health information, including information needs, seeking and sources used. Through her analysis, O’Brien identified three broad categories of HIS behavior in her participants, emphasizing that individuals moved between these categories at various times in their experience with the disease, i.e., the categories were more state-based as opposed to Baker’s (1994, 1996) trait-based categories. The first category was active seekers who sought information from a variety of sources (e.g., Internet, books, friends) without having it screened by others, stopping when they reached a “saturation point” and desiring more information “as new problems arose” (M. R. O'Brien, 2004, p. 966). The second category was selective seekers who used other people, or “buffers,” to screen information to make sure it would not be upsetting, and only desired information about specific problems they encountered as opposed to general information about the disease. In this way, having too much information about the disease would cause worry about their future health. The third, and final, of O’Brien’s categories was information avoiders, who avoided information because of fear and anxiety about the disease information, believing that they would come to experience all of the difficulties they would learn about. Apart from active seeking of information, O’Brien also described how individuals could be exposed passively to information about ALS through broadcast media (e.g., television, newspaper). This type of information was not perceived to be helpful, and in some cases was even detrimental, similar to a report by Green (2003) who commented on the implications of increased media reports on euthanasia for individuals with ALS.

2.3.3 Parkinson’s Disease

With respect to Parkinson’s disease in the HIS literature, Pinder (1990a, 1990b) was the first to discuss different information behaviours displayed by those living with the disease. Pinder’s sample included 15 individuals (10 males, 5 females) from London, England. Their average age was 63 years and they had lived with Parkinson’s disease for an average of just
over eight years. It is important to note that five of these participants had been diagnosed prior to the age of 50 which, by today’s conceptualization, would have met the criteria of YOPD. Pinder categorized the information behaviors of her participants according to three groups: seekers, weavers and avoiders. However, she described this categorization as being flexible, not as fixed traits, which varied over time for each individual.

*Seekers* were those who actively sought out information related to Parkinson’s, even if the information found was not favorable. For these participants, the need to learn about the disease outweighed any potential drawback or threat perceived from the information that was found. *Weavers* were more ambivalent towards information, sometimes desiring information and sometimes not. When information was sought, however, they would selectively interpret the information, or ‘weave it,’ to favor a “preferred view of themselves, rejecting those which struck a discordant note” (1990b, p. 82). For example, they would often draw on their knowledge of the variability of the disease, and comparisons with others living with Parkinson’s disease, to facilitate more positive self-perceptions. In contrast, *avoiders* were those participants who deliberately avoided information related to Parkinson’s, because of a fear that it would confirm unfavorable thoughts about their futures. Thus, avoiding information was a means of protecting themselves in light of this fear. Pinder also noted that early avoidance of information was facilitated, for both weavers and avoiders, by successful management of the disease through medication. In other words, the improvement they perceived from their medication reduced the need or desire to seek out health information.

Also within the Parkinson’s disease-related HIS literature, Macht, Gerlich, and Ellgring (2003) conducted a study on the information behavior of 33 “older persons” living with PD in Germany. All participants were over the age of 65, ranging from 65 to 84 years of age, and had lived with the disease for an average of nine years. The purpose of the study was to classify the information needs of these individuals, and identify any patterns with respect to how these needs had changed over time. To conduct this classification and identify patterns, interviews were structured to ask questions about their experiences prior to diagnosis, at the time of diagnosis and after the diagnosis. Of those participants expressing information needs, several categories of topic areas were described as being important, including causes, treatments, progression over time, coping strategies and experiential knowledge from others.
living with Parkinson’s. This information was sought from a variety of sources including, for example, health professionals, active seeking of audiovisual and print materials and friends and family members. However, talking with, and observing, others living with the disease was more valued because it was perceived as practical instead of “theoretical” information, and allowed individuals to make comparisons to their own symptoms and progression. Some of the participants expressed having no information needs in their experience with the disease, which Macht and colleagues attributed to their concerns about the reliability of available information, beliefs that the information wouldn’t change their situation, satisfaction with the existing knowledge, or because they denied having the disease. Variability across the participants made it difficult for the researchers to find a pattern in the changes in their needs over time. However, in a general sense, they described how needs for information at the time of diagnosis were centered on the disease itself, and in years after the diagnosis needs were focused more on coping strategies.

Surveying members of the United Kingdom Parkinson’s Disease Society, Williams (2005) sought to identify differences in the needs for information of individuals living with Parkinson’s according to age of onset. Williams stratified her sample according to age of onset, trying to account for the much smaller number of individuals living with YOPD. Of the 201 who completed the survey, approximately 25% of the participants were diagnosed prior to the age of 50, which was used as a cut off for operationalizing a diagnosis of YOPD. As a whole, the group were active seekers of health information, with half being vigilant of information all of the time and another third seeking information when they experienced a change in their condition. Compared to those diagnosed after 50, however, those with YOPD had a number of unique differences in their experiences with information needs and behaviour. More specifically, those with YOPD were less satisfied with the information they received after diagnosis because it was geared more towards older adults living with the disease. Instead they reported a greater need for information related to employment, disclosing the diagnosis to their children, family counseling and self-management strategies. Younger individuals also reported a need for the diagnosis to be provided in a more positive light, given the emotional nature of the diagnosis. Williams concluded by recommending a large qualitative, interview-based, study to better understand the relationship between age of onset and information seeking.
2.4 Research Questions

Based on my review of the HIS literature, there is a great need for research to focus on less commonly investigated chronic illnesses (Ayers & Kronenfeld, 2007; Baker, 1998; Lambert & Loiselle, 2007), including neurological conditions and YOPD in particular (Williams, 2005). This also fits with the WHO’s (2006) call to develop a greater understanding of Parkinson’s disease to enable the provision of better care for those living with the disease. In addressing this need, qualitative research has been highlighted as an important means to work to understand how and why HIS takes place, and the patterns of HIS over time, moving beyond just dimensions of information and method (Anker et al., 2011; Ayers & Kronenfeld, 2007; Lambert & Loiselle, 2007; Liang et al., 2011; Salander & Moynihan, 2010). Questions of how and why a process occurs are particularly well suited to grounded theory (Charmaz, 2006), which is the research methodology used in this research and will be described in detail in chapter three. In addition, the focus on Internet-based HIS has resulted in a need to better understand how offline and online information sources are integrated (Sillence et al., 2007). As well, there is a need to understand both active and passive means of acquiring health information, instead of just the conscious action to seek out health information, which neglects other ways that health information can be obtained (Case, 2012, 2002). In working to address these gaps in the literature, within the framework of the purpose of this study, this research sought to answer the following questions:

1. Why do individuals with YOPD decide to acquire health information related to their disease or, conversely, choose not to acquire such information?

2. How does one’s desire for health information related to YOPD, and the manner in which a person acquires such health information, change over time?

3. In the process of seeking health information, what strategies (active and passive) and what information sources (online and offline) are used by individuals with YOPD? Furthermore, why are these strategies and sources used?
3 Methodology and Methods

In making the connection between the purpose of this research, and how I worked to address my specific research questions, this chapter details the grounded theory methodology and methods that I have used, situated within the social constructionist paradigm. To clarify how I use these terms, figure 3.1 provides an overview of the differences between paradigm, methodology and methods within the context of this research, also helping to outline how this chapter is organized.

Figure 3.1: Relationships Between, and Underpinnings of, Qualitative Paradigm, Methodology and Methods

At the broadest level, a qualitative paradigm consists of one’s beliefs about reality and knowledge, i.e., ontology and epistemology, respectively (Guba & Lincoln, 1994). A broad description of the social constructionist paradigm, with respect to its ontological and epistemological positions, was provided in chapter one, where I located myself within this research. I position myself within this paradigm because this is how I view and understand the world, with respect to the creation of knowledge and the nature of reality, i.e., knowledge is constructed through social interactions and that reality is relative and raised out of a specific context. These beliefs are rooted in theory foundational to the paradigm. In the case of social constructionist research, the work of Peter Berger and Thomas Luckmann (1966), and Ludwik Fleck (1979) among others, are often discussed and will be briefly reviewed in this chapter.
Within qualitative research, there are a number of different methodologies, or ‘approaches,’ including grounded theory, phenomenology and ethnography among others, with one of the fundamental differences between them being their “foci or the primary objectives” (Creswell, 2007, p. 77). Regardless of the paradigm from which one is working, the objective of a grounded theory is to generate theory that is grounded in the data, which is also particularly useful in developing an understanding of a social process about which there is little existing knowledge (Birks & Mills, 2011; Charmaz, 2006, 2014; Creswell, 2007; Glaser & Strauss, 1967); such as understanding how individuals with YOPD become informed about their disease over time. According to Glaser and Strauss (1967), the proverbial fathers of grounded theory methodology, a theory has two main components: 1) categories, or the main “conceptual element[s] of a theory” (p. 36) and 2) hypothesized relationships between the different categories. Each category also has a number of elemental properties that help to form the backbone of the categories in a theory. Although hypotheses are generated by the researcher in relation to connections between the categories and their properties, Glaser and Strauss emphasize that these relationships should emerge from the data and not be forced by the researcher into existing theory. Thus, the adjective “grounded” describes a theory where the categories are generated based on the data that has been collected and are not based in pre-existing literature.

In creating this methodology, Glaser and Strauss, and especially Strauss, drew on symbolic interactionist theory, which emphasizes how meanings and interpretations are created out of social interactions between individuals (Charmaz, 2006, 2014). More specifically, individuals construct a sense of who they are, the meaning of a given situation, and society in general through social interactions with others, and that these constructions can change over time. Ontological and epistemological beliefs will also influence how the theory is generated, i.e., the methods used, and the knowledge claims resulting from the theory, i.e., its generalizability. The term methods refers to the specific strategies used to collect and analyze data, working within a specific paradigm and methodology. That is, the choice of methods will, in large part, be determined not only by the specific approach to the research but also the ontological and epistemological beliefs of the researcher(s). Such differences will be highlighted in this chapter, in presenting an overview of constructionist grounded theory and the methods used in conducting this research.
Instead of starting this chapter with the theoretical basis of social constructionism, it is necessary to first start with a focus on how grounded theory methodology emerged in the 1960s, just prior to the growth of more diverse ontological and epistemological beliefs, including social constructionism (Denzin & Lincoln, 2005). Such an order will provide an appreciation for how Charmaz’s (2006, 2014) constructionist grounded theory, which I have adopted in this research, differs from the original grounded theory described by Glaser and Strauss (1967). Although other versions of grounded theory methodology exist (Bryant & Charmaz, 2007c), my focus in this chapter will be on the foundational work of Glaser and Strauss and how Charmaz has used the methodology within the social constructionist paradigm. As much of grounded theory methodology is defined through the use of specific methods (Charmaz, 2006, 2014; Glaser & Strauss, 1967), structuring the chapter this way will also facilitate a transition to present the methods of data collection and analysis that I have used within this research. I end this chapter with a look at criteria for quality in qualitative research that helped to further structure and guide this research, and which are designed to help ‘bridge’ different conceptions of quality across qualitative paradigms and methodologies.

3.1 Origins of Grounded Theory Methodology

The first description of grounded theory came in 1967 with The Discovery of Grounded Theory, hereafter Discovery, which details the methods that were used by Glaser and Strauss in studying the awareness of dying in hospitals; a process for which there was very little ‘grounded’ knowledge about prior to this time. This book was published by Glaser and Strauss as a means to systematize qualitative inquiry in a predominantly quantitative research climate. As they note, “the path to systematization was guided by the pressure that quantitative verifications had put on all sociologists, to clarify and codify all research operations, no matter what the type of data” (p. 16). More specifically, during this time quantitative research dominated social science inquiry with a focus on verifying the grand theories of social science through the use of quantitative methods, as was acknowledged by Glaser and Strauss as a motivation for writing their book. The result was that qualitative research had become marginalized and criticized as not meeting quantitative standards of quality. Glaser and Strauss describe how they wanted to make “[theory] generation a legitimate enterprise, and [by] suggesting methods for it, we hope to provide the ingredients of a defense against internalized professional mandates dictating that sociologists research
and write in the verification rhetoric” (p. 7). A second and equally important motivation for their book, also alluded to in the passage above, was the absence of texts that taught students and directed researchers on how to conduct qualitative research. Most of this knowledge remained implicit, prior to the publication of Glaser and Strauss’ text.

In historical accounts of grounded theory, the diverse backgrounds of Glaser and Strauss, and their related contributions to the methodology, are often discussed (Bryant & Charmaz, 2007a, 2007b; Charmaz, 2006, 2014). For example, Charmaz describes how Glaser, trained at Columbia University, “imbued grounded theory with dispassionate empiricism, rigorous codified methods, emphasis on emergent discoveries, and its somewhat ambiguous specialized language that echoes quantitative methods” (2006, p. 7). Conversely, Charmaz describes how Strauss, trained at the University of Chicago, “brought notions of human agency, emergent processes, social and subjective meanings, problem solving practices, and the open-ended study of action to grounded theory” (2006, p. 7). Central to Strauss’ contribution was his training in symbolic interactionism that formed a theoretical basis for grounded theory, i.e., a focus on individual and collective action in given situations to understand a social process and generate a conditional theory (Bryant & Charmaz, 2007b).

3.1.1 Symbolic Interactionist Roots

Although a number of individuals figured prominently in the development of symbolic interactionism, the work of George Herbert Mead and Herbert Blumer is particularly informing; as Mead is considered to be the founder of the theory and Blumer, a student of Mead’s at the University of Chicago, integrated the work of many of those who contributed to the theory (Charon, 2010). In describing the influences on Mead’s thinking which led to the development of symbolic interactionism, Charon (2010) points to three main areas: 1) pragmatism; 2) evolutionary theory; and 3) behaviourism. With respect to his work in the philosophy of pragmatism, Charon describes how Mead emphasized the active interpretive process that individuals use to engage with their environment, and that individuals are selective in generating knowledge to only that which is most useful. Furthermore, pragmatism focuses on human action, and more specifically the causes, consequences and perceptions of actions. Influenced by the work of Charles Darwin, Charon also describes how Mead believed a number of qualities, including language and the ability to reason, developed naturally in humans over time giving them the ability to understand and act on
their environments rather than being passively controlled by it. Furthermore, Darwin influenced Mead in coming to understand the world as being dynamic, as opposed to static, emphasizing that social constructions are better viewed as ongoing processes rather than finished products. Finally, related to his pragmatist beliefs, Charon describes the influence of behaviourism on Mead being that his focus was on human behaviour. Different, however, from pure behaviourists, Mead emphasized the importance of not just physical behaviour but thinking as a behaviour that takes place in the human mind as well. It is in this perspective that Mead drew on to further integrate the importance of interpretation into symbolic interactionism.

Blumer (1969) describes three premises on which the nature of symbolic interactionism is built. The first premise being that human action towards any part of a society, including other people, places, things, etc. is based on the meaning an individual has ascribed to the situation. The second premise describes how this sense of meaning arises out of social interaction with others in society, i.e., rather than being implicitly known, meanings are constructed socially. The third premise described by Blumer is that these meanings are created, and changed, through each individuals’ interpretations of the parts of a society encountered, which then guide action. To summarize, through the lens of symbolic interactionist theory, Blumer describes human action, or human behaviour, as premised on socially constructed meanings that are developed and modified through previous interactions, but which are individually interpreted prior to taking action in any given situation. That is, previous experiences create meanings, and these meanings can change over time, but that before individuals do something they interpret those socially ascribed meanings that have been constructed in light of their own unique situation. Within the context of this research, for example, there may be socially constructed meanings associated with a diagnosis of Parkinson’s disease. However, the meaning of the diagnosis in any person’s life, and the subsequent actions they take, will be first interpreted individually after each person becomes diagnosed. The meaning of Parkinson’s disease may then change over time, based on the interpretations from subsequent experiences with the disease.

3.2 Growing Paradigmatic Diversity

Although Glaser and Strauss would not have been able to predict the success that grounded theory would experience in the ensuing decades, the conditions in the late 1960s were
primed for such a development to occur. Contemporary accounts of the impact of the text reaffirm the significance of its publication. According to Charmaz (2006), *Discovery* “provided a powerful argument that legitimized qualitative research as a credible methodological approach in its own right rather than simply a precursor for developing quantitative instruments” (p. 6). Indeed, within the historical development of qualitative research in North America, Denzin and Lincoln (2005) refer to the publication of *Discovery* as an important landmark in the development of qualitative research. Since the seminal work of Glaser and Strauss, grounded theory has arguably become the most popular qualitative methodology, used across the social sciences and the health sciences, but has undergone significant developments since its original description (Birks & Mills, 2011; Bryant & Charmaz, 2007a, 2007b; Denzin, 2007; Mills, Bonner, & Francis, 2008). Much of this subsequent development resulted from the proliferation of new ways of thinking and seeing the world that stood in stark contrast to positivist and post-positivist paradigmatic beliefs (Denzin & Lincoln, 2005), which started to formalize around the same time as the publication of *Discovery*. Due to its popularity, others have also claimed to use grounded theory methodology, picking and choosing certain aspects of the methodology, as a means to legitimize their work (Bryant & Charmaz, 2007a, 2007b). Given the different forms of the methodology that now exist, and are continuing to grow (Bryant & Charmaz, 2007c), it is important for me to define my specific approach to grounded theory within this research, and how it emerged out of the growth of more diverse ontological and epistemological beliefs. As described by Mills et al. (2008), “researchers, who first identify their ontological and epistemological position, are able to choose a point on the methodological spiral of grounded theory where they feel theoretically comfortable, which, in turn, will enable them to live out their beliefs in the process of inquiry” (p. 32). Therefore, the main reason I have limited my scope here is that I have positioned my work as a constructionist grounded theory, and to truly appreciate what this means, and what it looks like, it is necessary to contrast it with the more post-positivist grounded theory of Glaser and Strauss.

### 3.2.1 Evidence of Post-Positivism in *The Discovery of Grounded Theory*

To review, post-positivist qualitative research is the form of qualitative research that most closely resembles the ontological and epistemological beliefs of quantitative research (Lincoln & Guba, 2003, 2005; Lincoln et al., 2011; Ponterotto, 2005). That is, this type of research is based on the ontological premise that there is a true, probabilistic, external reality
that can be discovered, or at least closely approximated, if the influence of the researcher can be reduced or, better yet, eliminated from the research setting. Therefore, epistemologically speaking, post-positivists believe the result of the research process is objective knowledge that stands apart from the researcher. This realism stands in contrast to relativist ontology of the constructionist paradigm. Within relativist ontology, associated with a constructionist paradigm, a single external reality is seen as an illusion or even a “chimera” (Lincoln & Guba, 2003, p. 279), instead believing that reality is context-dependent and constructed through the interactions of the researchers and participants, and society more generally. In other words, the role of the researcher cannot be eliminated from the research setting, and that it is the voices of both the researchers and the participants that are woven together in the reality constructed in the research setting, and the resulting knowledge that is generated.

Just as a constructionist believes in the multi-voice, and historically situated, construction of reality, Discovery represents the collective ideas of Glaser and Strauss who had varied backgrounds and training. Although a tension between objectivist and interpretivist beliefs can sometimes be inferred through reading Discovery, for the most part it has been couched as a post-positivist text (Bryant & Charmaz, 2007a; Charmaz, 2003, 2006, 2014). Some examples from my own reading of Discovery that highlight its post-positivist beliefs include:

- An emphasis on collecting “a great amount of data” (1967, p. 211) for theory development, as opposed to a reflection on the factors influencing the collection and interpretation of the data.
- A view of the researcher as a passive observer who must divorce him/herself from the data being collected so that it does not impact on the analysis of the data collected.
- A view that grounded theory could be used with quantitative data, and “relaxed” (1967, p. 186) quantitative methods, to help with theory development. Chapter eight of Discovery is dedicated entirely to this topic.
- An emphasis on “empirical generalizations” and “explanatory and predictive power” (1967, p. 24) of the theories that are generated using the methodology.
- A view that in the later stages of a study data can be collected quickly and that “establishing rapport is often not necessary” (1967, p. 75).
Eventually, Glaser and Strauss parted ways in the subsequent development of grounded theory methodology. Mills et al. (2008) describe how Glaser continued with a traditional form of grounded theory that echoes post-positivist assumptions, and Strauss developed a more interpretive or evolved form of the methodology with Juliet Corbin. Furthermore, Reichertz (2007) adds that Strauss and Corbin’s version of grounded theory recognized the importance of “theoretical pre-knowledge” (p. 215) in the interpretive process, whereas Glaser maintained that the theory will “emerge” (p. 215) directly from the data. It was Kathy Charmaz, a student of Glaser and Strauss at The University of Chicago, who continued to evolve grounded theory with the explicit use of constructionist beliefs (Charmaz, 2003, 2006, 2014). Despite the divergent routes taken by Glaser and Strauss and Corbin, Charmaz still views these forms of grounded theory to be more closely aligned with post-positivism, although “Strauss and Corbin less so” (2003, p. 255). Charmaz has been very detailed with a description of grounded theory that fits more clearly with constructionist epistemology and ontology. Indeed, Charmaz’s work has been the major influence of others who have taken up a constructionist approach to the methodology (Mills et al., 2008) and, as such, is the main author that I have used to inform the methodology and methods used in this dissertation. Prior to describing constructionist grounded theory, I will first detail some of the theoretical origins of the social constructionist paradigm.

3.3 Development of Constructionist Thought

At nearly the same time that Glaser and Strauss (1967) had published Discovery, the work of several other authors started to bring attention to alternative paradigmatic views, contrasting the dominant discourse of the time. More specifically, as described by Bryant and Charmaz (2007a), the work of Peter Berger and Thomas Luckmann (1966) and others, like a translation of Ludwik Fleck’s (1979) earlier work from 1935, problematized the role of the researcher in the creation of knowledge. The basis of each of these texts is discussed in the sections that follow, to illustrate the basis and development of constructionist thought, and the social constructionist paradigm.
3.3.1 **The Social Construction of Reality**

Although they did not set out to create a new paradigm by which social scientists would position their work in terms of beliefs about the nature of reality and knowledge, Berger and Luckmann’s (1966) *The Social Construction of Reality* has been fundamental to the emergence of the constructionist paradigm (Bryant & Charmaz, 2007a). Central to Berger and Luckmann’s work is the distinction between the *natural* environment and the *human* environment. The development of humans takes place in both of these environments, interacting with one another in a given society. For example, the development of a child to an adult and then to an older adult is something that all humans can experience regardless of the society in which they live. In other words, the biological development of humans is something that, in most cases, progresses in a predictable way. However, the meaning of being at a particular stage of development, including the roles that can be played, such as driving a vehicle, can vary widely from one society to another and can change over time.

The idea that the natural and human environment interaction is ongoing and changing also helps to illustrate the concept of *historicity* within Berger and Luckmann’s work. That is, how a society is constructed is not static and changes over time, or in different historical periods. Although much more can be said about this interaction, the main focus of their text is on the human environment, as it represents what has been produced or constructed by the humans living within a specific society. More generally, Berger and Luckmann believe that “all social phenomena are constructions produced historically through human activity” (p. 98). In theorizing how the human environment is constructed, Berger and Luckmann focused on how knowledge in everyday life comes to be formed, known, and transmitted to others. Their thesis stemmed from the belief that this *everyday*, or taken for granted knowledge, is what actually “constitutes the fabric of meanings without which no society could exist” (p. 14). Furthermore, “the reality of everyday life is taken for granted as reality” (p. 23), thus being something that is objectively experienced, which has much to do with how everyday life is ordered.

Berger and Luckmann put a central focus on language, time, and social interactions as the ordering elements of a society, of which language is the “most important sign system of human society” (p. 35). We live our lives according to a calendar, knowing that our world existed before we were born and will continue to exist after we are gone. Similarly, our interactions with others in society serve to reinforce the way in which elements of a society
have been constructed and objectified. Language, however, can transcend both time and the social interactions we have personally experienced. More specifically, language allows us to speak of time, either the past, present or future, and communicate ideas with others sharing the same language. These ideas may not be something we personally experienced, but may represent part of the vast array of signs and symbols that appear as objective elements of society, e.g., religion, philosophy, art, science. In addition to being central to the objectified nature of a constructed society, language also allows each member of society to speak of their own subjective experience. That is, language can make subjective meanings “more real” (p. 36) and accessible to others by using an objective system recognized and understood by others. Thus, qualitative researchers working within this paradigm have a strong focus on understanding the language used by participants, the meaning of the language used, and how these meanings change over time.

3.3.1.1 Constructing Reality

If a society is socially constructed, then how does it become objectified and remain objectified over time? To answer this question, Berger and Luckmann point to two important social processes: 1) institutionalization, where specific behaviours and roles become agreed upon as serving important functions in a society; and 2) socialization, where institutions become internalized and legitimized by the members of the society.

**Institutionalization**

Berger and Luckmann describe how that in every society, various institutions have been constructed to “control” (p. 52) and “stabilize” (p. 54) the actions and interactions that are most relevant or most functional for its members. For example, governance, law, health care, education, family and labour are all institutions that can be found in societies around the world, but can vary greatly from one society to another. Each of these institutions is part of our everyday life, and their constructed nature is not immediately apparent because they become objectified as “undeniable facts” (p. 57), through what Berger and Luckmann refer to as the “reification of social reality” (p. 82). Reification refers to the idea that the influence members of a society play in creating institutions and roles can be lost from consciousness. Indeed, “the reified world is, by definition, a dehumanized world” (p. 82). Reification is most obvious when a person’s biography, or life experiences, doesn’t contain the specific
experience in which an institution or role was first created. For example, schools and hospitals are social creations, serving important societal functions, but historically did not always exist. They were constructed, and are now reified, as part of our everyday reality.

Essential to each of these institutions are the specific roles played by given members of a society, which are created but then develop and change over time. Roles are required to be played by particular individuals in order for the institution to be part of the experience of members of a society. For example, within modern health care systems there are individuals who are doctors, nurses, therapists, orderlies, maintenance staff and, of course, patients among many others. Roles have certain expectations or standards that are part of the stock of knowledge in a society. Doctors, nurses and therapists are involved in the direct care of patients, which is an action that would not be undertaken by others, such as those in administrative roles. The centrality of language in the social construction of a society is evident even in this brief description of institutionalization, where specific terms for both institutions and the roles within them, have been objectified and have meaning in a specific language and context. The idea of there being hospitals or clinics with doctors to go to when a person is sick is something that I have always known and have taken for granted as part of my everyday reality. However, from a historical point of view, this has not always been the case. The idea of there being hospitals and doctors is something that has developed over time, being constructed by the members of society to serve an important purpose, i.e., help us get better when we are sick. Reification then, is a part of the socialization process, where insight into how knowledge was constructed is passed off as being objective reality.

**Socialization**

From the moment we are born until the moment we die, we are continually socialized into the society in which we live; that is, “socialization is never total and never finished” (p. 126). We come into contact with different institutions and play different and simultaneous roles, according to our own personal biographies. These institutions and roles are *legitimized* and *integrated* by each individual through the socialization process, but at the same time are subjectively interpreted. Thus, Berger and Luckmann describe how “socialization is never completely successful” (p. 98), as individuals can question why things occur a certain way, or see relevance in other areas of human life not currently recognized by mainstream society. This helps to illustrate a second important distinction in the work of Berger and Luckmann
in that the human environment has both objective and subjective elements. More specifically, the subjective is “the reality as apprehended in individual consciousness” (p. 135) and the objective is “reality as institutionally defined” (p. 135). The relationship between the subjective and the objective is always ongoing, as a person’s experiences increase and his/her knowledge increase; indeed this interaction has been referred to as an “ongoing balancing act” (p. 123). This balancing act is described by Berger and Luckmann in terms of: a) Primary Socialization; b) Secondary Socialization; and c) Alternation.

a) Primary Socialization: Similar to the importance of language in the process of institutionalization, Berger and Luckmann believe language is “the most important content and the most important instrument of socialization” (p. 123). We learn how to speak a specific language, or language(s), initially from our parents and other close family members and friends, or who Berger and Luckmann refer to as our “significant others.” Our emotional attachment to these significant others helps to facilitate our initial socialization, and is one of the reasons why primary socialization is the most firmly rooted type of socialization in the development of our identity. Using a specific language, a child learns motivations, ways of interpreting the world, as well as socially defined sequences of maturation. Over time, roles and attitudes become abstracted from the individual to society more generally, or the appropriation of societal norms, representing the internalization of a society.

b) Secondary Socialization: Berger and Luckmann describe the hallmark of secondary socialization as “the acquisition of role-specific knowledge, [with] the roles being directly or indirectly rooted in the division of labor” (p. 127). Thus, secondary socialization mainly occurs through formal education and training, where specialized knowledge and language is acquired to later perform specific roles. For example, going to school to become a teacher, a doctor, a lawyer, or a mechanic are all examples of secondary socialization. An important distinction with primary socialization is that secondary socialization is more anonymous and less emotionally bound and, consequently, is a less firmly rooted part of the identity of an individual. For example, one can train to be a physiotherapist and then later decide to become a teacher or a doctor, which requires additional training and knowledge to be obtained.

c) Alternation: When socialization into a new role has the potential to significantly impact one’s identity, an individual will experience a type of re-socialization, which Berger and
Luckmann refer to as an alternation. Identity is, according to Berger and Luckmann, “a key element of subjective reality, and like all subjective reality … is maintained, modified, or even reshaped by social relations” (p. 159). Sometimes this new identity is chosen, and sometimes it is not. Any person, regardless of the society in which they live, can experience this extreme form of socialization, which Berger and Luckmann describe as “a lifelong threat to whatever subjective reality emerges” (p. 156). In the context of this dissertation, the most obvious example of an alternation would be the diagnosis of a chronic degenerative disease, such as YOPD. How does one incorporate this new identity, an identity relayed to them by a medical expert and not chosen, into their subjective reality?

Berger and Luckmann describe how the alternation process more resembles primary socialization of childhood, with the involvement of significant others with whom there is an emotional connection. In the context of a YOPD diagnosis, significant others could range from physicians and other health practitioners, to family members and others living with YOPD, depending on each person’s individual biography. The “significant others are the guides into the new reality” (pp. 144-145) and provide a structure for the alternation process to take place by playing particular roles. A more detailed discussion of the role of significant others in the lives of my participants living with YOPD will be presented in future sections of this dissertation.

Berger and Luckmann believe the most important element for the process of alternation to occur is “the availability of a legitimizing apparatus” (p. 146). Similar to other types of socialization, in order for alternation to occur the person’s new reality must be legitimized, but now must be done so in a way to support a change in identity. Part of this legitimation process involves moving through “stages by which [the new identity] is appropriated and maintained, and the abandonment or repudiation of all alternative realities” (p. 146). This apparatus and these different stages or patterns lie at the crux of my main research questions. More specifically, I have sought to identify patterns in how a person responds to a diagnosis of YOPD and incorporates this diagnosis into their identity. In addition to a broad understanding of what this apparatus entails, I have a specific interest in the role of health information seeking for those diagnosed with YOPD and the role that this information plays in the alternation process.
3.3.2 The Genesis and Development of a Scientific Fact

Moving from the broader view of knowledge and reality in the everyday lives of individuals presented by Berger and Luckmann (1966), the work of Ludwik Fleck (1979) also supports the belief in the social nature of the creation of knowledge and reality. More specifically, Fleck’s work describes the social construction of scientific facts, which Berger and Luckmann describe as a specific sign or symbol used in society at a given time in the process of socialization. Fleck sees cognition, including what is deemed as factual, as “the most socially-conditioned activity of man, and [that] knowledge is the paramount social creation” (p. 42).

Using syphilis as an example, Fleck illustrates the highly interpretive nature of knowledge creation in light of changing sociocultural conditions over time. That is, beliefs about syphilis changed from the religious to the astrological, to the metallurgical, to the hematological, and eventually to the etiological by 1935. Each of these different viewpoints, or what Fleck refers to as different thought styles, represent the changing interpretation of the factual nature of syphilis. When experiments produced errors or failures in the presence of competing thought styles the result was “adaptations and transformations of concepts” (p. 98) and the development of a new accepted thought style. These changes came about through the work of a specific thought collective, or those people with a special interest in the factual nature of syphilis. In other words, the reality of what syphilis was changed over time as a result of social forces, including cultural values and the development of new technologies. This reality is held to be true and factual by the thought collective at a given point in time but, as Fleck contends, is always subject to change. Indeed, Fleck refers to a given reality at a specific point in time as really the “harmony of illusions” (p. 38) of a thought collective, conceptualizing reality as being multifaceted and never permanent.

Fleck’s theory was based largely on the history of syphilis, while also drawing on other examples from medicine, such as the history of anatomy. However, an important component of his theory was that every person belongs to several different thought collectives at any given point in time. These collectives can be as small as two people, such as when friends or colleagues meet to discuss a specific topic, and can be as large as any social grouping of people, such as by role, race, class, etc. In any of these cases, each person brings to a setting a number of thought collectives each with contextualized thought styles, and thus will
influence the conversation in different ways. The result is a unique interaction between two people, or those a part of a larger group. Fleck comments that “he is a poor observer who does not notice that a stimulating conversation between two persons soon creates a condition in which each utters thoughts he would not have been able to produce either by himself or in different company” (p. 44). Epistemologically, extending this to a qualitative interview setting, where a researcher and a participant have formed a thought collective by meeting to discuss a topic, the discussion and knowledge generated will be contextualized within the thought collectives of whom each is a part. That is, every person is bringing to the setting their own unique biography that will generate an understanding grounded in the participants’ and researcher’s experiences and interpretations. More specifically, the knowledge generated from a research study is contextually-based, and that it would be an ‘illusion’ to assume that such an understanding would ever be complete or permanent.

3.4 Constructionist Grounded Theory

After reviewing social constructionist and symbolic interactionist theory, there are a number of commonalities between the theories that supports the use of them together in grounded theory (Bryant & Charmaz, 2007b; Charmaz, 2006, 2014). In particular, the two theories emphasize the importance of the interaction between unique human biographies working, through both physical action and interpretation, to construct a contextualized social reality. The two theories, also share an emphasis on the dynamic aspects of interpretation in the context of the social environment, which make them particularly well-suited for studying social processes. Keeping beliefs about knowledge and reality in mind, constructionist grounded theory is differentiated from other forms of the methodology based on how it views the theory generation process, as well as the possibilities and limits of the theory that is generated.

An important belief in constructionist grounded theory is that that knowledge and reality are “conditional” (Charmaz, 2003, p. 273). In other words, participants and researchers discuss topics with one another in unique social interactions, occurring at specific time points in history and in particular societies. According to Charmaz (2003, 2006, 2014) constructionist grounded theory recognizes that “data do not provide a window on reality. Rather, the ‘discovered’ reality arises from the interactive process and its temporal, cultural, and structural contexts” (2003, p. 273). That is, data are collected “under particular historical,
social, and situational conditions” (2006, p. 16). These unique conditions create “partial knowledge, multiple perspectives, diverse positions, uncertainties, and variation in both empirical experience and its theoretical rendering” (Bryant & Charmaz, 2007a, p. 51). These elements of a constructionist grounded theory are what helps to connect the methodology to its roots in social constructionist and symbolic interactionist theory.

The wording used by Charmaz in her description of the methodology parallels some of the main points of both Berger and Luckmann (1966), Fleck (1979) and Blumer (1969) in terms of the socially constructed nature of knowledge. Similar to Berger and Luckmann, and Blumer, the importance of social interaction is highlighted by Charmaz as an important element in the co-construction of knowledge. Both the researcher and the participants will be bringing their own biographies and subjective interpretations of their society into a social interaction; or, as Fleck describes, each person will bring his/her own set of thought collectives and corresponding thought styles that will create a unique set of social interactions. Furthermore, as has already been discussed, a temporal emphasis on the social construction of knowledge is evident in the work of Berger and Luckmann, Fleck and Blumer. For example, the reality of a scientific fact or social role at a given time can change over time, and can also be different from one society to another. The importance of social interaction, time, and place are all emphasized in the development of a constructionist grounded theory.

Given that a constructionist grounded theory is conditional in terms of the specific context of the data collected, the theory’s “conditional statements do not approach some level of generalizable truth” (Charmaz, 2003, p. 273). Moreover, due to the unique social interactions, and the specific context in which the data are collected, the constructed theory will produce “limited, tentative generalization, not universal statements” (Bryant & Charmaz, 2007a, p. 52). From a social constructionist’s point of view nothing is universal, as what is perceived to be reality is always subject to change (Berger & Luckmann, 1966; Fleck, 1979). However, this does not mean that the knowledge will not be useful to others. Instead, the knowledge generated can be used by others in similar, or comparable, contexts, in what Firestone (1993) refers to as analytic generalizability. This type of generalizability is more tentative and limited, and requires the future user of the theory to determine the applicability of it to a given setting.
3.4.1 Reflexivity

Given the importance of individual biography and subjective interpretation in social constructionist and symbolic interactionist theories, there is a recognition that grounded theorists need to be reflexive with respect to the influence of their own biography and interpretive perspectives they bring to the research setting. That is, being reflexive is the process of assessing, or scrutinizing, one’s own contribution to the theoretical knowledge generated (Charmaz, 2006, 2014). Indeed, the importance of reflexivity as a marker of quality in qualitative research has become more common in the last decade, especially as a type of ‘bridging criterion,’ with the growth of qualitative paradigms and the use of diverse qualitative approaches (M. J. Ravenek & Laliberte Rudman, 2013). Mruck and Mey (2007) describe the need to be reflexive throughout the entire research process, from generating research questions to data collection, analysis and writing, and that this process will be different depending on the paradigmatic position of the researcher. For example, constructionists see the biography of the researcher as inseparable from the knowledge that is generated, whereas post-positivists employ strategies to try and minimize the impact of their biography. In both cases, reflexivity can enhance the quality of the research, but the purpose of such a process is different because of differences in ontological and epistemological beliefs.

In situating myself within this research in chapter one, I described aspects of my biography directly relevant to my interest in the research topic and working with those living with YOPD. I continue to employ reflexivity throughout the remaining chapters of this dissertation, as a means of illustrating my influence on the generation of this grounded theory. For example, I came to understand through my analysis that I was interpreting “functioning,” a concept important in my theory, from a particular perspective that is part of my biography. Furthermore, specific experiences that I had during the research process, including the opportunity to present my work and participate in the World Parkinson Congress in Montreal in 2013, became part of my biography and also impacted the way I thought about particular topics within this theory. More about these biographical influences will be described later in the results and discussion, as it relates to specific aspects of the presentation and discussion of the theory I have generated. In the introductory chapter, I also spoke of the influence of a health consumerism culture, as a particular contextual influence upon this research, and will continue to add to the importance of cultural influences in the
discussion chapter. As Charmaz (2006, 2014) describes, being reflexive about the role of the cultural context of the research is an important aspect of understanding the socially constructed nature of a grounded theory.

In line with a view of knowledge and reality being constructed, Charmaz (2006) emphasizes “flexible guidelines, not methodological rules, recipes, and requirements” (p. 9). Specific strategies, or methods, used to conduct a grounded theory study need to “take into account the research contexts and researchers' positions, perspectives, priorities, and interactions” (Bryant & Charmaz, 2007b, p. 10). In other words, the specific methods used in a constructionist grounded theory need to be flexible to account for the diversity of contexts in which a study may occur. This view stands in contrast to post-positivist versions of the methodology, where Charmaz (2003) describes the methods as “prescriptive” and “reified into immutable rules” (p. 274). Regardless of the paradigm from which a grounded theorist works, there are a number of common elements to methods in grounded theory studies. Central to this commonality is the abductive nature of the reasoning used in the methods (Bryant & Charmaz, 2007a; Reichertz, 2007). The next section of this chapter will focus on describing abductive reasoning and how the main methods that make up grounded theory methodology are representative of this type of reasoning, before describing the specific methods that I used in this study.

### 3.5 Grounded Theory as an Abductive Methodology

Grounded theory is more than an inductive methodology, which it has been wrongfully accused of in the past, as it does much more than develop a theory by making observations and collecting data from individual cases (Reichertz, 2007; Richardson & Kramer, 2006). Instead, grounded theory has been more properly termed a form of abductive reasoning which, as Richardson and Kramer (2006) describe, involves “associating data with ideas” (p. 500). This association is done so in a way of combining both inductive and deductive elements, creating a hybrid form of reasoning (Bryant & Charmaz, 2007a; Charmaz, 2006, 2014). Although Glaser and Strauss do not specifically refer to the use of abduction in Discovery, the methods they espouse to be part of the methodology describe this type of reasoning (Bryant & Charmaz, 2007b). More specifically, abductive inference is where information is gathered and patterns form, which the researcher uses to generate potential explanations or hypotheses, i.e., induction, and then returns to the field to collect more data
to check the hypotheses, i.e. deduction (Bryant & Charmaz, 2007a; Charmaz, 2006, 2014). As Reichertz (2007) explains, this process is repeated throughout the study to refine hypotheses and build the grounded theory, as ideas about potential relationships between conceptual elements can be found at any stage of the research.

Drawing heavily on the original writings of Charles Peirce, who first described abduction in the late nineteenth century, Karen Locke (2007) discusses abductive reasoning as a combination of two forms of thinking. More specifically, she describes it as the simultaneous use of “irrational free-playing” with “rational controlled moves” (p. 569). The irrational or imaginative part of this duality, representing the creative element of abduction, is where a range of different ideas, including potential relationships between data, are posited. Locke emphasizes that this type of thinking moves theorists beyond description and into analysis, and at times leads to periods of “uncertainty and ambiguity” (p. 575) that is necessary for new theory generation. In contrast, the rational side of abduction involves scrutinizing the conjectures made during the creative process in a more direct and focused manner. In other words, it works to make the analysis less ambiguous and more certain. Although presented as two separate entities, Locke emphasizes that both the rational and irrational elements of abductive reasoning occur at the same time and throughout the process of theory generation. How does one know, however, when to stop sampling and stop analysis?

3.6 When Is a Grounded Theory Finished?

The term typically used to describe when a grounded theory study has reached completion is referred to as theoretical saturation; however, the point at which this occurs is “never precise” (Glaser & Strauss, 1967, p. 64). Essentially, theoretical saturation refers to the point at which collecting new data “no longer sparks new theoretical insights, nor reveals new properties of your core theoretical categories” (Charmaz, 2006, p. 113). However, Charmaz (2006, 2014) describes how many qualitative researches make the mistake of believing their theory to be saturated when data are simply repeated over and over. The emphasis is not on the repetition of data across sources, but lies in the properties and categories that make up the theory. This, of course, is much more difficult to achieve and is why Charmaz, and others, have been critical of the term saturation.
Instead of theoretical saturation, Ian Dey (1999) thinks the term “theoretical sufficiency” (p. 257) is more appropriate. Given the imprecise nature of determining when saturation has occurred, Dey believes that it is “impossible to validate this conjecture without actually coding all the data” (p. 257). Dey also adds to this argument with a critique of the theoretical coding and theoretical sampling procedures, which he believes may limit what eventually forms as the categories and properties of the theory. Dey’s view of the developing theory is more tentative, seeing that the categories developed are more suggested by the data. Given the contextual nature of the co-constructed theory, Dey’s view of a theory being theoretically “sufficient” as opposed to “saturated” is also in line with social constructionist thinking. As such, I have chosen to use theoretical sufficiency as a guide for helping me to determine the point at which to end my data collection and analysis. A theoretically sufficient grounded theory is achieved through the abductive nature of grounded theory methods, depth in data collection and analysis and reflexivity, which together support the development of categories and their properties.

3.7 Methods

One of the features of grounded theory methods is that data analysis starts at the same time as data collection (Charmaz, 2006, 2014; Glaser & Strauss, 1967). The logic behind this strategy is that the goal of a grounded theory study is to generate a theory from the data collected, and not to test an a priori hypothesis about the data. In other words, grounded theory methods offer the advantage of fine-tuning the means by which data are collected, and the focus of the data collected, to support theory development over time “while we gather data” (Charmaz, 2006, p. 14). To maximize clarity in describing the methods used in this study, however, data collection and data analysis will be presented separately.

3.7.1 Data Collection

In emphasizing her more flexible approach to grounded theory, Charmaz (2003, 2006, 2014) believes data should come from a variety of sources. These sources can either be elicited from participants directly, e.g., interviews, or they may already exist in the public domain as extant sources, e.g., autobiographies. Regardless of the data sources used, Charmaz emphasizes collecting “rich data” that “get[s] beneath the surface of social and subjective life” (2006, p. 13) and “reveal[s] participants views, feelings, intentions and actions as well
as the contexts and structures of their lives” (2006, p. 14). To gather rich data for this study, I chose to collect data from both elicited and extant sources (see Figure 3.2).

![Figure 3.2: Elicited and Extant Sources of Data Collection](image)

### 3.7.1.1 Elicited Data Collection

Elicited data for this study were collected over the course of four cycles, including one formative cycle and three theory-building cycles. Two separate ethics protocols were developed, i.e., one for the formative cycle and one for the theory-building cycles, and were approved by the University of Western Ontario – Health Science Research Ethics Board, prior to the start of each protocol. Notice of ethics approvals for these protocols can be found in Appendix A and Appendix B, respectively. Elicited data collection started in October 2011 and extended to the end of July 2013. An overview of the timing, and components, of each of these cycles is provided in figure 3.3, and will be described in detail below. All elicited data collection sessions were digitally recorded and subsequently transcribed verbatim by a private transcription company.
### Formative Cycle

<table>
<thead>
<tr>
<th>Cycle 1</th>
<th>Cycle 2</th>
<th>Cycle 3</th>
<th>Cycle 4</th>
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<tbody>
<tr>
<td>2 Focus Groups &amp; Written Exercise (n = 15)</td>
<td>Analysis &amp; Protocol Development</td>
<td>18 Interviews (n = 6) 1 Focus Group (n = 3) Analysis</td>
<td>18 Interviews (n = 6) 2 Focus Group (n = 9) Analysis</td>
</tr>
<tr>
<td>Analysis &amp; Protocol Development</td>
<td>Online Discussion Board (n = 6)</td>
<td>11 Interviews (n = 4) 1 Focus Group (n = 6) Analysis</td>
<td></td>
</tr>
<tr>
<td>October - January</td>
<td>February - April</td>
<td>May - June</td>
<td>July - November</td>
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#### Figure 3.3: Timing, and Components of, Elicited Data Collection

**a) Formative Cycle**

The formative cycle consisted of two separate focus groups held as optional ‘breakout sessions’ of a workshop designed for those living with YOPD that was hosted by the Parkinson Society Southwestern Ontario (PSSO) in October of 2011. Participants were recruited for this cycle through the Manager of Programs and Services at the PSSO who sent a direct mail advertisement for the workshop to those living with YOPD in the Southwestern Ontario region (see Appendix C). Based on the age range for YOPD provided in the literature (Quinn et al., 1987; Rana et al., 2012; Selikhova et al., 2009), I recruited those who were diagnosed between the ages of 21 and 55, and who could engage in conversation in English. Those interested in participating in the focus groups indicated their willingness to do so during the registration process for the workshop, which was handled by an administrative assistant working at the PSSO. As individuals registered for the workshop, the names and phone numbers of those wishing to participate in the focus groups were provided to me by the administrative assistant. I then called those individuals to review information about the study, answered any questions they had, and scheduled them for one of the two groups. I originally sought to recruit 10 individuals for each of the focus groups, but in the end I was only able to recruit 10 individuals for the first group and five individuals for the second group. Prior to participating in these groups, individuals read and initialed the letter of information and signed the consent form for this part of the study (see Appendix D).

There were two main goals of the focus groups in the formative cycle of data collection. First, I wanted to seek out varied experiences of individuals living with YOPD in Southwestern Ontario, related to their HIS behavior. This would allow me to develop greater...
theoretical sensitivity, prior to engaging in the subsequent theory-building cycles of data collection. Birks and Mills (2011) define such sensitivity as “the ability to recognize and extract from the data elements that have relevance for your emerging theory” (p. 59), and is described by Kelle (2007) as being a prerequisite for building categories in a grounded theory. Part of this sensitivity is developed through being reflexive about one’s personal biography and disciplinary perspectives, but is also developed throughout the research process as one engages with the data (Birks & Mills, 2011; Charmaz, 2006, 2014). Given the contentious place of the literature review in the grounded theory process (Birks & Mills, 2011; Bryant & Charmaz, 2007b; Charmaz, 2006, 2014; Wiener, 2007), and that very little research has previously looked at the HIS behaviour of those living with YOPD, these focus groups provided me with a way to develop theoretical sensitivity beyond being reflexive. Indeed, Birks and Mills discuss how focus groups are a common way to start grounded theory studies, prior to engaging in more in-depth forms of data collection. Second, given the difficulty previous researchers have had in recruiting those with YOPD (Fontenla & Gould, 2003), I wanted to gain insights from participants on how they thought future data collection should be structured to maximize participation and engagement with the study.

In meeting these two goals, each focus group was separated into five main parts (see Appendix E). After an introduction, participants completed a short written exercise (see Appendix F) where they provided basic demographic information and also answered two questions: 1) In your opinion, what is the most important information that can be given to someone newly diagnosed with YOPD? 2) In your opinion, what is the best way that this information can be delivered? This was done as a way to get participants thinking about their HIS behaviour, so that they would have immediate content available to them to participate in the group discussion; and was also collected at the end of the focus group as an additional source of data. After the written exercise, participants were asked to discuss amongst the group the various information topics and sources they had used since being diagnosed with YOPD. Prompts were provided to help facilitate the discussion and to stay within the time allotted for each focus group. In the last 20 minutes, before ending each group, participants were asked to discuss the types of data collection methods they felt would facilitate future participation of those living with YOPD in the study.
At the end of the formative focus groups, I had developed an initial, broad, understanding of the HIS experiences of a number of those living with YOPD, which provided me with a place to start in generating my grounded theory, including questions to ask once I started the theory-building cycles. For example, I learned that participants had varied experiences in being diagnosed with the disease; especially in relation to the time it took to get their diagnoses, their diagnostic encounters with their physicians, and the influence of their perceptions of the diagnosis on their HIS behaviour. The information sources and topics they identified varied greatly, with employment, finances and family dynamics being among the most important topics, and conferences, the Internet and support groups being the most important sources. As well, I gained an understanding of different strategies that I should offer to individuals as means to participate in the subsequent cycles of data collection, to facilitate recruitment and participation in the study. Suggestions for strategies provided by participants included incorporating a mechanism for ongoing participation, beyond single sessions, and taking advantage of both one-on-one interviews and group settings. Participants also wanted to have ways of participating that would allow them to think about their responses, such as communicating through email and receiving the interview guide ahead of data collection sessions. In addition to these strategies and suggestions, I also came to realize that I would need to change how I thought about defining YOPD as a diagnosis, as some of the group participants were diagnosed after age 55 but still thought of themselves as having YOPD. In many cases, these individuals, diagnosed after age 55, were still working; seeing employment as a more important factor than age in how they identified with the diagnosis. Beyond using this formative data to guide protocol development, it was also included and analyzed with the data collected in the theory-building cycles, which will be described in the next section.

b) Theory-Building Cycles

Taking into account the suggestions for data collection strategies provided by participants in the formative cycle, and the issue in how to define YOPD for the study, I worked with my advisory committee to put together the subsequent ethics protocol. Given the success of the formative focus groups, and the benefits individuals perceived in participating in them, we decided to continue using focus groups as one of the ways I would collect data. Participants also understood the value in meeting with me one-on-one because of the greater depth of
discussion that can be reached using this method. To facilitate a deep, and ‘rich,’ understanding of participants’ experiences (Charmaz, 2006, 2014), and that individuals wanted to participate in more than just one session, I designed the protocol so that up to three interviews could be conducted with each participant. As another way to allow participants to engage in the study over an extended period of time, I created a private online discussion board as an optional way for individuals to participate. Furthermore, participants could consent to receive updates and provide feedback through phone or email communication, if they did not want to participate in the online discussion board. Thus, a broad and diverse protocol for data collection was developed to facilitate the ability of those living with YOPD to take part in the study, in line with the suggestions provided during the formative focus groups. In negotiating the issue of defining YOPD for the study, I opted to allow individuals to self-identify as living with YOPD so as not to exclude anyone who felt they have the young-onset subtype of the disease for reasons other than their age of diagnosis.

Given that data are collected and analyzed simultaneously in a grounded theory (Charmaz, 2006, 2014; Glaser & Strauss, 1967), I designed data collection so that it would be completed over three subsequent cycles to give me time to conduct analysis while I collected data. Each of these theory-building cycles was scheduled so that I would aim to conduct interviews with up to six participants, and hold up to two focus groups, before breaking for several weeks to catch up on analysis and prepare for subsequent data collection. Participation in the formative cycle of data collection did not preclude participation in the theory-building cycles, but individuals could only participate in one focus group and one set of interviews. Similar to the formative cycle, participants were initially recruited for the theory-generating cycles through the Manager of Programs and Services at the PSSO. More specifically, the manager sent a letter outlining the study to those living with YOPD in Southwestern Ontario who had registered with the Society (see Appendix G). My contact information was provided in the letter, and those who were interested in the study were asked to contact me directly.

As individuals called and emailed me, I spoke with them about the study, answered any questions they had, and scheduled them for interviews, a focus group, or registered them for the online discussion board. Over time, I also recruited participants through the word-of-
mouth of others who had already participated in the study. Thus, sampling was initially convenience-based in cycle two and then also included snowball sampling as the study progressed into cycles three and four. A third type of sampling, i.e., theoretical sampling, was also used in the later stages of data collected and will be discussed in the analysis sections because of its role in helping to fill out properties of the developing theory. Prior to participating in any part of the theory-generating cycles, individuals completed and initialed the letter of information and signed the consent form (see Appendix H), and also completed a brief demographic questionnaire (Appendix I). As suggested by participants in the formative cycle, the interview guides were emailed to participants prior to each data collection session to allow individuals ample time to think about the questions and topics of discussion. Participants were encouraged to take breaks whenever they felt they needed to at any point during the interview or the focus group sessions.

In line with recommendations for conducting constructionist interviews from Charmaz (2006, 2014), the number of structured questions for each interview were limited to allow for more natural conversation and greater flexibility in pursuing, or probing, what participants discussed. As well, the questions focused on eliciting individual meanings and interpretations of their experiences, and specific actions taken by participants, following a symbolic interactionist emphasis on meaning and action. Interviews across the theory-building cycles ranged from 50 minutes to 120 minutes in length, averaging around 75 minutes. The three interviews were structured so that discussion moved from a broad overview of participants’ experiences living with YOPD in the first interview, to more specific questions about their HIS behaviour in the second interview, and then summary questions in the third interview (see Appendix J for sample interview guides). Over the cycles, the questions related to HIS and the summary questions I asked became more specific to my developing analysis, as will be described. To accommodate for the flexibility of constructionist grounded theory interviews, depending on how the discussion unfolded, in some cases questions were rearranged between the three interviews so that the flow of conversation was not disrupted in a given session. Field notes were taken at the end of each interview to record my initial thoughts and analysis of the interviews in relation to previous data, and to capture any pertinent non-verbal expressions or environmental factors that would not be captured by the transcripts or digital audio.
Across the cycles, the focus groups were all scheduled for 60 minutes. The groups were structured in such a way that I would present my analysis of the data up to the point of each group, with the aim of having participants reflect on what I presented in relation to their own experiences. During the groups, I encouraged participants to think of alternative explanations and divergent experiences with respect to their own biographies, to help me identify additional areas where I needed to sample. The first 20 minutes of the groups were allocated for me to present the findings, with the remaining 40 minutes left open for discussion amongst the participants. In this way, the focus groups acted similar to the theoretical group interviews discussed by Morse (2007) as a sampling strategy, but differ in that my focus groups occurred throughout the study instead of being limited to the end of the study. The focus groups in the theory-generating cycles were smaller in size compared to the formative cycle, which included a group of 10, so that they would be more manageable to facilitate and so that individuals would have greater opportunity to participate and contribute to the discussion (Birks & Mills, 2011).

Cycle two, or the first theory-building cycle, took place between February and April 2012, where six participants each took part in three in-depth interviews, and three participants took part in one focus group. Cycle three took place between July and November 2012, where another six participants each took part in three interviews with me, and two focus groups were conducted; one group had four participants and the other group had five participants. The fourth cycle took place between May and July 2013, where four participants took part in three in-depth interviews and one focus group was conducted with six participants. Across cycles two to four, from February 2012 to July 2013, the online discussion board was made available to consenting participants. However, use of the discussion board was limited to six participants, with the majority of participants preferring to follow-up with me through phone and email conversations. In the time between each of the theory-building cycles, and up to the point of writing this dissertation, the data were analyzed together with the extant data I had collected (see figure 3.3).

3.7.1.2 Extant Data Collection

Extant sources of data are those that “the researcher had no hand in shaping” (Charmaz, 2006, p. 35), but are nonetheless used in helping to address the research questions of a particular study. Among the many different types of extant texts are autobiographies of those
living with illness, which Charmaz includes in her own work on chronic illness. Adopting a similar approach, I sought out autobiographies written by individuals living with YOPD. Reading such texts was an additional means that I used to develop theoretical sensitivity throughout the research process, beyond being reflexive and in addition to the formative focus groups. To locate these autobiographies, I searched English book titles on Amazon.com during the data collection period, i.e., October 2011 to July 2013, using the phrase “young-onset Parkinson’s disease.” During this period I was able to locate 28 autobiographies, and from these I chose 14 to represent the diversity in experiences of those living with YOPD who had written autobiographies. Four autobiographies were read during cycle one, three during cycle two, three during cycle three, and four in the final data collection cycle.

As Charmaz (2006, 2014) describes, it is important to keep in mind that extant texts are written for varied purposes that may or may not be directly related to the topic of the research. As such, through my reading of these autobiographies, I extracted data from them that was relevant to HIS behaviour and related issues, using a data extraction form that I created for this study (see Appendix K). Data that were extracted included basic demographic information such as their age when they wrote the book and the age they were diagnosed, information related to their diagnostic experience, supports in their life, how they managed in the years after their diagnosis, and any specific references made to topics or sources of health information desired and sought out. Data extracted from these autobiographies were used to supplement the elicited data that I collected, and was analyzed together using data analysis methods for grounded theory.

3.7.2 Data Analysis

The data collected in a grounded theory study are analyzed as they are collected, through distinct steps of coding which, according to Charmaz (2006), allows researchers to “define what is happening in the data and begin to grapple with what it means” (p. 46). To facilitate the coding process, I stored the transcripts from elicited data sources, and the data extraction sheets for the 14 autobiographies, in the qualitative software program NVivo 10 for Windows from QSR International. Although the use of computer software in grounded theory research is still a topic of much debate, for fear of ‘dehumanizing’ the analytical process, it is becoming more commonplace (Birks & Mills, 2011; Charmaz, 2006, 2014;
Hesse-Biber, 2007). I chose to use the software mainly to store and organize the vast amount of data I had collected, and the thousands of codes that I generated through the process of analysis, rather than using the built-in analysis features that come with the program. With respect to different types of coding, Charmaz describes a progressive move from initial coding to focused coding, and eventually to theoretical coding as the theory starts to form.

Initial coding involves taking small segments of data, e.g., lines or sentences, and assigning a word or phrase that emphasizes the meaning or action described. According to Charmaz (2006, 2014), these types of initial codes help to prevent forcing the data into specific categories or existing theories. Charmaz emphasizes the use of gerunds, or words emphasizing action, to help keep the data grounded and focused on process for theoretical treatment. An example of initial coding in the transcript of one of my interviews with a participant, Joella (pseudonym), is illustrated in table 3.1. Initial codes were generated for the transcripts of the formative focus groups, as well as the interview and focus group transcripts of the theory-building cycles. In this way, although I did not transcribe the digital recordings, I was able to immerse myself in the data by conducting this very detailed initial coding process. As well, I coded the transcripts and listened to the digital recordings concurrently, while reviewing my field notes, to further immerse myself in the data during this process.

### Table 3.1: Initial Coding Example

<table>
<thead>
<tr>
<th>Transcript Excerpt</th>
<th>Initial Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interviewer:</strong> And so why after you were diagnosed, why did you go seeking that information?</td>
<td>Seeking because of denial</td>
</tr>
<tr>
<td><strong>Joella:</strong> Probably because I was in denial and I kind of wanted to prove them wrong. I also wanted to find out how to treat it, just in case I did have it. And things that I could do that would help it, as well. Like there’s one thing, you can go to the doctor and this and that, and the other thing. And they might give you a pill, they might not. They might send you to physio, they might not. But I was responsible for myself. That’s the person I realigned my, kind of my philosophy of life, not really, but it’s kind of philosophy – oh, excuse me. Philosophy of self. Philosophy of self.</td>
<td>Wanting to prove wrong</td>
</tr>
<tr>
<td></td>
<td>Desiring treatment information</td>
</tr>
<tr>
<td></td>
<td>Being personally responsible</td>
</tr>
<tr>
<td></td>
<td>Going to the doctor</td>
</tr>
<tr>
<td></td>
<td>Receiving medication</td>
</tr>
<tr>
<td></td>
<td>Being responsible for herself</td>
</tr>
<tr>
<td></td>
<td>Changing life philosophy</td>
</tr>
<tr>
<td></td>
<td>Thinking of identity</td>
</tr>
<tr>
<td></td>
<td>Putting herself first</td>
</tr>
<tr>
<td></td>
<td>Changing longstanding beliefs</td>
</tr>
<tr>
<td></td>
<td>Learning to address her needs</td>
</tr>
<tr>
<td></td>
<td>Differing from others</td>
</tr>
</tbody>
</table>
The purpose of focused coding is to condense the data by identifying the “most significant and/or frequent earlier codes” (Charmaz, 2006, p. 57). However, because data collection and analysis proceed simultaneously, focused coding is “not entirely a linear process” (Charmaz, 2006, p. 58). As more data are collected, codes are refined to better fit the data which helps to keep the developing theory focused and grounded in the data. That is, data are coded and re-coded as the theory develops over time. In grounded theory studies, this refinement process is referred to as constant comparison and involves comparing codes generated for data collected both within and across participants (Charmaz, 2003, 2006, 2014; Glaser & Strauss, 1967); see figure 3.4. In this way, I compared my initial codes that I had generated, both within and across the four cycles, as I collected data to identify my focused codes.

![Figure 3.4: Constant Comparison Process Across Data Collection Cycles](image)

These comparisons are documented in the memos written by grounded theorists to help bring the codes generated to a more theoretical level. Charmaz (2006) describes how memos “provide a space to become actively engaged in your materials, to develop your ideas, and to fine-tune your subsequent data-gathering” (p. 72). Although memos become more advanced and theoretical as the research process evolves, Charmaz does not believe there are prescriptions for what memos should look like and encourages theorists to “do what works for you” (p. 80). They are meant to be a personal space to think about the data, the codes, and the developing theory. It is through memos that the uncertainty and ambiguity that
Locke (2007) spoke of starts to be worked out in the grounded theory process. As I consider myself to be a visual learner, I generated many of my initial memos in the form of diagrams and would present these diagrams at the focus groups I held in the theory-building cycles as a way to present my findings up to that point in time. Figure 3.5 is an example of one of these diagrams that I created to represent the whole process of HIS in YOPD, which I presented at the focus groups in cycle three. Birks and Mills (2011) and Charmaz (2006, 2014) also talk about how memos provide a space to be reflexive about the data and analysis. It was through this process of creating memos and diagrams that I was able to see, for example, that I was thinking about functioning as I had previously understood it through my education. I will elaborate on this point further in chapter four, where I define functioning within my grounded theory.

Figure 3.5: Early Diagram Created Through Memoing

As my data collection and analysis continued, so did the constant comparison process. However, the comparisons made become more theoretical in nature and led to the development of theoretical codes (Charmaz, 2003, 2006, 2014). Through theoretical coding
the most important or significant focused codes are raised to higher conceptual levels of the
theory, i.e. categories and subcategories, and the relationships between them are described.
Coming from the social constructionist paradigm, Charmaz cautions grounded theorists that
these theoretical codes “may lend an aura of objectivity to an analysis” (2006, p. 66) but they
remain constructions based on the social interactions of the researcher and participants in a
particular context. As coding becomes more theoretical in nature, Charmaz describes how
memos also become more advanced and act as a place to define properties of the categories
and subcategories. Through this more advanced memoing process, the grounded theory takes
form and can be written into drafts.

Together with theoretical coding, the use of *theoretical sampling* directly supports the ability
to define properties of categories in memos, as specific data are sought out to serve this
purpose (Charmaz, 2003, 2006, 2014; Glaser & Strauss, 1967). This specific type of
sampling is used in the later stages of a grounded theory and limits the amount of data that
needs to be collected because it is focused on filling out the developing theory. Therefore,
this type of sampling stands in contrast to other types of sampling used in research, which as
Charmaz describes “is not about representing a population or increasing the statistical
generalizability of your results” (2006, p. 101). Furthermore, theoretical sampling is not
about collecting data until no new patterns emerge, or finding negative cases. Waiting to
complete theoretical sampling until the later stages of a study will help to keep the theory
grounded in the data collected and not forced into existing theory. In terms of choosing
which participants to theoretically sample, Glaser and Strauss (1967) put emphasis on
choosing those who “will help generate, to the fullest extent, as many properties of the
categories as possible, and that will help relate categories to each other and to their
properties” (p. 49). That is, based on the data collected and analysis completed, specific
types of participants are sought and specific questions are asked that help to *fill gaps* in the
categories developed and add complexity to the theory (Charmaz, 2003, 2006, 2014).

In analyzing my data for the first three cycles, for example, I came to understand that there
were different types, or stages, of acceptance that participants and autobiography authors
spoke of in their experiences. Prior to the start of the fourth cycle, I had only incorporated
this into my theory in that there existed different types and these coincided with progression
of the disease over time (see figure 3.5). As such, I theoretically sampled participants by
choosing those who had lived with the disease for several years and asked them specific questions geared at better defining these different acceptance stages. What was it that differentiated acceptance early after diagnosis from the addition stage of acceptance participants were speaking of several years after the diagnosis? As well, related more specifically to HIS, how did these stages relate to one’s desire and behaviour in seeking out health information? At the same time I collected this data in the fourth cycle, I continued the process of constant comparison and looked back to data I collected from the first three cycles.

Through theoretical coding and sampling, I also came to see that HIS was only one of several strategies used by participants to build resilience to the control they perceived to have lost from the disease. Thus, in the final theory-building cycle, I also focused on identifying and categorizing these other resilience strategies used by participants, both in the data I collected in the final cycle and in relation to the previous data I had already collected. It was through this constant comparison process, and reconceptualising how I understood HIS within my data, that I was able to identify my core category: managing uncertainty. The core category is the theoretical concept that subsumes and integrates the other theoretical categories developed in the grounded theory (Birks & Mills, 2011). Given that I position myself within the constructionist paradigm, however, it is important to note that this core category is contextualized within the experiences of those who participated in this study, the experiences of authors of whose autobiographies I included, and within my role as the researcher developing the theory.

Before turning to my results chapters, one other point is important to note in contrasting my earlier construction of the data with the final version that will be presented in my results. More specifically, in the earlier version I had included quality of life as an overarching concept, of which perceived control played an important part in defining quality of life (see figure 3.5). Part of my comprehensive exam for my doctoral studies looked at quality of life in relation to the International Classification of Functioning, Disability and Health, and the importance of both subjective and objective components of quality of life (M. J. Ravenek, Skarakis-Doyle, Spaulding, Jenkins, & Doyle, 2013). However, in returning to look at the data over time, through constant comparisons and theoretical sampling, I noted that quality of life as a concept was playing less of a role and, instead, perceived control remained at the
forefront of how participants and authors described their experiences. As such, I removed the concept of quality of life from the theory I generated in this study. In future work, I may return to look at the relationship between perceived control and quality of life in those living with YOPD, seeing that my desire to incorporate the concept into earlier versions of my theory was likely due to my personal interest rather than it being grounded in the data. In this way, the theory I present is better grounded in the data I collected, with my own personal biography being a part of the analytic process rather than prioritizing my biography over the data I collected.

3.8 Quality Criteria

As I discussed when I located myself within this research in chapter one, quality in qualitative research is something that I spent much time thinking about early into my doctoral studies. In particular, I was taken aback, and intrigued at the same time, that so many different conceptions of quality of qualitative research could co-exist in the literature. In coming to understand the different approaches to quality, I worked with Dr. Debbie Laliberte Rudman to place these approaches in relation to historical moments of qualitative research discussed by Denzin and Lincoln (2005), representative of changing sociopolitics (M. J. Ravenek & Laliberte Rudman, 2013). Through this process, we identified four main approaches to assess the quality of qualitative research, including: 1) qualitative criteria as quantitative criteria; 2) paradigm-specific criteria; 3) individual assessment; and 4) bridging criteria. These criteria are placed in relation to Denzin and Lincoln’s historical moments in figure 3.6. Although these criteria can be located in relation to various historical periods, all four approaches currently exist and are used by various individuals to assess qualitative quality. Given these conditions, individuals may assess qualitative research using inappropriate criteria, thus devaluing the research and its contribution. My focus here, however, will be on the bridging criteria that are part of the current historical moment, i.e., a fractured future, to describe the criteria I have worked towards, and will used to measure, quality within this research.

3 Parts of this section have been previously published (M. J. Ravenek & Laliberte Rudman, 2013). The content is included with permission of the publisher, as the authors retain the right to subsequent publication of the material after its initial publication in the journal, i.e., the International Journal of Qualitative Methods.
3.8.1 Bridging Criteria

In the present moment, Denzin and Lincoln (2005) discuss the backlash associated with qualitative methods within “‘Bush Science’ and the evidence-based social movement” (p. 20). Looking forward, these authors predict a fractured future where methodologists will divide themselves; quantitative researchers on one side where randomized trials stand as the gold standard and qualitative researchers on the other side where “socially and culturally responsive, communitarian, justice-oriented” (p. 1123) work is completed. In the latest Sage Handbook of Qualitative Research, Denzin and Lincoln (2011) continued to voice concern regarding the contemporary “politics of evidence” (p. 2), pointing to the positivist resistance to qualitative research in the alternative paradigms within an “increasingly conservative, neoliberal global environment” (p. 13). With regards to legitimization and quality assessment, if qualitative research is to stand united in this fractured future, conceptions of quality are needed that build points of connection, or bridges, across paradigms. More specifically, flexible criteria are needed that are unique to, and unify, qualitative work and, at the same time, are sensitive to diversity within and between paradigms and methodological approaches. Such criteria would point to considerations of relevance to all qualitative
researchers, while at the same time acknowledging that how the considerations are addressed will vary in relation to the paradigmatic, theoretical, and methodological locations of a particular qualitative project.

This bridging approach can be seen in several recently published pieces, including the work of Ballinger (2006), Morrow (2005), Tracy (2010), and Whittemore, Chase, and Mandle (2001). Many similarities exist across the criteria, considerations, or standards proposed by these authors (see table 3.2), signaling that a movement towards a general consensus or agreement has already begun on what criteria are important for, and can connect various forms of, qualitative research. For further description of the different criteria proposed by these authors, and the similarities between them, please refer to M. J. Ravenek and Laliberte Rudman (2013).

**Table 3.2: Comparable Concepts and Terms Associated with Bridging Criteria of Quality Assessment**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Worthy topic</td>
<td>Resonance</td>
<td>Social validity</td>
<td>Explicitness</td>
</tr>
<tr>
<td>Significant contribution</td>
<td>Convincing and relevant interpretation</td>
<td>Vividness</td>
<td></td>
</tr>
<tr>
<td>Rich rigor</td>
<td>Adequacy of data</td>
<td>Systematic research conduct</td>
<td>Creativity</td>
</tr>
<tr>
<td>Credibility</td>
<td>Adequacy of interpretation</td>
<td>Credibility</td>
<td>Authenticity</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Integrity</td>
</tr>
<tr>
<td>Sincerity</td>
<td>Subjectivity and reflexivity</td>
<td>Account of researcher role</td>
<td>Thoroughness</td>
</tr>
<tr>
<td>Meaningful coherence</td>
<td>Paradigm-specific criteria</td>
<td>Coherence</td>
<td>Sensitivity</td>
</tr>
<tr>
<td>Ethics</td>
<td></td>
<td></td>
<td>Sensitivity</td>
</tr>
</tbody>
</table>
Tracy (2010) describes how a common language framework for quality is needed amongst qualitative researchers if we are to make qualitative research more attractive to a variety of stakeholders, including funding agencies, policy makers, and society in general. This framework needs to be developed in ways that enable points of connection across various approaches to qualitative research, while simultaneously enabling and fostering diverse ways of thinking about and doing such research. There is still much room for discussion on which terms should be used in describing a bridging approach. In an attempt to synthesize the bridging criteria presented by Ballinger (2006), Morrow (2005), Tracy (2010), and Whittemore et al. (2001), and move the discussion forward, I worked with Dr. Laliberte Rudman to create five categories to describe the common emphases for quality described by these authors. These categories are presented in Table 3.3, with examples of questions that might be asked when assessing a piece of qualitative research.

In maintaining the flexible nature of these bridging criteria, the questions asked and responses will be dependent not only on the area of research under investigation but the specific approach (paradigm, methodology, and methods) used. For example, thoroughness and transparency will mean different things in a constructionist grounded theory compared to a critical ethnography or participatory research. It is, therefore, seen as the responsibility of the authors to describe how quality was achieved in terms that can be understood on a broader level, that is, in a bridging manner.
Table 3.3: Categories of Bridging Criteria and Associated Questions

<table>
<thead>
<tr>
<th>Category</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Value and Significance of the Research</td>
<td>Is the importance of the research and/or the value of the findings clearly presented and discussed by the authors in the work?</td>
</tr>
<tr>
<td>Thoroughness of Data Collection and Interpretation</td>
<td>Given the type of research conducted, did the author collect data as thoroughly as one would expect, i.e., from a variety of sources, using a variety of methods, including discrepant data? Given the type of research conducted, did the authors interpret the data as thoroughly as one would expect, i.e., different levels of coding, multiple coders, involvement of multiple authors and/or participants?</td>
</tr>
<tr>
<td>Transparency and Reflexivity of the Authors</td>
<td>Have the authors clearly described how the research was conducted, including any problems that arose and how the authors dealt with them? Have the authors talked about the completeness of the data and their findings? Have the authors been critical, or reflexive, of their influence on or contributions to the research process and end points?</td>
</tr>
<tr>
<td>Coherence of the Research Approach</td>
<td>Given the type of research conducted and the question(s) being asked, is there a “good fit” with the research methodology used? Given the type of research conducted, the question(s) being asked, and the research methodology used, is there a “good fit” with the research methods used? Given the type of research conducted, the question(s) being asked, and the research methodology and methods used, are the knowledge claims and applications described by the authors appropriate?</td>
</tr>
<tr>
<td>Due Regard for the Research Participants</td>
<td>Beyond meeting institutional requirements for ethics approval, have the authors in their description of how the research was conducted demonstrated responsibility for the well-being of the participants throughout the research process?</td>
</tr>
</tbody>
</table>

Although Charmaz (2006, 2014) describes a set of quality criteria specific to constructionist grounded theory research, including credibility, originality, resonance and usefulness, all of these criteria are subsumed within the bridging criteria I have described. More specifically, there is great overlap between Charmaz’s credibility criterion and the bridging criterion of *thoroughness of data collection and interpretation*. Both get at the depth and sufficiency of the data and analysis in the process of generating the grounded theory. Furthermore, Charmaz’s originality and usefulness criteria both overlap with the *social value and significance of the research* bridging criterion. These criteria all get at the significance of the
work in relation to existing ideas and practices, and its applicability in the ‘everyday’ life of
society. Finally, Charmaz’s resonance criterion overlaps with the transparency and
reflexivity bridging criterion. Both criteria relate to the need for researchers to describe the
completeness of their findings, and how the researchers and participants biographies were
negotiated during the research process and are represented in theory that was generated.
Although not explicitly listed as one of her quality criteria, Charmaz also speaks to the
importance of ethics in the research process, which has come to be an important, but less
frequently discussed, bridging criterion for quality. As well, in presenting her approach to
grounded theory and her quality criteria, Charmaz has already positioned herself
paradigmatically and espouses the importance of coherence in her writing. More specifically,
within the constructionist paradigm, she discusses the appropriate types of questions that a
constructionist grounded theory study can help to address, the flexibility in the use of
grounded theory methods, and the contextualized nature of the research findings.

As the bridging criteria I have described are socio-historically situated, they will need to
continue to be assessed over time as to their suitableness for assessing qualitative quality. In
line with my own paradigmatic position as a constructionist, these quality criteria, just like
any quality criteria, are social constructions. More specifically, they have been constructed
in light of a particular context, or sociopolitical climate, where evidence-based research is
valued to a higher degree than socially and culturally responsive research; a context that is
different than it was a decade ago and will likely be different a decade from now. This is the
context, however, within which I have conducted, and will evaluate, this research.
Chapter 4

4 Theory Overview and Core Category

Prior to describing the grounded theory that resulted from this research, a summary of the study participants involved and the extant autobiographical texts used, both of which contributed to the theory, are provided (section 4.1). The theory itself is then outlined with an overview of the main components (section 4.2), and a description of the core category (section 4.3). Chapter five will examine each of the components of the theory, and connections between them, in greater detail.

4.1 Study Participants and Autobiography Authors

Over the course of the four distinct, yet mutually informing, cycles of data collection, a total of 39 participants took part in this study in interviews, focus groups, an online discussion board, or a combination of these methods. Table 4.1 lists the study participants, their age of disease onset, the number of years they have lived with the disease, and the specific parts of data collection in which they took part. Pseudonyms have been provided to protect the identities of participants and to identify them in the passages used throughout this chapter and chapter five. Twenty six (67%) of the participants were male and 13 (33%) were female. Sixteen (41%) were working either full- or part-time, with the remaining participants having retired from the workforce or on a disability benefit. Thirty three (85%) of the participants were married at the time of their involvement in the study, with the remaining being divorced (7%), separated (5%) or single (3%).

The average age of disease onset for the participants was just over 47 years, ranging from 27 to 60 years of age. At the time of their involvement in this study, the average participant had lived with YOPD for just over seven years, ranging from less than one year to 19 years post-diagnosis. Sixteen of the participants took part in the interview portions of this study, with six participants in each of cycles one and two, and four participants in cycle three. In total, 47 interviews were conducted with the participants, across the cycles. Thirty-three of the participants took part in the six focus groups that were part of this study, including the two focus groups in the formative cycle, one group in cycle two, two groups in cycle three, and
one group in cycle four. Six of the participants also opted to take part in the online discussion board.

Table 4.1: Description of Study Participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age diagnosed</th>
<th>Years living with YOPD</th>
<th>Type of participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alecia</td>
<td>57</td>
<td>2</td>
<td>√</td>
</tr>
<tr>
<td>Alex</td>
<td>44</td>
<td>12</td>
<td>√</td>
</tr>
<tr>
<td>Aron</td>
<td>57</td>
<td>1</td>
<td>√</td>
</tr>
<tr>
<td>Bret</td>
<td>45</td>
<td>2</td>
<td>√</td>
</tr>
<tr>
<td>Carter</td>
<td>50</td>
<td>8</td>
<td>√</td>
</tr>
<tr>
<td>Clay</td>
<td>55</td>
<td>1</td>
<td>√</td>
</tr>
<tr>
<td>Corey</td>
<td>60</td>
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<td>Derek</td>
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<td>Hal</td>
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<td>√</td>
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<tr>
<td>Patti</td>
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<td>√</td>
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<td>Perice</td>
<td>45</td>
<td>3</td>
<td>√</td>
</tr>
<tr>
<td>Peter</td>
<td>47</td>
<td>9</td>
<td>√</td>
</tr>
<tr>
<td>Rey</td>
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<td>10</td>
<td>√</td>
</tr>
<tr>
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</tr>
<tr>
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<td>√</td>
</tr>
<tr>
<td>Sondra</td>
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<td>15</td>
<td>√</td>
</tr>
<tr>
<td>Suzanna</td>
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<td>15</td>
<td>√</td>
</tr>
<tr>
<td>Tobie</td>
<td>32</td>
<td>3</td>
<td>√</td>
</tr>
<tr>
<td>Torrence</td>
<td>46</td>
<td>1</td>
<td>√</td>
</tr>
<tr>
<td>Trevor</td>
<td>41</td>
<td>9</td>
<td>√</td>
</tr>
<tr>
<td>Walton</td>
<td>46</td>
<td>19</td>
<td>√</td>
</tr>
</tbody>
</table>

AVE 47.36  7.28  TOTALS
RANGE 27-60  0-19
SD 6.96  5.10

16  33  6
In addition to data collected with study participants, 14 autobiographies written by individuals living with YOPD were included as additional sources of extant data. Table 4.2 lists the authors of these books, their age of disease onset, the number of years they had lived with the disease and the date of publication of their books. Nine (64%) of the authors were male and five (36%) were female, however, Michael J Fox was included in this total twice as two of his books were used as extant sources. Information on employment and marital status at the time the books were written was not included by all of the authors. For this reason, summary information on these characteristics is not provided. The average age of disease onset for the authors was just over 36 years, ranging from 26 to 50 years of age. At the time of writing their books, the average author had lived with YOPD for just under 14 years, ranging from two to 27 years post-diagnosis.

Table 4.2: Description of Autobiography Authors

<table>
<thead>
<tr>
<th>Author</th>
<th>Year of publication</th>
<th>Age diagnosed</th>
<th>Years living with YOPD*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bill Harshaw</td>
<td>2001</td>
<td>37</td>
<td>20</td>
</tr>
<tr>
<td>Helmut Dubiel</td>
<td>2009</td>
<td>46</td>
<td>13</td>
</tr>
<tr>
<td>Joan Grady-Fitchett</td>
<td>1998</td>
<td>47</td>
<td>17</td>
</tr>
<tr>
<td>Joe Griffey</td>
<td>1998</td>
<td>39</td>
<td>27</td>
</tr>
<tr>
<td>Joseph Amodeo</td>
<td>2007</td>
<td>30</td>
<td>25</td>
</tr>
<tr>
<td>Kathleen Webster</td>
<td>2004</td>
<td>32</td>
<td>13</td>
</tr>
<tr>
<td>Michael J Fox</td>
<td>2002</td>
<td>29</td>
<td>11</td>
</tr>
<tr>
<td>Michael J Fox</td>
<td>2009</td>
<td>29</td>
<td>18</td>
</tr>
<tr>
<td>P Phan</td>
<td>2004</td>
<td>39</td>
<td>13</td>
</tr>
<tr>
<td>Patricia Lightner</td>
<td>2003</td>
<td>35</td>
<td>10</td>
</tr>
<tr>
<td>Richard Secklin</td>
<td>2010</td>
<td>50</td>
<td>8</td>
</tr>
<tr>
<td>Richard Wenmouth</td>
<td>2010</td>
<td>26</td>
<td>2</td>
</tr>
<tr>
<td>Sandy Gordon</td>
<td>1992</td>
<td>30</td>
<td>6</td>
</tr>
<tr>
<td>Sandy Andrews</td>
<td>2003</td>
<td>41</td>
<td>12</td>
</tr>
<tr>
<td><strong>AVE</strong></td>
<td><strong>36.43</strong></td>
<td><strong>13.93</strong></td>
<td></td>
</tr>
<tr>
<td><strong>RANGE</strong></td>
<td><strong>26-50</strong></td>
<td><strong>2-27</strong></td>
<td></td>
</tr>
<tr>
<td><strong>SD</strong></td>
<td><strong>7.57</strong></td>
<td><strong>6.94</strong></td>
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</tbody>
</table>

*Years living with YOPD based on date of publication. When the number of years was not explicitly provided by authors, it was calculated based on dates provided in the book.
4.2 An Overview of the Grounded Theory – Managing Uncertainty in Young-Onset Parkinson’s Disease

As depicted at the centre of figure 4.1, the core category of this grounded theory is “managing uncertainty.” Through experiencing the diagnosis of YOPD, and the subsequent progression of the disease over time, study participants and autobiography authors were confronted with uncertainty in their lives along two main lines. First, individuals experienced uncertainty with respect to their identities as young and middle-aged adults, deviating from the path normally taken by those of this age in society. Second, individuals experienced uncertainty with respect to their functioning, as the heterogeneous nature of Parkinson’s progression meant that it would not be possible to chart the exact course of how their disease would change over time, or even from day-to-day. This uncertainty resulted in feelings of lost control over their lives and increased grief from this loss. To try and regain a sense of control and reduce the grief they experienced, individuals worked to manage with this uncertainty by finding ways to reduce it.

Figure 4.1: An Overview of Managing Uncertainty in YOPD
One of the mechanisms used by individuals to manage with the identity and functioning uncertainty caused by the disease occurred through processes of “adjusting.” Within the overall theory, these processes are illustrated on the right side of figure 4.1. Initially, individuals worked to logically adjust to the diagnosis, weighing the evidence that they did indeed have the disease. In the second process, individuals worked to emotionally adjust to the uncertainty, which was described by individuals as “ongoing” given the progressive nature of the disease. In other words, it was expressed that emotional adjustment was never finished, as the progression of the disease continued to confront individuals with issues to which they needed to adjust. These processes, logical and emotional adjustment, are described in section 5.1, with an emphasis on how these processes were engaged in to manage the uncertainty and the ensuing grief.

A second mechanism through which individuals worked to manage with the uncertainty they experienced was to use different strategies to build their resilience. Within the overall theory, these processes are illustrated on the left side of figure 4.1. More specifically, individuals used internal and external strategies to change how they thought about their lives with the disease and their interactions with others. A third strategy used to build resilience to the uncertainty of living with YOPD was learning about Parkinson’s disease, drawing on information sources in their environments and their own bodily experiences living with the disease to build their knowledge. The internal and external strategies used by individuals are described in section 5.2, with a more focused look at the learning process in section 5.3. These strategies were used to manage with the uncertainty, largely by increasing individuals’ perceptions of having control over their lives.

Although the processes of adjustment were primarily used to reduce grief resulting from experience with the disease, and the strategies to build resilience were primarily used to increase control beliefs, overlap did occur. This overlap is represented in figure 4.1 via the bidirectional arrows between “adjusting” and “building resilience,” and the ring connecting the left and right sides of the graphic. For example, in order to logically accept the diagnosis, it was necessary for individuals to gain at least a basic understanding of Parkinson’s. Likewise, in order to move towards greater emotional acceptance, strategies to build resilience and increase perceptions of control were necessary. Thus, these two processes were used by individuals together in their experiences with YOPD to manage with the
uncertainty they experienced. Overlap between adjusting and strategies used to build resilience will be described throughout the sections of the results where such overlap occurred. Prior to outlining these processes, a detailed description of identity and functioning uncertainty in the experiences of participants and authors, and the resulting grief and lost sense of control, is provided in section 4.3. The sections of chapter five describe the different ways that individuals worked to manage with the uncertainty, in an effort to increase their sense of control and reduce the grief they experienced with the disease.

4.3 Functioning and Identity Uncertainty in the Lives of Individuals Living with YOPD

The uncertainty experienced by participants and authors was a core defining feature within this research. From the point of diagnosis, and over time as the disease progressed, individuals spoke of uncertainty, connecting this to issues of functioning and identity, and worked to find ways to manage with it in their daily lives. As a prelude to ways in which uncertainty was managed, the focus of this section is on how participants and authors expressed this uncertainty and the resulting grief and perceived loss of control. First, however, it is important to outline the conceptualizations of functioning and identity being used so that uncertainty in relation to each can be further discussed.

4.3.1 Conceptualizing Functioning

Working within the social constructionist paradigm, I recognize that my own personal biography influences the assumptions and conceptualizations I bring into the research setting; or, as Charmaz (2006) describes that “neither observer nor observed come to a scene untouched by the world” (p.15). My educational background in occupational therapy and rehabilitation science has provided me with a view of human functioning that differs from other disciplines, and has “nonetheless shape[d] [my] research topics and conceptual emphases” (p.16). More specifically, I have come to understand and view human functioning from a biopsychosocial perspective. This perspective views human functioning beyond the reductionist approach of the biomedical model, encouraging consideration of the interactions within and between biological, psychological and social components (Engel, 1977). The biopsychosocial perspective is described as being foundational to the way in which human functioning is portrayed in the International Classification of Functioning, Disability and Health (ICF), which was developed by the World Health Organization (WHO) in 2001. The
ICF has been instrumental in the development of my understanding of human functioning and, as such, is a “disciplinary perspective” (Charmaz, 2006, p. 17) that I bring to this research as the researcher.

At the individual level, the WHO (2001) describes human functioning within the ICF as the product of one’s: 1) body structures and functions, 2) activities and 3) participation. As its name implies, body structures and functions are defined by the WHO within the ICF as the “anatomical parts of the body” and the “physiological functions of body systems (including psychological functions)” (p.10). Activities are specific tasks or actions completed by an individual, such as walking, which require the coordination of body structures and functions to execute. Finally, participation is defined by the WHO as an individual’s “involvement in a life situation” (p.10). Although much criticism of the ICF has been discussed in the literature with respect to the WHO’s use of these terms, they do provide a means by which biological, psychological and social components of human functioning can be viewed (M. J. Ravenek et al., 2013). Within the ICF, however, these three levels of human functioning are not considered in isolation. More specifically, human functioning can also be influenced by a health condition (e.g., YOPD) and by various contextual factors internal (e.g., age, gender) and external (e.g., natural and built environment) to the individual (WHO, 2001). Thus, additional biological, psychological and social factors interact with the three levels of functioning to influence an individual’s overall level of functioning (M. J. Ravenek et al., 2013). In many ways then, the ICF is also congruent with a social constructionist’s perspective, where the functioning an individual experiences in a given situation is constructed through the interaction of his/her environment and personal biography.

As a sensitizing concept, use of this broad conceptualization of functioning provided a way to organize and think about data that related to what participants could and could not do, while being open to the factors influencing their functioning and issues of uncertainty (Charmaz, 2006, 2014). Therefore, “functioning uncertainty,” as it is defined in this research, refers to uncertainty that existed for participants with respect to their bodily structures and functions, their ability to carry out specific tasks, and their ability to participate in society. As will be described, this uncertainty was experienced in terms of their day-to-day functioning, and in terms of expected functioning in the future.
4.3.2 Conceptualizing Identity

Within the social constructionist paradigm, identity is also considered to be a socially constructed concept. In the methodology chapter, it was described how identity is a “key element of subjective reality” that is “maintained, modified, or even reshaped by social relations” (Berger & Luckmann, 1966, p. 159). In other words, identity can be defined as how we see ourselves in relation to others in society, and how we perceive being seen by others, in the ongoing process of socialization into society. Berger and Luckmann discuss different levels of socialization, where an individual comes to learn different roles played in society through interactions with members of institutions and other members of society. The socialization process is stratified such that particular roles are learned and acquired based on the stage of life for an individual. Over time, a person accumulates a number of roles which he/she plays simultaneously depending on his/her own personal biography. For example, someone can be a husband, father and teacher all at the same time.

Within this study, participants conveyed that there were particular roles they felt they needed to play but were made difficult because of the disease, especially in terms of their family life and employment. In many cases, these roles were specifically referred to as being central to how they viewed themselves and how they believed others viewed them. Thus, the two elements that are central to identity, and how it is defined within this research, are the social roles played by an individual and his/her stage of life. Other factors, like gender for example, are also important in considering identity. Within this study, gender, and what it means to be a male or female in a particular society, is subsumed within the different social roles that individuals are socialized into at a given time. Particular distinctions between male and female social roles will be discussed in relation to the uncertainty experienced by study participants and authors.

With this view of identity in mind, “identity uncertainty,” refers to uncertainty that existed for participants with respect to their ability to continue to perform specific, socially constructed, roles as young and middle-aged adults. Similar to functioning uncertainty, this was experienced not only in terms of their day-to-day lives but with their expected identity in the future as well.
4.3.3 Uncertainty at Diagnosis

For the majority of participants the time in which they received their diagnosis from a physician was, understandably, highly emotional. The diagnosis began a process of grieving at least partly attributed to the identity and functioning uncertainty associated with now being a person with YOPD. Participants had vivid recollections of the moment of diagnosis in their lives, and all shared an emphasis on the “numbing” and “shock” provoking effect of the doctor’s words. This response made it difficult for them to absorb any information provided by the physician after he/she had relayed the diagnosis, as several participants describe in the passages below.

**Shanna:** [The doctor] sat down and he said “in my best medical opinion, I believe you have Parkinson’s.” And of course that’s when, you know, he just kept on talking, just spewing it out and I sort of went blank and really shut down … I was zoned out at that point. I don’t think I heard anything more.

**Kalvin:** [The doctor] took his time and he tried to ease all of it and tried to explain it all and tried to prepare me for what he was telling me. But it was just a numb feeling. I know after my sisters asked me what he said and I couldn’t even remember because I was just numb. I was shocked.

**Jordan:** You don’t know what’s going on, you’re in shock. Like the doctor says “do you have any questions,” but your mind doesn’t register that. Your mind is processing the diagnosis. And he asked if you have any questions, which is a waste of time because I don’t have questions. I just got kicked in the head with a hammer.

The shock and numbing effect of the diagnosis on participants is representative of the perceived threat the diagnosis posed to their identities and functioning. They were no longer just Jordan the teacher or Patti the nurse; they now, according to the doctor, also had a progressive neurological condition. In a moment, their identities and their functioning became much less certain than they had been prior to the appointment. Different aspects of participants’ identity and functioning were threatened by the diagnosis resulting in this uncertainty.
4.3.3.1 Initial Functioning Uncertainty

At the time of diagnosis, the functioning of most participants had been minimally impacted by the disease; but the symptoms were enough for them to seek a medical opinion and receive a diagnosis of Parkinson’s disease. However, in the short time after their diagnoses, participants and authors also began to understand that it would not be possible to predict their future with the disease. As Sandi Gordon (1992) describes in her autobiography, physicians are often reluctant to try and answer questions from patients about the future.

“I longed for a concise picture of my future, to know exactly what lay ahead. Realizing today the erratic course of Parkinson's from one individual to another, I can now appreciate Dr. Hastings' evasive responses to my anxious questions. Many of my worries had to remain unresolved” (Gordon, 1992, p. 38).

More specifically, because of the variability of the disease, the specific symptoms that would develop, the medication side effects that would be experienced, and the rate of progression all remained largely uncertain for individuals early after diagnosis. Thus, the initial functioning uncertainty experienced by participants was more anticipatory in nature and related to a fear of the future because of the disease’s uncertain course.

Shanna: I’d say I have “what if” thoughts. What’s it gonna be like and you sometimes think about what am I gonna be like in the retirement years, and are we gonna be able to do anything, and how am I gonna be when the kids get older, and at their weddings, and grandkids … What my abilities are going to be? Can I make plans for the future?

Martha: But it’s funny how what runs through your mind – it’s fear. Parkinson’s, I think the biggest thing is it gives you fear like you’ve never had fear before.

Interviewer: Fear about what? Martha: Of the unknown, of what’s it going to do to you next.

Danny: Is it going to get worse? Will I lose some of – my biggest fear is probably my mobility. The one big thing that scares me, or not really scares me, is the mobility. Am I going to start falling down? Am I going to be able to walk properly? … I don’t know how my body will go, but it’s the fear of the unknown, I guess. Where am I going to be five years from now? You do start to ask yourself those questions.
The initial shock and numbness experienced by participants upon learning of their diagnoses can be seen as being rooted in the threats that it posed. One threat was related to the uncertain course the disease would take, leaving their future functioning uncertain. The result was that participants spoke of having a fear of the future. The other threat caused by the diagnosis related to the identity of participants. More specifically, the diagnosis also led them to become more uncertain about their identities in society as young to middle-aged adults.

4.3.3.2 Initial Identity Uncertainty

Given the role of physicians in Western culture, as experts with respect to health and the human body, individuals often seek physicians when they suspect something wrong with their health. One of the more obvious ways that this information is structured, and shared between people, is through the use of a diagnosis, i.e., the label or the name of the disease a person is most likely to have based on their presenting symptoms. For participants of this study, after seeking out help from one or more physicians, they were told they had YOPD; an immediate and enduring label identifying them as being individuals with a progressive neurological condition.

Within the interviews I conducted, and the YOPD autobiographies I read, participants and authors shared an understanding that by receiving this label they were transitioned into a changed identity as now being a person with YOPD. This change in their identity also contributed to the grief experienced by participants after diagnosis. In speaking of this grief, M. J. Fox (2002) talks about the freedom that he felt he had lost in the new “identity that I had no part in creating” (p. 146). This is not to say that participants and authors always immediately accepted this diagnosis from their physician(s), as receiving and processing the diagnosis was highly charged emotionally. However, in receiving the diagnosis from the physician, participants and authors no longer viewed themselves as “normal” or “healthy.” For example, in his autobiography, Helmut Dubiel (2009) speaks of his diagnosis as being the “point of a state of separation from other people, the irrevocable onset of exclusion from the circle of those who are (apparently still) ‘healthy’ and ‘normal’” (p. 31). Study participants also perceived this “state of separation,” which was caused by the diagnosis, as illustrated in the passages below.
Kennith: If friends ask what’s wrong then I will tell them. But it plays on you, not knowing if somebody judges you … it brings you down because you just don’t know. Thoughts of not being normal.

Interviewer: How did you feel after being diagnosed with Parkinson’s disease? Alex: You know, I was kind of clueless because at the time, you don’t feel any different than a normal person. And then all of a sudden, boom!

Even years after their diagnoses, speaking of the present time when they participated in the study, this perception of no longer being healthy or normal persisted, and attempts to evade social ‘outing’ were described. Descriptions of routines and interactions continued to be prefaced with a comparison to “normal” people.

Denis: With Parkinson’s I would rather call a restaurant and find out if they have wheelchair accessibility or if they’ll make my table reservation a table that I can without creating a scene sit at in a wheelchair and enjoy just like normal folks having the evening out.

Danny: You do your masking; whatever it takes; sit on your hand … and you wouldn’t normally – A normal person wouldn’t think about their hand, but I would do that, or if the leg starts to go, I cross the leg, or do what – it’s little things, but you become mentally aware of it. I never did before Parkinson’s.

Apart from being diagnosed with a progressive disease, there were unique aspects of being diagnosed with YOPD that made it particularly challenging for participants in terms of their identities. More specifically, Parkinson’s disease has been typically associated with older age. As they were diagnosed in young to middle-age adulthood, social norms produced expectations for participants that they should be healthy and productive members of society. So not only were participants diagnosed with a progressive disease, but they were diagnosed with an “old man’s disease” that was out of sync with what was considered normal in society. Patti and Richard Wenmouth (2010) help to situate these social norms in the passages below.

Patti: I thought how can I have Parkinson’s? I’m not 80. You know, like the typical picture.
“I ran from the room and into the nearest bathroom. I stood, hands resting on the basin, staring at my reflection in the mirror, and began sobbing. I had found my voice again, but the only words I could summon were, ‘Why me? I’m only 26 years old’” (Wenmouth, 2010, p. 5).

Cognizant of the social norms associated with young- and middle-age adults, many authors and participants spoke of the difficulty they experienced with respect to their changed identities. Kathleen Webster (2004) recalls the “embarrassment” caused by the diagnosis, whereas Jordan perceived that being diagnosed with Parkinson’s immediately made him an “old man” despite only being in his 40’s at the time.

“I was in the prime of my life. I was 33 years old, with a baby who needed me; I was in the best physical shape I had ever been in, and I was to finish graduate school next summer. Why me, why now? I was scared and embarrassed” (Webster, 2004).

**Jordan**: The afternoon of the diagnosis, I had a friend visiting from California. And she took a picture of me … and I look like I’m 99 years old because I became an old man right there and then. So that was my big issue with being diagnosed with an old man’s disease … **Interviewer**: How do you think that affected you, knowing that it was an old man’s disease? **Jordan**: Well, I was depressed because I was aging faster than I had planned to … that was the worse traumatic thing was the fact that I was aging. My life was over.

Although work has been done to bring more awareness to YOPD, evidenced by the growing number of support organizations for young adults with the disease, the majority of people with Parkinson’s are still diagnosed later in life (Muangpaisan et al., 2011). Shanna and Patti provide further support for the identity uncertainty experienced by participants early after diagnosis, describing how society has come to associate illness as being something more common, and perhaps even expected, in older adulthood. The result is that young- and middle-age adults who develop a chronic illness are left in limbo, uncertain of who they are and where they fit.

**Shanna**: It’s because it’s an old man’s disease and it’s still viewed that way. I know when people hear of somebody that’s in their senior, even with cancer, it’s like oh well, they’re 85 or they’re 65. And that’s not really the right mentality to have. But
when there are so few people that are diagnosed with this type of disease people just sort of fluff it off.

**Patti:** You know it's that, oh, it's grandma, she's 80 years old, tough luck, she has Parkinson's. Well, I'm sure grandma's not too thrilled with it, but at 80, she's probably less upset than if you were 40 and you can see that big promotion go by the wayside if you tell your company that you've got Parkinson's. Because even though they're not allowed to discriminate, you know if they got two people one that’s healthy and one person that's not, probably gonna lean towards promoting the person that's healthy because they're gonna be around.

The passage from Patti above helps to illustrate a close relationship that existed between identity and functioning uncertainty in the experiences of participants. As young adults who are expected to work and contribute to society, Patti and many others experienced fear and uncertainty about their future employment. As many participants and authors described, part of their identities were based on the roles and responsibilities they took on in their chosen professions, with their ability to carry out these roles and responsibilities being dependent on their bodily functioning. Thus, as the disease progressed and functioning declined, both identity and functioning uncertainty continued to be sources of grief.

4.3.3.3 “Losing Control”

In addition to leading participants and authors to experience grief after the diagnosis, the uncertainty they experienced also created a perception that they had lost control over the direction their lives were taking. More specifically, it was understood that the diagnosis, and the eventual progression, was something that was outside of their control. Parkinson’s disease was not caused by something they had done to themselves, and that over time it was going to get worse. For the most part, up until the time of their diagnoses participants and authors were in control of their lives. That is, they had been able to chart the direction of their lives by making choices about their education, where to live, work, etc. Parkinson’s disease was not one of those choices. The importance of perceived control, and the ongoing struggle to regain it, is talked about explicitly by Griffey (1998), Secklin (2010), Webster (2004), Gordon (1992) and Amodeo (2007), for example, in their autobiographies. Trevor helps to illustrate this perception of lost control after diagnosis in the passage below.
**Trevor:** I was distraught to be honest with you. I didn't know what the future held. You feel a lot of emotions. I felt insecure for the first time probably in my life. My destiny wasn't in my hands … The issue of losing control. All your life you've been able to steer in this direction, that direction, wherever you wanted to go and then all of a sudden you can't do that anymore. That was pretty hard to deal with.

The progressive nature of YOPD meant that, over time, control would continue to be an issue confronting participants and authors. Changes, and continued uncertainty, with respect to their identities and functioning persisted and challenged the belief that individuals had control over their lives.

4.3.4 Uncertainty with Progression

The uncertainty experienced by participants after the diagnosis of YOPD was not finite; it was ongoing and continued over time as they experienced progression of the disease. Perceived changes in identity because of the break from social norms and the fear of future functioning did not go away. Given that the original fear imposed by the diagnosis was of the future, it makes sense that the fear would not subside with the passage of time as it only brought participants closer to the future they feared. As Joan Grady-Fitchett (1998) describes, the Parkinson’s diagnosis “created fear, and you have to fight it all the time” (p. 193).

4.3.4.1 Continued Functioning Uncertainty

The initial fear generated by the diagnosis in terms of future functioning continued to be discussed by participants as something that was ongoing and ever-present. As has been described, there was a close relationship between identity and functioning uncertainty, but participants also discussed fear of specific functional issues that could develop. More often than not, these functional issues were those that posed the greatest threat to their independence and their mortality. For example, participants like Danny, who at the time of being interviewed were still working and driving, were worried about being able to continue participating in society as they had done up to that point.

**Danny:** I feel my body going through another change, not necessarily the next change, but ‘a’ change, and so it started to pop these questions like are you gonna stay working, are you gonna do this – so it’s putting a little more stress into my thought
process, and you start to say to yourself, you know am I gonna be able to function? Or like we just bought a new vehicle – am I gonna be able to drive for the next five years?

Other physically based difficulties associated with Parkinson’s were also a source of fear and uncertainty for participants. For example, Suzanna and Michail discuss fear and anxiety around swallowing issues that they had the potential to develop.

**Suzanna:** Anxiety will come up every once in a while. I mean that might just be because of the Parkinson’s itself, as a symptom of the Parkinson’s. But also, you know, when you have swallowing difficulties, you start to think what’s going to happen in the future? So there’ll be a little bit of anxiety around that.

**Michail:** Since I've been in it for the last eight years, our support group has lost two people that died of their symptoms. The one person I knew long before from where I grew up and he choked. The odd time I have to double swallow myself … Sometimes when I chew I have noticed that when I swallow it doesn’t seem to go down and then I've got to swallow again before it does go down.

For participants, like Sondra, this continued fear revolved around the potential for dementia and other cognitive difficulties that can be associated with Parkinson’s. For example, in the passage below, Sondra was asked about why she, in particular, feared the cognitive difficulties that could potentially occur.

**Sondra:** Because that’s the part that lets you take part in life … I did not want to know about dementia. Mobility problems I could handle, but I did not want to know about dementia … You can take away my mobility but don’t let my brain go. I don’t want to become demented … like am I going to get to the point where I’m in a nursing home? I’ve seen that. And it’s not pretty. And I don’t want my kids to see that.

Several autobiography authors also discuss this fear of dementia and other cognitive difficulties, including Joan Grady-Fitchett (1998) who talks about having a “constant fear of dementia” (p. 194). This fear was also discussed by Patti and Martha, in the context of difficulties that could arise in the future because of Parkinson’s.

**Patti:** There's a little bit of potential for cognitive impairment and that scares me. I thought of it more too that you’d become almost like an Alzheimer's patient.
Martha: I guess maybe the one constant thing is as we progress through this part of our life, we hope we don’t get the cognitive – the cognitive part always I hope stays with me.

The other way that participants spoke of this fear of the future, and what their functioning would be like, was in reference to not wanting to be a “burden” to others. Fear of being a burden implies that individuals feared eventually needing help from others, especially from family members, and that if this help was accepted it would further change their identity as being someone independent to someone dependent on others. Contextually, this speaks to the high value individuals place on independence in Western cultures (Eckersley, 2001; Markus & Kitayama, 1991).

Alex: I just don’t want to really be a burden. That’s why a lot of times I don’t even think about even getting married again because I don’t want my – as long as I don’t have to burden my family because they’ve all got lives to live. They have children. I know they love me, but the point is I don’t know. It’s like having a feeling of independence without burdening anyone else.

Kalvin: You want to know what’s in store for you. I want to know what my life is going to be like when I’m 10 years down the road, 15 years down the road, what I should expect. Should I expect to be living on my own? You know, those types of things. They shake me up a bit. Because I hate thinking that I’d be dependent on somebody. But that’s really the key thing, is what’s your dependency going to be like? And the answer is that they don’t know … You just don’t want to be a burden to people.

Alecia: You’re always just fearful of getting worse, you know, your symptoms getting worse, your brain not working, your feet not working, you injuring yourself somehow … I just feel like you don’t want to be a burden, which I’ve heard a lot of people at the Parkinson group say who are farther along in the disease than me. That’s a big word–nobody wants to be a burden on anybody.

Similar to the functioning uncertainty experienced by participants early after diagnosis, much of the ongoing functioning uncertainty continued to revolve around a fear of the future; that is, the uncertainty was more anticipatory in nature. Fear that they would
eventually develop dementia or swallowing difficulties, or lose their independence and become dependent on others. For many participants, however, some of this fear and uncertainty had become a reality in their day-to-day experience living with the disease.

4.3.4.1.1 Good Days and Bad Days

Similar to some of Charmaz’s (1991) work exploring chronic illness, one of the most common ways participants described experiencing uncertainty in their daily lives was through the distinction of having “good” and “bad” days. The element of uncertainty in this distinction was that participants had no way of knowing in advance if a day was going to be a good one or a bad one. On the whole, good days were those in which participants could be productive and their functioning was minimally impacted by the disease. Conversely, bad days were highlighted by more pronounced symptoms, such as balance impairment and tremor, and difficulty carrying out tasks and activities. Kalvin and Alecia help to elucidate this good and bad distinction in the passages below, when asked to describe what they meant by having good days and bad days.

**Kalvin:** There’s days that I feel like I have good balance, like not perfect balance, but that I do some things kind of almost normal … There’s days that are bad, that I’m bouncing off the wall. It’s like I just can’t get my balance … On a bad day, like I’ve fallen, I’ve dropped dishes. You’re just shaking. You can’t hold anything … There’s days I’ve been in the shower that I just feel like I’ve got no balance and I shouldn’t be in there. But there are other days I feel very, like I’ve got control of myself. I guess that’s the word, control. So some days you don’t feel like you’ve got control, and other days you do.

**Alecia:** A good day is waking up and being invigorated and getting out there and doing some positive things and being able to do the things that you have on your list … Things just move a little more smoothly. You’re in control of your symptoms, you know, your medication seems to work well, and you don’t feel as much like the patient or the person with the disease … And a bad day is you just can’t get yourself moving or you go to do something and you trip and you – your body is just not – your balance is gone or you’re just out of sync with yourself.
Kalvin and Alecia both describe good days as those in which they feel in “control,” implying that bad days were those in which they felt less control. As has been described, early after the diagnosis participants and authors perceived to had lost control in their lives, largely because of the threat posed by the disease. Being a marker of good and bad days, helps to illustrate how feelings of lost control also persisted in the day-to-day lives of individuals as well. As a result, participants and authors worked to try and regain some of this lost control, by trying to manage the uncertainty they experienced, so as to maximize their good days and, thus, their functioning.

4.3.4.1.2 On-Off Motor Fluctuations

Although a day may not be thought of as a short period of time participants also reported, and were observed to experience, more abrupt changes in their functioning. More specifically, the effectiveness of the medication used to treat Parkinson’s can become limited over time, so a person experiences improvement in their symptoms (“on”) for a short time (e.g., 2 hours) and then the medication becomes ineffective (“wears off”) and the symptoms of the disease return. These “on/off fluctuations” have long been recognized as a progression of the disease (Hardie, Lees, & Stern, 1984) and many studies are working to develop better treatments for this phenomenon (Olanow et al., 2013). In addition to on/off fluctuations, individuals can also develop involuntary writhing movements, termed dyskinesias, which occur during the “on” phase, usually at peak medication dosages. Thus, many participants and authors reported functioning uncertainty at several points in a given day, because of the side effects of Parkinson’s medication. Kathleen Webster (2004) and Lilia describe learning “first hand” what these terms meant through their experiences living with YOPD.

“I had learned first-hand what was meant when I heard the terms ‘on’ or ‘off.’ When my medicines were ‘on,’ I was able to function quite well. When the medicines wore ‘off,’ my PD symptoms were quite pronounced” (Webster, 2004).

Lilia: I really found out what my disease was in that first year I was off work.
Interviewer: And what was it? If you could describe it? Lilia: Well, I found out that I won’t be able to walk at times. And sometimes it lasted a long time and sometimes it didn’t, but I could sometimes go down for two hours where I couldn’t move … It was just so uncomfortable … And I don’t know how to explain it, but it was awful.
While interviewing a number of participants, I witnessed these abrupt changes in functioning that can occur in the time of peak medication dosage, i.e., dyskinesias, and between dosages, i.e., wearing off. For some this change was minor, such as a slight tremor or dyskinesia in a limb, but for Lilia, Joela and Martha these changes were pronounced. More specifically, during interviews with these three participants, there were periods where one or more of the interviews had to be postponed because of the discomfort caused by these transitory periods. Each of them would need to move around and stretch to try and offset the rigidity and spasms or involuntary movements they were experiencing, which made it difficult for them to sit and carry on a conversation. For Martha, during these periods which she referred to as “episodes,” she would sometimes need to lay flat on the ground to prevent her from losing her balance. The passage below is from a five minute interval with one of my interviews with Martha where she had a sudden change in her functioning but allowed me to continue recording.

**Martha**: Can we just stop for a minute? **Interviewer**: Absolutely. **Martha**: Okay. I just feel like I’m gonna spring here … The right half of my body’s going this way, and the left half wants to go the other way. **Interviewer**: Anything I can do for you?

**Martha**: No, it’s just I have to wait it out, I think. Yeah, it feels like wet cement starting to harden … Are your tape recorders still going? **Interviewer**: They are. Do you want me to turn them off? **Martha**: Yes, please. Just for a few minutes. Just in case I kinda scream or yell or swear or something. I don’t normally like to do that. Oh man. Actually, you can leave it on because this might be important … Yesterday was a better day, but this isn’t as good. If I go to the floor, you’re okay with that too, are you? **Interviewer**: Whatever you need to do. **Martha**: Whenever I go onto the floor, and I might be on there very shortly, just because I’m not balancing anymore, and this rocking back and forth, this is just to get some balance … Now I don’t do that in a store, unless I can avoid it – or at work. Excuse me, which makes it kinda worse – ah, there – because I have to hold onto the spasms longer, and I’m really getting frozen. Not frozen but like my muscles aren’t working … Often that’s where it’s starting from, it kinks up my right shoulder. So anyways, when I’m coming – I’m almost out of it now, but it tends to crisscross across my body. I’ll need someone because I can’t reach those spots to massage it. It’s almost over – there! That was a quick one, thankfully.
From one hour to the next, one day to the next and trying to look into their futures with the disease, functioning uncertainty played a central role in the lives of authors and participants. Although the fear of future problems that could occur was anticipatory, many participants spoke of the striking difference the disease can have on their functioning in their daily lives. For others, the unpredictable effects of the medication with disease progression increased their functioning uncertainty. This uncertainty with respect to their functioning contributed to a feeling of reduced control over their lives and also made it difficult for individuals to carry out roles that were part of their identities.

4.3.4.2 Continued Identity Uncertainty

“I felt as though I had lost my identity. I was no longer a husband, a home owner, a cop. I'm just an old man with Parkinson's disease” (Secklin, 2010).

The passage from Richard Secklin (2010) above hits on the two main areas where identity uncertainty continued to impact the lives of participants. That is, participants experienced uncertainty with respect to their roles as members of their families, and uncertainty with respect to roles in their employment. These two areas of identity uncertainty will be discussed with passages from participants and authors in the sections below.

4.3.4.2.1 Family Life

Within the confines of families, individuals hold and play numerous roles: husband, wife, mother, father, brother, sister, son, daughter, uncle, aunt, so on and so forth. Each of these roles has particular expectations and functions and, as has already been discussed, come to form part of an individual’s identity. For many participants, like Alecia and Martha, the progression of the disease posed a threat to identity within their family units, producing a feeling of vulnerability and uncertainty.

Alecia: I think it stems from losing part of your identity. You are who you are, and you have built yourself – your own self-confidence and who you are in relation to your kids, or your husband, or your friends. And having this just makes me more vulnerable, I think.
Martha: It seemed like my role in the family was to be a caregiver. So it was hard accepting care from someone else. And that was brand new for me because I was the healthiest in my family … I felt ashamed and embarrassed by it because I was a caregiver.

Parental Roles

As adults with children, identity uncertainty in family life was commonly discussed by participants and authors in terms of their changing roles as being parents. Kathleen Webster (2004), for example, describes in her autobiography how Parkinson’s, “had stolen my ability to play with my children.” Kalvin, who experienced long periods of fatigue because of the disease, had also started to experience a change in his role as a father to his children.

Kalvin: I have a real fatigue factor. I used to be able to go down and help [my children] around the house, and now I find working around the house I get just toasted really easy. I don’t – I just don’t have the strength that I used to, and I find that very frustrating because I like to work with tools, and I like to do things, and I’ve given [my son] all my tools because I can’t – I find I can’t do what I used to do.

In contrast, Kennith, who was still relatively early in the progression of the disease, spoke of identity uncertainty in terms of being able to play with his son in the future. In other words, because his functioning difficulties were largely being remedied by his medication, the uncertainty he experienced was more anticipatory and based on a fear of the changes that could occur.

Kennith: I have visions of not being able to play with my son. He’s five, well I guess he was four then. I’m thinking about even being able to be around to see him graduate because I’ve had that thought come through my mind. Yeah things like that … I had trouble picking my son up at one point. Just knowing what I went through before I had the medication, I don’t want that ever again. So it’s still a fear.

Spousal Roles

In some cases, participants experienced a significant change in their identity in relation to their family life because of the disease. In particular, there were instances where participants reported having been divorced by their spouse because of the diagnosis. Regardless of
whether or not there were significant marital issues leading up to the diagnosis, participants perceived that the root cause of the divorce was the diagnosis. The diagnosis created uncertainty regarding the future that was planned together, and when the spouse without YOPD was not able to manage with this uncertainty it was expressed as a reason for the divorce. Thus, the identities of participants and authors changed from being someone married and living with YOPD to now being divorced and living with YOPD.

Kalvin: I think personally she couldn’t deal with what was coming down the road, down the pipe as much. There were a few other issues that got blown out of whack. But I think one of the issues was that she couldn’t deal with this … I think if she would admit truthfully, I think she would admit that she couldn’t handle it; what was in store for the future. She couldn’t handle it right now, with the fidgetiness and the not sleeping at nights and that kind of stuff, so I think – I just saw that it was wearing on her. There’s lots of excuses, but that’s I think the big one.

Joella: He didn’t want a sick wife. Period. He found somebody else … It probably would have happened anyway, but I think the Parkinson’s just allowed him to cut and run, which is really, as my children said, “he abandoned us.”

A number of autobiography authors also experienced divorce with their spouse, either directly or indirectly relating this to the diagnosis, including Griffey (1998), Secklin (2010) and Phan (2004). This is not to say that participants and authors didn’t also experience new relationships, and even re-marry, after the diagnosis as some did. This too would represent a change in their identity in their family life, and this is important to note because not all changes in identity after the diagnosis were necessarily negative.

4.3.4.2.2 Employment

The second major life area where identity uncertainty continued to impact the lives of participants occurred with respect to their employment. Similar to roles individuals played in families, the roles they played in the workforce also formed a major part of how they viewed their identity. When these roles were taken away from participants, well before the socially expected time for individuals to be losing these roles, identity uncertainty ensued. Although it may have only started as fear of eventually needing to leave the workforce early, for many participants and authors this fear became a reality.
Suzanna: I think we all sort of identify ourselves with our occupations, particularly, I think, in the healthcare profession. Because it consumes you as much as it does, so I always think my identity was tied to being a [healthcare professional], and I enjoyed what I did. I loved my practice. I loved my patients. I liked having the privilege of being involved with their care. And to give that up was like giving up a part of me, particularly because it wasn’t my choice. It would have been different if it had been my choice, and I had decided myself, okay, now it’s time to slow down and stop because of whatever reason. But I wasn’t given that choice. It was sort of taken away from me, and that was a little bit harder to swallow.

Jordan: I was teaching languages, French, Japanese, and Spanish. And one of the things that goes with Parkinson’s is you can’t write anymore. I was able to write Chinese and Japanese script, Greek script, Russian script, Roman script, or French and English and Spanish, and now I can’t even write my name. So that’s one of those depressing realities that you have to surpass. You can’t write anymore. So my job was going very well. Everything was going very well. It was the end of the summer vacation, and I was getting excited for a nice slate of classes. And then it came to an abrupt end.

Again, in the passage from Jordan above we can see that there is a close connection between identity, i.e., being a language teacher, and the change in his functioning, i.e., no longer able to write, that contributed to him leaving his job as a teacher. Since he was no longer able to write and teach, his function and his identity became more uncertain. As has been discussed already in this chapter with respect to having good and bad days, the idea of losing a sense of control over one’s life is also evident in the passages above from Suzanna and Jordan. The choice of when to leave the workforce was taken away from them because of the changes in functioning they experienced as the disease progressed. This loss of control was also discussed by Bill Harshaw (2001) and Helmut Dubiel (2009) in their autobiographies, as both were forced to leave their respective workplace in the midst of their careers.

The social environment invariably plays an important role in one’s ability to continue to work, including the willingness and ability of employers to make accommodations. Certainly with legislation like the Ontarians with Disabilities Act (Service Ontario, 2001), such accommodations are becoming the rule instead of the exception. Indeed, many
participants had been able to continue working in their chosen professions, through compromise and accommodations from their employers. However, some workforces also come with additional social expectations, such as law enforcement, where following and upholding the law is an important part of being a police officer. For Richard Secklin (2010), who treated himself with marijuana to “relax” his body and improve his symptoms, the resulting guilt and uncertainty of his identity as a police officer eventually caused him to voluntarily leave the police force.

“Oh one particular day I suddenly quit my career law enforcement job without even giving notice. Shock over what I had done left me even more mystified. I had problems with sleep, mood swings, and everything … It was probably from the guilt. I wasn’t a real cop anymore, I cheated! … All I ever spent was $200.00 but I am still uneasy about this whole scenario, and still have nightmares over it” (Secklin, 2010).

Threats to, and changes in, employment and family roles formed the basis of the identity uncertainty experienced by participants and authors as the disease progressed. This uncertainty contributed to the grief and perceived loss of control in their lives. However, similar to family life, not all of the employment-related identity changes resulting from the progression of the disease were negative, as will be discussed. Roles with respect to engagement in leisure activities, like playing golf and hiking, were also changed through progression of the disease. However, perceived threat to, and uncertainty in, these roles were not a focus of what was discussed by participants and authors. A likely explanation for this is that leisure played less of a role in the identities of participants, compared to work and family roles.

Summary

The functioning and identity uncertainty experienced by participants and autobiography authors were at the core of this research. From the point of diagnosis and over time as the disease progressed, this uncertainty remained. In some cases anticipatory, because of the uncertain course of the disease, and in some cases experiential, because of the nature of the disease and its current treatment, the uncertainty touched important parts of participants’ lives. From employment and family roles to various aspects of human functioning, the lives of participants took a different route from the internalized norms and expectations of society.
Indeed, it was at the nexus between identity and functioning that much of the uncertainty experienced by participants developed. However, participants were not passive bystanders being confronted with this uncertainty. More specifically, they worked to try and manage the uncertainty, as will be described in chapter five.
Chapter 5

5 Adjustment and Resilience in YOPD

Through experiencing uncertainty with respect to their identity and functioning, and the associated grief and perceived loss of control, participants and authors used two different means to try and manage. First, participants worked through the grief they experienced and adjusted to the identity and functioning uncertainty in an attempt to “come to terms” with the diagnosis. In section 5.1, adjusting to YOPD and the processes subsumed within such a transition will be described. Coinciding with these adjustment processes, participants used various strategies to build resilience to the uncertainty they experienced to try and take back some of the control they perceived to have lost to the disease. These strategies will be described in more detail in sections 5.2 and 5.3.

5.1 Adjustment as a Means of Managing with the Uncertainty of YOPD

When participants were diagnosed with YOPD and confronted with uncertainty with respect to their identity and functioning, a grieving process began. They grieved because of the loss they perceived from this uncertainty, which was both anticipatory and experiential in nature, from the time of their diagnoses onward. Participants and autobiography authors described the different facets of this grief and how they adjusted to it over time, as a means of reducing their grief and managing the uncertainty they experienced. The idea that individuals grieved and adjusted to their diagnosis was apparent throughout the interviews and focus groups that I conducted. A number of study participants, given their educational backgrounds and their location in a Western context, found that they were able to relate their experiences in adjusting to Elizabeth- Kübler-Ross’ (1969) popularized stages of loss from her book On Death and Dying. Although these different stages were originally developed to describe the process that individuals went through when they were dying, as the book title implies, it nonetheless served an important function for participants to relate their own grief and experiences.
Joella: It’s like the stages of death, I think. You know that book Death and Dying by – I forget her name … Kübler-Ross. She describes the different phases of dying and I think when you’ve got a chronic disease, you go through the same type of thing. It might be a different title, but you go through the same thing.

Patti: I think doing nursing I, of course, always had to do psych papers on Kübler-Ross and the different stages … So, I found that, you know, there’s sort of a blurring of problems and I realized I was in different stages of either denial or acceptance.

Martha: I read her books in college, so I was aware of them for a long time. I graduated in 1980, and I read her stuff. So off and on, I could feel my mind going “yeah, Kübler-Ross is right” … and I’ve been aware that I’ve been going through her stages.

Descriptions of grief and adjustment, in light of the work of Elisabeth Kübler-Ross, were also used by autobiography authors to try and better understand their own emotional reactions in living with YOPD. M. J. Fox (2002) and Secklin (2010), for example, both refer to the work of Kübler-Ross in their transitions to living with YOPD. Sandi Gordon (1992), who also used Kübler-Ross’ stages in describing her experiences, discusses how she “partook in each of the five stages along the road to acceptance” which stemmed from her “bemoaning deprivation of a healthy future” (p. 63). These comparisons, and the usefulness that participants and authors saw in Kübler-Ross’ stages, led me to dig deeper in my work to try and tease out what this adjustment process consisted of and how it worked.

Participants of this study, and the authors of YOPD autobiographies, certainly have not been the first to use these stages in describing their process of grieving and adjustment. Indeed, in Kübler-Ross’ final book, published after her death in 2004, Kübler-Ross and Kessler (2005) extended the stages of loss and applied them to the grieving process more generally in On Grief and Grieving. Being a grounded theory, however, the adjustment process that I present is the process that participants underwent as they grieved the uncertainty caused by their diagnoses and the subsequent progression. What became apparent to me in my analysis was that this adjustment process was not straightforward and, in fact, was recognized by participants as being composed of multiple and ongoing levels of adjustment.
**Interviewer**: Just going back to your own version of Kübler-Ross’ stages. Where would you say you are now? **Joella**: Not dead yet! Although sometimes I felt like it, when I was first sick … I would say I am at acceptance level two. I think I accepted it once before, but it was on my terms, not Parkinson’s. And I guess maybe before, which is a better way, I think, if you can fight the Parkinson’s and say it’s not going to get the best of me.

**Alecia**: I think mentally, you can only deal with so much at a time, and that’s why it’s hard to accept it all at once. And each hurdle you come up against, probably makes you stronger and makes you more accepting over time.

These different levels or types of “acceptance” discussed by participants, namely logical and emotional acceptance, came to represent two separate, but closely related, sub-processes of grieving and adjustment.

5.1.1 **Sub-Processes of Adjustment**

Through analysis of my discussions with participants, and analysis of YOPD autobiographies, it became apparent to me that, at minimum, there were two distinct types of adjustment. These were, essentially, two separate sub-processes which together made up the adjustment process experienced by participants. The first type, logical adjustment, refers to the process that individuals went through in coming to agree with, or “accept” the evidence from experts that they did indeed have YOPD based on their presenting symptoms and difficulties. This ranged from logical denial to logical acceptance of the diagnosis, with unique characteristics that help to differentiate between the two.

Occurring subsequent to logical adjustment was the emotional adjustment process experienced by participants and authors, where individuals grieved the threat to, and uncertainty of, their identities and functioning resulting from the diagnosis. Similar to logical adjustment, emotional adjustment can be represented on a continuum, from emotional denial to emotional acceptance of this threat and uncertainty. As these two sub-processes were closely related, the adjustment process as a whole can be represented as a graph showing logical and emotional adjustment as intersecting continuums (see figure 5.1).
Figure 5.1: Sub-processes of Adjusting to the Uncertainty in YOPD

The dashed curve shown in figure 5.1 represents the typical means by which individuals came to adjust to the grief caused by their YOPD diagnosis over time. Starting on the bottom left, most individuals had at least a short period where they experienced both logical and emotional denial. Over time, however, individuals came to logically accept the idea that they did indeed have YOPD, which is illustrated in the figure by the initial steep rise in the curve. Once individuals logically accepted the diagnosis, they were able to start to grieve the implications the diagnosis had on their identity and functioning. For most individuals, this process of emotional adjustment was “ongoing,” given that the progression of the disease caused continued difficulties and uncertainty, represented by the flattening of the curve and the density of the colouring. More specifically, the dense colouring in the area of emotional acceptance illustrates that individuals spent the most amount of time in this area of the adjustment process. The coloured gradient above the curve represents variations in the adjustment process experienced by study participants and authors.

Two characteristics of this curve, i.e., the whole adjustment process, are important to point out. First, some degree of logical acceptance needed to be present before individuals could overcome the emotional denial and proceed towards greater emotional acceptance. It would not make sense that someone would begin the process of emotionally healing and managing
with the uncertainty caused by the diagnosis if they didn’t first accept that they had YOPD.
Second, it is important to note that the second part of the curve is bi-directional, further
illustrating the ongoing nature of the emotional adjustment process. There was never
complete and total emotional acceptance of the disease because it is a progressive disease
that continues to change and threaten an individual’s function and identity over time.

5.1.2 Logical Adjustment

As a first line of defense to the grief caused by the uncertainty of being diagnosed with
YOPD, individuals went through a process of logically adjusting to the disease. The term
‘logical’ is used to describe this type of adjustment because the process was centered on the
reasoning done by participants, in light of evidence and expert opinions, that they did indeed
have YOPD. Ranging from greater denial to greater acceptance, logical adjustment served a
largely protective mechanism. More specifically, by logically denying that they had YOPD,
participants and authors could postpone having to “come to terms” with the uncertainty of
the disease in an emotional sense. It’s reasonable that needing to navigate through such an
adjustment process would precede emotional adjustment, as one would want to make sure
that they didn’t grieve and make changes in their life unnecessarily, i.e., if the initial
diagnosis proved to be a mistake. At the same time, given the seriousness of the diagnosis,
reconciling such a change to their identity and future functioning was not something that
participants were willing or able to do hastily. In the passage below, Martha describes this
protective characteristic of logical adjustment, and more specifically of logical denial, in
light of what accepting the diagnosis would mean for her.

**Martha:** It was okay for me to be in denial, because it was protecting me, I guess,
until I was ready to figure it out. I was in denial for a very long time … **Interviewer:**
What is it, when you were in denial, that you were trying to protect yourself from?
**Martha:** I’m embarrassed by it. I’m insulted by it too, but more like it’s very
embarrassing, because it’s out there. It’s not like a tiny thing inside you can just say,
“oh, it’s a hiccup or whatever.” **Interviewer:** So, the denial then was protecting
yourself from the embarrassment of having Parkinson’s? **Martha:** From the horror of
it. And the horror of it is going to be here a long time.
5.1.2.1 Logical Denial

With respect to the continuum of logical adjustment (see figure 5.1), participants who logically denied the diagnosis were those who were not convinced by the existing evidence and expert opinion that they did indeed have the disease. Through analysis of the data collected, three specific behaviors were most characteristic of participants who were logically denying their diagnoses, which all related to gathering or avoiding additional information and evidence related to YOPD.

Avoidance of Health Information Seeking

At the extreme end of logical denial, some participants reported avoiding all information related to Parkinson’s as a way of initially managing with the diagnosis. This characteristic is described in the passages from participants below, again, illustrating the protective function that logical denial served in reducing the need to think about the threat and uncertainty posed by the diagnosis. These passages show the responses from participants when asked if they sought out any information related to Parkinson’s after they first received their diagnosis.

Alecia: No, I didn't at that point. No, I didn't. I think I was in denial. I didn't really want that to be part of the picture, so I didn't pursue it.

Suzanna: Not really because I didn’t believe him for one thing, and I was sort of in denial of it even being a possibility, and probably deep down didn’t really want to read something that might give any credence to what he had told me … I didn’t want to read anything that would sway my opinion otherwise.

Patti: Not too much. I didn’t really want to. I don’t know. I was trying not to think about it. Like I initially went to my doctor and had lab work done. And he says after Christmas we’ll, you know – “I’ll call you back in.” And I didn’t wanna think about it … I kept my head pretty ostrich-like until I went to see the neurologist.
A second characteristic of those displaying logical denial, related to information behaviours, was seeking out health information to generate for themselves a differential diagnosis or an alternative perceived to be less serious than YOPD. As described in the passage from Trevor below, the motivation behind such information seeking was the seriousness of the threat and uncertainty posed by YOPD. Accordingly, finding an alternative to YOPD would remove the threat and uncertainty and, thus, eliminate the need to reconcile the emotional nature of significant changes to one’s identity and functioning.

**Interviewer:** So what was the purpose of collecting all that information? **Trevor:** I was really looking for an alternative to Parkinson’s disease I think in many ways. I was struggling just coming to terms with the idea that I could possibly have PD … If I was looking for information on PD, it was almost to prove that I didn’t have PD. And so that’s how it unfolded … I was looking for anything that would give me an alternative to PD because at that stage, my mind was fixed on the idea of “oh God, how am I going to support my family with PD?” To me, it was a summary sentence. I was going to be hanged in a few years … It’s interesting because initially I knew the wearing off and fatigue were Parkinson's but I wanted to find some other reason. So we went through thyroid dysfunction. I had thyroid tests. They were normal. We went through the meds and virtually – I was on 7 or 8 meds and 6 or 7 of them had fatigue as a potential side effect, so we went down that alley. We got to the end and 3 months after coming off everything I was still dealing with the same problems.

Michael J. Fox (2002) and Joe Griffey (1998) also describe this type of behaviour in their initial denial of their diagnoses. Both M. J. Fox and Griffey report clinging to the typical descriptions of Parkinson’s they read as support they didn’t have YOPD. More specifically, they didn’t believe they could have Parkinson’s at such a young age because it was supposed to only occur later in life. In other words, the information they focused on was that which supported the idea that there was an alternative explanation to their difficulties.
“I clung on to the one fact that was always printed in any of these articles, and that was the statement that this disease rarely appeared in people my age. I used that statement like a security blanket for a long time, because I was really hoping that I did not have Parkinson's disease” (Griffey, 1998, p. 91).

In some cases, participants and authors were initially misdiagnosed with having something other than YOPD before eventually receiving the correct diagnosis. Such was the case for Sandi Gordon (1992) who was originally misdiagnosed as having sensory nerve damage instead of YOPD. Gordon describes how she used the misdiagnosis as a “defense mechanism against the fear” (p. 23) in her initial denial after becoming diagnosed with Parkinson’s. Whether it was a “defense mechanism” or a “security blanket,” the wording used by both Gordon and Griffey help to further illustrate the idea that logical denial served a protective function for participants and authors. More specifically, it was protecting them from the fear and uncertainty that would result if they accepted that they did have YOPD.

**Seeking Second Medical Opinions**

The final, and most common, characteristic displayed by participants and authors, who were experiencing logical denial of their diagnoses, was seeking out additional neurologists to evaluate them and provide a second opinion. Webster (2004), Secklin (2010), M. J. Fox (2002), Grady-Fitchett (1998) and Dubiel (2009), for example, all describe seeking out second, or even more, opinions from different neurologists. Similar to the first two characteristics of logical denial, the purpose of seeking out additional medical opinions was to find an alternative diagnosis, i.e., to find someone that would tell them they didn’t have YOPD.

**Trevor:** It was partly getting second opinions. It was talking to other people that I guess who I respected in terms of their medical or pathophysiology backgrounds. I mean, I even ended up speaking with some of my colleagues in pharmaceutical companies and stuff. And I was offered access to eminent people in the states and stuff like that. So I didn’t actually take that offer up. But that’s how far and wide I went with it. I was prepared to really consider all options.
Shanna: I think I held out hope at the beginning and, as I said, just carried on as best I could but with the sort of black cloud lingering. I really didn’t let myself get too far ahead with it until I think I was waiting till I got that second opinion.

The three characteristics described above address the most common behaviours of participants and authors who logically denied having YOPD shortly after receiving their initial diagnoses. The time that it took participants to work through this denial and logically accept their diagnosis varied greatly between individuals. It is important to note, however, that not all participants or authors experienced logical denial, as some individuals were willing to accept their diagnosis from the original physician who diagnosed them without any additional information seeking. For this latter group of participants and authors, this speaks to the power of the socially constructed roles in our society, where the recognition, and value, of the knowledge held by physicians appeared to be accepted without difficulty. One interesting characteristic of many of those who did report experiencing this logical form of denial was that they had previous training and/or work experience in the medical field. For Trevor, Suzanna, Patti, Alecia and Martha, for example, their inside knowledge of the medical field seemed to reduce the degree to which the social role of the physician had been reified; that is, that medical diagnoses were accepted and left unquestioned. Regardless of time, or background, all participants and authors eventually reported that they had accepted they had YOPD. If they hadn’t, they likely would not have written a book about their experiences with YOPD, or would not have participated in a research project on YOPD.

5.1.2.2 Logical Acceptance

Logical acceptance represented a point for participants and authors where the evidence and expert opinion set out before them supported that their diagnoses were correct. Despite how they felt about it emotionally, they were able to reason that they had YOPD and not something else. Related to the information behaviours described in logical denial, seeking out additional medical opinions did not result in an alternative diagnosis. This is to say, the additional neurologists only confirmed what had been said by the initial diagnosing physician. This confirmation of the diagnosis from multiple physicians, led participants to transition out of logical denial and towards greater logical acceptance; acceptance that they did indeed have YOPD and it was not something else. For Joan Grady-Fitchett (1998) who received her second opinion from Dr. Melvin Yahr, arguably among the most recognized
neurologists specializing in Parkinson’s disease in the world, it meant that she “couldn’t escape the fact that I really was ill” (p. 25). For Shanna, after receiving her second opinion and confirmation that she had YOPD, she disregarded appeals from her close friends and family about getting additional opinions from neurologists.

Shanna: There was a time after the second diagnosis when it was the absorption of it. And then sharing of the news with that small group of people. And then of course they’re like, “well, you need to get another opinion.” And so it was trying to take everything in and decide what I was gonna do. And the thought of another opinion, I thought how many more people can you see? Are you gonna get the same story?

This transition from logical denial to logical acceptance was also supported when the information materials that participants sought out early after their diagnoses resonated with the difficulties and symptoms they were experiencing. Seeing the symptoms of Parkinson’s in writing, and seeing the same symptoms in their own experiences, reinforced the idea that they had YOPD.

Danny: Again, I had started doing the research a little bit and finding information. Like the sense of smell thing, I didn’t realize – I knew that something was going wrong even in that area for months, but there wasn’t the correlation of it. I’m going, “Yeah, I don’t think I’ve been able to smell things for months.” And the handwriting was something else I read up on. Oh, wow, this is me to a tee. The restless leg was sort of what I had, maybe not quite. There was enough similarities that I’d say, yeah, every point was almost like bang on.

Another experience among participants and authors, which facilitated the transition to logical acceptance, occurred when they had been prescribed Parkinson’s medication early after their diagnoses. When individuals took the medication and perceived an improvement in their symptoms and difficulties, it provided additional evidence for them that their diagnosis of YOPD was correct. Michael J. Fox (2002) and Richard Wenmouth (2010), for example, both describe this medication confirmation process in their autobiographies, as do Danny and Kennith in the passages below.
Danny: And it was really when I got onto the medicines and in seeing, okay, this is starting to react a little bit, that’s when it really hit home that, okay, this is what you’ve got. Obviously, the pills are starting to help. And so that was when reality really sunk in.

Kennith: It took about three or four days for the medication to actually – for me to notice that I was taking the medication. And that’s when I think once I got back to not having the symptoms, that’s when it – just knowing that they can come back just kind of all got to me there, yeah. Interviewer: So the effectiveness of the medication kind of was a clue to you that it was Parkinson’s? Kennith: Yes. Because now this medication is working, so that’s got to be what it is. And the “why me?” came in for sure.

As alluded to by Kennith and Danny in the passages above, when participants and authors came to logically accept their diagnoses, it immediately confronted them with the emotional “reality” of the uncertainty of living with YOPD. For many, this was signified with asking the question: “why me?” This question served as a marker for this transition out of the logical adjustment process and into the emotional adjustment process. In asking, “why me?” participants recognized and accepted that they did in fact have the disease but managing with the diagnosis emotionally had only just begun. No longer could they be “protected” by the thoughts of not having YOPD, as logically they now understood they had the disease.

5.1.3 Emotional Adjustment

As logical adjustment was more of a reasoning process conducted by participants in coming to accept that they had YOPD, emotional adjustment describes the process used by participants to manage the grief caused by logically accepting the diagnosis. The uncertainty of both their identities and their functioning was no longer just a possibility, but now a “reality.” This second, and more complex, adjustment process was recognized by participants as starting only after the logical adjustment process had been navigated.

Suzanna: The second denial was after the actual confirmation of the diagnosis. And that was more of an emotional denial. I mean mentally and I guess – from a factual point of view, I knew I had Parkinson’s disease, but I wasn’t emotionally ready to accept it. So that was a different kind of denial.
“I understood that the medical facts all pointed toward a confirmed diagnosis; that I would have to at least behave as if I really had this disease, research the proper medications, take whichever one was indicated, and so on. But I hadn’t really fully surrendered my denial” (M. J. Fox, 2002, p. 147).

As detailed in the passages above from Michael J. Fox and Suzanna, emotional denial succeeded logical acceptance in the overall process of adjustment described by participants and authors. Similar to logical adjustment, emotional adjustment can be visualized as a continuum ranging from greater denial on one end to greater acceptance on the other end (see figure 5.1).

5.1.3.1 Emotional Denial

Emotional denial was characterized by an emotional element and a behavioural element. If logical denial represented a first-line defense to the grief caused by the uncertainty of being diagnosed with YOPD, then emotional denial was the final defense used by participants and authors in trying to “protect” themselves. In emotionally denying the diagnosis, participants and authors started to grieve the identity and functioning uncertainty with which they were now confronted. More specifically, emotional denial was not the result of the absence of emotions, but rather logical acceptance had caused significant and troubling emotions to surface. In response to these emotions, and the uncertainty caused by the disease, participants and authors discussed specific behaviours they displayed in further denying the disease in their lives.

5.1.3.1.1 Emotional Element of Emotional Denial

As discussed at the end of the section on logical adjustment, the question “why me?” served as a marker for the end of logical adjustment and the start of emotional adjustment. Many study participants and autobiography authors including, for example, Harshaw (2001), Secklin (2010), Lightner (2003), Phan (2004) and Wenmouth (2010), talk explicitly about asking this question. For some, this question had religious origins and for others this question had a more literal sense causing them to look back into their past to try and identify where and how they may have developed the disease. In trying to answer this question for themselves, regardless of the way it was framed, participants and authors started to experience these difficult emotions, consisting of primarily anger and depression.
Participants and authors spoke of being angry, at least initially, with a variety of people whom they felt had contributed to the situation in which they found themselves. Some authors and participants spoke explicitly of being angry with God, questioning whether the diagnosis was a punishment or a test of faith they had to endure. Others spoke about being angry with physicians who delivered their initial diagnoses, and as a means of ‘shooting the messenger’ sought out another physician for continued care.

**Patti:** I found that I was angry at times after I learned about having Parkinson’s. I was almost to the point of being morose. You know, I was angry at the doctor maybe a bit more so than I should’ve been.

“Secretly, during the long nights when I didn't sleep, the inevitable questions would come to mind: ‘Why me, God? What have I done to deserve this? It's a hell of a punishment. Was I that bad?’” (Harshaw, 2001, p. 43).

Regardless of who the anger was initially directed at, participants and authors usually came to understand that their anger resulted from the identity and functioning uncertainty that the diagnosis of YOPD had caused. As discussed in section 4.3 on uncertainty, the adult years are supposed to be the “prime” of life, instead of a time to manage with a chronic illness that would impact employment prospects and the ability to contribute to family life.

**Suzanna:** I was just angry that I had to deal with it. Angry that it was hanging over my head at the prime of my life. And I think that’s what happens with young-onset patients, is that it affects us when we’re at the prime of our lives. We might have young families at home, or we’re just at the peak of our careers or we’re going to try to become financially established. And to have to deal with what I felt was really more a nuisance than anything else, it made me angry.

**Patti:** People really do have to come to terms with the illness and even sometimes after you have, you get mad at it and you know, don’t accept it … I was upset that I wasn't able to work for a while and then it turned out I ended up having to go on disability and quit work, and so in the early stages I found it really overwhelming and just upsetting. And I think too it was upsetting for the whole family.
It is important to emphasize that not all participants experienced anger right away, but for those who did it was easy for them to recognize as being part of their emotional reaction to the diagnosis. In the same vein, the time participants spent being angry also varied widely between participants and authors. Some were only angry a brief period, while others spent years being angry at specific individuals or at their life situation in general. Those who didn’t report being angry after their diagnoses were primarily those participants and authors who were initially less impacted in their functioning and work and family roles. However, because of the progressive nature of the condition, eventually many more participants and authors spoke of being angry at different times because of the ongoing emotional adjustment process in response to changing identity and functioning.

Depression was commonly reported by study participants and autobiography authors including, for example, Gordon (1992), Webster (2004), Dubiel (2009), Andrews (2003), Secklin (2010), Griffey (1998) and Harshaw (2001). Compared to anger, depression was more complicated to situate within the adjustment process proper. Part of the reason for this difficulty was that depression has been discussed in the literature (e.g., McDonald, Richard, & DeLong, 2003), and was also understood by participants and authors, to be either part of the disease pathology and/or a reaction to the diagnosis. Regardless of the etiology, participants and authors did speak about specific reactions they experienced to their diagnoses and the uncertainty it caused as being, at least to some degree, part of the depression they experienced. Similar to anger, the depression reported by participants and authors stemmed from the identity and functioning uncertainty caused by the disease.

Kennith: There was the 'why me' stage. I don’t know how long it lasted. But the general depression has been there for a while. Looking back, I was pretty much depressed the whole time. **Interviewer:** So when do you think your depression started? **Kennith:** When I couldn’t play the drums and just little – little things like that just – I can’t do this anymore. And I can’t do this anymore. It just – slowly swallowed me up.

*Jordan:* I was depressed because I was aging faster than I had planned to kind of thing … Like it’s not always a rose garden. Even now I sometimes think like is this worth it, like when you cannot do your share of the family life for example and things like that. That’s another thing that I think you learn that like when you are
sixty-five and you retire it’s normal, but when you are forty-seven and retire it’s not normal. It’s always in the back of your mind.

In some cases, depression was also connected by participants to a general lack of information about the disease, and lack of guidance provided by physicians after a diagnosis. Thus, even prior to learning of the uncertainty in their identity and functioning, some participants experienced depression because of uncertainty at a more general level; that is, because of the lack of information and guidance initially provided.

Denis: For the next two years [after my diagnosis], I was off on another planet. The way the specialist presented the diagnosis to us and the lack of additional information, or places to go, or things to read, and no insight into what I had to do to combat the disease, no follow-up appointments or appointments with other professionals to get skills to deal with it, and the depression I went into took away my ability to observe what it was doing to [my wife].

Similar to anger, it is also important to note that not every person reported experiencing depression. Furthermore, for those who did report depression as an emotional reaction, it was not necessarily diagnosed by a physician but in some cases a general feeling or mood perceived by the participants and authors. Also similar to anger, those who were most likely to report being depressed after the diagnosis were those who’s functioning, and roles in their family life and employment, had been impacted by the disease. The progressive nature of YOPD meant that depression, either as a formal diagnosis or as a perceived mood, remained a threat in light of the identity and functioning uncertainty of the disease.

5.1.3.1.2 Behavioural Element of Emotional Denial

Just as there were specific behaviours seen in the experiences of participants and authors in logical denial, there were also specific behaviours characteristic of those in terms of emotionally denying the disease. Both of these behaviours revolved around the idea of avoidance, in an emotional sense and a social sense. More specifically, participants and authors spoke of avoiding thoughts and situations that would confront them with the uncertainty of the diagnosis, or require them to explain their changing identity and function to others.
Emotional Avoidance - Staying Busy

As anger and depression are not emotions desired by individuals, one of the behaviours displayed by those emotionally denying the diagnosis was to “stay busy” as a way of avoiding having to think about the disease. That is, the easiest way to manage the emotions were to avoid them and this was done by keeping themselves so busy with other things in their lives that they didn’t have the opportunity to think about the disease. As Andrews (2003) discusses in her autobiography, after her diagnosis she just wanted to “take my pills and live my life,” lying to herself and others that the disease would never get worse. Given the uncertainty the disease held for participants and authors in terms of their identity, often it was family and work life that participants threw themselves into as a way of staying busy and avoiding their emotions.

Interviewer: So you are still working full-time? Kalvin: Yeah, that’s just to keep me busy, keep my mind occupied, not by choice … it keeps me active, it keeps me going. Interviewer: What does it keep your mind off of? Kalvin: The Parkinson’s in some ways. It just keeps me active. It keeps my mind busy. I don’t know what I would do if I was to retire … I don’t know what I would do. I honestly don’t know what I would do if I was sitting at home; I don’t know. By me working I don’t think of it all the time; I get my mind off of it.

Shanna: I was thinking of the negative of course what’s going to happen, the changes. Can I deal with that? And I was sort of in a negative mindset. But at the same time I think the busyness kind of takes over as well, the everyday life. And I guess it’s good in a sense … I got up every day and I got the kids to school. I did what I had to do. I took care of the house. So nothing really changed, which I think in a sense is good. Because I think if my mind had slowed down and I’d let it wander then I would really be in a bad place.

Social Avoidance - Building Walls and Hiding Symptoms

The second type of avoidance behaviour displayed by those experiencing emotional denial was a social avoidance. More specifically, participants and authors spoke of avoiding social situations, and “building walls,” where they would be asked about their health or visible symptoms. Related to this type of avoidance, individuals spoke about the effort they put into
“hiding” their symptoms of the disease, so as not to raise the suspicion of others that something was wrong. For example, Sandi Gordon (1992) talks about “avoiding people whenever it was feasible” (p.29) and, when it wasn’t possible, used strategies like “serving finger foods” (p.29) to hide her difficulty using kitchen utensils. Helmut Dubiel (2009) describes this social avoidance as being a type of “schizoid attitude: a (still partial) admission of the disease to myself and those who were close to me, with denial and secrecy toward my social environment” (p.62). As Alecia and Suzanna describe in the passages below, this social avoidance and secrecy was premised on wanting to preserve, or protect, one’s identity in light of the uncertainty caused by YOPD.

Alecia: You’re always just fearful of getting worse, you know, your symptoms getting worse, your brain not working, your feet not working, you injuring yourself somehow easily. And part of it is, too, it’s the way people treat you. I remember thinking right off the bat, I didn't want to tell a lot of people because I didn't want them to treat me differently. So in a way, you kind of aren’t accepting it, but in a way you are. You still want to be your old self, but you know you’re not kind of thing.

Suzanna: Up until then, I viewed the Parkinson’s as a flaw. And I didn’t want to let that show. So that’s why I put up a wall … be it wrong or right. That’s just the way it gets me through situations … Interviewer: What is it that you’re building up a wall for? Suzanna: From having probably to emotionally face a situation, to emotionally face the diagnosis would have been the reason. To emotionally face prospects for my future would be the reason. Because it’s hard. I mean, undeniably, it’s much easier to ignore something than to emotionally face it.

More related to the uncertainty with respect to their employment future, often the effort to conceal or “hide” symptoms was talked about by participants and authors as being done at work. As Joe Griffey (1998) describes this was often due to the “fear” (p.37) that colleagues or employers would see them exhibiting their symptoms, believing that they would get fired if it was known they had YOPD. This fear is captured in the passages from participants below, which also illustrates that this fear and behaviour occurred subsequent to logically accepting the diagnosis.
Martha: I had still a lot of strain, physical strain, and I was just trying to hide things. I knew what was going on by this point, but I was afraid of the diagnosis. I was afraid of getting fired … I didn’t know what I was going to do next. So I was always on edge to see what do I have to hide.

Lilia: I was hiding it for survival. Interviewer: For survival? Lilia: For keeping my job. I knew I had it, but I just, I just didn’t think anybody needed to know I had it until it was necessary, and I just kept it to myself … I just went way out of my way to make sure that no one could tie me into it. And that lasted for well, I’d say I did it for 10 years.

Michail: I don't want to be labeled at work. They let too many people go at work with disabilities. So as long as I can hide it, I just keep working. So nobody knows at work.

This fear, and the belief in needing to hide symptoms for employment “survival,” speaks to the social stigma of disability perceived by participants and authors. As already mentioned in the section on uncertainty, much of this fear of dismissal from work is now theoretically unnecessary because of legislation like the Ontarians with Disabilities Act (Service Ontario, 2001) and amendments to the Canadian Human Rights Act (Treasury Board of Canada Secretariat, 2011). At the time, however, for those participants and authors working with YOPD before the beginning of the twenty-first century, dismissal may have been a real possibility. This speaks to the importance of the always changing social structure of society, constructed through the actions and involvement of those living in society. For participants who had this fear, when asked they were not aware of such legislation.

5.1.3.2 The “Fork in the Road” - Transitioning Out of Emotional Denial

In making the transition out of emotional denial and toward emotional acceptance, the avoidance characteristic of emotional denial no longer worked for participants and authors. The progression of the disease, with its functioning and identity implications, confronted individuals and forced them to either “come to terms” with the diagnosis or continue to live with depression and anger. The uncertainty, combined with the decline they had experienced, thus, reached a tipping point. For M. J. Fox (2002), “the relentless assault and accumulating damage” caused by YOPD forced him to make a decision: “adopt a siege
mentality – or embark upon a journey” (p.5). This represented the “fork in the road” that Danny speaks of in the passage below, where individuals had the choice to take action against the uncertainty or to passively accept it as being something out of their control.

Danny: You've basically come to a fork in the road in your life, there's a fork in the road, and you can go this way or you can go that way. I could choose to go left and try to make this thing work as best I can, or I could have just gave up and said, “nah, you know. It is what it is and let's just sit at home until it happens.”

Although sometimes participants and authors came to this “fork” on their own, for others, like Suzanna, the perceived need to take action was also catalyzed through feedback they received from others in their support network. In the passage below, Suzanna describes how the progression of the disease, combined with comments from her family, friends and healthcare professionals, caused her to introspect and choose a higher road.

Suzanna: Eventually Parkinson’s catches up with you, and eventually the symptoms became so much so that I really couldn’t hide it anymore, and I had to sort of face it … I didn’t like the person that I was becoming. I was normally a very happy-go-lucky person, and I felt myself burdened all the time. So I recognized that as being an issue. The second thing is I had my husband and my neurologist and my friends were telling me that I was changing as a person, and that I was doing myself an injustice by ignoring the disease, and not taking care of myself to the level that I needed to take care of myself, and denying my children a productive mother in the future. So that was a big thing. So that kind of prodding, I guess, initiated that kind of introspection and realization that I couldn’t control the disease, but I could control how I was going to react to the disease.

As alluded to in the passages above from Danny and Suzanna, the transition toward emotional acceptance was marked by a change in their belief about the disease. More specifically, the uncertainty caused by YOPD was no longer seen as something entirely outside of their control. They may not have been able to control the fact that they had the disease, and that over time it would progress, but they believed that there were specific aspects of their identity and functioning that they did have the power to influence.
5.1.3.3 Emotional Acceptance

“Acceptance does not mean I have passively resigned myself to the fact that I have Parkinson's disease, and must bravely endure the consequences. Instead, acceptance implies that I have become well-informed on the subject of Parkinson's disease, so that my symptoms can be best managed” (Gordon, 1992, p. 69).

In describing how participants and authors came to reach emotional acceptance, it is first important to highlight two features which cannot be understated. First, as the passage above from Sandi Gordon (1992) describes, emotional acceptance was not a passive process. It required a great deal of work on the part of individuals to “come to terms” with the diagnosis by thinking about their identity and their functioning in a new light. Second, emotional acceptance was an ongoing process. The progressive nature of YOPD meant that over time participants and authors were faced with continued changes in their functioning and identity, both of which required emotional reconciliation. Referring back to figure 5.1, this point is emphasized by the colour density and the bi-directional arrow in the part of the curve illustrating emotional acceptance.

It is important to note that the amount of work required by an individual at a given point in time, to reach and maintain a degree of emotional acceptance, was directly related to the extent their disease had progressed. For those who had been minimally impacted by the disease, it was not difficult for them to emotionally accept where they were in their experience with YOPD. However, for those who had experienced significant progression, and whose independence and participation in meaningful roles and activities were affected, it was much more difficult. The specific characteristics highlighted by participants and authors who had reached a degree of emotional acceptance will be discussed. Again, these characteristics emphasize the belief that they could influence, or “control,” some aspects of their identity and functioning in spite of having YOPD.

5.1.3.4 Being “Proactive” in a Life with YOPD

Instead of waiting for the next changes to occur, resulting from the progression of Parkinson’s, individuals who had reached emotional acceptance described the need to be “proactive.” As Suzanna describes, being proactive was not just a thought process but it became a way of life which inspired a new way of looking at one’s functioning and identity.
Suzanna: As I felt that burden lift, then I started to become more positive and more proactive. Interviewer: So for you, what does it mean to be proactive? Suzanna: Proactive means taking control over the situation. So I would say I’m proactive in a personal way, in that – in terms of lifestyle modification and educating myself about research that’s going on. That’s sort of how I’ve been proactive in my own life. And being proactive and more of a Parkinson’s community point of view in terms of trying to educate [others] is proactive from trying to help the community in general as well. So, there’s different ways you can be proactive.

The passage from Suzanna, above, speaks to the importance of two elements of proactivity discussed by participants and authors. First, being proactive was defined as a way for them to take back some measure of control in their lives, emphasizing the important role that perceived control played in light of the uncertainty of YOPD. Second, it was possible to be proactive at an individual level and also within the larger “Parkinson’s community.” These elements speak to some of the different ways individuals sought to preserve their functioning and identity, and restore some of the control that was initially perceived to be lost. However, the progressive nature of YOPD meant that, over time, it would require more and more work to maintain. As Alecia describes in the passage below, without a sense of control in one’s life, it was easy to fall back into the negative thoughts and emotions characteristic of earlier parts of the emotional adjustment process.

Alecia: I think when you lose control in any situation, then you just become more vulnerable to depression or you become more vulnerable to your body just sort of falling apart … Although, you don’t have complete control. Being proactive makes you feel at least you’re doing something for yourself, that you’re not just sitting back and letting it attack you.

Being Proactive at the Individual Level

After logically accepting the disease, many participants and authors were motivated to overcome the grief they were experiencing because of the uncertainty of the disease. One of the means by which they were able to do this was finding ways they could be proactive in their own lives, trying to maximize their function and minimize the impact of the disease; and thus, in doing so, try to regain a sense of control. It was in this way that seeking out
information related to Parkinson’s, and developing a base of knowledge about the disease, became important. More specifically, the knowledge individuals gained helped them to develop a plan with respect to specific strategies they could use in their own lives to feel as if they could influence their future, short- and long-term, with the disease.

**Trevor**: All the information that I got was gathered together. And I then put a plan in place. I’m going to do A, B, C, and D. In fact, I found an action plan that I must have made about five months ago just last night. And I’m looking at it, and I’m going done that, done that, done that. **Interviewer**: What was the plan? **Trevor**: It was a line chart. On the left, the problem, and on the right, the answer or potential alleviation strategy. So for example, fatigue had a straight line to exercise. Another line from fatigue to meds and stuff like that. So it’s sort of these are the problems, and here are the potential answers.

**Danny**: My wife and I sat down together and said okay, look, you go this way, I'll go this way, let's just see what we can get and just bring all the information back and then we'll decipher the same ideas or we'll write down these, let's make a list. What's probably gonna happen, what is happening now and what can we do to fight it … I want to delay this as long as I possibly can. I want to see my grand-kids grow up, I want to do everything … we learned as much about Parkinson’s as we could first. What it did for me was it helped formulate that game plan … it helped to make the map clear, like the roadmap that we want to go down. I think that's where the information helped.

As Danny describes, and which is illustrated further below, many participants and authors viewed their need to be proactive at the individual level in terms of it being a confrontation; that is, individual versus Parkinson’s disease. This is not surprising given that the choice to be proactive was, in essence, a choice to confront and change the course of their experience, and anticipated future, with the disease. As Phan (2004) describes in his autobiography, “just because I accepted the fact that I have Parkinson’s does not mean that I accepted defeat. I’m still fighting.” Gordon (1992) also talks about how she was vigilant with her vocal exercises as a way to “guard” (p.121) her ability to speak and communicate with others. Thus, being proactive in their lives meant that participants and authors would do whatever they could to influence the “relentless progress of this creepy villain” (Griffey, 1998, p. 179) to make their
lives as comfortable as possible. The most common way this was discussed, at the individual level, was through lifestyle management strategies like exercising and being more nutrition conscious.

**Trevor:** I dramatically increased my physical activity and dropped my weight. I developed an attitude towards Parkinson's which was almost a combative one. It's interesting because you'll see on the websites people will say, “F-U-C-K-P-D.” and stuff like this. They're voicing the way they feel about it. In many ways that's very much how I feel.

**Jordan:** I lost 20 pounds in the last few months so that was a big thing and I got fit. I had to find a way to fight it and that was the way, I put the gloves, the weightlifting gloves on and I fought it with that. So that’s why with a passion I was like, “Get out of my way, I’m doing this program.”… There’s a need for feeling control. I don’t control my body movements anymore … Like the shaking. I can’t do anything to control that. But I control other things in my life, and working out was the only physical control that I had over the Parkinson’s.

*Being Proactive at the Community Level*

In the larger picture, of now being part of the “Parkinson’s community,” participants and authors spoke of many different ways of getting involved and being proactive. Similar to the desire to be proactive at the individual level, contributing at this level helped individuals restore some of the lost control that was perceived, especially as it related to their identities. More specifically, being proactive at the community level was less dependent on a person’s level of functioning than what was described at the individual level. Thus, even as the disease progressed and functioning declined, participants and authors were still able to be proactive by staying involved and contributing to their “community.” For example, volunteering for research studies to help to improve their lives and the lives of others living with the disease, taking leadership roles within a support group and fundraising to support Parkinson’s support organizations and research efforts were all discussed as ways of being proactive.
**Interviewer:** What was your motivation behind doing the fundraiser? **Shanna:** Find a cure for sure. And I think the big thing was that in [this area] and surrounding areas I’d never seen a fundraiser for it. So just for awareness, and the lack of awareness out there. Because there’s certain things that are so focused on when there’s all these other things that aren’t in the forefront.

**Interviewer:** What has motivated you to want to participate in research? **Kennith:** If I can help out in any way I want to help. I was inspired by Michael J. Fox. It’s my way of giving back I guess in some respect. Because I want to help find a cure … And actually I was thinking about doing some fundraising coming up here shortly.

As alluded to by Kennith, Michael J. Fox is perhaps the most well-known example of an individual with YOPD getting involved and being proactive at the community level, especially with the time and effort he put in to start the Michael J. Fox Foundation for Parkinson’s Research (MJFF). Many participants spoke of the inspiration provided by Fox, and appreciation for the work he has done in the Parkinson’s community. M. J. Fox (2009) details much of his work in starting the MJFF in his book, *Always Looking Up*, which was, not surprisingly, very popular among participants of this study. To date, the MJFF has raised and awarded more than $400 million to researchers working towards the Foundation’s goal of finding a cure for Parkinson’s disease (MJFF, 2014). Regardless of the extent to which individuals had contributed to the community, getting involved, and being proactive in, the Parkinson’s community implies that a significant change had to occur for this to happen. More specifically, participants and authors had to come to see themselves, and allow others to see them, as a person with YOPD. Thus, an important change in their identity took place, which is the second characteristic discussed by those who had reached emotional acceptance.

### 5.1.3.5 Redefining Identity as a Person Living with YOPD

**Jordan:** You have to redefine yourself and that takes a while, you mourn who you were, then you become somebody else.

In coming to reach emotional acceptance, participants and authors needed to “redefine” how they saw themselves and, thus, how others in society would also see them. As Jordan alludes to above, this is not something that happens overnight and takes time for such a change to occur. Similar to the first characteristic of emotional acceptance, redefining their identity...
was a way for individuals to feel increased control in their lives. More specifically, the amount of time it took to occur, and the manner in which it occurred, were means by which participants and authors could exert this control. With respect to control over timing, they chose when, and to whom, they would disclose their diagnoses; and with respect to control over how it happened, they chose to play new roles that would allow them to maintain parts of the identity they felt were threatened.

**Disclosing**

An important marker in the process by which individuals redefined their identities relates to how they disclosed their diagnoses to others over time. More specifically, participants and authors spoke of disclosing in a hierarchical manner where those closest to them, usually immediate family and close friends, were told first with others being told more slowly over time. Disclosing to others was a means by which participants and authors were able to control how they believe they were perceived by others and, thus, how they perceived themselves. Being given the diagnosis by a physician was something outside of their control, which had an immediate impact on their identity in terms of the uncertainty it created. This initial uncertainty created a degree of self-consciousness, and perceived stigma, which needed to be overcome in “bits,” as Alecia and Patti describe in the passages below.

**Alecia:** For a long time, I didn't tell people. Like, I didn't want people watching me. You know, when you think somebody has something, especially Parkinson’s, when you look at Michael J. Fox, people watched him … So I think you’re just self-conscious of suddenly thinking everybody’s gonna notice, so you don’t tell people all at once. You tell people as important as they are to you first, and as it goes out from there, you know, people that you don’t see that much, I didn't tell for six months, or for nine months, or a year. **Interviewer:** Where do you think that self-consciousness stems from? **Alecia:** The self-consciousness, I think it stems from losing part of your identity … your mind can only deal with a small portion at a time so I think it's important to kind of deal with a little bit of it with your closest family or whatever and then take a breath and carry on with your life and then deal with a little bit more. Because you have to get comfortable within your own skin with what's happening and not become so emotionally upset about it.
Patti: I disclosed it to who I thought it was necessary first. And, I didn’t like telling people. I don’t know why, but it was like a failure or something … I think it was, you know, that stigma of having a chronic illness that people associated with old age … I didn’t want that because I’ve always, you know, felt that I was very much in control of my own life. And so, I just didn’t tell people until like it became, until I felt comfortable with it myself I think. And, that took me a while. And then, once I started getting comfortable with it and started going, “okay now, let’s see what I can do to make the best out of my situation,” then I started feeling comfortable.

By disclosing to others slowly over time, it gave participants and authors time to grieve and “come to terms” with their diagnoses, the changes it had caused and to decide how they wanted to “redefine” themselves in a way in which they were “comfortable.” As such, an important marker signifying that participants and authors had reached a degree of emotional acceptance occurred when they were able to disclose their diagnoses to others in more public settings. In this way, they had become comfortable with who they were in their changed identities. Such a public included the Parkinson’s community, of which they now had become a part.

New Roles

In describing how individuals redefined their identities as people with YOPD, there is a great deal of overlap with the earlier section in terms of the different ways participants and authors became proactive in the Parkinson’s community. When participants and authors had reached emotional acceptance, they often took on roles which would allow them to contribute to this community. The roles chosen were those in which participants and authors had the greatest interest, knowledge and experience, and were often closely linked to their pre-YOPD identities. For example, Kathleen Webster (2004) was forced to retire early from her job teaching in the public school system, but over time became more involved in Parkinson’s organizations, especially for those with YOPD. In these new roles, she was able to maintain part of her past identity of being a teacher. Instead of teaching school children, however, now she taught adults about Parkinson’s and advocating for the needs of those with the disease. Similar to Webster, several study participants including Jordan, Trevor, Suzanna, Joella and Patti also identified themselves as being, to varying degrees, educators prior to being diagnosed with YOPD. The new roles they took on in the Parkinson’s
community, whether it was through volunteering for research or teaching others, also allowed them to maintain part of their pre-YOPD identities. Suzanna and Patti provide examples in the passages below.

**Suzanna:** As an advocate, I talk about empowering yourself and accepting the diagnosis. When you talk the talk a lot, it also does reinforce your own belief system, that’s the right way to approach the disease. Sort of reinforces my own acceptance of the disease to tell others about it. I also feel useful in terms of my career because that was a big thing that I enjoyed was that contact with people and educating them. So I felt a great loss once I had stopped work, so being able to reach others that are looking to me as to be a resource for them sort of validates that need in myself.

**Patti:** I was used to working at a college. I was used to being with young kids, college kids, people that usually wanted to be there, not forced to be there because if you don't want to be there, you don't go, right? And yet [volunteering] was also something that would help me, so here is something that was close to home that was specific to my illness. I really got along well, I liked the students. And so, I almost felt like I was back at school.

Feeling that they, once again, had some degree of control in their lives with respect to their identity and functioning, through being proactive and redefining themselves, was an important perception held by those who had reached a degree of emotional acceptance. However, several other strategies, apart from those discussed in this chapter, also contributed to increase participants’ and authors’ perceived control. These strategies helped individuals manage with the uncertainty caused by the diagnosis and the subsequent progression, by building resilience they could draw on over time. Although being proactive and redefining oneself were important characteristics of negotiating a degree of emotional acceptance, as has been described, it was a long road between the diagnosis and reaching this point in the adjustment process. The different strategies used by participants to build their resilience to, and manage with, the uncertainty help to illustrate the work done by participants between emotional denial and emotional acceptance; and which would continue to be drawn on over time as the disease progressed.
5.2 Strategies Used To Build Resilience in YOPD

In the process of emotional adjustment, individuals worked through the grief caused by the identity and functioning uncertainty they experienced to try and return a feeling of control to their lives. The level of control sought was that which was personally acceptable and, thus, different across participants and authors, and changed over time. To attain their desired level of control at a given point in the adjustment process, individuals drew on a number of resilience strategies. Some of these strategies were cognitive in nature, some were behavioural in nature, and others were a combination of the two types. These strategies represented the “emotional work” done by individuals during emotional adjustment. Over time, as the disease progressed, individuals continued to draw on these strategies as a means of being resilient to the changes in their identity and functioning coinciding with the progression (see figure 5.2). As such, within the context of this research, resilience is defined as an individual’s defense to elements in his/her life posing a threat to emotional well-being, i.e., the uncertainty caused by YOPD and the resulting loss of control perceived.

Figure 5.2: Timing and Types of Strategies Used in Building Resilience to YOPD

As illustrated in figure 5.2, the strategies used by participants and authors in building their resilience can be grouped according to three broad categories: 1) Internal strategies: which were largely cognitive, reflect changes in the perspectives and beliefs held by individuals; 2) External strategies: which were largely behavioural, reflect changes in the way individuals interacted with others, and with society more generally; and 3) Learning about Parkinson’s
disease: which was both cognitive and behavioural in nature, where information related to YOPD was sought out (behavioral) and became part of one’s knowledge base (cognitive). Each of these categories will be explored in more detail in the remainder of this section.

5.2.1 Internal Strategies

The internal strategies used by participants and authors, in response to the uncertainty caused by YOPD, reflect specific changes they had made in their perspectives and beliefs about the disease, and about life more generally. Perspectives and beliefs refer to the different ways that individuals thought about and understood situations and events that arose out of their interactions with others in society. Thus, they were internal to each person, socially shaped, and at least partly within the control of each individual to change or re-construct. For participants and authors, these changes represented some of the ways they worked to manage with the uncertainty and, in effect, tried to return a feeling of control to their lives. Social and self-comparisons, changes in time perspective and spirituality will be discussed as internal strategies used by participants and authors, in an effort to build their resilience while emotionally adjusting to the disease over time.

5.2.1.1 Social and Self-Comparisons

Making comparisons to the experiences of others, i.e., social comparison, and to previous experiences they had lived through, i.e., self-comparison, were discussed frequently by participants and authors within this research. Three prevalent examples of comparison used by individuals included comparison of YOPD to “worse” diseases, to diseases they had previously been successful in overcoming, and to the health uncertainty in the life of any person. As will be described, drawing such comparisons helped participants and authors increase their resilience to the uncertainty of living with YOPD.

*Constructing an Illness Hierarchy - “It Could Have Been Worse”*

In coming to learn about Parkinson’s disease, and emotionally adjust to the diagnosis, participants and authors developed an illness hierarchy that helped to reduce the immensity of the meaning of their diagnoses. More specifically, in positioning YOPD as being less serious than other diagnoses they could have developed, the potential difficulties resulting from Parkinson’s were minimized which facilitated a less threatening perspective of having the disease. Within this hierarchy, amyotrophic lateral sclerosis (ALS), also known as Lou
Gehrig's disease, and multiple sclerosis (MS) were two diseases in particular centered out by participants and authors as being “worse” diagnoses. As described by one participant, Clay, Parkinson’s was viewed as being “the Cadillac” of neurological diseases. Construction of this hierarchy was very common for both participants and authors (e.g., Griffey, 1998; Harshaw, 2001; Secklin, 2010) and proved to be most supportive for those who had personally known someone having such a “worse” disease. In this way, the reality of the difficulties caused by these other illnesses was more tangible, and easier to draw from for comparison.

Alecia: I tried to keep a positive attitude, thinking that well, ALS would be worse, and that’s what my husband’s mother died of, ALS. And that’s a worse disease, or you know, just some of the other things that can happen to you. So I didn't think it was the worst thing in the world. It was gonna slow me down, but it wasn’t gonna kill me too quickly. Interviewer: And did you find yourself comparing Parkinson’s to other potential diagnoses, other than ALS? Alecia: Yeah, like I had known people that had MS as well. And yes, I think in general, you kind of think in terms of well, I’m glad I don’t have that disease, or this disease is better to have kind of thing, just to make yourself feel better, I think.

Denis: When I get low and forget to be thankful for where I’m at, that’s an easy motivator for me to be thankful and I am very thankful that I have the mental abilities that I have. I would be so scared of life with Lou Gehrig’s disease. I think that’s so sad. I had an uncle by marriage, who was one of my favorite uncles, and he died with that and the last three years of his life there was no sense going to see him. He hadn’t a clue and that’s not the person that I knew and cherished. Interviewer: So how do you use that image of other conditions you consider worse to help with having Parkinson’s? Denis: The realization that there are many things that would be less desirable for me to have, or more horrific in its impact on my abilities. Just as a simple motivation trigger. It doesn’t take much. I just have to ring that appreciation into my mind and it works very effectively.
Although it is alluded to by Alecia and Denis in the passages above, Sondra describes more specifically the two parameters on which this illness hierarchy was built around: disability and mortality. Through considering other potential illnesses a person could develop, the threat and uncertainty in identity and functioning caused by YOPD were minimized.

**Sondra:** It could have been worse. I could have come out of there with an MS diagnosis, which I consider to be worse, in my opinion – and ALS, multiple system atrophy, a brain tumor, you know? Like I'm down here, you know, with Parkinson's. **Interviewer:** Why do you think you made that comparison? What did it mean for you to do that? **Sondra:** I guess it was, basically, level of disability and level of mortality, you know? MS – the people I know are a little more seriously ill. I guess there's lots out there that aren't, but the ones I know, you know? And ALS, well, it speaks for itself, you know? And multiple systems atrophy isn't much better. So, that was my criteria.

For the majority of participants and authors using this strategy, they describe this illness hierarchy as something they came to construct on their own. However, for some individuals, like Shanna, for example, this type of disease comparison was also facilitated by feedback and comments from physicians.

**Shanna:** [My physician] said for all the problems you can have in your brain, like MS and the other diseases, he said “Parkinson’s is probably the best one.” He said that with the technology and the medications they’ve got the ability to keep people’s lives, their daily living in good shape for 30 years or so. The thing is they don’t know what the progression is going to be and everybody’s different. So we just treat it.

Regardless of whether or not individuals with MS, ALS, cancer or multiple systems atrophy would agree with such a hierarchy, participants and authors used this belief system to their advantage. More specifically, by minimizing the uncertainty and threat caused by the YOPD diagnosis, they were able to increase their resilience to the emotional difficulties they encountered through the adjustment process. In some cases, however, participants also had experience with other serious health issues in addition to being diagnosed with YOPD, prompting a different type of comparison within one’s own health history.
Health History

Over the course of their lives, participants and authors had accumulated experience, or a history, with various health concerns; some minor and some more serious. In a similar way that comparing the YOPD diagnosis to other “worse” diagnoses helped individuals, having previously managed with and overcome a serious illness was perceived to have increased one’s resilience to the Parkinson’s diagnosis. In effect, individuals performed a self-comparison in terms of the health difficulties they had overcome with the threat they perceived from YOPD. In the passages below, Trevor and Michail describe how they believe having overcome thoracic outlet syndrome and malignant melanoma, respectively, helped them manage with the emotional difficulties resulting from later being diagnosed with YOPD.

Michail: With the Parkinson's, [the doctor] explained it's not like the cancer. He knew that I had cancer. He said, “It's not like the cancer where you would've had more chances of dying from it … The Parkinson's won't kill you. You'll have a good long life. It's not going to be ten years or something like that. You'll run a normal life, but your symptoms will get worse and of course you'll be on meds” … The cancer was the scariest thing in my life. The day I was diagnosed, I was driving around blank. Yeah, like I was just totally flabbergasted. He asked “how are you with this one?” And I said, “actually I’m fine.” I said, “because I know it’s not as much as a severity or a seriousness as what the cancer was” … Now it would have been totally different circumstances if I wasn’t diagnosed with cancer, or I was diagnosed with Parkinson’s right off the bat. Probably would have affected me a lot worse.

Trevor: It’s made me more adversity tolerant – almost being able to feed off it in some ways. Sort of a “no surrender” attitude, no backing away from it, no giving in – and it’s sort of hardened me in many ways. I don’t mean that in any way that I’m a tough guy because I’m not. I’m soft. It hardened me mentally … I definitely don’t see Parkinson’s as a worse situation. It’s not a great situation to be in. But I think by responding to it positively, you’re going to make the impact of it less at the very least … Resilience and tenacity. They’re both good words to use. In terms of tenacious, in not being prepared to give up, and resilience in terms of not being prepared to give
in. And the two are slightly different. So resilience is almost where your back is against the wall. Whereas tenacious is where you’re chasing the monster. And so yeah, the two things work hand in hand.

The tenacity that Trevor speaks of, in “chasing the monster,” illustrates that in addition to making him more resilient to the uncertainty, overcoming thoracic outlet syndrome likely also supported his desire to be proactive in emotionally adjusting to YOPD. Apart from previous health concerns that individuals had overcome, one’s resilience to the uncertainty caused by YOPD was also impacted by health concerns that were still ongoing in their lives. More specifically, participants like Kalvin found it difficult to emotionally adjust to the disease, as it was only one of several health concerns he was experiencing.

**Interviewer:** So in addition to Parkinson’s, you have a lot of other things going on, too. **Kalvin:** Yeah. Diabetes, high blood pressure, big problem with my heart and heartbeat … **Interviewer:** So now having Parkinson’s, but also having those other things, how do you think that’s affected your perspective of Parkinson’s? **Kalvin:** Probably – I’d say that it’s a little bit more whitewashed, maybe, because I don’t know which one to concentrate on, you know … I know the blood pressure is weight. I know that the heart is weight related. I know that there’s other problems with the heart … So it’s just – like I don’t know which one to worry about.

With respect to the health history of participants, an individual’s resilience was either strengthened or weakened depending on whether or not serious health issues were occurring at the same time as YOPD, or whether they had been successfully overcome. Experiencing past success with serious illness provided participants with a means of minimizing the uncertainty from YOPD fostering a belief that, comparatively speaking, Parkinson’s would be easier to manage. Conversely, the “whitewashing” effect of multiple co-morbidities, of which YOPD was only a part, minimized Kalvin’s resilience and made it more difficult to emotionally adjust to YOPD.

**General Comparisons - The Universality of Health Uncertainty**

Beyond the health histories of participants, and the idea of an illness hierarchy, some participants were also able to manage with the uncertainty resulting from YOPD by comparing their experiences in a general sense. More specifically, that no individual can
predict the future and what their health is going to be like, regardless of whether or not they have YOPD. This type of comparison was more common in participants and authors who had personal experience losing loved ones at a young age. For example, after the sudden death of a friend, Phan (2004) talked about no longer “moan[ing] about getting older. Many of us don’t get that chance.” With respect to study participants, Martha and Shanna both had experienced the loss of younger family members to accident or illness. Having experienced such losses, helped them to understand and appreciate that health uncertainty is more universal and, in effect, helped them to increase their resilience and minimize the perceived threat from YOPD.

Martha: When I was telling some of my sisters, I said to them, especially the one that has Parkinson’s in her family, the older one, I said “well, I live out in the country. There are lots of accidents. I could have been hit by a truck by now. So it’s this or that or whatever” … There was a farm accident not too long ago, the father and two boys. The three died immediately. It can happen. Things happen. It’s this or that, Parkinson’s or whatever. This is just lasting a little bit longer.

Shanna: People’s bodies are going to start to change and fail and get issues – I think none of us are immune. Very few people go through life without having to deal with something. I sort of look at it that way … Interviewer: Making comparisons to loss that any person might deal with, how does that help you? Shanna: It’s a comfort and an opportunity not to let the fear take hold too strongly. I think we all have our fears, it’s just how much they take over and the uncertainty of not knowing. You can’t sit and wait for things to come and that’s sort of where I’m trying to keep my head set and just deal with things as they come … I keep going back to we’re all in the same boat. Some people have their lives kind of set in stone and they think they know their path and the way it’s going to be. But none of us know what our future holds.

Understanding that every person is susceptible to illness and accidents, and will one day die, was a way for Martha and Shanna to increase their resilience to the uncertainty of YOPD by normalizing it within the general human experience; i.e., “none of us know what our future holds.” This type of perspective was, thus, much different from just a belief that Parkinson’s was easier to manage in comparison to other health issues. Although all of these comparisons served to increase resilience, thinking about health uncertainty in this broader
context also illustrated another important change that took place in the perspectives of participants and authors. More specifically, the uncertainty of the future prompted individuals to start to change how they thought about, and related to, time.

5.2.1.2 Time Perspective

For study participants and authors, the uncertainty with respect to how the disease would progress, and the difficulties they would experience over time, produced fear of their futures. As a way to regain a feeling of being in control of their lives, and increase their resilience, individuals spoke of focusing on, and living more in, the present, as a strategy to manage with this fear. This change in perspective of time, from future to present focus, is discussed explicitly by Phan (2004), Gordon (1992), Secklin (2010) and Amodeo (2007) in their autobiographies. Alecia and Patti also describe this change, and the reason for the change, in their own experiences living with YOPD in the passages below.

**Alecia:** I think that focusing on the present just doesn't make you get so overwhelmed with life in general, and jumping too far into the future, which is the unknown because this disease is different for everybody. So you don't know in five years what you're gonna be dealing with … I think it's too overwhelming to look at the future … So I think it's better just to stay within your own focus of what's going on with you and stay positive with that and deal with that. I think it's better than jumping too far into the future.

**Patti:** I think in a sense I don’t like to plan long range. If I wanna do something, I wanna do it now while I feel I could do it. Even with, you know, my husband saying four more years and I can retire and then we can do this and this. And I’m trying to say, well that’s a good plan, but if you really wanna do something, let’s do it now. And I could be off too. I might be just fine in four years. But I don’t wanna take the chance. I can see the progression – and it is a continual – every year there’s a little slide and you have to add a little something to get you back, to boost yourself up. So I don’t wanna plan long range. You know whereas before I knew about Parkinson's I was thinking okay, we’re gonna go to Europe in a couple years – it was, you know, all fun stuff.
The switch in time perspective, from future to present, was far from simple for individuals because of the potential implications such a change meant in their relationships with others. More specifically, as Patti alluded to in the passage above, there can sometimes be a difference in the time perspective of the person living with YOPD and his/her spouse. Making plans for future vacations, and all the “fun stuff,” were all of a sudden more complex. Alecia also experienced this difference in time perspective with her husband, who was worried about future housing arrangements at a time when she was not emotionally ready to do so because of her fear of the future.

Alecia: At times, yeah. My husband tries to think too much in the future like when I won't be able to do the stairs at the cottage or that we'll have to move to a different house because we won't be able to use the upstairs, that kind of thing. I try not to think that far ahead but it's just, who knows? You don't know how fast your disease is gonna progress … I’m still thinking that I can do everything, just a little bit slower, a little bit more carefully. And he’s ten miles down the road, thinking of the next stage, which I’m not – I’m not ready for. I can only take so much.

Sandi Gordon (1992) believes that spouses of individuals living with YOPD also go through a grieving and adjustment process. Although the experiences of spouses was not a focus of this research, it was apparent in the descriptions provided by some participants, like Alecia and Patti, that at the very least both the person with YOPD and his/her spouse can develop a fear of the future. As described in the passage from Gordon below, resilience may be more optimally strengthened when both individuals are on the same page in terms of perspectives of time.

“Paul managed to put the past behind, refused to fret about the future, and instead, wisely focused on our present lives. Paul has always had an admirable ability to remain genuinely optimistic and confident during adverse times. This time was no exception. Paul was certain we would grow to accept our dubious challenge if we dealt with it just one day at a time” (Gordon, 1992, p. 39).

Coinciding with this change in focus to the present, some participants also discussed a change in their priorities where they were motivated to now make the most of their remaining time of higher functioning they believed they had left before it would be too late.
In essence, there was a degree to which time was perceived to have been compressed for them, because of the uncertainty of their futures. By doing items on their “bucket list” sooner, participants and authors took advantage of the control they felt they still had in their lives.

**Joella:** I just got to my bucket list a few years earlier and I just went for it.

**Interviewer:** So what was on your bucket list? **Joella:** I wanted to go to the jazz bar and listen to singers there. That was an ongoing bucket list item. I wanted to relearn piano because I lost a lot of it and so I played piano for friends at the Christmas party one year. So I guess the bucket list stuff would be play piano and enjoy your friends. I also desperately wanted to go to see the Art Gallery of Ontario, so I did that.

**Sondra:** It was just a change in philosophy of life. All of a sudden, my bucket list got really full of things that I wanted to do … We decided that we were going to get to the bucket list, and so we took a cruise. We took the Rocky Mountaineer Train through the Rockies. Oh, we've been on numerous cruises. We went to Vegas. We had more fun in that couple of years than we'd had in a long time.

Whether their bucket lists contained travel plans, or a desire to relearn lost skills, participants who experienced this compression of time exerted control in their lives by doing the things they valued and wanted to accomplish before they felt the control to do so would be taken away from them. This change in perspective of time helped to minimize the impact of the disease, in an emotional sense, because it reduced what they felt like they would be losing from the disease in the future.

5.2.1.3 Spirituality

The final internal strategy used by participants and authors to increase their resilience to YOPD related to their spiritual beliefs and practices. As already discussed, the diagnosis prompted some participants and authors to become angry with “God.” However, in the process of adjusting to the disease, and overcoming this anger, some participants drew on spiritual beliefs they held as a way to help “come to terms” with the disease. The YOPD autobiographies included in this study contained many references to the role of spirituality, whether it was a specific religion or a general belief in a higher power. Just like the other strategies discussed, spirituality was drawn on in different ways and to different degrees by
participants and authors. For example, Lightner (2003), who drew on spirituality to a greater extent than other authors, went as far as incorporating parts of sermons into her book to help describe how she thought about the disease. Sandi Gordon (1992) talked about becoming more involved with her church and, over time, “began relying more on my faith” (p.24).

Prior to neurosurgery to treat Parkinson’s, Webster (2004) talks about praying to ask God to “guide my surgeon’s hands. It was God who would determine the outcome of the operation with its success or failure; what was meant to be will be.” M. J. Fox (2009) also speaks of the importance of spirituality, believing that “faith is the third leg of the stool” (p. 201) on which he sits, with optimism and knowledge making up the other two legs.

When it was discussed by participants as being something they relied on in helping them adjust to Parkinson’s, I had the opportunity to ask more pointed questions about how their spiritual beliefs had helped them. In a much different way than what was discussed by autobiography authors, study participants spoke of spirituality in making them more resilient because of their beliefs in an afterlife, and that their body in their current lives were only vessels for their spirit or soul. In other words, they believed Parkinson’s disease was not part of their soul and, thus, that they would not have Parkinson’s in the afterlife. In this way, their beliefs helped them regain a sense of being in control, limiting the impact they perceived the disease could play in their life.

**Interviewer:** I was wondering why you refer to your body as ‘the body,’ as if it was distinct from yourself. **Denis:** To some extent I believe that what is me is in the nature of a living organism. Some might call it your soul … I believe that there is a life after this one, that I may not have the form in this body with me, but I will still have the essence that is me; the personality, the ideas, the accumulated experiences. All that said, it is easier, I think, for me to cope with having Parkinson’s or whatever other challenge if it is just the case in which my essence is housed that has the malfunction called Parkinson’s and not the dweller.

**Alex:** My spirit will go to heaven and my body will stay six feet under. When I get up to heaven, the Lord says that he has many rooms in his house. And I know there’ll be one there for me … that’s when the pain, the suffering is gone. So that stays in the body. My belief is that it stays in the body 6 feet under in the casket. But the spirit rises to be with the Lord. **Interviewer:** And does that give you comfort
knowing that in heaven your soul won’t have Parkinson’s? **Alex:** That’s right. And if I meet people along the way, and I’m sure that’s what we’ve been told through different sermons and stuff like that, that I’ll be a happy camper again. Because I know I don’t have to think about what’s going on down below.

**Martha:** It’s not in my soul. It’s just here. This is like our recyclable container. **Interviewer:** So how has that helped you? **Martha:** I think that turned the corner of the denial. Yeah, absolutely it did. I can’t tell you what year or when that was. It was – it’s more recently. It’s been more than a year or two. It’s just like, “Oh, hey, wait a minute. This is just like something I have to go through right now, but it’s not gonna be – like it’s not adhered to me as a person, like as a soul.”

Beyond holding specific spiritual beliefs, the religious communities in which they interacted with, and were supported by, also helped some individuals to become more resilient to the uncertainty caused by the disease. Drawing on supports was one example of an external strategy used by participants and authors, which will be described in more detail in the next section.

### 5.2.2 External Strategies

The external strategies used by participants and authors, in response to the uncertainty caused by YOPD, reflect changes they had made in the way they expressed their emotions and interacted with others in society. That is, they were more behavioral in nature in comparison to the internal strategies. In most cases, these changes reflect decisions made by individuals to draw on others for support, or to end relationships perceived to be detrimental to their resilience. As a means of interacting with society on a broader level, however, participants and authors also used strategies to express the emotions they felt throughout the adjustment process. Sometimes these emotions were shared with others, and sometimes they were kept more private. For participants and authors, drawing on these resilience strategies represented some of the ways they worked to manage with the uncertainty and, in effect, tried to return a feeling of control to their lives.
5.2.2.1 Writing

As a way of expressing how they felt about their lives, in adjusting to life with YOPD, many individuals used writing as a means of externalizing their emotions. Writing was something they were able to do to increase their resilience to the uncertainty caused by the disease, providing a feeling of more control over these emotions, by getting them down on paper or typed into a computer. Regardless of whether or not it was shared with others, writing was used by individuals as a way to build resilience in response to the grief and uncertainty they experienced because of the disease. When it was shared, it was often reported to have been done as a means of trying to help others who were also, or in the future would be, affected by the disease. In other words, beyond being beneficial for themselves, sharing their writing was also a way for them to be proactive in the Parkinson’s community.

Within this research, the most obvious example of writing completed by individuals and shared publicly were the autobiographies collected as part of the study data. Fourteen published autobiographies written by those living with YOPD, describing their experiences with the disease, were collected and analyzed in conjunction with the other data. Fourteen was really only a sample of all of the autobiographies written by those living with YOPD, of which the total number has only grown since my data collection period ended. In many of the books, the authors explicitly describe the purpose behind writing them as a way to try and help others diagnosed with YOPD (Amodeo, 2007; Grady-Fitchett, 1998; Griffey, 1998; Lightner, 2003; Phan, 2004; Secklin, 2010; Webster, 2004; Wenmouth, 2010). One specific passage from Wenmouth (2010), below, stands out in the description of this purpose.

“My wish is that my story will bring hope for other young sufferers. There is light at the end of the tunnel. There is no denying that it has been a tremendously difficult journey, but you can and will get through it” (Wenmouth, 2010, p. 147).

Beyond the autobiographies, both participants and authors also engaged in other types of writing to emotionally manage with the disease and build their resilience. More specifically, individuals wrote poetry as a creative way to express themselves and what they experienced at various points in the adjustment process. For example, Lilia had written a poem as a way to express how she felt when she was dyskinetic, which was often misinterpreted by others.
Lilia: I make it clear in the poem that people measure me by my dyskinesia, but when I get dyskinesia, I’m happy because I’m not hurting. And, and if I’m not moving around, if I’m not moving, that’s when I hurt. And that’s when they think I’m doing great. It’s ironic because really they’re wrong … I share the poem with everybody I can, because it’s me, it’s what I was going through at the time, and I will share it with anybody that wants to hear it, because I want to share it and I want them to share it as well … and if my poem was something that might have helped somebody or helped more than one person. That’s good. That makes me happy.

Amodeo (2007), Grady-Fitchett (1998), Griffey (1998), Harshaw (2001), Secklin (2010) and Webster (2004) all included poetry they had written in their autobiographies. Of these authors, the work of Amodeo stands out because of the extent to which he drew on his poetry in writing his book. Many of the poems he wrote resonate with the concepts already discussed in this research in terms of some of the different ways individuals emotionally adjusted to the disease. For example, his poems talk about the importance of living in the present, being proactive, control and spirituality. Furthermore, Amodeo describes poetry as his “escape” from life with YOPD and a safe way of communicating his feelings with others.

Writing about their experiences was something within the control of participants and authors, and by externalizing how they felt they were able to not only help themselves but also believed doing so had the potential to help others when it was shared publicly. Whether in the form of a poem, a journal entry, a blog entry or a book, writing was a personal exercise that appeared to have a therapeutic benefit for individuals. Moving outside of how individuals externalized their emotions to increase their resilience, external strategies also involved making changes in the relationships individuals had with others.

5.2.2.2 Pruning of Negative Relationships

A second means by which individuals talked about being able to exert control in their lives, and build their resilience, related to changes they made in their relationships with others. One change in particular involved pruning more negative people from their lives, as a way to help themselves stay positive, and not waste their time and energy. Similar to the way a tree is pruned to help it continue to grow, individuals picked who they wanted to have in their
lives, so that they wouldn’t be weighed down emotionally by others. In the passages below, Shanna and Danny provide two examples of this pruning strategy.

**Shanna:** Knowing that it’s here that it’s not going away. It sort of made me look at everything with work and friendships and relationships it makes you start to think about what is it that you really want and that sort of makes you happy. And kind of clear the clutter … Like I had a couple friendships that would suck you dry and not letting all the small stuff clutter you because you don’t have time for it. And the people that are complaining about I didn’t sleep last night … I sit there and I think if you only knew what I had to deal with every day … If it’s not legit it’s like I don’t wanna hear it. Unless you’re dying or bleeding I don’t wanna hear it because I don’t have the energy to deal with that because I have to keep myself positive every day. And some days it’s just I can’t handle anybody else’s problems … You’ve only got so much time and so much energy and you definitely have to pick and choose.

**Danny:** Of the 200 that were at the conference, they were there for a reason. They wanted information. They wanted to make their lives better and they were pretty positive for the most part. I can only think of maybe one that was not that positive but I even used that as a positive like, okay man, you're really negative. And I would talk to him for a couple of minutes, but then it was like okay I don't want you in my life because I only want to surround myself with people that are going in the right direction. Not just in Parkinson's but everyday life and so, you know, you're not rude to him, but you’re just like, nope, I don't want to go down your road.

Apart from “pruning” negative people from their lives who were going to make it more difficult to be resilient to Parkinson’s disease, individuals also spoke of other ways they changed their relationships with others. More specifically, individuals sought out others with whom they felt they would be able to relate, as people going through the same, or related, difficulties in their own lives.

5.2.2.3 **Drawing on Social Supports**

As a means of increasing their resilience, participants and authors described drawing on supports in society, both individuals and groups, to help them adjust to living with Parkinson’s over time. In some cases these supports were specific to Parkinson’s, and in
some cases they were not. When the supports weren’t other individuals living with Parkinson’s, they were still individuals living with a serious health issue. From an emotional point of view, drawing on these supports helped to increase resilience in two ways. First, seeking out this support helped to normalize their experiences, given the uncertainty in their identities and no longer feeling like “normal” adults. Second, in seeking out this support, they found people with whom they didn’t have to “hide” their symptoms. More specifically, in addition to playing a role in how they viewed themselves, i.e., redefining their identities, disclosing to others was used to increase their resilience by lifting the “burden” felt in terms of hiding their difficulties from others. As Suzanna describes in the passage below, the social avoidance and work to hide her disease from others created an emotional “burden” for herself, which was “lifted” as she began to disclose to others.

**Suzanna**: I didn’t think that hiding the disease and hiding my diagnosis and trying to pretend like everything was fine, and putting on that happy face that I had done for so long, that mask that I had worn for as long as I’d worn it, I didn’t think that was a burden until I let it go. Until I started to disclose to my family and my friends and other people that I had this issue. That I had felt such a burden being lifted from me, that I really didn’t know it existed prior to that disclosure.

*Persons Living with a Non-Parkinson’s Health Issue*

When individuals sought out support from someone living with a non-Parkinson’s health issue, it was usually for one of two reasons. More specifically, it was either an issue of geography or an issue of adjustment. With respect to adjustment, seeking support from someone who could understand and relate to difficulties of being an adult with a serious illness was more of a transitional step to eventually connecting with others living with Parkinson’s. Such a step was described by Shanna who sought out support from a woman she knew was living with a rare form of cancer that was typically associated with older age, similar to YOPD.

**Shanna**: She has a cancer that usually older people get, so it was related in that degree as far as my Parkinson’s and the type of cancer that she had … People who don’t get it don’t understand. As I said, life goes on, because they’re not having to deal with things. So it was more of an emotional support I’d say … she just can
relate. So it’s good to talk to somebody … Interviewer: So why did you seek her out, instead of someone with Parkinson’s? Shanna: Because she doesn’t have what I have. But going through what she went through, she would understand the challenges in a similar but different way because what she was going through was different … It’s different I think when I’m associating with a group of people all with Parkinson’s. It’s because if this person is worse, that could be me … I think it would bother me seeing that – because I can only handle so much, with seeing the different stages and the way certain people are, and how it’s affected them. Because it could be me. Do you know what I mean? It’s just closer to home.

Although Shanna did slowly start connecting to others living with YOPD over time, spending time with this friend allowed her to manage with some of the difficult emotions she experienced; especially those feelings related to the uncertainty of her future functioning. In this way, she exerted control over the relationships she chose to have, as a means to help “handle” adjusting to Parkinson’s at her own pace. As mentioned, a second reason why individuals sought out others with a non-Parkinson’s health issue related more to geography. More specifically, those living in rural areas had fewer opportunities to connect face-to-face with others living with YOPD. Martha, for example, developed a close friendship with a neighbour living with MS with whom she felt an emotional bond because of going through similar challenges as adults.

Martha: One of my neighbors has MS. A newly married man, a new father, very young. So he and I get together once in a while … Him and I just kind of compare notes … We just talk to each other about how it’s been for each of us. “How are you getting through your day?” Like that kind of thing because he’s a farmer, and he’s got a new baby. And he doesn’t have benefits either. Just like how is it going and that kind of thing, just really personal for the two of us … So I think we have a kinship that we would never have had before … The bond is that we have a challenge. Both of us each have a challenge.

In each case, for Shanna and Martha, connecting with others living with a serious health issue provided an opportunity to find common ground in difficulties they had experienced. In other words, these friendships acted as supports to help to normalize their experiences as adults living with a serious health issue. The strength of this connection, and the degree to
which experiences were normalized, however, were increased when supports specific to Parkinson’s were sought out by individuals.

*Other People Living with Parkinson’s*

**Denis:** They have an insight, having made the journey earlier than I have. They have an insight into the various ups and downs that you can experience – the isolation that you can feel sometimes and you can forget that you have people out there who care and they’re reminding you.

In the process of emotionally adjusting to the disease, participants and authors were often motivated to connect with other individuals who also lived with Parkinson’s as a way of normalizing their own difficulties and experiences. As Denis alludes to in the passage above, other people living with Parkinson’s share an appreciation for or “insight into the various ups and downs.” This ability to relate to others going through the same difficulties, and who were also diagnosed with the same illness, was a way for individuals to receive support, and build resilience to the uncertainty of the disease, in the process of emotional adjustment.

There were several different settings whereby individuals with Parkinson’s spoke of connecting with one another, the most common of which was the support group setting. However, Parkinson’s support groups, similar to other settings, proved to be very complex to understand because of the differences in age and functioning that can exist among the group’s members. More specifically, the experiences of younger and older adults with Parkinson’s are not always identical because of the stage of life in which the disease has occurred. As already described in terms of identity and functioning uncertainty, employment and raising children were two of the more obvious distinctions noted by participants. Furthermore, in trying to build their resilience to the uncertainty caused by the disease, there was often a reluctance or avoidance of general Parkinson’s support groups. These attitudes were accentuated when physicians relayed these beliefs to their YOPD patients, as was the case for Kathleen Webster (2004) and Shanna. Both individuals were told by their diagnosing physicians to avoid support groups because of the age of typical attendees and that they would view their futures by going to the meetings.
Shanna: I started checking out support groups. [My neurologist] says support groups aren’t the greatest thing because most of the people are older and they’re more advanced and you’re sitting in this environment, newly diagnosed, not at that stage yet. So I wasn’t too interested in support groups plus I couldn’t really find any for young onset … I don’t wanna be involved with a group of seniors that are advanced because it’s just to me it’s just not healthy.

In addition to these difficulties, meeting logistics, like time of day and location, could also make it difficult for younger people with Parkinson’s to participate if they were still working and raising a family. As such, for various reasons, general Parkinson’s support groups didn’t always meet the needs of individuals with YOPD. To better meet these needs, participants and authors of autobiographies spoke of organizing and/or attending support groups specifically for younger individuals with Parkinson’s. Peter and Patti were two such participants involved in organizing a YOPD support group in their community, motivated by the age and functioning differences between themselves and those in the general Parkinson’s support group.

Interviewer: So why did you feel the need to start up the support group? Peter: Well, because there was only one in [our community]. It was at an old-age home. Patti had gone there once and just the scene wasn’t the best for somebody with young onset. Interviewer: What do you mean by that, that “the scene wasn’t best?” Peter: Well, there were people in wheelchairs -- for somebody that was first diagnosed, they don’t want to see all that.

For Peter and Patti, the fear and uncertainty they experienced with respect to their future functioning made the general support group an unfavorable place to go to for support. This type of organizational effort was also reported by Gordon (1992) and Trevor in their areas, because of unmet needs of those with YOPD in their communities.

Trevor: I went to a support group and it was a general PD support group and I was the youngest by about 10 years, so there was a gap between me and the next youngest. The talk was all about retirement planning and I just felt very uncomfortable there. I felt completely out of place. It felt irrelevant to me … I'm setting up a YOPD support group in [my community] with a guy off the Facebook
group … We've got [the Parkinson Society] involved. So, we're sort of getting that off the ground.

As a way to find emotional support, in a way that helped them to build resilience, participants and authors often sought out others with YOPD. In many cases, this required individuals to construct these settings in their communities because such settings didn’t already exist. The differences in stage of life, combined with more advanced symptomatology, proved to be too difficult for many individuals to perceive a benefit from regular Parkinson’s support groups. Instead of helping to manage with the disease uncertainty, it was believed that these regular support groups would have only increased their uncertainty and fear of the future. In addition to providing emotional support, however, various individuals and groups were also drawn on as sources of information related to Parkinson’s, which leads to the final of the three strategies used by participants to increase their resilience to the disease, i.e., learning about Parkinson’s disease.

5.2.3 Learning About Parkinson’s Disease

In addition to its role in helping participants and authors come to logically accept that they had YOPD, learning about Parkinson’s disease also played an important role in emotional adjustment. More specifically, learning about Parkinson’s was a transitional strategy, between internal and external, where information related to YOPD was sought out and became part of one’s knowledge base. In other words, information existed external to the individual, which then became internalized as a base of knowledge through this learning process. The learning that was done by participants and authors was used to help with emotional adjustment by “empowering” individuals to be proactive. That is, learning about how Parkinson’s could be managed provided a belief that there were things they could personally do to influence their experience with YOPD, providing a feeling of increased control over the disease. Suzanna describes the role of knowledge in terms of “empowerment” in the passage below.

Suzanna: I think once you embrace the diagnosis and educate yourself in terms of what you need to do, empowerment naturally follows, and empowerment includes control. Because you definitely do feel a lack of control. And I felt, like I said to you before, in terms of stopping work, I felt it was not within my control. I had no
choice but to stop. I wasn’t given a choice, and that feeling of lack of control was definitely there until the time I stopped work. But once I stopped work and recognized that now I was able to sort of – I was able to sort of chart my own path on how I was going to move forward with this disease, kind of box it in terms of this is Parkinson’s. It’s part of my life, but it’s not my life. Allowed me to take back some sense of control.

In a similar way that knowledge empowered Suzanna to believe she could “chart my own path,” Danny describes how information helped him generate a “game plan” or a “map” in terms of how he was going to “fight” Parkinson’s disease in his own life. Thus, learning about Parkinson’s facilitated the ability of participants and authors to be proactive in their lives, especially at the individual level.

Danny: I had to have the information or I'm sure I wouldn't be at the point I'm at today. So it has helped. It doesn't solve everything, but it's helped me put my game plan together. And it's helped me to get into the mindset that I'm in now … I think what the information did for me was it helped formulate that game plan. And I'll use the exercise and diet as kind of part of that, but I think the mindset is also part of that too … it helped to maybe make the map clear, like the roadmap that we want to go down. I think that's where the information helped.

Trevor also describes the feeling of empowerment he received after reading about the importance of exercise for people with YOPD, and one autobiography in particular that provided an example of what exercise can do for people with the disease. As an alternative to being passive, and not having any control over Parkinson’s, the knowledge Trevor acquired helped him to see that he could influence the course of his experience with YOPD.

Interviewer: What was it about the autobiographies that drew you to them? Trevor: I found a lot of them to be invigorating, motivating. There was this one by a guy who was a personal trainer and he sort of – Parkinson’s disease nearly buried him initially. I guess because he didn’t deal with it very well. And he then sort of fell back on physical fitness. And he’s done tremendously well. And so it was stuff like that that sort of gave me a sort of option in terms of being able to influence it to some
extent that really was refreshing. Because the other opinion is you’ve got six years to get done what you’re going to get done and then forget it.

Many different sources of information were used by participants and authors to build a knowledge base related to Parkinson’s, and this learning occurred in different ways. The next section looks more specifically at these information sources, the way knowledge was acquired, and changes in how information was accessed over time in relation to building resilience to the uncertainty caused by YOPD.

Summary

The internal and external strategies used by participants and authors, in addition to learning about Parkinson’s disease, help to illustrate the variety of ways that individuals worked to emotionally adjust to the disease. More specifically, these three strategies helped participants and authors become more resilient to the uncertainty caused by YOPD, helping to return some of the control that was perceived to have been lost to the disease. It is important to note that any given individual did not use all of the strategies discussed in this chapter, as each person found the strategies that worked best for him/her. Furthermore, the strategies used by individuals changed over time as the disease progressed. When certain strategies, like rigorous physical exercise, were no longer possible for individuals, strategies were changed or other strategies were drawn on as means to continue being resilient to the disease. In other words, just as emotional acceptance was ongoing in light of changes resulting from the disease, so too were the different ways individuals worked to maintain resilience and manage with the emotional difficulties they encountered.

5.3 The Accumulation and Filtering of Knowledge in the Process Of Learning about Parkinson’s Disease

For some individuals, learning about Parkinson’s disease started well before they received their formal diagnoses from a physician. For others, this learning process didn’t really get started until years after their diagnoses. This variability was related to the close relationship between learning and how an individual adjusted to the uncertainty caused by the disease. In previous sections, the roles of knowledge in the processes of logical and emotional adjustment have been described. The focus of this section is on how information, external to
the individual, became internalized as knowledge over time. As the original objective of this research was to identify the process through which individuals with YOPD sought health information, this section illustrates how the information seeking process was embedded within a larger process of adjustment as a specific resilience strategy. If I hadn’t paid attention to this larger adjustment process, and expanded my focus and sampling of data, I likely would have missed the complex nature of the health information seeking in the lives of participants and authors.

This internalization, or learning, process involved two distinct actions. First, information sought out by individuals became internalized and contributed to the accumulated knowledge related to Parkinson’s held by that individual. Second, through the individual’s bodily experience living with the disease, the knowledge was filtered in a way that made it personally relevant to each person. Specific patterns in terms of how information sources were used over time to accumulate knowledge will also be discussed, in relation to the adjustment process experienced by individuals.

5.3.1 The Accumulation of Knowledge Related to Parkinson’s

For participants of this study, and autobiography authors, information related to Parkinson’s disease became a priority after their diagnoses and over time as they adjusted to life with the disease. Driving the need to increase one’s knowledge related to Parkinson’s, and making it a priority, was the uncertainty caused by the disease. In this section, the sources used by individuals to accumulate this knowledge base, as well as the means by which it was accumulated, will be described.

Knowledge Sources

Through analysis of the data collected, sources of health knowledge related to Parkinson’s could be broken down into two broad categories: 1) Pre-existing health knowledge known to the participants prior to the formal diagnoses, or what I have termed “recalled knowledge;” and 2) Knowledge learned by individuals after their formal diagnoses, which I have termed “acquired knowledge.” Cumulatively, the knowledge obtained from these sources contributed to the “accumulated knowledge” of a participant at a given point in time (see figure 5.3). Accumulated knowledge is, thus, a theoretical concept used to depict all of the information learned by individuals and turned into knowledge after their diagnoses,
combined with their recalled knowledge. It is unique to each individual, and is also highly dynamic given that with new experiences and additional information seeking it can change over time.

Figure 5.3: Pre- and Post-Diagnosis Sources Used in the Accumulation of Health Knowledge Related to Parkinson’s

Information Acquisition after Diagnosis

Prior to being learned by individuals, and turned into acquired knowledge, information obtained by individuals post-diagnosis came from one of two types of sources, extant or elicited, as illustrated in figure 5.3. Extant sources refer to those sources holding information related to Parkinson’s disease, in a relatively static manner, in the environments where participants and authors lived. Conversely, elicited sources refer to sources where information was generated by individuals through interactions with other people. With both extant and elicited sources, information could be acquired actively or passively by an individual. Within this research, the active accumulation of information refers to information seeking instigated by the individual for the purpose of increasing one’s own knowledge base. In contrast, the passive accumulation of information describes a situation where information was obtained by an individual that was more secondary to another purpose or experience. More detailed descriptions of each, active and passive, will be provided as they relate to the two types of information sources.
5.3.1.1 Recalled Knowledge

Some participants had accumulated health knowledge related to Parkinson’s prior to their formal diagnoses. Although the extent of this knowledge varied widely among participants, from no prior knowledge to a substantial knowledge base, the presence or absence of this knowledge played an important role in subsequent information seeking behaviour. In cases where individuals had pre-existing knowledge it came from one, or a combination, of the following information sources: 1) formal education; 2) media; 3) family or friends affected by PD; and 4) preliminary information seeking. Examples of each of these sources will be described below with supporting passages.

Formal Education

Three participants had formal education and experience working in different areas of the medical field. Suzanna and Trevor both held doctorates and Patti was trained as a nurse, prior to working in their respective health professions. Although the extent of their knowledge base and exposure to Parkinson’s during their education, training and subsequent employment varied greatly, all three had a similar reaction to the diagnosis based on their pre-existing knowledge. More specifically, they all held a bias that Parkinson’s was associated with old age.

Suzanna: I knew about Parkinson’s disease from sort of a vague recollection in medical school lectures or something ... the anatomy, the sort of general pathophysiology, how the disease progresses, the medications used, that sort of thing. But the patients that I had in my practice were all so much older and had so much more typical symptoms, or what I thought were typical symptoms of Parkinson’s at any age.

Trevor: Well, all I knew about Parkinson’s was the sort of late onset typical picture. The hunched man shuffling. I knew enough about Parkinson’s to understand it represented a loss of dopamine production in the brain. It was really my sort of neuropathology knowledge that I was leaning on. And the idea of a young onset Parkinson’s hadn’t really entered my head ... again, in my mind, it was associated with older age onset.
**Patti:** I knew it was an old person’s disease. I have a background in nursing, so I remember like maybe two lines from a nursing textbook; you know, ‘old person’s disease’ and ‘shaking.’ That’s about it. Because I never really dealt with patients with Parkinson's in my nursing career. So I knew a little bit, but almost nothing.

Given that the first description of YOPD in academic literature did not occur until 1987 (Quinn et al.), it is not surprising that little to no information about YOPD was included in the formal education curricula studied by these participants. Based on their ages, these participants graduated from their programs either just prior to or just after 1987 and, thus, before YOPD became more prevalent in the literature. The result, as they have described, is that they were left with a view of Parkinson’s as being more associated with older age, i.e., “an old person’s disease.” Being diagnosed with what they only had known to be associated with older age contributed to the uncertainty with respect to their identities as middle-aged adults.

**Media**

In contrast to formal education, which did not seem to emphasize the possibility of YOPD for participants, several individuals spoke of knowing about YOPD prior to their diagnoses because of seeing and hearing about Michael J. Fox in the media. Although this knowledge lacked the depth of other sources, as it only provided individuals with a brief description of the disease, it was impactful in the sense that it gave an exemplar face of someone living with YOPD.

**Shanna:** The only thing that I could relate to was just knowing the little bit about Parkinson’s, but I’d never done research and I think it was probably just from Michael J. Fox coming out with his diagnosis.

**Patti:** I thought, “How can I have Parkinson’s? I’m not 80.” You know, like that typical onset and then found out, oh gee, you know, Michael J. Fox isn’t 80. And, at that time, it was sort of you know, the only other person you knew about.

The result of this knowledge was that the autobiographies written by Michael J. Fox in the years after he publicly disclosed his diagnosis became initial books that participants would turn to, or would receive from others, after their own diagnoses.
A number of participants also had pre-existing health knowledge related to Parkinson’s because of having a family member or a friend with the disease. For example, both Jammie and Alecia had parents who had lived with Parkinson’s, and Denis had an aunt he recalled who also lived with the disease.

**Jammie:** I knew that something wasn’t quite right. In my case, my dad had had Parkinson’s as well, and I think I knew in my gut that that’s probably what I had. I just - there were too many similarities between how I was feeling and what I had seen in my dad … I knew what was going on. It wasn’t great news to get, but at least I knew what I was dealing with. So there was a sense of relief. Yeah, in terms of acceptance, I didn’t struggle with that very long.

By providing him with an idea of the types of difficulties he would experience, some of the initial uncertainty resulting from the diagnosis was reduced and, thus, made accepting the diagnosis less difficult for Jammie. Similarly, Alecia’s knowledge related to Parkinson’s from seeing her mother live with it also reduced some of the initial shock often described by those with little or no prior knowledge of the disease.

**Alecia:** My mother had Parkinson’s and she passed away with it … She was diagnosed when she was about 79 or 80, and she died when she was almost 85. So for five years, you know, we watched her kind of deteriorate with it. And in the end, she was in a wheelchair. **Interviewer:** How do you think seeing your mother with Parkinson’s disease, how do you think that influenced your initial reactions? **Alecia:** Maybe for me, it wasn’t as scary as it might have been for somebody who didn't have it – who didn't know anybody close that had it because deep down, that’s maybe not what killed her, per se. The swallowing and everything was difficult and she lost a lot of weight. But by then, she was in her 80s, so I mean it wasn’t the worst thing in the world.

Jammie and Alecia both had regular contact with their parents, which helped them to accumulate a picture of Parkinson’s over an extended period of time. In contrast, Denis’ prior knowledge related to Parkinson’s from his aunt was more limited and came at a time when his aunt’s disease had progressed to an advanced stage.
Denis: My only exposure to Parkinson’s was a family member by marriage who had been hospitalized all of my life. She was my Aunt. I had known her to be hospitalized for some 30-odd years and had very poor quality of life. That was scary, having only that brief experience to think about to compare to … She basically had been almost in a vegetable state by the time I was old enough to be aware of her condition. And she didn’t live long after that.

In some cases pre-existing knowledge related to Parkinson’s helped to mitigate negative emotions that come after receiving the diagnosis, as in the experience of Jammie and Alecia; and in some cases this knowledge served to intensify the negative emotions, as in the experience of Denis. Denis’ limited exposure to his aunt’s experience with Parkinson’s left him with a negative impression of the disease and contributed to a more difficult emotional reaction to his own diagnosis many years later.

Preliminary Health Information Seeking

For some participants, when they began experiencing unusual bodily symptoms prior to their diagnoses, they started to seek out health information. In some cases, this preliminary seeking of information led to identifying the diagnosis before formally receiving it, as was the experience of both Helmut Dubiel (2009) and Richard Secklin (2010) described in their YOPD autobiographies. Contextually speaking, one’s ability to conduct such preliminary health information seeking has been facilitated by the development of computer technology and the Internet. Prior to broad availability of the Internet and home computers in the 1990s (Leiner et al., 1997), those wanting to seek out health information would need to find medical books or, instead, go directly to a physician. For example, in Sandi Gordon’s (1992) YOPD autobiography, there is no reference to using the Internet to seek out health information. Instead, diagnosed prior to the 1990’s, Sandi relied initially on her physicians and books written about Parkinson’s as information sources.

As was the case for Kennith, sometimes preliminary health information seeking was initiated after comments from others about a visible or more overt difficulty. For example, Kennith experienced both physical and social difficulties prior to his diagnosis at age 42, and was motivated to seek out preliminary health information because of feedback he received from a
friend and co-worker. Prior to his diagnosis, because of the information seeking he had conducted, he already had suspected his difficulties may be the result of Parkinson’s disease.

**Kennith:** I’m in a band, I play guitar. And the first time anybody ever said something to me was when I was trying to take a fence down. There was a wire I had to undo and [my friend] says, “How do you play guitar and shake – when you shake like that.” So that was the first comment, and then at work, the first comment was “You’ve got a communication problem.” And that really struck me as odd because that’s the first time anyone said anything to me about it. So as soon as he said that, I almost went into like a research mode. Because then at that point, I thought something’s up … [And] I had figured at one point it was Parkinson’s, but you don’t know until you’re told obviously. Parkinson’s was coming up [in my research] because of the tremors.

Although a number of participants in this study had some idea of the nature of Parkinson’s disease prior to diagnosis, through the information sources described above, the vast majority of participants had no such knowledge. Thus, for most participants, the first instance of uncertainty with Parkinson’s was in not knowing anything about the disease, which contributed to a difficult emotional reaction to the diagnosis. The passages below describe the responses of a number of participants when asked the question: When you received your diagnosis of Parkinson’s, what if anything did you know about Parkinson’s at that point in time?

**Michail:** Nothing at all. Nobody in our family had it that I knew of … I asked my mom and Dad and as far as they knew there was nobody ever diagnosed with it. So I was the first and knew absolutely nothing about it.

**Lilia:** To tell you the truth, I didn’t know nothing about Parkinson’s. I’d heard of Parkinson’s and I knew it was a mobility problem, but that was the extent of it. I didn’t know much more than that.

**Jordan:** I knew nothing about Parkinson’s. I barely knew how to spell the word.

To try and manage with the uncertainty after the diagnosis, participants sought to increase their health knowledge related to the disease by drawing on extant and elicited information.
sources. As has been described, learning about Parkinson’s and increasing one’s knowledge base about the disease was one of the means used by participants to increase their resilience in the face of the uncertainty caused by the disease.

5.3.1.2 Extant Sources

Extant sources of information refer to those sources offering information on a topic that was created on a particular date by a particular author or authors, and do not allow dynamic interaction on the part of the reader. In other words, these are pre-existing sources that hold information in a relatively static manner for the reader to obtain simply through reading or listening to the material presented. Participants and authors drew on a wide variety of extant sources to increase their health knowledge related to Parkinson’s (see table 5.1), which could either be actively or passively acquired by individuals.

Table 5.1: Examples of Extant Sources of Information Related to Parkinson’s Disease Used by Individuals with YOPD

<table>
<thead>
<tr>
<th>Internet Sources</th>
<th>Print Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Canadian Parkinson Society Websites (e.g., Parkinson Society of Canada)</td>
<td>• Regional and National Newspapers</td>
</tr>
<tr>
<td>• International Parkinson Society Websites (e.g., Michael J Fox Foundation, Parkinson’s Disease Foundation, Parkinson’s UK)</td>
<td>• Autobiographies (e.g., Lucky Man, Always Looking Up)</td>
</tr>
<tr>
<td>• Medical Websites (e.g., Mayo Clinic, MedlinePlus)</td>
<td>• Medical Books (e.g., One Step at a Time)</td>
</tr>
<tr>
<td>• Society Newsletters (e.g., American Parkinson Disease Association - National Young Onset Center)</td>
<td>• Society Newsletters (e.g., The Parkinson’s Update Magazine)</td>
</tr>
</tbody>
</table>

| Broadcast Media | |
|------------------| |
| • Radio Programs (e.g., Robert Rodgers) | • Society Pamphlets (e.g., Parkinson’s: The Facts) |
| • Television Programs (e.g., 60 Minutes, Evening News) | • Academic Journal Articles |
| • Documentaries (e.g., Adventures of an Incurable Optimist) | |
| • Movies (e.g., Saving Milly, Love and Other Drugs) | |
Active Extant Sources

Active extant sources refer to those extant sources that participants sought out through their own purposeful seeking of information related to Parkinson’s. An example for each of the categories of extant sources described in table 5.1 is provided below with supporting passages from participants.

Internet Source Example

Used to find health information by tens of millions of people around the world each year (Rice, 2006), the Internet has become a readily available tool to help individuals seek out information relevant to their own health concerns. Due to its broad accessibility, most participants reported actively using the Internet as an initial means of trying to find information about Parkinson’s after their diagnosis.

**Lilia:** The diagnosis overwhelms you and you’re thinking about it all, but I didn’t know. I couldn’t wait to get home to get on the Internet to find out what it was. And that’s what I did. I came home and looked on the Internet.

**Patti:** I went online right away and, you know, just typed in “Parkinson’s” and then realized there were Parkinson's societies. And I knew enough from doing research in other areas that you wanted to make sure it was a sort of well-known, legitimate website.

Geographically speaking, the Internet has also made it easier for people in more rural locations to access health information, as described by Kathleen Webster (2004) in her YOPD autobiography who lived in rural Pennsylvania when she was diagnosed. However, as alluded to by Patti above, one of the drawbacks to the mass of information available on the Internet is concerns about the legitimacy and reliability of the content. Participants and authors were not naive to the importance of finding legitimate websites. Webster (2004), for example, advocates using multiple Internet sources when searching for information on Parkinson’s to help ensure the reliability of the information, concerned about the amount of false information that is online. Participants, like Joella and Sondra, were especially concerned when sites were promoting miracle cures for the disease.
**Joella:** I mostly use the Mayo Clinic … If you’re not on a reliable site sometimes they get this crazy “Oh, it’s a cure for Parkinson’s,” you know.

**Sondra:** I think I go more to the Internet because it’s more up-to-date, more complete … I usually go to Medline or I go to Mayo Clinic, just ones that are laid out the way I want. I don’t like the ones that are – “This is Sandy talking. When I got up this morning, my fingers were twitching. Do I have Parkinson’s?” If you go to the Mayo Clinic or Medline it’s more in depth, it’s not wishy-washy.

Sondra mentioned another important point with respect to extant Internet sources in that they often provided more current information and content depth, compared to other extant sources like books or pamphlets. The value of current information for people living with Parkinson’s also crosses into the emotional domain, as Patricia Lightner (2003) described in her YOPD autobiography. More specifically, Lightner found it difficult to find hope and became emotionally distraught after she initially sought out older medical books in her local library that didn’t include current advances in treatment for people living with Parkinson’s. For her, the information provided a “gloom and doom” (p. 96) prognosis of the disease.

In summary, extant Internet sources were perceived by participants as valuable sources which they used to actively seek out health information related to Parkinson’s because of their availability and the currentness and depth of the information. Drawbacks of Internet websites, however, were that the legitimacy of the sources always needed to be determined and that this determination was often left to the participants and authors to make for themselves.

**Print Source Example - Autobiographies**

Among the most commonly sought out extant sources after participants were diagnosed with YOPD were the autobiographical books written by Michael J. Fox (2002, 2009), including *Lucky Man* and *Always Looking Up*. As mentioned in the previous section on recalled knowledge, because of the popularity of Fox and the public nature of his diagnosis, many people were drawn to his books as a person they knew living with YOPD.
**Patti:** He's young, he's saying “yeah, I've had problems, but look, I'm still working, I'm still doing the kind of work I like. I have a supportive spouse. I have a bad day and then that's fine. I can still play hockey.” So there's all those things that a younger person can sort of identify with so that's sort of nice.

In contrast to the less personal, matter-of-fact medical knowledge obtained from static Internet websites and medical books, autobiographies like those written by Michael J. Fox gave a more personal and relatable account of the disease. The advocacy and fundraising work completed by Fox and his Foundation have also made him a role model among those living with the disease. In the passages below, Kalvin and Alecia describe why they were drawn to Fox’s autobiographies.

**Kalvin:** I think it’s because you know him. You know because you’ve seen him so much. But I think overall, I think it’s because it’s somebody with young Parkinson’s. And I think it’s somebody that’s not just sitting on their behind and letting it fester. He’s out there doing his thing … I would say his books give you – they give you an insight as to what’s to come, how he deals with it and all that kind of stuff. It gives it to you in a way that you can hear it better, a little softer than some of the other ways you can hear it. His books are good so far as they give you, well, I wouldn’t say hope, but they certainly give you a comforting feeling that there’s things to do out there to make things better.

**Alecia:** Well, because he’s been such an advocate for the disease, and I like to read, so I enjoyed his first book a lot. In his second book, he gets more into the research … It just made you feel like he was part of the family of Parkinson’s you know, like these people that have it and you just felt, you know, there’s a lot of support out there for him, which was great. And it just gave you a positive feeling about being part of this disease, you know, that you weren’t alone.

Through the ability to relate to others living with the disease in these autobiographies, participants were able to reduce perceptions of isolation, and were also given the impression that there were things they could personally do to make the best of a difficult situation. In other words, the knowledge they gained from these books helped individuals increase their resilience to the uncertainty caused by Parkinson’s. As Trevor describes in the passage
below, knowledge related to Parkinson’s through some of these autobiographical books played an important role in fostering control beliefs.

**Trevor:** I think what some books have done for me have shown me that I have some level of control, coming back to one of the original issues, that I can influence the outcome.

There are many more autobiographies written by people living with YOPD other than those written by Fox, and I have included several of these as additional sources of data for this research. As described above, the celebrity status of Fox certainly contributed to participants being drawn to his books, but even in earlier YOPD autobiographies authors spoke of using personal stories of those living with the disease as a source of information. For example in the autobiographies by Gordon (1992), Griffey (1998) and Webster (2004), all of these authors refer to having read the autobiography by Sidney Dorros (1989) shortly after their own diagnoses. Therefore, beyond the celebrity, people are still drawn to reading and learning about the experiences of others as a way to increase their own resilience in adjusting to the disease.

**Broadcast Media Example - Movies**

Perhaps the least common actively sought extant source of health information related to Parkinson’s by participants were various broadcasts of programs that included a character with YOPD. This is likely because of the lower volume of Parkinson’s related broadcast media available, and because some types of broadcasts only include a character of someone living with Parkinson’s who may not necessarily have Parkinson’s in real-life. It should be noted that data collection for this study was completed in the early fall of 2013 before the start of the Michael J. Fox Show on NBC where Fox actually plays a character with YOPD. Had data collection continued after the show aired, it is likely that participants would have had more to say about this type of knowledge source.

With respect to movies in this category, the two discussed by participants were *Saving Milly* a 2005 film based on a true story, and *Love and Other Drugs* a 2010 fiction. Alex and Jordan spoke of these two movies during our interviews, but each found value in the knowledge they gained from them in different ways. Alex primarily used the character Milly, from *Saving Milly*, as an example of a person with an advanced and aggressive form of
Parkinson’s disease to which he compared his own symptoms and progression. As has been described, social comparison can play an important role in helping to manage uncertainty caused by the diagnosis of YOPD. Thus for Alex, who compared his disease and progression more favorably to that displayed by Milly in the movie, he was able to find some relief from the uncertainty of living with Parkinson’s. This relief, however, didn’t completely resolve thoughts about his future and the shroud of uncertainty that is always present.

**Alex:** I use it to kind of give me an uplift and say, “Hey, it’s not that bad because I can still talk,” because I can still put the vision in my mind of that movie called *Saving Milly* and that was like a Parkinson’s plus movie. And I just, I’ve seen it about three or four times, I just wish I don’t have to ever have to go that far.

In contrast, Jordan found that he was able to relate to some of the attitudes and behaviors portrayed by the character living with YOPD, Maggie, in *Love and Other Drugs*. More specifically, he was able to relate to her active avoidance of developing new social relationships and difficulty with commitments and thoughts of the future, which he experienced himself early on with YOPD. In terms of educating the public, Jordan also found it valuable that Maggie didn’t fit into the typical stereotype of older people living with the disease and who, like himself, didn’t always exhibit symptoms typically associated with Parkinson’s.

**Jordan:** I like the portrait of her Parkinson’s because she won’t connect to anything and she just wants to have sex with the guy. She got into a relationship and then we go to where you say “there’s no tomorrow, so why bother planning, why bother getting involved with somebody, why bother making ties with people” … It’s a very good portrayal of us with Parkinson’s … She said that, “I don’t want you to get hooked to me because I won’t be here for long.” And he [the male co-star] goes to her as a Parkinsonian and he’s very touched by her in fact. I could associate with her completely … I could associate with the woman in *Love and Other Drugs* because it touched – it was done, the research was very well done. She also broke the stereotype of the disease in that she wasn’t an old woman. She wasn’t shaking left right and center because I don’t shake either. I don’t shake.
Passive Extant Sources

In contrast to active extant sources, passive extant sources refer to extant sources of information that were acquired secondary to another purpose, or passed to participants through another person. An example for each of the categories of extant sources described in table 5.1 is provided below with supporting passages from participants and authors.

Internet Source Example

In addition to study participants, the family members of participants also used the Internet to do their own information seeking to learn about Parkinson’s and would share the information they gained. Therefore, when this sharing occurred, it was possible for participants to increase their knowledge without having actively sought out the information themselves. In the examples below, Michail and Alecia describe how their children provided them with information about Parkinson’s from different websites.

**Michail:** At university [my daughter] did a project and picked Parkinson's. And I think that's where she really got to know a lot more on it. And actually, she had mentioned some of the things I didn't know about it. What she used for looking up on the net was more informative than some of my books were. So she knows a lot about it.

**Alecia:** [My daughter] has pulled some stuff up on the computer before and had me come look at it or whatever, my symptoms at the time and that kinda thing. But I haven’t looked to see if there’s any articles on there or anything.

Although this information came from a family member, it would still be considered an example of an extant source as the family member was only facilitating the acquisition of the extant information.

Print Source Example

Print sources were the most common type of extant source that were passively acquired by participants. More specifically, information materials from the local Parkinson Society and books on Parkinson’s disease were frequently shared with participants from others. As described by participants and authors, often this type of sharing occurred shortly after an
individual became diagnosed and disclosed their diagnosis to others who provided the materials as a means of trying to be supportive; or the print sources were provided by the diagnosing physician. The perceived value of these sources had much to do with the extent to which a person was able to adjust to their diagnosis in the short time after receiving their diagnosis or disclosing it to others.

For some people, receiving print information about Parkinson’s disease immediately after the diagnosis from the physician was actually counterproductive because of the initial emotional impact of the diagnosis. For example, in her autobiography, Patricia Lightner (2003) discussed how she threw the materials that her physician gave her in the garbage when she got home after he confirmed her diagnosis, recalling “it was the last thing that I wanted to read” (p.15). Likewise, Torrence was provided a book on Parkinson’s from his physician after his diagnosis, which did not meet his actual need for information at that time.

**Torrence:** When I was diagnosed my neurologist handed me a book and said, you know, “Here is a book that you can read, you can learn a little bit about Parkinson’s.” First of all, the diagnosis for me was a complete utter shock. I was not expecting that at all, so there was a lot of emotional baggage that went immediately after the diagnosis. But you know, there was no discussion of how to handle that, you know I was kind of left on my own. And then it turned out that the book he handed me was actually not meant for patients, it is more for doctors, and the book was ten years out of date, which you know I didn’t really realize until after I got through it and I started reading the credits.

This is not to say that participants did not desire information from their physicians after the diagnosis as most did. In the passage above, Torrence describes how the information he desired after the diagnosis was related more to helping with the emotional difficulties instead of medical information about the disease. This was also the case for many others participants and authors, who expressed feeling that they were left to adjust on their own after being given the diagnosis. Contact with the Parkinson Society was seen more broadly as a resource that could help with both emotional and informational needs, instead of being a single source of information providing only medical facts about the disease. The passages from Alecia and Kalvin below illustrate how initial contact with, and materials from, the Society can sometimes occur passively through another person.
Alecia: When I was first diagnosed, my sister immediately called the Parkinson's Society and she got lots of the books and stuff. [The Society] sent out lots of information for both of us. That was important, so I think the Society is a great place to go.

Kalvin: The Parkinson’s Society is great about sending out stuff; they’re great at that … I don’t know how I got the first information from them. I do know that I – there was a friend of my sister’s that belongs to the Parkinson’s Society and she did bring some stuff up to my sister who brang it to me.

In addition to contact with the Parkinson Society, other people to whom participants disclosed their diagnosis would sometimes offer support by providing them with autobiographies written by those living with YOPD. Similar to other passively acquired print materials, such as those offered by physicians, the value of these books depended on the extent to which they could emotionally help participants. In other words, it was valued if they were able to relate to the person in the autobiography and if the autobiography portrayed a positive message about managing with the disease.

Suzanna: A friend of mine sent me a book, thinking it was a good idea. I might even still have it somewhere. I’ll bring it down. About somebody who’d written about their life, about young onset Parkinson’s. It was a very – it didn’t paint a good picture of their process or their journey. So it was a bit of a downer. So I didn’t actually end up reading it.

Not all passive sources occurred through another person. Sometimes extant information related to Parkinson’s was passively acquired secondary to another activity, such as watching television or other broadcast media.

Broadcast Media Example

Just as broadcast media sources were the least common of the actively acquired extant sources, they were also the least common passively acquired extant sources used by participants. When broadcast media was used in this manner it usually occurred when participants were scanning or surfing channels to try and find something to watch. In other
words, the broadcast media only became a source of information by chance, secondary to the desire to finding a show to watch or listen to in their spare time.

**Patti:** I go a long time where I just sort of scan briefly. But then if something – you see something on TV. There was a special on brain plasticity and that was on and all of a sudden everybody’s watching the TV or somebody’s taped it and you watch it again, and you go wow … It’s not just one little specific area in the brain. And that’s – I always find that interesting.

**Kalvin:** I was watching Primetime or 60 Minutes, I don’t know what it was, one night. And they showed – they were interviewing this guy with Parkinson’s and I was really enjoying listening to it and learning more about it and then they went on to where he had the surgery [deep brain stimulation], and they actually showed them doing the surgery and I just, I turned the TV at that point. It was too much information … How they tap into your brain and do that. At a certain point, that could be an option. And I would hate to have anybody in my brain. But I guess you have to deal with what you do at the time.

As described by Kalvin above, there is a timing element to the value of information from various sources. The more relevant the information is perceived to be at a given point in time, the more value placed on it. For Kalvin, who was still working and functioning at a satisfactory level, the idea of having neurosurgery was difficult to imagine. The result was that he changed the channel. Conversely, someone who is having more functioning difficulty at a given point in time could find information on surgical treatments more valuable. Such was the case for Sandy Andrews (2003) who, also after coming across a 60 Minutes episode that included a segment on deep brain stimulation, was prompted to do additional seeking for information about the surgery. Seeing the surgery as one of her last hopes, Andrews did eventually have the surgery. This temporal quality in the value of information perceived by individuals, based largely on its personal relevance at a given time, will be discussed in more detail later in this chapter.

**Summary**

Whether actively or passively acquired, extant information sources were usually the earliest sources used by participants to increase their knowledge related to Parkinson’s after
The benefits of extant sources were that, generally speaking, they are broadly available and easily accessible and, thus, also easily shared with participants by others. They could be accessed in the privacy of a person’s home, without the need to disclose to others; however, as discussed, most participants do disclose to those closest to them shortly after receiving the diagnosis. Print and Internet based extant sources were more commonly used by participants, with broadcast media playing less of a role as an extant information source. Regardless of the type of extant source, however, they could be limited and perceived as less useful based on their date of publication. The more dated the source, the less useful it was perceived to be by participants. This is not surprising given that advances in the medical field can occur quickly. Elicited sources of information, in contrast, helped to overcome this potential drawback and also allowed participants to engage more with the information in ways that fit with personal circumstances and needs.

5.3.1.3 Elicited Sources

Elicited sources of information refer to specific individuals, groups and/or programs that participants drew on for information related to Parkinson’s, allowing for interaction and engagement. These sources were dynamic and allowed individuals to ask questions directly through the interaction, or to acquire information by observing the other(s) involved in the interaction. Furthermore, these sources were not fixed to a specific point in time, as was a limitation of extant sources. Individuals were able to interact with the source once, or through continued and ongoing interaction over time on different occasions. Regardless of when the interaction took place, and how many interactions occurred, each interaction involved the active and/or passive sharing of the source’s own knowledge.

In order to take advantage of the benefits afforded by elicited information sources, participants needed to disclose their diagnoses to others outside of their closest friends and family. For most participants disclosing followed this type of hierarchical pattern and, as has been described, was closely associated with how a participant had been able to emotionally adjust to the uncertainty caused by the diagnosis. Participants in this study drew on a wide variety of elicited sources to acquire health knowledge related to Parkinson’s (see table 5.2).
Table 5.2: Examples of Elicited Sources of Information Related to Parkinson’s Disease Used by Individuals with YOPD

<table>
<thead>
<tr>
<th>Individuals: Caregiver / Carepartners</th>
<th>Health Providers (e.g., physicians, nurses, pharmacists)</th>
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<tbody>
<tr>
<td></td>
<td>Friends Working in the Medical Field</td>
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<tr>
<td></td>
<td>Other People Living with Parkinson’s</td>
</tr>
<tr>
<td></td>
<td>Caregiver (Carepartner) of Other People Living with Parkinson’s</td>
</tr>
<tr>
<td></td>
<td>Person Living with Non-Parkinson’s Health Issue</td>
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<tr>
<td></td>
<td>Researchers</td>
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<td></td>
<td>Support Organization Staff</td>
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<tr>
<th>In-Person Groups: Parkinson’s Support Groups</th>
<th>Parkinson’s Exercise Groups</th>
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<td></td>
<td>Study Focus Groups</td>
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<tr>
<th>Virtual Groups: Private Facebook Groups for Parkinson’s</th>
<th>Parkinson’s Chat Rooms</th>
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<tr>
<th>Support Organization Programs: Board Membership</th>
<th>Webinars</th>
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<td></td>
<td>Conferences</td>
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Active Elicited Sources

Active elicited sources refer to those elicited sources that participants sought out and engaged with in an interaction through their own purposeful seeking of information related to Parkinson’s disease. Examples from each of the categories of elicited sources described in table 5.2 are provided below with supporting passages from participants and authors.

Individuals: Caregiver / Carepartners

In the data I collected, various terms were used to describe the person closest to, and caring for, the person living with Parkinson’s; wife, husband, child, friend, caregiver, carepartner and even “ParkinSIDEian” (Gordon, 1992) being examples of some of these terms. Regardless of what term was used, however, various participants were able to describe the value of learning from these people given their proximity to, and intimate familiarity with, the disease. Interactions with these sources usually occurred in the context of support group meetings.
Michail: Well, they've been dealing with it longer than myself. I'll ask them – a lot of the time, if it's not themselves, it'll be the caregiver, which is usually the wife … Usually it’s the caregivers, you will find out more from. Yeah. Maybe they are more open too … I’ll get more answers from the caregivers than from the ones with Parkinson’s because a lot of them, they’ve had it for so long they can’t remember back that far.

Individuals: Support Organization Staff

When participants reached out to support organizations dedicated to helping those with Parkinson’s, such as the Parkinson Society Canada and its regional offices, the staff of these organizations were perceived as being very helpful; both emotionally and in terms of providing information about the disease. Below, Lilia and Jordan talk about interacting and learning from specific staff members at these organizations.

Lilia: Actually, the first discussion I ever had that was really good was with the Parkinson’s Society in [the city]. I called there and I remember closing my office door and I talked, I betcha I talked for an hour … It just, it opened all the doors for me. It just gave me a sense of where I was at. It was really good. It was the best thing – I think staff at the Parkinson’s Society has actually helped me several times that way … Like [she] certainly seems to know all about Parkinson’s and what people go through. It’s never a doubt – I’ve never doubted that once with her, discussions I’ve had with her.

Jordan: I think for young-onset it would be that there is help out there if you need it; that there’s a Parkinson’s Society of Canada … The main thing is to be put in touch with the organization. That's what the role of the neurologist should be when he gives the diagnosis … The prescription the doctor gave me didn't save my life when I was depressed, crying my eyes out thinking my life is over, it was the Society.

Prior to starting data collection for this study, I had the fortunate opportunity to work at a Parkinson Society office for a period of time, in a role that allowed me to interact with young people living with Parkinson’s who were calling to seek information. The people with whom I spoke were all at different stages of experience with the disease and, thus, had very different questions. In most cases, discussion was centered on the programs and services
offered by the Society. Things like providing information about support groups in different areas, contact information for the offices of movement disorder specialists and sending out packages about the Society were among the more common things I completed. Part of this role, however, was also giving these individuals a chance to tell their story and vent about the difficulties and challenges they had experienced. It was as if they had reached a tipping point where they could no longer burden these issues alone and needed to seek out help from others.

In-Person Groups: Support Groups and Study Focus Groups

The most common type of in-person group discussed by participants, as an elicited source of information, were support groups specific to Parkinson’s disease. Important issues raised by participants with respect to Parkinson’s support groups, from the perspective of younger people living with the disease, have already been discussed earlier in this chapter. The other type of in-person group included in this section describes the unique role that focus groups, which were part of the data collection cycles of this study, played in being an elicited source of information for participants.

Most study participants and autobiography authors reported at least some experience with Parkinson’s support groups as a source of information related to the disease. The support group setting is obviously very complex, but within each of the meetings much information is exchanged between participants of the group. In many ways, this information shared and knowledge gained by participants in these settings can even be more valued than other sources, such as information from physicians. Danny and Sandi Gordon (1992) describe in the passages below.

**Danny:** I want to hear their story because that’s more important to me is how do they deal with things and what can I use … I probably brought two or three points home and, okay, I’m going to try that. It doesn’t mean it’s going to work for me, but – and yeah, they are not doctors. They are just regular Joe’s that have it. But that means more to me than probably – and I don’t mean this in a mean way, but the doctor will tell you, but he’s reading from the textbook. These guys are singing the hymns. I want to talk to those guys … People will talk about this is what they do on a daily basis, what they go through and you just learn.
“One of the easiest, and most effective ways to become knowledgeable about Parkinson's, is by joining a support group. Parkinsonians have the edge on doctors, even neurologists, when it comes to understanding certain (but not all!) aspects of the disease. They also have the most comprehensive list of coping techniques. Doctors are limited to what they can observe, read, or speculate. The Parkinsonian acquires his knowledge from living with the disease day and night” (Gordon, 1992, pp. 69-70).

Support groups for Parkinson’s disease offered a means for study participants to interact with one another, share information and learn from each other. However, many other group settings could also facilitate such interaction to occur.

A finding of this study that I was not expecting occurred when participants spoke about the focus groups I held in the data collection cycles of this study as being another elicited information source. More specifically, as part of my data collection, I conducted a total of six focus groups. The passages from participants below describe how the focus groups were not only helping me complete my study, but they were also mutually beneficial for them as well.

**Kalvin**: I think these focus groups are really good. I hope they’re giving you information, they’re giving me information because I’ve learned from everybody things and I’ve still got questions that I didn’t know and that’s - I’m learning from them. But hopefully they’re helping you out. I think they’re good discussions, I think they’re good to hear.

**Cynde**: I think the focus group is good because there is more in each of us then we know and when we hear somebody talking we go: “Oh my God, yeah, I thought that and here is my experience” … I’m leaving here feeling more empowered, more knowledgeable, and you are going with what you need and what you are going to build on.

Group settings, however, are not just limited to in-person settings as the development of computer and Internet technologies has facilitated the growth of virtual groups for people sharing similar interests and/or difficulties. This category of elicited information sources will be discussed in the next section.
Virtual Groups: Facebook

Among the most popular, and most recognizable, of the virtual groups discussed by participants were those created on Facebook. However, even before Facebook became popular in the past decade, many of the authors of YOPD autobiographies spoke of having visited and used Parkinson’s chat rooms online (e.g., Andrews, 2003; M. J. Fox, 2002; Lightner, 2003; Phan, 2004; Webster, 2004). Allowing individuals with YOPD to connect with one another from different parts of the world in a relatively anonymous manner, at any hour of the day, it was no wonder that these groups were well utilized as an information source.

Given the difficulty that participants described in finding support groups specific for those who are younger and living with Parkinson’s, it is not surprising that several participants reported using Facebook to connect with others with YOPD. Similar to Internet-based extant information sources, Facebook is easily accessible through any Internet-enabled device. The difference with Facebook, however, is that it allows individuals to connect with and interact with one another privately or in a group setting. For participants of this study who used Facebook groups as an elicited information source, these groups were privately organized and specific to YOPD. This means that posts made in the groups were not publicly accessible and members were usually invited to join through others already part of the group. These settings, generally, helped to provide greater privacy to the group members and the discussions had within the group while providing a setting for those affected by YOPD to share and learn from one another. Both Trevor and Suzanna utilized Facebook groups specific to those for YOPD as sources of information.

**Trevor:** I think most of all, I needed to speak with other people who were in my position. And that was not, how would you say, straightforward in terms of access to other people until, all of a sudden, I found the sites on Facebook … I’m now on two Facebook groups, which almost have the same people on them … And so I just, for a number of months really, was very active in terms of particularly reading those websites because some of the information you pick up is incredible.
Suzanna: I was used to Facebook, I’d been on Facebook for quite a while … Again, Facebook is sort of conducive to our difficulties with sleep and insomnia. There’s always someone on at odd hours of the night, but you’re up and that sparks conversation and you go from there. There’s always people that are, I mean its anyone from someone who’s just newly diagnosed last week up to people like me who’ve had it for 15, 16 years, so a wide range of people.

As valuable as virtual groups can be for individuals, especially for those in more remote areas or regions lacking YOPD specific groups, some participants noted the need for a degree of caution when interacting with others online. This danger of virtual support was raised by Peter who had a negative experience using a chat room.

Peter: Getting back to this Internet thing -- well, I think that you need support and the people around you, they’re the people that you should be looking at for support. Entering [an online group] can get you and grab you. You’re getting support from a computer, from printed word and you’re ignoring the rest of the real world that’s around you. I got sucked into that. It almost cost me my marriage. So I’ve got strong feelings about chat rooms and getting on … A lot of it is to the heart, people pouring out their hearts, but you’re still, you’ve got the button, you turn it off and now that world’s gone. You’re in your real world and you’ve been ignoring your real world for so long. I’m sure I’m not the only one that’s gotten caught up in that. So that’s one warning.

Just like in-person groups, the dynamics of virtual groups were complex and brought with them advantages and disadvantages for those who chose to utilize them for information. Irrespective of the dangers of these types of groups they were, nonetheless, used by participants and autobiography authors as a source of information related to Parkinson’s. One of the other ways that individuals with Parkinson’s came into contact with one another was by attending the different programs, such as conferences, put on by Parkinson’s support organizations.
Support Organization Programs

Although not all Parkinson’s support organizations are able to fund conferences that aim to provide current and relevant information for people affected by the disease, many are able to organize such events. Conferences organized by the various Parkinson Societies in Ontario, Canada, where this study was conducted, were discussed by participants as being a valuable source of information.

**Hal:** I have been dealing with Parkinson’s for 14 years and we are veterans of many, many, many, many, many conferences and I think conferences are, probably; have been our best source of information.

**Kalvin:** I think I’ve been lucky that I’ve gone to the conferences I have and seminars. And to be honest with you, if there’s one this weekend I’d go again probably, hoping that, again, I would get something that I haven’t got now, out of it.

Similar to issues that arose with support groups, in-person conferences brought individuals with Parkinson’s of various ages, and at various stages of the disease, into contact with one another. For some, this was challenging and deterred them from participating in future conferences. Additionally, information shared at more general Parkinson’s conferences may not have been the type of information that was desired by those with YOPD. As such, some participants spoke of a preference for conferences organized specifically for YOPD.

**Michail:** The last seminar really helped a lot. More or less narrowed down a lot more, and explained a lot more than what the general Parkinson’s seminar that we went to in [the city]. Yeah, because it was relating to young onsets … My wife and I found that really interesting.

**Jordan:** I went to young onset Parkinson conferences in the States because the States has an organization that has a conference every year specializing in young onset. And they discourage you to go if you are above 55. And that’s how I met other Parkinsonians that were younger … Some persons don’t go to a Parkinson conference because it’s too difficult, until they realize that it is different. Because there are too many cases that will freak you out, so you don’t want to go. I was lucky
that I got involved with the young onset conferences where I saw young onsets like me.

Summary

The main distinction between extant and elicited information sources used by participants was that elicited sources brought participants into direct, or virtual, contact with others. This contact allowed for interaction between participants and various individuals and groups having an interest in, or knowledge of, Parkinson’s. Similar to extant information sources, however, information from elicited sources could also be obtained passively as well.

Passive Elicited Sources

In contrast to active elicited sources, passive elicited sources refer to instances where participants gained knowledge related to Parkinson’s by observing the information sources rather than actively engaging with them. However, it is important to note that information could be acquired from elicited sources through active and passive means at the same time, depending on the particular setting and situation. For the most part, the passive acquisition of information through elicited sources was limited only to interactions between those with Parkinson’s.

The primary mechanism which individuals used to acquire information passively from elicited sources was through social comparison. More specifically, individuals observed others with Parkinson’s and drew comparisons between their own symptoms, side effects, difficulties and overall progression to that of the other person. As described earlier in this chapter, social comparison was a strategy used by participants and authors to manage with the uncertainty caused by the diagnosis. Thus, passively acquired information from elicited sources was one additional means through which social comparison was used in the context of building resilience. Examples for each of the categories of elicited sources described in table 5.2 are provided below with supporting passages from participants and authors.
Individuals: Other People Living with Parkinson’s

Although in most cases interactions between people with Parkinson’s occurred in group settings, and settings created by support organizations, there were certain circumstances where participants came into contact with others living with the disease one-on-one as well. One such circumstance occurred when friendships developed out of the group settings. Sondra and Joella, both participants of this study, were two such individuals that met in a support group and developed a friendship outside of the group. Through this time spent together, Sondra provides an example of how information can be passively acquired through social comparison.

**Interviewer:** So when you talked about Parkinson’s with Joella, what types of things would you talk about? **Sondra:** It’s almost comparing differences because see she has on/off times. She takes different medication. We talk about things that are maybe helpful. But I think the biggest problem with Joella and I is that, she does have the on/off problem and I don’t. So, we are going to go grocery shopping and she has to say, okay I’m going to take my pill at two o’clock and I have to get there – we have to get all our errands done and get back before she goes off her meds and the same with the Super Walk. I go, “Joella, you’re not here.” She’s frozen back there somewhere. So, she sort of lets me see that – she makes me feel grateful that I’m not there yet.

A second situation where individuals living with Parkinson’s would come into contact with one another, one-on-one, occurred when a living family member also had the disease. Although having a relative with Parkinson’s can be a source of recalled knowledge, as previously discussed, continued learning and sharing of information also occurred during subsequent interactions. Such was the case for Martha, for example, who describes the passive acquisition of information through observation and comparison with her sister.

**Martha:** It’s just like I knew about Parkinson’s obviously from my sister, and it wasn’t looking good. And she had a big, huge symptom much different than what I was experiencing. Her whole right arm was constantly moving like this. And she’s taller and bigger and much heavier than I’ve ever been.
The final situation that will be discussed where participants came into private contact with another person with Parkinson’s occurred for those working in the health field. Suzanna, for example, had limited exposure to younger people with Parkinson’s early after her diagnosis. In the passage below, she recalls how observing the decline in those she treated with the disease made it more difficult for her to emotionally adjust to the disease.

Suzanna: Initially, emotionally, I would say it was hard because I sort of knew or know what the future held or holds for people with Parkinson’s at the moment. And the decline that I saw in my own patients with Parkinson’s was a barrier to my own acceptance in some ways, and I think that was a difficult part.

In-Person Groups: Support Groups

By virtue of being in a setting where other people with Parkinson’s were present and interacting with one another, participants reported learning in these settings by listening to the discussion without contributing, or by observing other people with different symptoms and side effects. As described in the previous section on active elicited sources, support groups can be valuable sources of information. Although the motivation for creating YOPD support groups was partly because of the desire to speak with others about issues more relevant to young adults, like employment and parenting, the other motivation was premised on the difficulty seeing others at more advanced stages. This rationale implies that information was acquired passively through observing others in later stages of the disease.

Alecia: Whether you realize it or not, every time you go you probably learn more about Parkinson’s just from watching these other people or listening to them. And I think that as a group, as I said, everybody there or there's somebody always with them that has stories to tell or things to enlighten.

Alex: I guess the only reason I’m scared of the wheelchair is that almost every member, except for the caregivers, every Parkinson’s person, especially the males, whenever they come to the meetings, they’re in a wheelchair.

As has been an ongoing theme in many of the sections of the results presented thus far, there was a high degree of emotionality that existed in the experiences of participants and authors. The different emotions experienced by individuals had much to do with the manner in which
they had grieved the uncertainty caused by the diagnosis. For Alex, in the passage above, observing that many of the other male members of his support group were in wheelchairs created fear because it reinforced the uncertainty of his own future functioning with the disease. This is an example of a time where learning could actually wear on a person’s resilience, instead of building it up to support emotional adjustment.

Virtual Groups: Facebook

Although virtual groups, like Facebook, brought individuals with Parkinson’s into contact with one another, making observations of others were less frequently discussed. This is not surprising, given that the interaction is virtual and not conducive to the way we make observations in-person, i.e., using our vision. Instead, the passive acquisition of information in virtual groups was more frequently talked about in terms of viewing and learning from the posts of others without being directly part of the conversation.

**Trevor:** For example, the protein issue is all about intake. That’s what we think about. And one guy last week said have you thought about if you are constipated, and I’ve never – it wasn’t directed to me. It was to somebody else. But I never thought about that. And he was basically saying, of course, if you’re constipated, [the medication] doesn’t make it down to your gut. It needs to get absorbed in the duodenum I guess, rather than in the stomach itself. Or a lot of it is at any rate. So he was sort of saying if you’re constipated, you’re going to have off periods as well. And so little facts like that. And as it happens, I don’t have any problems with constipation thankfully. But in the future, if I do, I’ll be able to work out what the implications of that are before it happens … So, there’s all sorts of information just coming in to me. And I was just soaking it up like a sponge.

Although Trevor wasn’t involved in the conversation between the other two members of the Facebook group, he still perceived to have acquired valuable information that might be of use to him in the future: “But in the future, if I do …” Again, it is the uncertainty of the future for participants that motivated the acquisition of information related to the disease. That is, acquiring information about the disease was one of the many ways that participants attempted to manage with this uncertainty in building a sense of resilience.
Support Organization Programs: Conferences

Apart from the presentations made by experts on particular topics, individuals with Parkinson’s would sit at tables and talk with one another between conference presentations and on breaks. Being in a setting with so many other people with the disease provided the opportunity to just observe and listen to others describe their experiences with the disease, allowing for social comparisons to be made. Thus, participants spoke of these conferences as being a setting where information was acquired both actively and passively through interactions with others living with Parkinson’s. In the case of Danny, for example, experiences at these conferences drove home the heterogeneity and uncertainty inherent in the disease.

**Danny:** I was just more or less listening and taking all the information in and saying okay I'm not that bad or no I'm not – that doesn't sound like one of my symptoms because I'm not in that stage or I'm not in that style. And again, very, very much awareness because at the table there was what, ten people, and then some of them were couples so there wasn't all Parkinson's, but maybe five or six people that had Parkinson's. No two of us were the same at all, not even close. So again, it does bring home the harsh reality that it's a hard disease to really nail down because like I said, there was hardly no symptoms I had that these people had but we're all heading in the same direction, but getting there is this totally different path.

**Summary**

Interactions with individuals, groups (virtual and in-person) and programs organized by support organizations for Parkinson’s provided participants with opportunities to learn more about the disease. This learning occurred actively, by directly engaging with the source, and passively, by observing or listening to the source. Both active and passive acquisition of information from elicited sources was possible, especially in those settings that brought individuals with the disease into direct contact with one another. The concept of social comparison was further discussed, especially with respect to passive sources, where information was obtained by observing and listening to others living with the disease.
5.3.2 The Filtering of Accumulated Knowledge

In the process of learning about Parkinson’s disease, participants and authors described using their own bodily experience living with the disease as a means of making their accumulated knowledge more personally relevant. In other words, they used their bodies to “filter” the knowledge they had accumulated. After being filtered, the result was an “experiential knowledge” base that helped them to better understand, and manage within, their own personal experience with YOPD (see figure 5.4). Through a process of reflection, experiential knowledge could also be compared to one’s accumulated knowledge, as a means of self-comparison to provide information about progression and to guide subsequent information seeking. One’s bodily experience was always available to individuals to filter knowledge they had accumulated, and because of its direct relevance to each person, it was highly valued by participants and authors.

SuZanna: We talked about that, sort of comparing yourself to yourself, and knowing what works for you and what doesn’t work for you. You definitely learn from your own experiences of just living with the disease much more than sort of reading about it for sure. Beginning to understand what works for you because the whole spectrum right, some people certain things will work and others won’t and people progress at different rates and experience different side effects, so sort of trying different things is a definite source of information.

Figure 5.4: The Filtering of Accumulated Knowledge Using Bodily Experience
5.3.2.1 “Trial and Error” and Experimentation

This active use of one’s own body in the process of learning about Parkinson’s was often described by participants with reference to “trial and error” or “experimenting” with various management strategies. As described by Sandi Gordon (1992) in the passage below, the use of one’s own body as a tool to accumulate personally relevant knowledge facilitated “control” perceptions in the process of adjusting to the uncertainty caused by the disease.

“A lot of knowledge is accumulated through a personal process of trial and error. Even with a wealth of information, Parkinson's has a way of surprising the patient with the unexpected and unexplainable change of plans, never allowing him to have full control over his life. However, by realizing the need to be flexible and learning how to roll with the punches, Parkinsonians can still retain the vantage point over their disease” (Gordon, 1992, p. 61).

The two main areas where individuals used their bodily experience to generate experiential knowledge occurred with respect to medication regimens and other lifestyle based management strategies, such as exercise, nutrition and time management. These areas relate directly to the strategies used by individuals in being proactive in their lives, discussed in the chapter on adjustment, further emphasizing the importance of learning about Parkinson’s as a strategy used during the adjustment process.

Medication Regimens

With respect to taking medication for Parkinson’s disease, “trial and error” was discussed by participants in terms of trying to minimize the side effects and maximize the benefits of the medication. This experimentation with drug type and dosage was an ongoing process, with participants relying on feedback from their bodies to optimize their medication regimens.

Danny: Well, for me, that’s the way most of this has been. A lot of trial and error. I mean, I know [my doctor] has said, “Try this medicine. You’re allowed to take four a day, but if you can do it with one, good.” So it’s been experimental, I guess, in a lot of things … I mean, I’m still experimenting today and this is three years after having it. So I think that’s ongoing. I just know my own body. And I know when something is working or something is not working.
**Patti:** Unfortunately it was real trial and error with the medication initially and I had a lot of side effects and, you know, felt crappy until I ended up on the medication that was the one around for the longest. But, you know … some of the medications I tried for months to see if I could get it regulated and it just, you know it took almost a year I think to get on the right medication.

To accommodate for this idiosyncratic optimization process, several participants reported that their physicians worked with them to experiment with the timing of their medication to find optimal levels that worked for their lifestyles. Thus, physicians and participants both recognized the importance of experimental knowledge in a joint effort to use bodily feedback to maximize individual functioning. The allowance afforded to participants by their physicians was often within defined parameters, and was not surprising given that most participants reported wait-times of half a year or more to see their neurologists.

**Lilia:** [My doctor] was really good with letting me experiment with my drugs. Because I got to a point with him that I had to experiment because it wasn’t working. And he let me do, he let me do that. He said I understood enough what was going on. So it was okay. It was an okay relationship.

**Trevor:** I’m noticing as I drop the [medication] that I’m getting dyskinesia less and less. And I’m able to drop the [medication] at the moment to reduce the dosage without any ill effects. And I also seem to have some level of flexibility with my timing as well. I don’t have to be bang on the 10:00am, 1:00pm time points, which in a way is not a good thing because then it makes me push it more. But I, at some point, if I can get my 10:00am dose down to one tablet, I think the next thing I do is actually try four hour intervals again. **Interviewer:** So with your medication, do you just make these adjustments on your own? Or do you make adjustments in consultation with your physician? **Trevor:** I make them in cooperation with him … the trial and error issue is continually being tested and modifying my meds and stuff and that sort of thing.

Apart from medication, several other management strategies were used by participants where “trial and error,” “experimentation” and the resulting bodily feedback were used to
increase knowledge of their disease. To some extent, however, these other management strategies were still impacted by medication regimens.

*Lifestyle Based Management Strategies*

The three main lifestyle based management strategies used by participants, which resulted in an increased understanding of their disease through bodily feedback were i) physical exercise; ii) meal planning; and iii) time management.

Physical Exercise

Participants reported directly perceiving benefits of physical exercise on their Parkinson’s symptoms and related issues, like sleep quality, mood and medication needs. Thus, by participating in different types of exercise, participants learned that it could have an impact on their symptoms and bodily experience of Parkinson’s. This feedback resulted in an increased desire and motivation to exercise, so that the benefits would continue to be experienced.

**Danny:** After exercise, you know what, you feel pretty good. And you’re pumped up a little bit. And it actually does take the tremor away a little bit, at least for me it does. I can’t say that for everybody. If I do a fast walk for two miles, I’m tired, but after I sit down, I feel pretty good … I try to exercise like an hour or so before bed so my body kind of unwinds a bit. Boy, those are good days. And those are the nights you can get some sleep, not much more than four or five hours, but it’s a deeper sleep. I don’t wake up a couple times where even on a restless night you’re waking up or you’re not really even in a sound sleep. The exercise for me totally helps … It’s something, for me, I just need to do. And I feel better overall.

**Suzanna:** I had always been fairly active in terms of exercise. But I think I became much more diligent. I was not diligent for the first part of it. I had sort of lost a lot of – because I was so busy with everything else, exercise also fell by the wayside. But now I do notice that my symptoms are better. My mood is better. My medication needs are less if I exercise regularly. And my pain is less and my sleep is better. So seeing all those positive effects of exercise has really kind of drilled it into me that I need to do it.
Although exercising was the most talked about lifestyle management strategy, meal planning and time management were also actively used by participants and resulted in increased experiential knowledge.

Meal Planning

Just as some participants found exercising to impact their need for medication, participants also found that particular foods or drinks would impact the effectiveness of their medication. As a result, through “trial and error” and “experimentation,” participants learned to plan their meals in such a way to not adversely impact their medication and, thus, maximize their functioning.

**Danny:** Just little things like do you drink something before bed, do you have a late night snack if you’re taking a pill on an empty stomach. I found sometimes that’s good or bad. Little things like that. So it’s been a lot of trial and error. I’m not a drinker, but at night, I like to have a pop or a ginger ale or something like that. Can I even have a ginger ale late at night because will that do something? Sometimes yes, sometimes no. It just depends what you’re doing or eating … but I had to learn that all by myself.

**Patti:** Like I didn’t know protein effected your medication. I’m going, “well what do you do when you eat, when you have to take your pills every two hours? So, you know you mean don’t eat protein anymore?” And then you find out that no, that would be silly. It does make a difference. If you’re feeling crappy for two days after you eat a honking big steak, you’re not gonna do it anymore … I know that if I have one glass of wine it’s fine, but if I have two I’m gonna be not feeling good. It’s not worth it.

**Trevor:** There was a few things that started to nag away at me and one was that if I ate a steak, then the day after all my symptoms would be worse … Now I know it relates to protein uptake in the gut … And then later on, I discovered that dairy was a problem, particularly eggs … High protein again. And then milk in the morning on my cereal, it took the edge off my dopamine. So now I have almond milk. And that works tremendously well.
After learning which foods and drinks would impact their medication, participants either avoided those foods or drinks, found alternatives, or consumed them well in advance or after their Parkinson’s medication. Thus, time management was an important strategy used by participants for meal planning, which carried over into other aspects of their lives as well.

Time Management

As participants came to understand the impact of the disease on their functioning throughout the day, they were able to plan accordingly to try and maintain a sense of normalcy in their lives. For Patti, this planning revolved around managing her fatigue to have the energy to participate with her family in the evenings. For Michail, this planning revolved around taking specific shifts at his workplace to minimize his symptoms and enabling him to continue to work.

**Patti:** When my fatigue was bad, was an issue, well, once I realized that if you're zooming around too much during the morning and not getting a rest in the afternoon, you're gonna be grumpy and tired and not eat right in the evening which is when I wanted to be better because that's when I'd see my family. So I learned, hey, just take an hour rest in the afternoon or a half an hour, could be 15 minutes, just to relax and sort of power down and that helps … I learned what to do to make myself feel better and usually, most times, it works fairly well … So you can't put your head in the sand, but you don't have to spend your whole time just dealing with it either. So it's that happy medium of trying to get as normal a life as possible.

**Michail:** I like to work midnights – I do 12-hour shifts. So I like nights versus days because I'm not a morning person. I find when I'm on days getting up early, I do show a lot more signs than if I were to say get up at 9:00 in the morning versus 5:00 in the morning. Whereas, if I stay on a straight rotation of nights – I work 12-hours shifts. So I work three days one week and four the next. I have so much time off in between that I feel a lot better than I do switching in and out of the days and nights on the same week. It has made a big difference.
Summary

For participants of this study, trial and error and experimentation were used with respect to medication, exercise, diet and time management to build their experiential knowledge base. This knowledge, specific to their own experience with the disease, was used to try and minimize the uncertainty of the disease and, in doing so, build their resilience. However, in addition to contributing to experiential knowledge, bodily experience living with the disease could also be compared to all of the knowledge that an individual had accumulated.

5.3.2.2 Reflecting on Disease Progression

As the progression of Parkinson’s is heterogeneous, i.e., unique from one person to the next, it was difficult for any of the participants or authors to know how their disease would progress over time. In other words, there was long-term functioning uncertainty inherent in the lives of individuals living with Parkinson’s. Although progression could not be predicted it could be assessed retrospectively by those participants who had lived with the disease for a longer period of time. More specifically, through a process of reflection, individuals were able to compare their bodily experience with the disease at a given point in time to their accumulated knowledge of the disease (see figure 5.4). Over time, these comparisons allowed individuals to come to an understanding of how they believed their disease had progressed. This type of reflection was done during the process of logical adjustment, in coming to rationally accept the idea that they had YOPD, but also continued over time to manage with the uncertainty of disease progression.

When these reflections resulted in a positive self-comparison, it contributed to an individual’s resilience by providing a belief that they were managing well with the disease. Such was the case for both Helmut Dubiel (2009) and Jammie, for example, who describe their comparisons in the passages below.

“Now that I am able to look back on several years of experience with the disease, I am forced to admit to myself that I had been fortunate things hadn't turned out worse. My Parkinson's was progressing at a slower rate than the original prognoses had led me to expect” (Dubiel, 2009, p. 61).
Jammie: If I can maintain the stage I’m at right now, I’d be happy … I can’t offer saying this for ten years from now but right now, to somebody just diagnosed, I could say, “I’ve had this for ten years and I think I’m doing pretty good still.” So I could give somebody ten years of “hey, it’s not that bad.”

However, if individuals were dissatisfied with their self-comparison, it made it more difficult for them to be resilient because they felt as if they were losing ground to the progress of the disease. Such was the case for both Kalvin and Danny, for example, who describe their comparisons in the passages below.

Kalvin: I see the way that I’ve progressed in the period of time since I’ve been diagnosed. And I don’t like the way that it’s developed this quick. To really describe it to you. It’s life-altering. It’s the opposite of somebody telling you that you won the lottery.

Danny: It’s gotten worse. The tremors in the hand certainly got worse. My handwriting is gone from bad to non-existent almost. Now just recently my right leg is starting with that restless leg syndrome, not even just more at night, but all day almost. Even when I'm standing there I kind of feel my leg, not twitching, but I can tell it’s starting to have an effect. To me it sounds like it’s going down the right side.

When self-comparisons created a perception that the disease was progressing, individuals were motivated to draw on various strategies to build their resilience. With respect to learning about Parkinson’s disease, new bodily experiences that signified the disease was progressing became the focus of information seeking. In other words, experiential knowledge, and this process of reflection, played an important role in the patterns of how information seeking changed over time.

5.3.3 Patterns of Information Seeking

An overview of all of the different topics, or foci, of information sought out by participants in the extant and elicited sources described would be a daunting task. The heterogeneity of the disease made much of the information sought unique to each individual. A broad trend, however, could be discerned in how the type of information sought by participants, and the type of information sources used, changed over time. This trend was predicated on
participants’ bodily experience with the disease, at the time of diagnosis and over time as the disease progressed. This trend can best be described as a change from primarily general information seeking using extant sources to more specific information seeking using elicited sources.

5.3.3.1 General Information Seeking and Extant Sources

Initially, after receiving their diagnosis and starting the process of seeking out information related to Parkinson’s, participants focused primarily on general information about the disease. This type of information included things such as an overview of potential symptoms, medications used to treat Parkinson’s disease, and potential causes of the disease.

Kalvin: I think I just Googled Parkinson’s in general. I don’t think there was anything specific that I can remember that I was looking for at the time. I was trying to get as much general information as I could. But I mean you keep coming back to why, and you keep coming back to you’ve got to deal with it as it comes, and you don’t know how it’s coming.

Sondra: [My doctor] had put me on Amantadine, right away, so I looked up Amantadine and you know stuff like that. But I didn’t go into, like at that point for instance, I don’t remember looking up like about my kidney’s or other problems. I don’t remember looking up subsidiary things. I just looked up the general stuff.

Danny: I would say it's much more specific information I'm looking for now whereas the first two years it was just let's find everything … We read everything but and we just wanted to know in general what was Parkinson's, because again we came at it with almost zero knowledge. That's where we learned about dopamine, that's where we learned how it works in the brain and what things would help. So that was general. Now it's more specific. That would be the difference.

As can be gleaned from the passages above, this general information was primarily obtained through extant knowledge sources (websites, news articles, books), as these sources were readily available to participants. This general information provided individuals with the knowledge they needed to logically adjust to the diagnosis and to start making initial changes to their lifestyle. When specific bodily changes started to occur, and at least became
more certain to the extent that an individual would experience an issue, such as problems with their bowel or bladder, information seeking shifted to those more specific issues.

5.3.3.2 Specific Information Seeking and Elicited Sources

Once participants were satisfied with their general understanding of the disease and a specific issue surfaced, the foci shifted towards information on topics related to those issues, or specific information seeking. For example, problems sleeping at night, concerns about employment, questions about pregnancy and deep brain stimulation were specific issues experienced by participants and authors. As has been discussed, when progression was perceived through self-comparison, it weighed on an individual’s resilience in the process of emotional adjustment. As a strategy to build resilience to these changes, specific information seeking focused on finding answers to more “practical” and “tangible” concerns. This type of information seeking provided individuals with the knowledge they needed to be proactive in managing with concerns they encountered with their bodies in the progression of the disease. For Jordan, specific information seeking at the time of our interview centered on sleep issues. For Lilia, who experienced more severe side effects from her medications, she was now interested in learning about deep brain stimulation.

**Jordan:** I’m more focused now on what information I need. For example at the conference last spring there was a talk about sleeping. I learned a lot about sleeping because I’m having trouble sleeping. That was information that was tangible for me to kind of relate it. Because sometimes you have something going on with you and you don’t know if it’s Parkinson or something else … Like you don’t have a gauge to say was this caused by Parkinson or if it’s caused by the medication. That very tangible information is very good. Same thing with the [support group] meeting where the nurse was talking about hallucinations and things like that. That’s practical information for my living … My needs are changing, so I didn’t have any question about sleep problems when I was diagnosed at the beginning but I do now. So as I go along I need more information about specific things.

**Lilia:** Initially, I just read different things about Parkinson’s and I didn’t read about DBS [deep brain stimulation]. I didn’t know about DBS … If I knew about it, it was foggy, and in fact I didn’t pay attention to it. When I finished work and I
[participated in a research study], there was a guy there that said, “Are you in line for the DBS?” He said, “Boy, if I have a chance, I’m getting it.” And that was the first time I thought, “Well, what is this guy talking about?” So I looked into it and, and it was a very short period of time from there that I was considered a good candidate. It wasn’t in my realm of what I needed to know at the time, so I never looked – Well, then I started looking into it, so then I started gobbling it all up. I’ve been doing a lot of homework because I didn’t want to have DBS without knowing – I’ve done a lot of research and talked to a lot of people … We talked to a fellow from [another city], and his wife told me that he was a hermit before his DBS … Every time I see [my doctor], we talk about it because that would be the next step for me.

Given the age of individuals when they are diagnosed with YOPD, the topic of having children and the impact of the disease and medications on the pregnancy were questions for which information was also specifically sought out. As a male with Parkinson’s, this issue was investigated by Richard Wenmouth (2010) and his wife as they were preparing for a child. As females with Parkinson’s, this was an issue for Kathleen Webster (2004) and for Suzanna. In the case for each of these individuals, there was no concrete evidence available because of the rarity of younger individuals being on Parkinson’s medication and having a child.

“My OB/GYN said that he did not know if the meds could harm the fetus. His suggestion was to be off my meds for three months before conception. It sounded like good advice. My neurologist told us that because this disease usually targets those past childbearing age that he agreed with staying off the meds for three months … it still has not been a thoroughly researched topic” (Webster, 2004).

**Interviewer:** So what was that experience like? Being pregnant and having Parkinson’s? **Suzanna:** Well, the first one wasn’t so bad because I wasn’t on medication at that point. So I was just more disabled by the morning sickness that seemed to last all day, than anything else. The second and third time that I was pregnant and with Parkinson’s was a lot more difficult because I had to – at least for the first trimester, try to reduce my medication significantly, if not stop, most of them.
Whereas general information tended to be sought in extant sources, specific information was more commonly sought using elicited sources. For example, in the passages above, participants and autobiography authors speak of seeking out answers to these questions from conference presentations, support group meetings, physicians and talking to other people with Parkinson’s. This shift was, in part, the result of difficulty finding the specific information participants desired in the extant sources, which didn’t allow for interaction and to have personally relevant aspects of questions answered.

5.3.3.3 Divergences from the Patterns

Although the patterns just described, i.e., general information and extant sources to later specific information and elicited sources, held true for most study participants there were a few exceptions that must also be noted. The first exception to this trend occurred if participants were satisfied with their existing (or recalled) level of general knowledge of the disease by the time they were diagnosed. Very few participants of this study fit this scenario, and were primarily those participants with advanced health degrees, like Suzanna.

Suzanna: When you’re first diagnosed, having spoken with so many people, you really do just need the basics. You need to know what this is about, what you can do, what your future is gonna hold, that sort of thing. How medications work, very general things as opposed to when you’ve been dealing with it for a number of years and maybe more specific things like particular symptoms or managing complications or dealing with certain things that will eventually come up like employment and disability and financial planning, future planning that sort of thing. The needs are very different, although in my situation I didn’t really need to seek out the general stuff as much as the specifics.

It is also important to note that general information seeking and the use of extant sources do not entirely precede specific information seeking and the use of elicited sources. As was the case, both types of information seeking occur at the same time, with both extant and elicited knowledge sources used. The most obvious example of this would be when physicians, i.e., an elicited information source, relays the diagnosis and try to answer initial questions after giving the diagnosis. However, the shift over time is toward more specific concerns based on the bodily experiences of participants and the use of more elicited sources. Thus, these
patterns can be visualized on a grid of intersecting continuums (see figure 5.5), with general and specific information seeking, and extant and elicited sources, on opposite ends.

![Figure 5.5: Patterns of Info Seeking and Use of Knowledge Sources](image)

As illustrated in figure 5.5, information seeking is primarily general early in the process and then becomes more specific over time. Likewise, information is drawn primarily from extant information sources early and then more from elicited sources later in the process. These changes coincide with the changes in the adjustment process as well, where the more general / more extant information helps with logical adjustment and the more specific / more elicited information helps with emotional adjustment. The dashed line in figure 5.5 is used to represent the typical changes that occurred for participants, with the approximate locations of logical and emotional adjustment.

A third divergence of this pattern important to point out is that the time at which the information seeking process started also varied among participants, and appeared directly related to the process of adjustment they went through. More specifically, participants grieved and worked to adjust to the uncertainty in their functioning and identity. Referring back to figure 5.5, the differences in the adjustment process experienced by each individual is the reason why the start of the typical pattern was not the point of diagnosis but, rather, the point at which information seeking began. This is important to point out because for some
individuals who logically denied the diagnosis, they would sometimes avoid information related to Parkinson’s in which case information seeking would not have started.

Summary

Apart from helping to filter accumulated knowledge into experiential, or personally relevant, knowledge, bodily experience living with Parkinson’s disease also played an important role with respect to information seeking. More specifically, bodily experience was used by individuals to guide the change from general to specific information seeking over time. When participants encountered trouble sleeping or were experiencing significant side effects from medication, for example, they sought out this specific information using, primarily, elicited knowledge sources. This more focused information seeking, enabled individuals to respond to their progression in a way to try and manage with their unique concerns and, thus, build their resilience to the disease in the ongoing process of emotional adjustment. Learning about Parkinson’s was a complex process, closely linked with logical and emotional adjustment, serving as one of the three categories of strategies used by individuals to build their resilience to the uncertainty caused by the disease.
Chapter 6

6 Discussion and Conclusion

The purpose of this research was to understand the collective experience of individuals living with YOPD in becoming informed about their disease. As the grounded theory developed, it became apparent that the manner in which individuals became informed was entangled in a larger process of adjusting to, and managing with the uncertainty of, YOPD. Indeed, managing uncertainty was the core category around which processes of adjustment occurred, and resilience strategies were used. In this way, becoming informed, or learning, about Parkinson’s was one of several strategies identified through which individuals used to build their resilience over time. Within this research, resilience was defined as an individual’s defense to the threat imposed by the uncertainty caused by the disease, with its resulting grief and loss of perceived control. After interpreting the core category, this chapter is organized in such a way to first address the original research questions related to how, and why, individuals became informed about YOPD, and how this changed over time, while later discussing the other resilience strategies identified in the context of chronic illness research. Given the integrated manner through which these resilience strategies were used in relation to the management of uncertainty, many of these topics will be discussed together. Included in this discussion, the tension between logics of choice and care in the experiences of individuals with YOPD, as well as the discourse around individual responsibility for health and the rise of the body are also examined. The chapter ends with a return to look at how quality was achieved in this research, as well as considerations for future research.

6.1 Managing Uncertainty

In trying to identify why individuals chose to acquire health information, or chose not to acquire health information, at various points in their experience living with YOPD, understanding the uncertainty caused by the diagnosis became paramount. More specifically, patterns of health information acquisition described by those in this study were related to how individuals had adjusted to, and managed with, this uncertainty in their lives. Within this research, individuals experienced uncertainty in relation to their identities and their functioning as young- and middle-aged adults, both at the time of diagnosis and over time as the disease progressed. Uncertainty is well recognized as being a part of the collective
chonic illness experience (e.g., Ayers & Kronenfeld, 2007; Bury, 1982; Charmaz, 1991, 1994, 1995; Mast, 1995; Mishel, 1988, 1990) and specifically a part of the experience of those living with Parkinson’s disease (Habermann, 1996; Nijhof, 1996; Pinder, 1988, 1990a, 1990b, 1992a; Sanders-Dewey, Mullins, & Chaney, 2001). Furthermore, in Parkinson’s disease, uncertainty has also been described in the experiences of individuals’ family members (Sanders-Dewey et al., 2001; Schrag et al., 2004) and in the experiences of health professionals providing individuals care (Pinder, 1988, 1990a, 1990b, 1992a, 1992b).

Although not described explicitly in terms of identity and functioning uncertainty, the chronic illness literature is filled with parallels to the concepts developed in this grounded theory. For example, Kathy Charmaz’s (1994) description of ‘identity dilemmas’, which evolved out of her grounded theory work with chronically ill men, bears much similarity to the uncertainty experienced by individuals with YOPD in this study. Charmaz defines these dilemmas as resulting from “losing valued attributes, physical functions, social roles, and personal pursuits through illness and their corresponding valued identities” (p. 269). In this way, identity dilemmas encompass both the loss of social roles, which is how identity was operationalized in this research, and various aspects of human functioning.

Another frequently cited example of research related to the uncertainty experienced by young- and middle-aged adults living with chronic illness is the work of Michael Bury (1982). In his work with individuals living with rheumatoid arthritis, he describes the uncertainty they experienced resulting from the limited knowledge available on the effectiveness of treatments and the progression of the disease, similar to the functioning uncertainty experienced by individuals with YOPD in this study. Bury describes the illness, and this uncertainty, as a ‘disruption’ for those at this point in their adult lives. A parallel can also be drawn for identity uncertainty in the experiences of Bury’s participants, as he describes the diagnosis as having disrupted “taken for granted assumptions” causing a “rethinking of the person’s biography” (p.169). More specifically, he describes how cultural assumptions about illness caused his participants to ‘rethink’ how they thought about themselves, or their identities. Again, this is similar to the description of having to ‘redefine’ one’s identity provided by those with YOPD in this research at different points in their experience with the disease.
Related more specifically to the Parkinson’s disease literature, the work of Pinder (1988, 1990a, 1990b, 1992a), Habermann (1996), Nijhof (1996), and Roger and Medved (2010) highlight examples of how the disease created uncertainty related to individual’s identity and functioning. For the participants in Nijhof’s study, three specific areas of uncertainty were identified, which all related to a ‘lack of trust’ the participants perceived in various aspects of their lives. The first area was a ‘lack of trust in the body,’ especially related to aspects of their functioning which were rooted in no longer feeling in control of their bodies. The remaining two areas were a ‘lack of trust in self’ and holding a view of ‘an untrustworthy world.’ Together these areas were related to aspects of an individual’s identity, stemming from reduced confidence and/or physical ability to do activities, or roles, they previously performed in their social worlds. Habermann and Pinder didn’t specify ‘areas’ or ‘categories’ of uncertainty, but both describe the many different aspects of a person’s life that became uncertain after the diagnosis. This uncertainty ranged from their knowledge and expectations about disease progression, treatment effectiveness, as well as their ability to perform work and family roles. Roger and Medved have also described the importance of ‘managing identity’ in Parkinson’s disease, but this management was framed as a cooperative effort of the person living with the disease and his/her spouse. Although the participants in the work of Pinder, Nijhof, Habermann, and Roger and Medved were ‘mixed,’ relative to including both individuals living with young-onset and later-onset Parkinson’s disease, these similarities provide support for the importance of identity and functioning uncertainty in the experiences of those living with the disease.

Related to acquiring health information, information seeking has been cited as one means individuals use to manage with, and reduce, uncertainty in experiences with chronic illness (Afifi & Weiner, 2004; Baker, 1994, 1996, 1998; Mast, 1995; Mishel, 1988; Pinder, 1990a, 1990b; Sklar, 2007). Similar to the way health information was used in this study, Pinder (1990a, 1990b) described how HIS helped individuals with Parkinson’s disease to manage anxiety caused by the uncertainty, and lack of control they felt in their lives; and also helped individuals incorporate the idea of having the disease into their identities. Mast (1995) and Mischel (1988) describe information seeking as a problem-focused coping, or a mobilizing, strategy in the context of managing uncertainty in chronic illness. These are in contrast to more emotion-focused coping, or affect management, strategies which involve distancing and avoidance behaviors. Charmaz (1994) also describes ‘bracketing’ as a means of
managing uncertainty through avoiding thoughts about uncertainty. It is important to note that individuals with YOPD in this study also displayed emotion-focused, or ‘bracketing,’ strategies which were primarily seen in the behaviours characteristic of emotional denial. In contrast, information seeking occurred in the process of reaching logical and emotional acceptance.

6.1.1 Early Uncertainty: Managing After Diagnosis

In the time after their diagnoses, individuals with YOPD in this study learned it would not be possible to predict the course of the disease which, combined with the variety of potential difficulties associated with Parkinson’s disease, created a fear of their future functioning. Placing a high value on independence as part of their identities, they feared the potential of becoming dependent, or a “burden,” on others over time. Together, the identity and functioning uncertainty early in their experiences with the disease caused anticipatory grief and created a perception that individuals were losing control over their bodies and their lives.

Developing a fear of the future is also frequently discussed in the chronic illness and Parkinson’s literature, especially in relation to the uncertainty about one’s functioning into the future. Bury’s (1982) young- and middle-aged participants with arthritis talked about how the diagnosis created a fear of the future where “expectations and plans that individuals hold for the future have to be re-examined” (p. 169) and a fear of becoming dependent on others developed over time. Pinder (1992a) also describes a fear of the future in her participants with Parkinson’s disease as stemming from a fear of “gradually losing control over one's mental faculties and bodily functions, of being helpless and dependent in a culture which places a high premium on self-reliance and independence” (p. 17). Other Parkinson’s research also resonates the important role of these socio-cultural assumptions, where the uncertainty resulting from the diagnosis causes a fear of the future (Fontenla & Gould, 2003; Nijhof, 1996) with an emphasis on needing to be in control, and being independent, as important parts of one’s identity (Roger & Medved, 2010). As Bury discusses, young- and middle-aged adults with chronic illness feel a cultural pressure to be in control, and to be productive members of society, so the idea of becoming dependent on others is ‘out of sync’ or ‘disruptive’ to their expected flow of life.
Holmes et al. (2013) also describe the ambivalence towards receiving help that individuals with Parkinson’s disease often discuss, especially help from family and friends emphasizing that they do not want to be a burden on those closest to them. That is, they want to remain independent and in control of their bodies and their lives. Within this research, however, those with YOPD were willing to accept support, especially information and emotional support, from others living with the same disease or a friend with a different chronic illness. Thus, a difference must be drawn between receiving support from family members and friends, and one’s willingness to accept support from those who are also young and live with an illness. This difference relates to Goffman’s (1963) work on stigma, where individuals feel more normal and less self-conscious in the presence of others living with a similar stigmatized identity. Goffman further describes that during these encounters, individuals may share information and emotional support with one another, forming an in-group alignment:

“Knowing from their own experience what it is like to have this particular stigma, some of them can provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support and for the comfort of feeling at home, at ease, accepted as a person who really is like any other normal person” (p.20).

According to Mishel (1990), uncertainty is undesired, especially related to one’s health where individuals strive for control and predictability, given that health is essential to one’s survival. As was observed in this study on YOPD, reactions like “shock” and “numbness” after one’s diagnosis were common, and are usually a response to thoughts that arise about one’s own mortality (Charmaz, 1994; Pinder, 1992a). The result is that individuals try to manage with health-related uncertainty by finding ways to perceive greater control in their lives. As has been described, one of these management strategies is acquiring health information related to the disease to identify ways, or to develop a ‘plan,’ for how control can be retained. Indeed, two of the ‘dilemmas’ that Charmaz (1994) speaks of in her identity research are of the need ‘to stay active’ and the need ‘to stay independent.’ When independence and individualism are threatened by chronic illness, the fear of becoming a burden on others, and losing control, are demeaning to one’s identity within socio-cultural
contexts that hold out independence and self-reliance as ideal traits of adults (Charmaz, 1983).

In the neurological disease literature, the importance of perceived control has been addressed in a recent systematic review conducted by Eccles and Simpson (2011) where studies assessing perceptions of control in Parkinson’s disease, MS and ALS were identified and evaluated. In general, greater well-being, greater functioning and reduced disability were typically associated with having greater perceived control; however, the authors describe how these results may be limited to Western culture, where an emphasis is placed on individuality and independence. With respect to age, Eccles and Simpson describe some evidence that younger adults are more likely to believe in the importance of having personal control over their illness compared to older adults who may favour gaining control through treatment from physicians. It is possible that this difference may also be due to a generational difference in authority attributed to medicine – an authority being challenged and diffused through rise of consumerism in relation to health and health care (Fafard, 2006).

Pinder (1990a, 1992a) and Sklar (2007) describe how the effort to try and maintain control of one’s life, in living with an illness, is often described in combative terms. Such terms have previously been described by M. J. Ravenek and Schneider (2009) with respect to the motivations of younger individuals with Parkinson’s for participating in physical activity; and similar terms were also found in this research where those with YOPD spoke of being in a fight against Parkinson’s disease to try and maintain control over their lives. Such military metaphors, similar to consumer metaphors, have often been used in discussing healthcare, both of which emphasize the importance of control (Annas, 1995). Illness metaphors have been studied with a number of illnesses, including cancer, for example, where bodily experiences and comparisons to normal, healthy bodies, figure prominently (Gibbs & Franks, 2002). In this way, illness metaphors help to illustrate the complex changes and uncertainties part of a socio-culturally bound illness experience which, in this study, revolved around identity and functioning uncertainty and the quest to regain control.

For the participants with YOPD in this research, identity uncertainty after diagnosis was also created through a perception that Parkinson’s disease was associated with older age, i.e., it was an “old man’s disease” and that having a chronic illness meant that they were no longer
“normal.” This perception speaks to the differences between the *natural* and the *normal* discourses of the body in aging research discussed by Jones and Higgs (2010) where advances in science and technology are changing socio-cultural beliefs about aging. The *natural* discourse of aging refers to the natural decline in physical and mental function traditionally embedded in Western culture, and has been fostered by religious and political institutions. However, science and technology are changing this discourse to one of *normalcy*, in that function and independence can be prolonged with compressed periods of ill health in older age. Such a discourse emphasizes “youth rather than health, and suggest[s] limitless life-extension” (p. 1517), contrasting sharply with the natural discourse where aging is supposed to be associated with disease and disability because that is the natural cycle of life. When science and technology are not able to return one to normalcy, however, individuals living with illness come to see themselves as no longer “normal” because of these socio-cultural beliefs about ageing. Such was the case for participants with YOPD in this study, who not only had an illness that could not be cured by science and technology, but were also diagnosed with an illness that has traditionally been associated with older age.

Again, the chronic illness and Parkinson’s disease literature are filled with examples that corroborate age-related illness beliefs, and the idea that the point of diagnosis is symbolic as a point of separation from others without a diagnosed illness. For Bury’s (1982) participants, the diagnosis of arthritis “marked a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging” (p. 171). Part of this ‘damage’ was caused by beliefs about arthritis, and that as young- and middle-aged adults it was a sign of ‘premature aging’ because it was a ‘disease of the elderly.’ Further evidence for these age-related illness beliefs come from research on stroke (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004; Pound, Gompertz, & Ebrahim, 1998) and osteoarthritis (Sanders, Donovan, & Dieppe, 2002) where elderly participants came to see these diagnoses as *part in parcel* with reaching old-age and, thus, less disruptive to their identities. Faircloth et al. (2004) describes this phenomenon as a culturally held assumption about illness, and that older age “creates a ‘discourse of normality’” (p.248) with respect to illness beliefs and one’s ‘biographical flow.’

In the Parkinson’s disease literature, the diagnosis has also been described as ‘premature social aging,’ especially for younger individuals diagnosed with the disease (Fontenla &
Gould, 2003; Singer, 1974). The results of Pinder’s (1990a, 1992a) research paints a more complex picture, as there was a mix of young-onset and older-onset individuals living with Parkinson’s disease who took part in her work. Pinder found that regardless of age, the diagnosis was perceived as a threat to her participants’ identities and created a perception of ‘being old.’ That is, even those who were already in older age may not have previously identified themselves as being old until they received the diagnosis. Pinder still attributes this to a broader view of disease and illness as being more common in old age, but her results contrast with the research by Faircloth et al. (2004), Pound et al. (1998) and Sanders et al. (2002) where being in old age was part in parcel with illness, or part of the flow of life. This speaks to the power of socio-cultural beliefs about age and illness, and how pervasive they can be in the lives of those with chronic illness.

6.1.2 Continued Uncertainty: Living with YOPD

Over time, the uncertainty experienced by individuals with YOPD in this study continued to manifest itself as a fear of future functional difficulties they could develop, especially in relation to swallowing and cognition, and becoming a burden on others. Beyond the uncertainty related to their future functioning, individuals also experienced uncertainty in their daily experiences with the disease as they experienced progression. These experiences were frequently described in terms of having ‘good days’ and ‘bad days,’ with it being difficult to anticipate when one would have a good or bad day. In these descriptions, the importance of feeling in control over their bodies was further illustrated, as ‘good days’ were categorized as days in which they felt greater control and were minimally impacted by the disease in their daily functioning. Apart from good and bad days, some participants also experienced functioning uncertainty throughout the course of each day with periods of alternating, ‘on’ or ‘off,’ function as a result of the limited duration of effect of the Parkinson’s medication as the disease progressed.

Conceptualizing ‘good days’ and ‘bad days’ according to perceived control is also described explicitly in Charmaz’s (1991) work entitled Good Days and Bad Days. More specifically, bad days were those that were more ‘intrusive’ in the lives of her participants, based on the presence and severity of symptoms that impacted on one’s daily functioning. Charmaz describes how “the kinds of activities possible, amount of productivity, degree of choice, and amount of control all figure heavily in evaluating the day” (p. 49). Furthermore, Charmaz
describes the type of day as ‘intertwined’ with the identities of individuals, in terms of “the self they recognize, acknowledge, and wish to be” (p.50). Thus, by individuals with YOPD defining the type of day according to perceptions of control and the intrusiveness of their symptoms, individuals were both valuing and recognizing a decline in their function and perceived control. Over time, as the disease progresses, Charmaz discusses how these criteria ‘shift downward’ in such a way that individuals adjust to a particular level of functioning and control. A ‘bad day’ in the early years of an illness can easily be measured as a ‘good day’ after having lived with a disease for many years and experienced progressive decline.

The power in Charmaz’s (1991) observation is that parts of one’s identity are redefined over time to support a more positive perception of oneself which, as already described, was a strategy used by individuals with YOPD in this study. Such a strategy also relates to Berger and Luckmann’s (1966) third type of socialization, i.e., alternation, where individuals are socialized into a new role that has a significant impact on their identity. Thus, for those living with YOPD in this study, the process of alternation and its legitimization is akin to the process of managing uncertainty, where adjustment to this changed identity took place over time. That is, in managing with the uncertainty caused by the disease, individuals adjusted first at a logical, or rational, level, and then continued to adjust emotionally over time as the disease progressed. Bodily experience living with the disease, combined with knowledge acquired related to the disease, served to legitimize this changed identity through these levels of adjustment.

With progression of the disease, and ongoing uncertainty related to future functioning, individuals also continued to experience uncertainty in relation to their identities. More specifically, this uncertainty was experienced in terms of the ability of participants to carry out their expected roles at work and with their families, as parents and spouses. Concern over such roles are well documented in research involving those with YOPD (Fontenla & Gould, 2003; Martikainen et al., 2006; Murphy et al., 2013; Schrag & Banks, 2006; Schrag et al., 2003). Pinder (1990a, 1992a) also describes explicitly how for her participants, the disease called into question “assumptions about sustaining roles within the family or at work” (1990a, p. 2) in a society that values independence (social, economic, physical), bringing about anxiety, fear and distress. This relationship between identity, independence
and employment is also discussed by those with Parkinson’s in Habermann’s (1996) research. She describes how:

“They struggled with issues related to productivity in society, financial dependence on their spouses, and loss of their identities as working persons … Work was seen as a measure of usefulness to society, and work was experienced as a measure of independence. Thus not working meant losing one's independence” (pp. 407-408).

Related to chronic illness more generally, Bury (1982) and Charmaz (1994, 1995) similarly described the importance of family and work roles in young- and middle-aged adults who participated in their research.

6.2 Identity and Functioning Nexus

The previous section has emphasized important aspects of the identities and functioning of individuals with YOPD, and other chronic illnesses, that became uncertain after diagnosis and as the disease progressed over time. Although I separated identity and functioning uncertainty into two distinct categories, much overlap between the two occurred. More specifically, at various points in the experiences of those with YOPD, there was a close connection, or nexus, between identity and functioning uncertainty.

The idea of a nexus between identity and functioning corresponds to greater emphasis on the body in the management of identity, in the context of contemporary consumer culture. Lupton (1994), for example, describes how corporations have leveraged commercial advertising to “valorize the glamour and eroticism of the physically active body” (p. 116). Consumer culture’s emphasis on the body has also created a preoccupation with fitness, which as Bauman (2001) describes, is problematic. More specifically, fitness is ambiguous and lacks an “upper limit” with a “never-to-be-reached horizon looming forever in the future” (p. 226). That is, in emphasizing fitness, consumer culture has created a preoccupation with a goal that can never be completely achieved. At the centre of this preoccupation is one’s body, which becomes objectified and worked on, in pursuit of this unachievable goal.
In analysing this *rise of the body*, Shilling (2007) describes how discussions of embodiment were ‘absently-present’ in foundational social science theory, but have become more overt because of socio-cultural developments of the 20th century. Beyond contemporary consumer culture and the rise of capitalism, Shilling also describes how the body has become part of contemporary discussions of identity because of: the growth of alternative health practices that promote bodily awareness, like yoga and Oriental health practices; ‘second wave’ feminism within a patriarchal society; advances in science and technology like the Human Genome Project; changes in national governance over health focussing on greater individual responsibility; and an academic interest in embodiment.

Within this research on YOPD, the identity-functioning nexus was most evident at the social level, i.e., social norms and social participation, where socio-cultural assumptions had the greatest influence, as illustrated in figure 6.1. These assumptions, and the experiences of those with YOPD, coincide with the contemporary emphasis on the body, where expectations for control over one’s body to carry out roles created uncertainty between one’s identity and functioning.

![Figure 6.1: Socio-cultural Assumptions and the Identity-Functioning Nexus](image-url)
In terms of social norms, particular levels of functioning were expected or considered ‘normal’ based on a person’s stage of life. For example, the functioning considered normal for a child is different than that considered normal for an adult, which is also different than that considered normal for an older adult. Beyond evidence for this socio-cultural assumption in the results of this research on YOPD, other research detailing age-related illness beliefs have already been described where illness has typically been seen as a normal part of older age and is abnormal when it occurs younger in life (Faircloth et al., 2004; Fontenla & Gould, 2003; Pound et al., 1998; Sanders et al., 2002; Singer, 1974). Young- and middle-age adults, instead of managing with illness, were supposed to be managing with work responsibilities and raising a family.

In terms of social participation, the various roles individuals played in life, such as employment and family roles, require a certain level of functioning to be able to perform. For example, if a person with YOPD was not able to walk or speak it would be difficult for a person to perform the role of police officer, and would also be difficult to participate in roles within one’s family as a young- or middle-aged adult; as was the case for Richard Secklin (2010), who is the author of a YOPD autobiography included in this study.

Berger and Luckmann (1966) also talked explicitly about this linkage between “organism and identity” (p. 165). Although not framed in the same way that functioning is defined within this research, they describe the interplay between the biology of humans and identity that occurs through the process of socialization. That is, in order to be socialized into, and maintain, roles that are normally associated with a specific stage of life, a certain level of functioning is required. Given this emphasis on the inter-relationship between identity and functioning, work on occupational identity and cultural beliefs is particularly informing, as many references have been made to socio-cultural assumptions influencing identity in chronic illness.

6.2.1 Occupational Identity and the Identity-Functioning Nexus

The term occupation refers to all of the activities that we do as human beings, often grouped according to three broad areas: activities of daily living, work and play (Kielhofner, 2002); or similarly, self-care, productivity and leisure (Unruh, Versnel, & Kerr, 2002). Occupational identity emerges through one’s previous engagement in occupations.
throughout life, as well as one’s desire for future participation in occupations (Kielhofner, 2002); and is representative of the collective aspects of one’s being, i.e., physical, affective, cognitive and spiritual, in performing occupations (Unruh et al., 2002). Further, occupational identity is enacted in, and is influenced by, the various aspects of an individual’s environment (Kielhofner, 2002; Unruh et al., 2002). Together, occupational identity conceptually forefronts the centrality of various types of occupational engagement, including role performance, relationships with others, values and perception, for the maintenance and negotiation of identity (Laliberte Rudman, 2002). Such a concept, then, helps to situate a discussion of the identity-functioning nexus, especially with respect to the influence of socio-cultural aspects of one’s environment in relation to identity and functioning.

Using Kluckhohn and Strodtbeck’s framework of cultural value orientations, Laliberte Rudman and Dennhardt (2008) illustrate how dominant Western cultural beliefs have influenced the construction of knowledge related to occupational identity. Focusing on four of these value orientations, including orientations to time, activity, relations and man-nature, Laliberte Rudman and Dennhardt describe constructions of occupational identity in terms of a “future orientation, achievement-based doing, individual choice, and mastery over nature” (p.159). More specifically, these orientations relate to a view of identity focused on individuals working towards a desired future, maintaining personal autonomy over their lives, overcoming difficulties imposed by ‘nature,’ including disease and disability, and having an orientation to attaining personal achievements. Although the purpose of their paper was to raise cultural consciousness in relation to conceptualizations of occupational identity, and how identity may be viewed differently in other cultures, their results also help to inform prevailing beliefs about the identity-functioning nexus within my Western-based research. More specifically, these same value orientations, representative of broader Western cultural beliefs, were embedded within how participants had constructed assumptions about their own identities as young- and middle-aged adults prior to their diagnoses with YOPD. That is, they were future orientated, they desired to maintain control over their functioning and identity as independent adults, and they had certain expectations for themselves, especially related to their work and family roles.

These same value orientations also permeated the other Western-based chronic illness literature that has been alluded to already in earlier parts of this section. The diagnosis of
YOPD caused a ‘disruption’ from these beliefs and assumptions, such that their future, independence, work and family roles and ability to maintain control in their lives were all threatened by the uncertainty they experience from the disease. Therefore, this uncertainty was a by-product of socio-cultural norms and expectations and is why, in many cases, the uncertainty occurred at the nexus between identity and functioning.

6.3 Adjustment and Patterns of Acquiring Health Information

The results of this research illustrate that participants’ desire for health information changed over time in relation to how they had adjusted to the disease, both logically and emotionally. These sub-processes of adjustment ranged on a continuum from greater denial to greater acceptance. Although there is some opposition to the use of a denial-acceptance framework in the chronic illness literature (e.g., Telford, Kralik, & Koch, 2006), it is important to note that such a framework within this research was ‘grounded’ in the illness experiences and biographies of those who took part in this study. More specifically, many participants and authors were drawn to the different ‘stages’ proposed by Elizabeth Kübler-Ross (1969) to understand and structure their experiences. Although it is possible that some health providers may have encouraged individuals to adopt this framework, as is a critique of Telford et al., this did not appear to be the case in my research. For example, many spoke of having learned about Kübler-Ross prior to the onset of their illness which they then utilized as part of their socio-cultural stock of knowledge to draw from in structuring their experiences with YOPD. Indeed, narrative theorists such as Gubrium and Holstein (2009), whose work is located in social constructionism, have argued that people draw upon broader discursive resources to make sense of and convey their experiences; thus, participants drew upon Kübler-Ross to make sense of their grief and convey how this had been experienced over time. Once I identified this structuring, I explored it further and categorized the ‘types’ of denial and acceptance that individuals spoke of in my interactions with them, and in their autobiographies. The idea that there are different types of acceptance in Parkinson’s disease is also supported by Pinder’s (1990a) research who described how “those patients who felt that they ‘accepted’ the situation were accepting the fact of having PD rather than accepting the various personal and social consequences of the illness” (p. 87). This type of distinction, then, is similar to the logical and emotional categories of denial and acceptance that I identified in this research.
During logical denial, individuals worked to protect themselves from the potential threat of the diagnosis by either avoiding health information related to Parkinson’s or trying to locate information, and second medical opinions, that would refute the original diagnosis. Although the amount of time any person would spend in logical denial varied, ultimately when the health information, the second opinions and their bodily experiences reinforced that they did indeed have YOPD, they were able to logically accept having the disease. Assessing oneself in relation to acquired health information was also discussed by participants with Parkinson’s disease in Pinder’s (1990a, 1990b) work, but this was not framed as being part of a process of adjusting to the disease. Similar to logical denial, emotional denial was also largely protective in nature, given the potential threat the disease represented to their identity and functioning into the future. Anger and depression were commonly reported by those experiencing emotional denial, and to manage with these emotions and avoid thinking about the threat posed by the disease, individuals employed emotional and social avoidance behaviours. This included working to avoid thoughts about the disease by ‘staying busy’ in their work and family lives, while at the same time ‘building walls’ around themselves to hide their difficulties from others. Health information seeking was also avoided during this time as it provided further reminder of the threat the disease posed to their futures.

Although previous Parkinson’s research has not looked specifically at the role of acquiring health information in the adjustment process, there is a body of research that has looked at coping strategies used by those with the disease in relation to various markers of health. Typically, this research has demonstrated greater rates of distress, like depression and anxiety, and poorer physical health in those who employ emotion-focused coping strategies like avoidance and distancing (Evans & Norman, 2009; Frazier, 2000; Moore & Seeney, 2007; Sanders-Dewey et al., 2001). Conversely, more problem-focused, or cognitive and behavioural strategies, such as information seeking, exercising and talking with others about the disease, have been associated with less distress (Ehmann, Beninger, Gawel, & Riopelle, 1990). Based on these findings, many of the researchers looking at this area have suggested encouraging patient education and HIS as a therapeutic strategy. However, the results of this research on YOPD suggest this strategy for therapy should not be used without first considering how each individual has adjusted to the disease. That is, depending on how a person has adjusted, their need and desire for information changes, and that this adjustment
process is highly personal. Thus, a global recommendation about providing patient education, and encouraging HIS, would not be appropriate.

Furthermore, although denial can be categorized as an emotion-focused strategy, many participants described denial as having served a ‘protective’ function for them in their experience with YOPD. More specifically, it allowed them to continue with their lives until: 1) there was enough evidence that they had YOPD, i.e., logical denial; and later 2) the disease impacted their life enough that they perceived a change needed to be made, i.e., emotional denial. Kübler-Ross (1969) and Kübler-Ross and Kessler (2005) also discuss the protective function of denial in research on grief, describing it “as a buffer after unexpected shocking news, [that] allows the patient to collect himself and, with time, mobilize other, less radical defenses” (1969, p. 52). Other research also suggests that avoidance towards health information, during periods of uncertainty, can also be functional for individuals, i.e., “an essential survival device” (Pinder, 1990a, p. 88) and, thus, would be “inappropriate to consider it maladaptive” (Afifi & Weiner, 2004, p. 183). Although avoidance behaviours may be associated with greater distress and poorer physical health in Parkinson’s disease, the association should not be interpreted to mean that such behaviours result in these outcomes. Instead, avoidance could be a means of managing with declines in health and greater distress, as would happen after a diagnosis and over time as the disease progresses. This latter interpretation is supported by the results of this research, where adjustment to YOPD is viewed as a process rather than an outcome.

Eventually, individuals with YOPD in this study came to reach a tipping point with their avoidance behaviours and viewed themselves at a ‘fork in the road’ of their lives. They could continue to deny the threat to their future, by continuing to avoid thoughts and information about the disease as well as social encounters, or they could start to take action against the disease. As has been described already, this action was often described in ‘combative’ terms, similar to previous Parkinson’s research (Pinder, 1990a, 1992a; M. J. Ravenek & Schneider, 2009). Health information sought during this time was used to provide strategies, and to develop a ‘plan,’ that would enable individuals to engage in this fight. Such information included various lifestyle management strategies, like exercise and nutritional information, in relation to the disease and maximizing treatment effectiveness. Using health information in this way allowed individuals to perceive greater control in their
experience with the disease. The importance of perceived control has been previously described in relation to adjusting to chronic illness (Fournier, de Ridder, & Bensing, 2002; Stanton, Revenson, & Tennen, 2007), and also in adjusting to Parkinson’s disease specifically (Dakof & Mendelsohn, 1989; Eccles, Murray, & Simpson, 2011; Eccles & Simpson, 2011; McQuillen, Licht, & Licht, 2003). In comparison to disease severity, greater psychosocial adjustment to Parkinson’s disease, measured on a scale assessing things like depression, attitude, locus of control and acceptance, has also been associated with higher levels of quality of life (Suzukamo, Ohbu, Kondo, Kohmoto, & Fukuhara, 2006).

Given Western cultural beliefs about ‘controlling’ one’s body (Laliberte Rudman & Dennhardt, 2008), it is not surprising that individuals with YOPD looked to health information about exercise and nutrition as a means to enact this control. Such beliefs are also rooted in contemporary discourse around individual responsibility for health (Fullagar, 2002; Rose, 2001). Within this discourse, health promotion policy has focussed on “enhancing the obligations that individuals and families have for monitoring and managing their own health [where] every citizen must now become an active partner in the drive for health, accepting their responsibility for securing their own well-being” (Rose, 2001, p. 6). Evidence for this shift can also be seen in greater emphasis on health risk and, more specifically, minimizing health risk and promoting awareness of individual risk factors for preventable health issues, including the importance of exercise and nutrition. In describing this discourse, Rose (2001) uses the term ethopolitics to refer to “the politics of life itself and how it should be lived” (p. 18). Broader research on HIS has also identified that information related to exercise and nutrition are among the most common topics sought out by Internet users in Canada (Underhill & McKeown, 2008) and in the United States (S. Fox & Jones, 2009).

The progressive nature of YOPD meant that working to maintain these control beliefs in their fight against the disease would be ongoing. More specifically, the emotional adjustment process was ongoing, shifting between periods of denial and acceptance in relation to the changes they experienced. In this way, for most individuals, HIS became less general over time and more geared to managing the specific difficulties they encountered in their experience with the disease. This pattern of seeking health information, i.e., from more general to more specific and practical information coinciding with bodily changes and
disease progression, has also previously been discussed in Parkinson’s research (Macht et al., 2003; Pinder, 1990a, 1990b; Williams, 2005) and research on other progressive neurological conditions (Baker, 1998; Hepworth et al., 2003; M. R. O'Brien, 2004).

The idea that adjustment to the loss and uncertainty brought about by chronic illness is ongoing, and highly individual, is well recognized in the literature (Charmaz, 1991, 1995; Eccles et al., 2011; Pinder, 1990a, 1990b; Sklar, 2007; Stanton et al., 2007). For example, Pinder (1990b) describes how “coming to terms” with Parkinson’s involved “many stops, starts, hesitations and even U-turns” (p. 89) for her participants. Even the work of Elizabeth Kübler-Ross (1969), in the way it was originally intended, portrays the different ‘stages’ of grief in response to loss as being ongoing and personal. In her final book, Kübler-Ross and Kessler (2005) describe how the different stages have been ‘misunderstood’ since their first publication.

“They have been very misunderstood over the past three decades. They were never meant to help tuck messy emotions into neat packages. They are responses to loss that many people have, but there is not a typical response to loss, as there is no typical loss. Our grief is as individual as our lives … They are tools to help us frame and identify what we may be feeling. But they are not stops on some linear timeline in grief. Not everyone goes through all of them or goes in a prescribed order” (p.7).

As has been described at the beginning of this section, individuals with YOPD were drawn to Kübler-Ross’ stages as a discursive means of structuring their experiences with the disease. Through this research, I worked with individuals to identify two different types of denial and acceptance, as well as other grief reactions, like anger and depression, which were individual to each person and occurred in an ongoing process of adjustment.

Although adjustment to Parkinson’s was ongoing for those with YOPD, it also became more difficult to make adjustments over time as one’s functioning declined. This type of difficulty has also been described by Dakof and Mendelsohn (1989), Eccles et al. (2011) and Pinder (1990a), especially in terms of one’s reluctance in giving up greater control to the disease over time. In her description of adapting to chronic illness, Charmaz (1991, 1995) attributes this difficulty to the ongoing conflict between one’s bodily experiences and his/her identity with the illness. In overcoming this conflict, individuals make ‘identity trade-offs’
over time as the disease progresses to try and preserve a positive perception of themselves. In this way, Charmaz describes how an individual comes to see him/herself as more than just their body and an illness. The challenge of incorporating a failed, dysfunctional, or disabled body into identity may be increasingly challenging with the rise of somatic culture, in which the body is proposed to be increasingly a central marker of identity (Lupton, 1994; Rose, 2001; Shilling, 2007). Such identity trade-offs for participants with YOPD in this study involved finding ways to engage in the Parkinson’s community that allowed them to find meaningful roles. These roles included things like advocacy work, fundraising and educating others which, in a way, allowed them to retain part of their previous employment roles they had given up. Through these trade-offs, they were able to maintain a positive perception of themselves, i.e., their identity, as the disease progressed over time.

Charmaz (1995) also makes an important temporal distinction between struggling against to later struggling with chronic illness, which is highly relevant to the distinction between emotional denial and emotional acceptance in this research. She describes first how young-and middle-aged adults can feel betrayed by their bodies after being diagnosed with a chronic illness and experiencing subsequent bodily changes. The diagnosis, and these changes, coincides with difficult emotional reactions, like anger and regret, in relation to a sense of lost control and mastery over their bodies. Thus, the emotional denial I identified in those living with YOPD is similar to this state identified by Charmaz in her participants, which precedes struggling against the illness. Similar to the combative language used in describing their experiences with YOPD, Charmaz describes how those who struggle against chronic illness “view their illness as the enemy with whom they must battle … [and] hope to regain their past identities” (p. 663). This type of combative attitude was representative of those working towards emotional acceptance, after having reached a tipping point with the negative emotions caused by their diagnoses and bodily changes over time.

In contrast, in struggling with illness, Charmaz (1995) describes how individuals desire control over their bodies to live as ‘normal’ lives possible. This change reflects greater acceptance rather than objectification of the body, along with greater monitoring of one’s body. Such a change is representative of the emotional acceptance described by those with YOPD in this research, where individuals made ongoing adjustments in their life to try and
maintain their sense of control and normalcy. Also, over time, as one emotionally adjusted to living with YOPD, greater emphasis was placed on using one’s body to filter knowledge acquired through other sources to make decisions that would support perceived control. Within this filtering process, as a feedback mechanism, individuals also monitored changes in their bodies prompting them to seek out specific information coinciding with those bodily changes. The ongoing nature of emotional adjustment, meant that at different times an individual may struggle against and struggle with their illness as they experienced progression of the disease.

An important difference to note in Charmaz’s (1995) description of adaptation to chronic illness is that participants in this study with YOPD did not reach a point of ‘surrender’ to the disease, or an “end of the quest for control over illness” (p.659). Individuals continued to push for control through making identity trade-offs. Charmaz emphasizes that this process of surrendering is not the same as ‘giving up,’ but was a way for her participants to resolve the conflict between body and identity once they felt they could no longer do anything to influence, or control, their experience with the disease. In this way, “they transcend their bodies as they surrender control. The self is of the body yet beyond it” (p. 675). Given that participants with YOPD who took part in this study had not reached a degree of progression where they were severely restricted with their functioning, it is possible that those who do experience such difficulty may reach a point of ‘surrender.’ Conversely, it is also possible that individuals with YOPD may never reach this point as Charmaz’s participants were primarily those with serious and intrusive illnesses that could lead to death. Charmaz’s description of this process also emphasizes the ‘flow’ in the transitioning to surrender, which is similar to the way age-related illness beliefs have been described (Faircloth et al., 2004; Pound et al., 1998; Sanders et al., 2002). As such, in addition to functioning and progression, the younger age of individuals and mortality characteristics of YOPD may also have been factors in not identifying such ‘surrender’ to the disease.

Finally, with respect to types of HIS research, the results of this study illustrate that the different ‘contexts’ of HIS behaviour discussed by Lambert and Loiselle (2007), are not necessarily distinct. In reviewing the HIS literature, they talked about how HIS was usually conducted in one of three contexts: in response to a health threat, to help make decisions, and for health promotion in relation to a threat. However, within the experience of
individuals living with YOPD, all three of these contexts were discussed at different times. More specifically, HIS may occur after the initial diagnosis as a way to logically adjust to the diagnosis, and over time an individual may use health information to help make treatment decisions and develop a plan for promoting their health during emotional adjustment. Limiting research to one specific context may miss important interactions that take place across these contexts, and that the same individual may act differently depending on how they have adjusted to living with a specific illness.

6.4 Strategies and Sources Used in Becoming Informed about Parkinson’s Disease

In describing the strategies and sources used in acquiring health information by individuals with YOPD, I drew the distinction between extant and elicited sources. Charmaz (2006) uses a similar distinction to describe different types of textual data that can be included in a research study. Finding this useful in categorizing types of information, I adapted it as a means of organizing types of information sources in this study. Drawing this distinction was helpful given the vast number of information sources reported by those in this research, as well as other studies investigating information seeking behaviour, and also proved useful when looking at patterns in how sources were accessed and used over time.

6.4.1 Extant Sources

Extant sources were those which provided information in a relatively static manner, published on a specific date and remained accessible over time with no further interaction between the source and the recipient. Examples of extant sources included static Internet pages, print sources like books, newsletters and pamphlets, and broadcast media including documentaries and television programs. Use of these types of sources are well documented in the HIS literature (e.g., Johnson & Case, 2012; Macht et al., 2003; Marrie et al., 2013; Williams, 2005). As the focus of this research was not just on active HIS but also how individuals acquired health information passively, it became apparent that family members and friends were sometimes involved in seeking out health information and then providing it to individuals. S. Fox and Rainie (2000) and S. Fox and Jones (2009) also describe how family members and friends of an individual with a health condition often seek out information for themselves and for the person affected by the condition. Furthermore, through watching television or listening to the radio, sometimes information related to
Parkinson’s was acquired without purposeful, active seeking. Depending on how an individual had adjusted to the disease, at times they were receptive to receiving extant information passively and at times they were not. Green (2003) and M. R. O'Brien (2004) have also discussed the ambivalence towards unsolicited information from print and broadcast media in those living with ALS. The specific ambivalence Green and O’Brien were speaking of was in relation to the high volume of information during this time, i.e., 2003-2004, about euthanasia for individuals with ALS in the United Kingdom. Although Parkinson’s disease is not a terminal diagnosis, as is ALS, this research supports the idea that the content of the information, in addition to the type of source providing it, are important to consider in relation to how an individual has adjusted to living with an illness.

6.4.2 Elicited Sources

Elicited sources, in contrast, were those that allowed for greater interaction between the individual and the source, were not limited to a specific date, and provided a means for personal questions to be asked of the source. Examples of elicited sources included various individuals like health care providers and other people living with Parkinson’s, various in-person groups like support groups, virtual groups like those on Facebook, and programs offered by Parkinson’s support organizations. These types of sources are also commonly discussed in the HIS literature (e.g., Johnson & Case, 2012; Macht et al., 2003; Marrie et al., 2013; Williams, 2005), with social media becoming more popular as a source of health information in recent years (S. Fox & Jones, 2009); a trend that is expected to continue. Resulting from the interactional nature of elicited sources, individuals were also impacted emotionally by these sources beyond just acquiring health information. Other research on group interactions, virtual and in-person, has also illustrated the emotional and informational nature of support shared by individuals living with a chronic illness (Burrows et al., 2000; Colineau & Paris, 2010; Cotten, 2001; Lustria et al., 2009; M. O'Brien, Dodd, & Bilney, 2008). For those with YOPD, sometimes these interactions were perceived to be beneficial, and sometimes they were not. For example, with respect to support groups and meeting other individuals living with Parkinson’s disease, individuals with YOPD in this study had a preference for interacting with others the same age. This type of age-preference in those living with YOPD was also described by Williams (2005), given the unique needs and concerns of those living with Parkinson’s at a younger age. Part of this preference was rooted in how individuals living with acquired elicited information passively.
In the case of elicited sources, information could be obtained passively through observing people living with chronic illness rather than actively engaging with them; especially other people living with Parkinson’s. Thus, social comparison was a primary mechanism by which information could be acquired passively from individual and group situations. Social comparison has long been recognized as a strategy for managing uncertainty (Festinger, 1954), especially in times when individuals perceive having reduced control over their lives in chronic illness (Arigo, Suls, & Smyth, 2012; Tennen, McKee, & Affleck, 2000). Social comparison has also been used as a strategy with respect to uncertainty about one’s identity in, and between, social groups (Hogg, 2000). The goal of these comparisons, then, is to reduce uncertainty about one’s functioning and identity, both of which were uses of social comparison by individuals with YOPD in this study. Although previous research has not studied social comparison specifically in the context of Parkinson’s disease, the phenomena has been recognized in studies involving those with the disease (e.g., Charlton & Barrow, 2002; Macht et al., 2003; Pinder, 1990a; M. J. Ravenek & Schneider, 2009). Of particular note, Pinder describes how individuals with Parkinson’s disease used social comparisons to try and return a perception of greater control to their lives. She describes the use of both positive and negative comparison to ‘referents,’ i.e., others with the disease, similar to the idea of making upward and downward comparisons in the social comparison literature (Arigo et al., 2012). Upward, or positive, comparisons provided a role model for individuals to look up to, and downward, or negative, comparisons were used to make individuals feel better about themselves by comparing their situation to someone with greater progression or more severe disability. With respect to upward comparisons, Pinder’s participants described looking up to Katherine Hepburn as a role model with the disease. Similarly, my participants reported looking up to Michael J. Fox for everything he has done for the Parkinson’s community. Although both of these examples are of celebrities, it is important to note that such comparisons are not limited to these types of referents, but the narrative of someone’s success living with the disease made it easier for such comparisons to be made. Pinder was correct to point out that negative comparisons were not a form of someone denying the disease, but a strategy to manage with the uncertainty and threat to their identity; further illustrating the intricate relationship between identity, functioning and adjustment.

Through social comparisons made in relation to others attending conferences and support groups, a number of individuals in this study spoke of the distress they experienced, and the
desire to create their own support groups for those with YOPD, or to attend YOPD-specific conferences. Beyond age, individuals with YOPD became distressed by observing those with more advanced symptoms. A similar finding, with respect to observing the disability level of support group members, is also discussed by Charlton and Barrow (2002) in contrasting characteristics of those who attended Parkinson’s support groups with those who chose not to attend the groups. Therefore, downward comparisons may produce a positive perception of oneself in relation to others with the disease, but such a positive perception does not mean that he/she will want to associate with those individuals in a group setting. The likely reason for this was seeing individuals at advanced stages, especially for younger individuals, not only created identity uncertainty in relation to age-beliefs about Parkinson’s disease, but also contributed to a greater fear of the future. More specifically, this fear was increased because seeing individuals with advanced progression provided evidence of the potential disability that could result, and that their own future functioning was largely uncertain. Thus, social comparisons are more complex when age-related beliefs about the disease are added to uncertain beliefs about future functioning in those with YOPD.

Over time, individuals with YOPD started to rely more on elicited sources for their health information, because of the difficulty they perceived in being able to obtain the specific information they desired through extant sources. Williams (2005) also described how elicited sources, including physicians, specialist nurses, other people living with Parkinson’s, and family and friends, were also perceived to be more helpful than extant sources like broadcast media and informational DVDs. To gain access to more elicited sources related to Parkinson’s, however, individuals needed to disclose their diagnoses to others. Thus, the importance of adjustment in relation to accessing health information is again illustrated, as disclosing more openly to others was characteristic of an individual who was emotionally adjusting to the disease and moving towards a degree of emotional acceptance. Indeed, disclosing to others is another ‘dilemma’ that Charmaz (1991) speaks of in her research on chronic illness. When paced over time, Charmaz believes disclosing is a means of maintaining control over one’s identity and emotions. She also differentiates this type of ‘protective disclosing’ from more ‘spontaneous disclosing’ that can occur when a person has not incorporated the idea of having the illness into his/her identity. Such disclosing was discussed by a limited number of individuals with YOPD in this study, and this usually occurred in the short period after diagnosis during logical denial. Once an individual with
YOPD had logically accepted the diagnosis, they moved to the more protective disclosing as a means of exerting control over how they were perceived by others.

Haines et al. (2006) also found that the most common concern, among a mixed sample of individuals with young- and later-onset Parkinson’s disease, in disclosing to others was related to how they perceived they would be viewed by others, i.e., issues of identity. Similar to the results of this research on YOPD, Haines et al. found that individuals disclosed in a relatively hierarchical manner, where 90% disclosed to their family members within the first year while 25% waited a year or longer to disclose at work. Furthermore, younger individuals who were employed were more likely than others to wait longer before disclosing to others. Regardless of how long it took individuals to disclose, Haines et al. describe how after disclosing almost all individuals reported being positively supported by those they told. Thus, similar to this research on YOPD, disclosing was a means of accessing greater support, including informational support, over time as one emotionally adjusted to the uncertainty and disclosed to others.

6.4.3 Recalled Knowledge

In accumulating a base of knowledge about YOPD, individuals in this study relied on recalled knowledge they had about the disease prior to their diagnoses, in addition to the information they acquired afterward from extant and elicited sources. This recalled knowledge came from a variety of sources, including formal education like medical school or nursing programs, the media with a particular emphasis on knowledge related to Michael J. Fox, family members or friends with Parkinson’s, as well as any preliminary HIS they had conducted prior to their formal diagnoses. Baker (1996) also described how individuals with MS had an existing base of knowledge prior to their diagnoses if they had a family member living with the disease, or if they had worked in the medical field. Seeking out health information prior to a formal diagnosis to collect information about potential diagnoses has also been reported as a common use of health information sought online (S. Fox & Rainie, 2000; Hay et al., 2008; Marrie et al., 2013).

The degree to which a person was knowledgeable about Parkinson’s prior to their diagnosis of YOPD appeared to influence the use of elicited and extant sources after their diagnosis; however, this depended on the way in which the prior knowledge was perceived. For
example, those with formal education about the disease often did not feel the need or desire to consult as many extant sources because of their existing general knowledge base about the disease. Furthermore, those with friends and/or relatives living with Parkinson’s used social comparison to try and predict the means by which the disease would progress and how it would affect their own lives. In cases where this comparison provided a positive image of the disease, i.e., slow progression and minimal impact, it helped with one’s adjustment and desire to seek out health information. In contrast, when this comparison provided a negative image, i.e., fast progression and significant impact, it hampered a person’s initial adjustment to the disease and HIS. Faircloth et al. (2004) found that in those with prior knowledge of stroke before experiencing a stroke, the impact of the difficulties they experienced were minimized; however, Faircloth et al. were emphasizing the ‘flow’ that such knowledge contributed, especially related to age-beliefs about illness, as opposed to its potential for greater ‘disruption’. That is, older adults experiencing stroke used knowledge about stroke to reinforce more natural beliefs about illness and the aging process. Thus, this research involving those with YOPD helps to illustrate that an individual’s existing base of health knowledge on a topic can have a significant impact on their post-diagnosis HIS, influenced by one’s perception of the knowledge and the extent to which it hampered or facilitated adjustment to living with the disease. This speaks to the importance described by Stanton et al. (2007) in identifying pre-morbid influences on adjustment to chronic illness.

6.5 Embodied Learning

Beyond extant and elicited information sources, and recalled knowledge, individuals also relied on their own bodily experience living with the disease as a means to ‘filter’ the knowledge they had accumulated. This was often described in terms of ‘experimenting’ and using ‘trial and error,’ and also occurred through a process of personal reflection, or self-comparison, in terms of the degree to which the disease had progressed. The outcome from this ‘filtering’ process was personally relevant, or ‘experiential knowledge,’ which also directed subsequent HIS related to their own personal situation and experience with the disease. For example, if specific exercises or medication regimens were perceived to improve their bodily experience, they were continued. If this didn’t result in an improvement, however, or if the disease progressed and a change in their functioning was perceived, additional information seeking and filtering occurred. In this example, different exercises or medication dosage and timing, or different strategies altogether would be used.
Bury (1982) also describes how uncertainty in chronic illness often “throws individuals back on their own stock of knowledge and biographical experience” (p.174). That is, uncertainty creates a situation where individuals come to rely more on their own bodily experiences, and knowledge learned from these experiences, to reduce uncertainty.

The value of using one’s body in learning about managing with the uncertainty of Parkinson’s disease is also talked about explicitly by Habermann (1996), where individuals turned to their bodies as knowledge sources because of the limits of extant sources, or ‘book knowledge.’ In other words, they couldn’t find out what they desired from extant sources, or even care providers, and, thus, turned to their own bodies as a means to personalize knowledge about the disease. Also similar to those with YOPD in this study, Habermann’s participants developed experiential knowledge related to managing their medications and their lifestyle, e.g., diet and activity, in ways to maximize their functioning throughout the day. Unfortunately, this type of knowledge wasn’t perceived to be valued by care providers, making those with Parkinson’s disease feel as if they were ‘cheating’ or ‘lying’ to them by making changes based on their personal experiences. This contrasts with the results of Pinder’s (1990a, 1990b) study, and this research on YOPD, where experiential knowledge was described as being valued by physicians who often provided parameters within which individuals could make adjustments to their medications as they needed.

Habermann (1996) also discusses how her participants were vigilant with ‘bodily monitoring’ in such a way that they were very aware of subtle changes with their symptoms and progression of the disease. Again, the uncertain nature of the progression of Parkinson’s disease prompted individuals to focus more on their bodies to try and identify when changes were occurring. Such vigilance was also described by participants with YOPD in this study, especially with respect to making self-comparisons of their progression over time. Charmaz (1991, 1995) discusses this in terms of a ‘dialectical self’ that develops with uncertainty in chronic illness, where individuals have “a heightened awareness of one’s body” and the belief that they can “perceive nuances of physical changes” (1991, p. 70). Charmaz sees this as part of the process of adapting to a chronic illness, and that “comparing their present body with their past body” (1995, p. 662) is part of experiencing a chronic illness. When these self-comparisons create a perception that the body has changed, it creates a tension between one’s body and his/her identity. Individuals view this change as a reduction in their
perceived control over their body and, as a result, may objectify their body in an effort to take back some of the control perceived to be lost. Important in these perceptions are socio-cultural beliefs for appearance and function, as well as health promotion policy designed, in essence, to promote such bodily vigilance (Bauman, 2001; Lupton, 1994; Rose, 2001; Shilling, 2007). Thus, it is not surprising that individuals with YOPD turned to their medication and lifestyle regimens, like exercise, nutrition and time management, where the body was used to try and maximize their functioning and to maintain their social roles.

The importance of one’s individual bodily experience in illness is also discussed by Frank (2013), viewing narratives of the body in illness as being increasingly common with the dissatisfaction associated with paternalistic medicine. Similar to what has been discussed in the section, Frank has also talked about the body objectification process in the context of illness, and the desire for control over one’s body, especially in relation to social standards, as two of the ‘types’ of bodies that individuals describe in their illness narratives. More specifically, he describes these body types as ‘the disciplined body’ and the ‘mirroring body.’ The disciplined body is focused on control and predictability through regimentation, and the body becomes objectified as ‘it.’ The mirroring body is focused on ‘mirroring’ images of others’ bodies that are healthier, creating a desire to be like those other bodies. Similar to the disciplined body, the mirroring body also seeks predictability, but instead of performance is a desire for predictability over appearance. Thus, the importance of social standards in how the body is viewed is emphasized. Frank’s description of the mirroring body also relates well to the idea of upward comparison, or the use of models, in the context of chronic illness research. When individuals with YOPD observed someone else with the disease doing well, they were often intrigued about what that person was doing and had a desire to ‘mirror’ them. More specifically, the experimental knowledge developed by those over time to maximize functioning, especially in relation to specific difficulties, are often sought out as an elicited source of health information. Macht et al. (2003) and Williams (2005), for example, both describe how acquiring experimental knowledge from others living with the disease is often among the most valued of health information sources. Likewise, in this research on YOPD, individuals discussed valuing practical, experience-based, information from others as sometimes even being more valuable than information they receive from physicians.
6.6 A Logic of Care: Implications for Care Providers and Patient Education Program Design

The idea of a tension existing between logics of care and choice discussed by Mol (2008) and Henwood et al. (2011) was supported by the results of this research on YOPD. More specifically, participants and authors expressed a need for a logic of care, i.e., for greater emotional help after their diagnoses instead of just information about the disease and their treatment options. The latter is more reminiscent of a consumeristic approach to health care, representative of a logic of choice. As Henwood et al. describe, information and care are “inextricably - if uneasily - linked” (p. 2028) and that there is a need to “inform with care” (p. 2030) where health information, in combination with the emotional needs of the patient, are considered together. Also emphasized in a logic of care, as individuals adjusted to living with YOPD over time they desired specific, and personally relevant, information related to Parkinson’s. Given the difficulty in obtaining this information from extant sources, and the static nature of extant sources, individuals drew more on elicited sources, including others living with Parkinson’s, and their own bodily experiences, to address their individual needs. Thus, similar to Mol and Henwood et al., although individuals in this study may have been socialized into a health care system focusing on empowerment through choice and information, i.e., a logic of choice, they desired treatment based on a logic of care. Hepworth et al. (2003) and Williams (2005) have also described the importance for physicians to provide information with care after telling a patient they have a progressive neurological disease.

This logic, i.e., that individuals desire personalized care and care that considers their physical and emotional needs, has long been recognized by researchers. For example, Elizabeth Kübler-Ross (1969) describes that “if we could teach our students the value of science and technology simultaneously with the art and science of inter-human relationships, of human and total patient-care, it would be real progress” (p. 31). Given that more than 30 years have passed since Kübler-Ross first published this passage, and that individuals living with illness today are still desiring greater care from their physicians, there is still more work to be done. In helping to create ‘progress’ on this front, the results of this research on YOPD provide a framework in working to better understand the experiences of those with YOPD, and in the process can help to better enact a logic of care.
Individuals with chronic illness still desire to receive information from their physicians, even if they do search for health information on their own (Cotten & Gupta, 2004; Henwood et al., 2003; Sillence et al., 2007). This resonates with comments from individuals with YOPD in this study, many of whom were disappointed that they were mainly told about the disease and not about how to manage with their emotions after the diagnosis. Even more specific than their emotions, physicians need to understand and acknowledge the uncertainty that results for their patients after giving a diagnosis like YOPD (Mishel, 1990). Indeed, Aujoulat, Marcolongo, Bonadiman, and Deccache (2008) describe how aspects of identity and control are often overlooked in empowerment discourse, but nonetheless are important in the management of illness.

According to Pinder (1990a, 1992a, 1992b, 1993), the differences in how patients and physicians manage with uncertainty about Parkinson’s disease can bring about miscommunication, believing that it is necessary to openly discuss the uncertainty in a positive way to foster the patient-physician relationship. Discussing uncertainty with individuals living with Parkinson’s disease will help to identify areas where health care professionals can provide more nuanced care for individuals; as in a logic of care. In discussing this uncertainty, it will also be important for physicians to understand and discuss the information seeking behaviours of their patients (Anker et al., 2011; Bischoff & Kelley, 1999; Morahan-Martin, 2004); as this information can provide insight into how they are adjusting to the illness and can also facilitate opportunities for physicians to provide specific help that their patients desire. Furthermore, physicians need to acknowledge the role that experiential knowledge plays in helping individuals with YOPD maintain a sense of control in their lives; and should encourage opportunities for such knowledge to be generated, given its highly personal nature in helping individuals to maximize function and control. Such an approach would help to provide hope to individuals, which as Groopman (2004) describes in his book *The Anatomy of Hope*, is closely linked with perceptions of control:

“Hope can only arrive when you recognize that there are options and you have genuine choices. Hope can flourish only when you believe that what you do can make a difference, that your actions can bring a future different from the present. To have hope, then, is to acquire a belief in your ability to have some control over your
circumstances. You are no longer entirely at the mercy of forces outside yourself” (p. 26).

In reviewing the literature of chronic illness adjustment, Stanton et al. (2007) describe the need for such research to focus on translating findings into interventions. As a means to help move closer to incorporating the findings of this research into interventions for those with YOPD, I provide commentary on changes that might prove useful for patient education programs for those with YOPD. I also discuss two booklets that were generated out of this research with participants, as a means to help those newly diagnosed with the disease and physicians. These booklets will be the focus of subsequent research on YOPD that I will conduct in the near future.

6.6.1 Patient Education Programs

As described in chapter one of this dissertation, patient education programs for individuals living with Parkinson’s disease have yielded conflicting findings, sometimes illustrating positive outcomes, sometimes not showing any differences from control groups, and at least in one study showing a negative outcome for participants (see table 1.1). In an effort to try and improve patient education programs for those with YOPD in the future, this research has illustrated two important points with respect to the design of such programs.

First, health information should be provided with consideration of how each person has adjusted to living with the disease. More specifically, this research has illustrated that at specific points in the adjustment process, a person may not desire any health information and, thus, such a program will likely not be useful. Furthermore, the needs of individuals with YOPD in this study became more specific over time to concerns they were experiencing in their own lives. Accordingly, education programs for individuals with YOPD would benefit from being more tailored to individual needs rather than the provision of standardized health information. These recommendations further emphasize the need to inform with care, instead of assuming that individuals, or consumers, are always empowered through the provision of information in a logic of choice.

A second insight from the results of this research, in relation to patient education programs, is the nature in which they are structured. As described in chapter one, the Parkinson’s education programs completed to date combined younger and older individuals living with
Parkinson’s into the same group. In some cases, these interventions involved the group coming together in a formal classroom setting. The results of this study suggest that would not be wise to do in cases where individuals with YOPD are involved. Many of the participants expressed a desire to be in groups with other younger people living with Parkinson’s disease, instead of being in mixed groups which can contribute to the identity and functioning uncertainty they experience.

6.6.2 Advice Booklets

To assist those with some of the emotional issues that can occur after receiving the diagnosis, and the unique issues faced by those with YOPD, I worked with participants to develop two advice booklets. Similar to the results of Williams (2005), participants in this study wanted to receive a booklet from their physicians after the diagnosis in order to ‘anchor’ them once they got home, and in the days and weeks afterward. At the conclusion of the interviews in the early stages of data collection, participants were asked specifically what advice they would give to someone newly diagnosed with the disease, as well as what advice they would give to a diagnosing physician. Additionally, the focus group and interview participants in the later stages of this project reviewed the advice compiled and added to this knowledge base with their own thoughts and experiences. These booklets represent the collective voice of the participants with YOPD who took part in this study, in combination with my voice as the researcher.

The first booklet I created with participants is entitled *YOPD: Advice for Those Newly Diagnosed From Individuals Currently Living with YOPD* (see Appendix L). This booklet is designed as a tool for physicians to give to their newly diagnosed patients as an alternative to more medically based print sources, which are not always meeting the immediate needs of patients. The purpose of the booklet is to try and reduce some of the uncertainty that individuals might experience, in relation to their identity and functioning. Believing that it is better to be proactive in managing this uncertainty to perceive greater control in their lives, participants provided advice on a number of topics they felt were important for those newly diagnosed to consider. For example, it describes strategies that individuals can use related to their work and family lives, if they perceive uncertainty with respect to these areas. It also provides tools that individuals can use to track their questions, and bodily changes they experience over time, to facilitate communication with their physician. Given that there is a
need to help the public better evaluate the quality of health information (Anker et al., 2011), and that participants sometimes questioned the quality of information they found, the booklet contains some strategies for assessing the quality of online health information. It also provides a list of online resources that participants found useful in their experiences, of which contain information related to Parkinson’s disease from credible organizations.

The second advice booklet I created with participants is entitled *YOPD: Advice for Physicians From Individuals Living With YOPD* (see Appendix M). The booklet is designed specifically for physicians responsible for diagnosing and treating those with YOPD. The purposes of this booklet are to help bring more attention to the emotional issues that can arise after the YOPD diagnosis, and describe how participants felt the physician can help. In other words, this booklet represents how participants thought that physicians could better enact a logic of care with individuals living with YOPD. For example, the booklet describes the importance of following-up with individuals after giving a diagnosis, and how they can help to provide hope and foster control beliefs, through the information they provide. That is, it is designed to help physicians to think about ways they can inform with care.

Both booklets are currently being prepared for public dissemination, so that the maximum number of people can benefit from the advice participants in this study had for those newly diagnosed and for physicians. Subsequent research on these booklets will involve gathering feedback from those who access them after their diagnoses, others currently living with YOPD, and physicians from across Canada. Such continued feedback over time will allow additional versions of these booklets to be made, with perhaps specific emphases for particular regions of Canada, while also being sensitive to changing needs of those with YOPD.

### 6.7 Other Resilience Strategies

Outside of this research, resilience has been described as an ambiguous concept, with many different definitions and ‘types’ existing in the literature including, for example, physiological resilience and spiritual resilience (Allen, Haley, Harris, Fowler, & Pruthi, 2011). Grounded within the collective experiences of those living with YOPD in this study, resilience was defined as an individual’s defense to elements in his/her life posing a threat to emotional well-being, i.e., the uncertainty caused by YOPD and the resulting loss of control
perceived. This defense could be bolstered through the use of various strategies to try and regain a sense of control in their lives. Learning about Parkinson’s disease, through the accumulation and filtering of knowledge, was one of these strategies. However, in coming to understand how individuals learned about Parkinson’s disease, and the role that it played, a number of other resilience strategies were also identified. These strategies were organized as either being internal or external, where internal strategies involved individuals changing various perspectives and beliefs they held, and external strategies were more behavioural and involved changes individuals made in their interactions with others. Bury (1982) also talks about how the uncertainty from living with a chronic illness can lead to the “mobilisation of resources” (p. 170), both internal and external to a person. Similarly, Mishel (1990) describes how individuals often redefine their priorities and life perspectives when faced with uncertainty resulting from illness. In this way, the different resilience strategies identified in this research, worked to produce the same outcome as those identified by Bury and Mishel where uncertainty would be reduced. In reviewing the literature related to resilience, Trivedi, Bosworth, and Jackson (2011) point out a number of problems with how the concept has been conceptualized in relation to the experiences of those living with chronic illness. More specifically, they describe how resilience is often referred to as a trait that pre-exists in an individual before the onset of a stressor. Additionally, existing conceptualizations don’t consider that individuals can recover from emotional stress, and that stress can be additive and weigh on one’s resilience over time, e.g., experiencing progressive functional loss. Seeing resilience as more of a continuum, Trivedi et al. describe how “individuals exist in a state of equilibrium and that resilience is the process through which individuals maintain or regain equilibrium over time” (p. 185). In this way, resilience is conceptualized as being more dynamic, where individuals are motivated to return to equilibrium, similar to how it was constructed in this research on YOPD with respect to one’s motivation to minimize uncertainty and regain perceived control. This description of resilience, in terms of equilibrium, is also particularly well suited to a symbolic interactionist perspective, where human action is seen as starting from an impulse that has disrupted one’s sense of equilibrium leading to a feeling of discomfort that creates a need to restore the equilibrium (Charon, 2010). In line with a shift in the chronic illness adjustment literature identified by de Ridder, Geenen, Kuijer, and van Middendorp (2008), this section discusses some of the other strategies used by individuals with YOPD to
build their resilience in an effort to take back some of the control they perceived to have lost in their lives from the uncertainty caused by the disease.

6.7.1 Internal Resilience Strategies

Social comparison has already been discussed in the context of this research, especially as a means of passively acquiring health information from elicited sources, and comparing one’s own disease progression across different time-points. However, social comparison was also used in the context of constructing an illness hierarchy to build resilience to the uncertainty caused by the disease. Within this hierarchy, Parkinson’s disease was perceived by participants to be less serious of a threat than other diseases, like MS and ALS, using disability and mortality as the parameters for constructing this hierarchy. Social comparison, and specifically making ‘downward comparisons,’ where individuals perceive themselves and their situation more favourably, has been previously described as an emotion focused strategy for managing uncertainty (Tennen et al., 2000), especially for those with progressive health conditions (Arigo et al., 2012). This illness hierarchy, then, is an extension of making downward social comparisons. It is interesting that Pinder (1988, 1990a, 1992a) describes how physicians, in managing their own uncertainty related to treating those with Parkinson’s, often used this same hierarchy. Although it was not clear from Pinder’s description whether or not this hierarchy was shared with patients, as it was by physicians with some participants with YOPD in this study, it was similarly premised on issues of disability and mortality. The idea that both physicians and patients with YOPD came to construct the same illness hierarchy, across time zones and time periods, provides further support for the strong influence of Western cultural values, especially of bodily control and independence (Frank, 2013; Laliberte Rudman & Dennhardt, 2008), in the illness narratives of individuals in these countries.

Also rooted in Western cultural beliefs is the value that individuals place on the importance of the future in their perspective of time (Laliberte Rudman & Dennhardt, 2008). Through experiencing YOPD, however, individuals in this study came to develop a fear of the future in relation to one’s uncertain future functioning and identity. To minimize this uncertainty, and fear, individuals changed their perspective of time to become more focused on the present compared to the future. That is, individuals could perceive greater control in their lives if they focused on each day, as opposed to the future which was uncertain. This change
in time perspective, i.e., from the future to the present, is also described by others in the chronic illness and Parkinson’s disease literature. For example, participants with Parkinson’s disease in the work of Pinder (1990a) and Habermann (1996) also described this shift in time perspective from the future to the present, because of the uncertainty associated with the future. Investigating some of the more positive aspects of living with illness, Sklar (2007) has described the development of a new appreciation for time, and a focus on the present, as one of the ‘gifts’ that are sometimes described by those living with illness. Furthermore, Charmaz (1991, 1994) describes how the uncertainty resulting from chronic illness can cause individuals to develop “a resolve to live in the present” (1994, p. 275). According to Charmaz, this present focus, or ‘living one day at a time,’ is a way that individuals with chronic illness manage their identity in light of future uncertainty, as “it gives a sense of control over one's actions and, by extension, a sense of control over self and situation” (1991, p. 178). Charmaz contrasts this time perspective with ‘existing from day to day,’ which she describes occurring in individuals who have lost a belief in having control in their lives with illness. She describes this perspective as being common in those with more advanced progression or severe illness, and is also impacted by socioeconomic status where those living in poverty are more likely to describe this time perspective. This distinction was not described by those with YOPD in this study, but will be important for future research to investigate, especially considering that the majority of participants in this study were higher functioning and were of higher socioeconomic status.

A third internal strategy used by some of the individuals with YOPD in this study was to draw on their spirituality as a source of resilience in managing with the uncertainty caused by the disease. In referring to this strategy as spirituality, it acknowledges the broader, multidimensional and existential, perspectives that individuals may hold, beyond just religion, to manage with their illness (O'Neill & Kenny, 1998; Riley et al., 1998). For example, participants with YOPD in this study often described their spirituality in relation to beliefs in an afterlife, as a means to regain a sense of control in their lives. Through these beliefs, individuals were able to minimize the impact of the disease, seeing it as only part of their bodies and not their souls. Groopman (2004) also describes how belief in an afterlife can help individuals with illness retain a sense of hope and control in their lives with illness. Previous research has also identified the importance of spirituality in adjusting to uncertainty caused by chronic illness (Landis, 1996; McNulty, Livneh, & Wilson, 2004; Riley et al.,
It is important to note that not all participants, or authors, with YOPD drew on spiritual beliefs as a way to manage with the uncertainty caused by the disease. Instead, it was one of several different resilience strategies available to, and used by, individuals in an effort to restore their ‘equilibrium,’ or sense of control, in their lives.

### 6.7.2 External Resilience Strategies

From painting, poetry and other forms of writing, various creative forms of expression have often been observed in those living with Parkinson’s disease (Inzelberg, 2013). Although Inzelberg describes this increased creativity as possibly resulting from treatment with levodopa and dopamine agonists, vis-à-vis a dopamine-creativity hypothesis, not all individuals treated with such medication develop a creative drive or creative talents. Instead, within this research on YOPD, creative expressions were viewed as a strategy that some individuals used to build their resilience to the uncertainty caused by the disease. Participants spoke of using their creativity as a way to express their feelings to others, and to try also help others living with the disease. Indeed, many of the autobiographies that were included as sources of data in this research had descriptions by the authors of the hope that the books would help others affected by the disease. The mere fact that so many individuals with chronic illness, including Parkinson’s disease, are now writing books and poetry about their illness experiences also speaks to the greater emphasis on the value of one’s bodily experience compared to previous historical periods (Frank, 2013). However, beyond writing books and poetry, advances in technology are also allowing those living with Parkinson’s disease to express their creativity in other forms.

Reflecting on my experience attending the World Parkinson Congress (WPC) in Montreal, Canada in October of 2013, I can see that there is a growing interest and role in creative expressions of those living with Parkinson’s disease. Part of this increased role came from the WPC holding opportunities like a video competition to give those living with the disease the space to create a video to describe their own experiences; and part of this also came from several documentaries that were showcased at the WPC. These short-videos and documentaries were primarily based on and/or completed by younger people living with Parkinson’s. For example, the winning video in 2013 entitled *Smaller: A Poem About Parkinson’s* by Andy McDowell, is based on a poem that Andy wrote to his young children to describe the impact of the disease on his life, after being diagnosed at age 43. The film
can still be viewed by searching the title on YouTube, along with many of the other videos submitted to the competition. A popular documentary shown at the 2013 WPC was *The Astronaut’s Secret*, which detailed Rich Clifford’s experience being diagnosed with Parkinson’s at age 42, but who continued to work as a NASA astronaut for several years without publicly sharing his diagnosis. The WPC video competition and documentaries provided a creative outlet for people living with Parkinson’s to share their experiences in a public space that was mutually appreciated by creators and viewers, all having an interest in Parkinson’s disease. Similar to autobiographies, these broadcast medias offer an opportunity for people with Parkinson’s disease to relate to the experiences of others living with the same disease, while also engaging their creative side. Given the digital-world in which we currently live, it is not unreasonable to think that many people with YOPD diagnosed now and in the future will continue to view these videos and use them as sources of information.

In trying to improve their resilience in living with YOPD, individuals also spoke of both ‘pruning’ and ‘drawing on’ various relationships in their lives to maximize their social supports. Those relationships that were deemed to be counter-supportive were ended, or ‘pruned,’ and those that had the potential to add to one’s resilience were strengthened and new ones were added. The importance of social support is well identified in the chronic illness literature, as a means for individuals to manage with, and adjust to, living with a chronic illness (e.g., Gallant, 2003; Stanton et al., 2007; Trivedi et al., 2011); and has also been specifically discussed in relation to Parkinson’s disease (Backer, 2000; M. J. Ravenek & Schneider, 2009; Simpson, Haines, Lekwuwa, Wardle, & Crawford, 2006). However, more of an emphasis in this literature is placed on the additions individuals make to their support networks, as opposed to effort to remove negative relationships from their lives. In controlling which relationships would remain, or become, a part of individuals’ lives with YOPD, they were better able to manage with the uncertainty caused by the disease. In moving towards emotional acceptance, many individuals also took on roles in the Parkinson’s community to help others affected by the disease. This type of behaviour has also been described by A. M. Lee and Poole (2005) where individuals with chronic illness became educators or advocates as a way to find meaning and benefit out of their illness experiences. Such roles also helped individuals with YOPD manage with the identity uncertainty they experienced, especially when these roles helped them to maintain aspects of the roles they had given up because of the disease. Indeed, Sklar (2007) discusses this type
of altruistic behaviour as another ‘gift’ sometimes perceived in the experiences of those living with illness, where “by helping others, they were able to better integrate the illness into their own lives” (p. 176).

6.8 Reflections on Quality

As presented in the methodology and methods chapter, and introduced when I located myself within this research, understanding quality in qualitative research is something I have been cognizant of since I began my doctoral studies. Having developed this understanding (M. J. Ravenek & Laliberte Rudman, 2013), I conducted this research with an appreciation for how I could work to achieve quality by paying attention to particular areas of emphasis throughout the research process. In the sections below, I discuss each of these areas in the context of the research I have conducted.

6.8.1 Social Value and Significance of the Research

The value and significance of conducting this research was established in the introduction and literature review, with respect to the unique needs and concerns of those living with YOPD in a time when neurological illness is becoming increasingly common. Changing population demographics, combined with increases in life expectancy, have contributed to this surge in neurological disease for which the WHO (2006) believes the health care systems of countries around the world are not prepared to handle. Of particular note, the WHO recognizes the need for greater knowledge related to the provision of care for individuals with neurological disease, like Parkinson’s disease. Furthermore, limited work has been completed on the information needs of those living with YOPD, combined with a need to better understand patterns of information seeking in those living with chronic illnesses where qualitative research is particularly valuable.

This research contributes to the understanding of the process of HIS in those with YOPD by recognizing its place in relation to how individuals have adjusted to living with the disease; and, in particular, how they have adjusted to the uncertainty they experience in relation to their functioning and identities. Additionally, it provides a framework for understanding the variety of ways that individuals come to be informed about Parkinson’s disease, beyond the active means of seeking out health information. More specifically, it highlights the importance of prior knowledge about the disease, the passive means by which information
can be acquired, and how individuals filter knowledge they accumulate through their bodily experiences with the disease. In a culture that emphasizes consumerism and choice in health care, the results of this study help to illustrate the problems with this logic in the needs of those diagnosed with YOPD. That is, there is a need for care providers to inform with care, taking into account the emotional reactions of individuals, as well as their specific needs for information over time in relation to how they have adjusted to living with the disease. Together with this theory of how individuals with YOPD manage uncertainty, advice booklets developed out of this research seek to help individuals and physicians work together in managing with the emotions and some of the potential issues that can arise after a diagnosis of YOPD.

6.8.2 Thoroughness of Data Collection and Interpretation

In constructing this grounded theory, a great deal of data were collected from a variety of sources using diverse methods. More specifically, this grounded theory represents the collective experience of 39 individuals living with YOPD, in addition to the experiences of 14 individuals with the disease who have published their own autobiographies. In collecting data from study participants, five focus groups, and 47 in-depth interviews were conducted, in addition to a private online discussion board. Such diversity in opportunities to participate was a recommendation of those who took part in the formative cycle of data collection, emphasizing the importance of providing choices to participate. Such an approach was also necessary, given the difficulty that can be experienced in trying to recruit individuals with YOPD to participate in research as was experienced by Fontenla and Gould (2003). All of the data collected from these sources were coded multiple times using the initial and focused coding strategies described by Charmaz (2006), before raising specific codes to categories and finally identifying the core category of the theory: managing uncertainty. I was responsible for coding and analyzing all of the data that I collected, but in doing so received feedback in the process of developing the theory. More specifically, during advisory committee meetings I would present my evolving results to my committee and we would discuss the results and potential directions to pursue. I would also present my analysis during focus groups that I held, with the purpose of trying to identify divergent experiences from what were represented in the theory. Such an approach, for example, helped to identify the importance of considering pre-existing health conditions on how an individual adjusted to the diagnosis of YOPD.
6.8.3 Transparency and Reflexivity of the Author

This dissertation has been presented in a way that is true to the manner in which the theory evolved. That is, I started with the original purpose of understanding how individuals with YOPD became informed over time, which became embedded within processes of adjustment and developing resilience to the uncertainty caused by the disease. As these were findings that developed in the context of constructing the theory, I did not start this dissertation by talking about adjustment and resilience. Instead, I position the research in relation to my original purpose and research questions and then describe how understanding the process of becoming informed involved a need to expand my focus to also look at adjustment and resilience. If I only focused on my original research questions, and had not allowed the theory to emerge in the manner that it did, I would likely have missed the highly inter-related nature of the processes involved in managing identity and functioning uncertainty in YOPD. This speaks to the value of a social constructionist approach, which allows for co-construction and an iterative process.

As I described in the methodology and methods chapter, coming from a social constructionist position, I am more inclined to agree with Dey (1999) that it is not possible to completely saturate the categories of a theory because you can never truly know when saturation has occurred. Instead, I believe that the categories I have constructed sufficiently reflect the processes through which individuals with YOPD managed uncertainty in their lives. Sufficiency, like saturation, is not about the repetition of data across sources, but is about the properties of the categories in the theory (Charmaz, 2006). In this way, the properties of the categories I constructed in the context of the experiences of participants, like managing uncertainty, building resilience and adjusting to YOPD, were sufficiently grounded in the data I collected.

Although some of the original research on Parkinson’s I conducted (M. J. Ravenek & Schneider, 2009) emphasized the importance of perceived control in Parkinson’s disease, I was careful in allowing the concept to emerge within the context of this research on YOPD. As I came to understand, this emphasis on bodily control is embedded within Western cultural beliefs (Eckersley, 2001; Frank, 2013; Laliberte Rudman & Dennhardt, 2008; Mol, 2008) and thus, it was not surprising to see it become such an important concept within this research where control over one’s body became threatened through illness. Working at the
Parkinson Society Southwestern Ontario, and attending the World Parkinson Congress in Montreal in the fall of 2013, also helped to sensitize me to particular concepts that developed in the context of my research. For example, in seeing the value that individuals placed on the videos and documentaries created by those living with YOPD at the World Congress, I also came to see the value of strategies beyond information seeking that contributed to the resilience individuals built in their lives. Had I not attended the World Congress, I cannot say for sure whether or not I would have come to see the importance of these external strategies. This speaks to the importance of my own biography, as the researcher, in coming to construct the theory, together with the experiences of those living with YOPD. Again, had this work been positioned within the post-positivist paradigm, such understandings and contributions to the theory would not be coherent with the paradigm. However, as a social constructionist, I acknowledge that role that I play as the researcher, and all that I bring to the research setting, as having an impact on the theory I generated with my participants.

6.8.4 Coherence of the Research Approach

Given my original purpose and research questions, i.e., a focus on how individuals became informed about their disease over time, and why particular strategies were used, a grounded theory approach was well suited to answer these types of questions (Charmaz, 2006). How and why questions speak to understanding process, and it was the process of becoming informed about Parkinson’s disease that most interested me; and which was well-positioned in the literature as a piece of research that needed to be done. In trying to understand such a social process, Charmaz emphasizes the use of ‘flexible’ guidelines for collecting data to fit the needs and unique circumstances where process-research may be conducted. In line with this flexible approach, as I have described already, I chose a variety of methods to collect data to try and enable the participation of those with YOPD in this study. Charmaz is also explicit about the value of extant texts as a source of data, i.e., published autobiographies, which she and others (e.g., Frank, 2013), have drawn in the context of generating theory. I also allowed individuals to self-identify as having YOPD, instead of imposing strict limits on inclusion and exclusion from the study, given the discrepancy that exists in the literature around the constructed nature of parameters for a YOPD diagnosis. Thus, those who identified themselves as being ‘young’ and having been diagnosed with Parkinson’s disease provided a perspective on the disease of which I was interested in learning about. In some cases, those participants who didn’t fit the traditional criteria, i.e., diagnosed between 21 and
55 years of age, were still working and/or had children at home. Likely one of the reasons why there exists such a difficulty in defining YOPD is the changing nature of retirement and parenthood, where individuals may work and raise children until later ages than what fit with previous cultural norms (O'Rand, 2012).

Given that this research was conducted from a social constructionist position, the knowledge claims that I make are contextualized in the sense that they are not generalizable to any situation involving those with YOPD. Of particular note, a person living with YOPD outside of a country with Western cultural beliefs, such as rural northern Tanzania (Mshana, Dotchin, & Walker, 2011), for example, might very well find this theory foreign. Furthermore, given differences within, and across, health care systems of those countries not predicated on Western cultural beliefs, this theory likely still doesn’t generalize to the experiences of all people living with YOPD in these countries. Qualitative researchers may very well feel a sociocultural pressure to generalize their findings (Glaser, 2007). Generalizability, however, is not a focus of social constructionist research, and was certainly not a primary goal of this research. Instead, the focus was on generating a detailed, contextualized, theory that was grounded in the collective experience of a group of people living with YOPD; in conjunction with my own biography as the researcher. Thus, the limited generalizability of this research is not a limitation, rather, it is a strength. In describing this more tentative generalizability that can be drawn from this research, I refer to Firestone’s (1993) description of ‘analytic generalizability.’ This type of generalizability is well suited to theories, especially those using theoretical sampling and thorough data collection and interpretation. As I see it as the researcher’s responsibility to describe how quality was achieved in the research setting (M. J. Ravenek & Laliberte Rudman, 2013), Firestone sees it as the responsibility of the reader to determine the extent to which the findings of a study can be generalized to a particular situation. In making this determination, the similarity of the context in which this study was conducted needs to be weighed against the context of the setting where the results might be applied. In generating the advice booklet for those newly diagnosed, and remaining true to a social constructionist position, I emphasize that the advice provided should be viewed as “suggestions” and that they need to be weighed in relation to each person’s unique situation (see page 6 of Appendix L). Similarly, in the advice booklet for physicians, I describe the advice as a resource, emphasizing specific areas they should “consider” in their interactions with those living with
YOPD; and that the booklet is by no means prescriptive given the unique situation of each individual living with the disease (see page 9 of Appendix M).

6.8.5 Due Regard for the Research Participants

An equally important, but less discussed, area of quality in research relates to the ways in which situational and relational ethics were upheld in the research process (M. J. Ravenek & Laliberte Rudman, 2013). This refers to how responsibility for the well-being of participants was maintained across situations where the participants were involved in the research, as well as the relationship between the researcher and the participants. In discussing some of these ethical issues with a fellow student, we came to understand that there are a number of common issues that can arise when conducting research with young- and middle-aged adults living with rarer neurological conditions (LaDonna & Ravenek, In Press). For example, motor impairment caused by YOPD, e.g., muscle rigidity, combined with side effects from medication, e.g., dyskinesia, can make artificial social encounters like an interview difficult for some participants. Thus, emphasizing that individuals were free to take breaks any time they wanted, in addition to allowing them to choose where the interviews were conducted, helped participants feel more comfortable. Another issue that arose in some interviews, for both LaDonna and myself, involved participants making comments about suicide. Even if these were ‘offhand’ comments, when this occurred it was important to make sure that individuals did not have an active plan and to describe the supports that were available for them. Fortunately, none of my participants who commented about suicide were actively suicidal at that time and were usually referring to feelings they had felt in the past during a period of depression after their diagnoses. Again, the well-being of the participants should always be a priority in the research setting, given the emotions that talking about illness can evoke. In addition to participant well-being, it is also important for researchers to build in their own support systems to discuss difficult issues, like suicide, that might arise during data collection. For me, I was able to debrief with my advisory committee whenever such events occurred, and also had the opportunity to engage in dialogue with LaDonna who was conducting equally sensitive research with those living with Huntington’s disease.

Ethically, you always want study participants to perceive a benefit from participating in a research project. Beyond knowing that this research sought to help others newly diagnosed in the future, it was comforting for me to learn that participants also perceived an immediate
benefit from participation. More specifically, as my study brought people together who were living with a relatively rare neurological condition, many individuals spoke of how much they appreciated being able to speak to others living with YOPD in the study focus groups. Additionally, by giving individuals the option to join a private online discussion board, they were able to continue this interaction, and were also able to remain involved with the project beyond participating in focus groups and interviews.

6.9 Future Research

As I have acknowledged the contextualized nature of the results of this study, it will be important for future research to build on the theory that I have constructed within this research. An important extension of this research would include looking at the experiences of those with YOPD in countries with non-Western cultural values, or even within Canada to look at the experiences of those with diverse cultural backgrounds. The present analysis also did not consider gender as a potential axis of difference, which may contribute to refinement of the theory beyond the collective experience described in this theory and, thus, warrants further consideration. Furthermore, understanding the experiences of children and spouses of those with YOPD, and how they manage with uncertainty caused by their family member’s diagnosis (Sanders-Dewey et al., 2001; Schrag et al., 2004) will provide important knowledge about differences in this management and, potentially, how communication can be improved. Evidence from this research indicates that information seeking, and information sharing, may be one of these strategies, but much remains to be understood.

I have described the categories of this grounded theory as being sufficiently developed. However, given that YOPD is not a fatal condition and individuals can still live for decades after their diagnoses, it is likely that additional types of adjustment exist beyond logical and emotional. For example, Charmaz (1991, 1995) suggests there may be a point of ‘surrender’ to chronic illness, when an individual perceives they have lost all control to the disease. She also describes a unique perspective of time, i.e., existing from day to day, for those with more advanced illness, and those living in poverty, that was not described by participants in this study. Future research should sample individuals who have lived with YOPD for longer periods of time, and who also live below the poverty line, to better understand how adjustment and resilience strategies change over time, and may differ with lower socioeconomic status.
Within the contemporary *rise of the body*, or the greater focus of the body in discourses of identity (Lupton, 1994; Rose, 2001; Shilling, 2007), this research has only started to elucidate the way in which the body can be used as a source of knowledge; or more specifically a *filter* through which accumulated knowledge is turned into experiential knowledge. Further study of how this filtering mechanism operates, or how individuals learn to read their bodies, what they monitor, and how they come to ‘know’ things about their bodies, will add to this literature.

Further, as rare as YOPD is, the juvenile-onset form of the disease, i.e., diagnosed prior to 21 years of age, is even rarer and has yet to be sufficiently researched, especially related to issues of adjustment and resilience. In the same vein, given the constructed nature of defining YOPD from the other subtypes of the disease, and that there is some discussion of the need to redefine the diagnostic criteria for Parkinson’s disease altogether (Berg et al., 2013), greater research is needed to understand the best means of defining YOPD beyond just age. Such a definition will need to consider the unique psychosocial aspects of the disease, in combination with changing norms for raising children and retirement which are occurring later in life compared to previous decades.

As I have discussed already, future work that I plan to conduct involves gathering feedback on the booklets from others living with YOPD, and physicians, from across Canada. Such feedback will be important to identify differences in specific regions of the country where other advice may be deemed necessary for these types of booklets to prove useful. Beyond collecting feedback and creating different versions of these booklets, it will also be important to evaluate the usefulness of the booklets in the experiences of those newly diagnosed and in the experiences of physicians. A number of suggestions have also been provided that might improve the outcomes for patient education programs for individuals with YOPD, which future research should trial to determine potential improvements from existing programs. Finally, given the growing role of social media in providing health information (S. Fox & Jones, 2009), like Facebook and Twitter, future research should seek to better understand how those with YOPD engage with this media in relation to adjusting to the disease and developing resilience. This is also an area where I have a particular interest (K. Ravenek & Ravenek, 2013) and plan to conduct such research in the future.
6.10 Conclusion

With the original purpose of trying to identify the different ways that individuals with YOPD became informed about their disease, to try and improve knowledge related to the provision of care, this study became much broader as it emerged from prospectus to theory. Similar to the way that a camera lens would zoom out to take in more of the scenery, to better understand the role that health information played in the lives of those with YOPD, and how patterns of acquisition changed over time, I needed to re-focus my lens. In doing so, I was able to see that health information acquisition was closely related to how individuals had adjusted to living with the disease, and that this was only one of a number of strategies used by those living with YOPD to build their resilience to the uncertainty caused by the disease. Experiencing uncertainty related to their functioning and their identities, as young- and middle-aged adults, in a culture that values bodily control, health, independence and an orientation towards the future, individuals with YOPD used these strategies to minimize the uncertainty they experienced. By minimizing uncertainty, they were able to maintain a perception of being in control of their lives, which required ongoing negotiation as the disease progressed and functioning declined. Identity and functioning uncertainty have been described in detail in chapter four, and the strategies used to manage these uncertainties are described in chapter five. Periods of health information avoidance and the active acquisition of health information were common throughout the experiences of individuals, and served protective and empowerment functions at different times in the process of adjustment. In coming to understand how individuals with YOPD learned about their disease, the role of experiential knowledge and use of one’s body in filtering knowledge to make it personally relevant was emphasized. As described, the results of this research have important implications for providing care and education to those with YOPD, but the direct applicability of these findings need to be considered with respect to the context in which this research was conducted. Suggestions for future research have also been provided, to build on the theory constructed with participants in this study.
References


Appendices

Appendix A: Ethics Approval for Formative Cycle of Data Collection

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Sandi Spaulding
Review Number: 18340E
Review Level: Delegated
Approved Local Adult Participants: 36
Approved Local Minor Participants: 0
Protocol Title: Information Needs for Individuals with Young-Onset Parkinson’s: A Pilot Project Using Focus Groups to Help Direct Future Research
Department & Institution: Occupational Therapy, University of Western Ontario
Sponsor: Canadian Institutes of Health Research

Ethics Approval Date: August 19, 2011
Expiry Date: September 30, 2012
Documents Reviewed & Approved & Documents Received for Information:

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<tr>
<th>Document Name</th>
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<tr>
<td>UWO Protocol</td>
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<td>Letter of Information &amp; Consent</td>
<td>Version A</td>
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<tr>
<td>Advertisement</td>
<td>APPENDIX E – Workshop Flyer and Registration Form</td>
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This is to notify you that the University of Western Ontario Research Ethics Board for Health Sciences Research involving Human Subjects (HSRERB) which is organized and operated according to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and the Health Canada/CCQ Good Clinical Practice Procedures: Consolidated Guidelines, and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this HSRERB also complies with the membership requirements for HSRERBs as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSRERB's periodic requests for surveillance and monitoring information. If you require an updated approved notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the HSRERB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussions related to, nor vote on, such studies when they are presented to the HSRERB.

The Chair of the HSRERB is Dr. Joseph Gilbert. The UWO HSRERB is registered with the U.S. Department of Health & Human Services under the IRB registration number HHS0002246.

[Signature]

[Ethics Office to Contact for Further Information]

[This is an official document. Please retain the original in your files.

The University of Western Ontario
Office of Research Ethics]
Principal Investigator: Dr. Sandi Spaulding  
File Number: 101477  
Review Level: Delegated  
Approved Local Adult Participants: 20  
Approved Local Minor Participants: 0  
Protocol Title: Information Needs for Individuals with Young-Onset Parkinson’s: A Pilot Project Using Focus Groups to Help  
Direct Future Research.  
Department & Institution: Health Sciences/Occupational Therapy, Western University  
Sponsor: Canadian Institutes of Health Research  

Ethics Approval Date: September 14, 2012  
Expiry Date: September 30, 2013  
Documents Reviewed & Approved:  
Documents Received for Information:  

<table>
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<th>Document Name</th>
<th>Comments</th>
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<tr>
<td>Revised Study</td>
<td>The study end date has been extended to September 30, 2013 to allow for continuation of the project.</td>
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This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB’s as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB’s periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000040.

Signature

Ethics Officer to Contact for Further Information

Anna Sutherland  Grace Kelly  Shae Walcutt

This is an official document. Please retain the original in your files.
Appendix B: Ethics Approval for Theory Building Cycles of Data Collection
Appendix C: Formative Focus Group Advertisement

PARKinson Society Southwestern Ontario
Société Parkinson Sud-Ouest de l’Ontario

Presents:

Life in Balance
Young-Onset Parkinson’s Workshop

Date: Saturday, October 22\textsuperscript{nd}, 2011
Time: 9:00 a.m. – 4:00 p.m.
Location: [ ]

Do you identify yourself or your spouse as a person with Young-Onset Parkinson’s? Join us for this full-day workshop designed to bring together people that are affected by Young-Onset Parkinson’s.

Speaker Topics include:

- Understanding Your Rights as an Employee in the Workplace
- Sexual Relationships and Parkinson’s: Understanding Changes
- Family Matters: Disclosing Diagnosis to Family and Friends
- Planning Your Financial Future

*Informational Needs for Individuals with Young-Onset Parkinson’s: Helping to Direct Current Research

*This session is part of a research study attempting to identify specific informational needs of individuals diagnosed with Young-Onset Parkinson’s, as well as the most appropriate means of providing such information. Those interested in taking part will be contacted by the research team (from the contact information you provide during registration), prior to the workshop so that any questions related to the project can be answered. Informed consent will also need to be given at the time of the workshop in order to participate. Up to 20 individuals with Young-Onset Parkinson’s will be able to participate (4 per session).

Call [ ] at Parkinson Society Southwestern Ontario at [ ] to register. Space is limited.
Appendix D: Formative Focus Group - Letter of Information and Consent Form

Letter of Information

Study Title: Information Needs for Individuals with Young-Onset Parkinson’s: A Pilot Project Using Focus Groups to Help Direct Future Research

Research Team:
Dr. Sandi Spaulding, PhD
Professor, School of Occupational Therapy
University of Western Ontario

Mr. Michael Ravenek, PhD Candidate
Health & Rehabilitation Sciences,
University of Western Ontario

Dr. Mary Jenkins, MD
Associate Professor, Movement Disorders
Program, Clinical Neurological Sciences,
University of Western Ontario

Dr. Debbie Laliberte Rudman, PhD
Associate Professor, School of
Occupational Therapy
University of Western Ontario

You are invited to take part in a research study that aims to learn from people who have previously been diagnosed with young-onset Parkinson’s disease (YOPD). This is the term used to describe a diagnosis of Parkinson’s when individuals are 55 years of age or younger.

Based on your own experiences, we want to learn: 1) what information you perceive as being important for individuals with YOPD to know after they are diagnosed; and 2) what sources of information you have used to acquire information about Parkinson’s disease and your experiences with these sources. Additionally, we will be asking for your input for the design of a future research project on this topic.

Approximately 20 people will be taking part in two separate focus groups (10 in each group) during the workshop hosted by the Parkinson’s Society of Canada on October 22, 2011 in London Ontario. To participate in this study, you need to be between 20 and 65 years of age, have previously been diagnosed with Parkinson’s during or before the age of 55, and be able to engage in a conversation in English.

Participant Initials: ________
What will I have to do if I choose to take part?
You will be asked to take part in a focus group consisting of up to 9 other people who have also been diagnosed with YOPD. Before the start of the focus group, you will also be asked to complete a brief written response to two questions relating to the topic of the study, and answer a few questions that will enable the researchers to describe who participated in the study (specifically, your marital status, occupation, number of children, and the age you were diagnosed with PD). The focus group will last approximately 60 minutes and has been designed as one of the ‘breakout sessions’ for the Parkinson’s Society of Canada workshop.

In this focus group, you will be asked to share and discuss with other group members your thoughts and experiences related to what information is most important for someone diagnosed with YOPD to be given. As well, the group will discuss different sources that they have used to acquire information about PD, and what they feel is the best way to provide information to those with YOPD. The research team will also seek the groups’ opinion on how best to design a research project investigating information needs for those with YOPD. Two members of the research team will help to facilitate the discussion between the focus group participants.

Are there any risks or discomforts?
There are no known risks associated with taking part in this research. Occasionally some people experience discomfort when they talk about health issues. You are free to choose what you will and will not discuss.

What are the benefits of taking part?
Your firsthand experience of living with YOPD, what information you have found useful or not useful, what sources you have used to acquire information, and how you think a study on this topic should be designed is very important information that only you can provide. Information you share will be presented to others through publications and at conferences and meetings, but your name will not be used. As a result, your views may help influence the way future research is completed on this topic, and also help with the development of information materials for individuals with YOPD. Your identity will never be released in any publication or presentation.
What happens to the information that I tell you?
The focus groups will be audio-recorded. What you say will be typed out. Written responses that you choose to provide before the start of the focus group will also be typed out. The only people who will listen to the recording and see the typed out data will be the researchers and a typist. To protect your identity, a unique number and letter code will be used to identify recordings and written responses. Focus group members are asked to keep everything that they hear confidential and not to discuss it outside of the meeting. However, we cannot guarantee that confidentiality will be maintained by group members. Quotes from the focus groups and written responses will be included in future publications and presentations and will be identified using codes and pseudonyms (made up names). Any identifying information from the quotes, such as the names of other people, will be removed or changed prior to their use in publications or presentations. Information about the descriptive characteristics of the participants will be grouped to describe the group. All data will be locked in a secure place at the University of Western Ontario. Information and will be erased and shredded/disposed of after 10 years.

Voluntary Participation:
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you do drop out of the study, any information that you have provided may still be used as part of the findings. You do not have to provide a written response to the questions posed to you before the start of the focus group. You can choose not to answer questions that you are asked in the focus group. Being in this study or dropping out will not affect the services available to you through the Parkinson’s Society of Canada or any other services you receive.

Other Information about this Study:
We hope that you will participate in this important research. If you have any questions or wish additional information, you may contact: Mr. Michael Ravenek at [contact information] or Dr. Sandi Spaulding at [contact information]

If you have any questions about the conduct of this study or your rights as a research participant, you may contact: the Office of Research Ethics at the University of Western Ontario: [contact information]

Representatives of the University of Western Ontario Ethics Board may contact you or require access to your study related record to monitor the conduct of this research.

This letter is for you to keep.
**Consent Form**

**Study Title:** Information Needs for Individuals with Young-Onset Parkinson’s: A Pilot Project Using Focus Groups to Help Direct Future Research

I have read the contents of the letter of information, I have had the nature of the study explained to me and I agree to participate. All of my questions have been answered to my satisfaction.

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<tr>
<th>Signature of Person Obtaining Consent</th>
<th>Printed Name</th>
<th>Date</th>
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Participant Initials: _________
Appendix E: Formative Cycle - Focus Group Discussion Guide

I. Introduction (~5 minutes)
   - Moderators
   - Purpose: To discuss the importance of researching information needs for individuals with young-onset PD and developing corresponding information materials
   - Microphones, Audio-recorders
   - Confidentiality of the discussion
   - Introductions:
     - First Name
     - Age Diagnosed // Years Living w/ PD

II. Written Exercise (~5 minutes)
   - In your opinion, what is the most important information that can be given to someone newly diagnosed with young-onset PD?
   - In your opinion, what is the best way that this information can be delivered?

III. Information Needs Discussion (~25 minutes)
   - Learning about PD after being diagnosed
     - Topics about which you sought information
       - ‘Most important topic / information’
     - Topics you did not desire to learn about
     - Factors influencing information seeking
   - Sources of information
     - Major sources of information
       - ‘Best way for information to be delivered’
       - Expectations of different sources (e.g., physicians, PSC, government)
     - Satisfaction with sources and information obtained

IV. Research Project Discussion (~20 minutes)
   - Importance of research project
     - Perceived need for development of materials
   - Data collection methods
     - Best way to collect information on this topic
     - Advantages / disadvantages of different methods
   - Other things research team should think about when collecting data

V. Closing (~5 minutes)
   - Remaining comments / questions
   - Thank you
Appendix F: Formative Cycle - Focus Group Questionnaire and Warm-up Activity

Participant Code: ____________________  Focus Group (Please circle)  A  B

Marital Status:  Married  Divorced  Separated  Widowed  Single
(Please circle)

# of Children (If applicable) ____________  Age Diagnosed with Parkinson's ____________

Employment Status  Full-Time  Part-Time  Unemployed  Retired  Volunteer  Disability
(Please circle)

In the space below, please briefly respond to each of the following questions. With your permission, this piece of paper will be collected by the research team at the end of the focus group to aid with the research.

1. In your opinion, what is the most important information that can be given to someone newly diagnosed with young-onset PD?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

2. In your opinion, what is the best way that the information you described in question #1 can be delivered to someone?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
January 31, 2012

As the Manager of Programs and Services at Parkinson Society Southwestern Ontario (PSSO), I am dedicated to the continued improvement of programs and services for people living with Parkinson’s disease. One such way that we can strive to improve the programs and services available is by collaborating with research teams conducting important research in these areas. As a member of our client database at PSSO, I am contacting you to tell you about an opportunity to participate in a research project aimed at improving programs and services for people living with young-onset Parkinson’s disease (YOPD).

The following paragraphs will describe the study and what you would have to do if you wanted to participate. Participation in this study is voluntary. Being in this study or dropping out will not affect the services available to you through PSSO or any other services you receive.

**Project Description**

This specific research project is being conducted by a research team at the University of Western Ontario in London, Ontario. These researchers are seeking to learn about the experiences of those diagnosed with YOPD, what information (if any) was sought out after diagnosis, as well as when and how people located information. Results of this study will help to direct the development of information materials for individuals with YOPD and physicians. Once developed these materials may help future individuals diagnosed with this condition in coping and adjustment, and may assist physicians to provide this population with appropriate support during and after diagnosis.

Approximately 48 people will be taking part in this study: 18 individuals will complete in-depth interviews and 30 individuals will participate in 1 of 6 focus groups. After participants take part in the interviews and/or a focus group, participants will also have the opportunity contribute to a private online discussion board to continue discussion related to this study with the research team and with other participants.

To participate in this study, you need to be 20 years of age or older, identify yourself as having been diagnosed with YOPD, and be able to engage in a conversation in English.

**What will I have to do if I choose to take part?**

For individuals taking part in interviews, you will be asked to complete 3 separate interview sessions. Each session will have a specific focus. The focus of Session 1 will be on understanding your diagnosis experience and your life surrounding the time of your diagnosis. The focus of Session
2 will be on understanding what information you have sought out as a result of being diagnosed with PD (if any), as well as when and how you sought out this information. The focus of Session 3 will be a reflection of the first 2 sessions, where you will be asked to think of advice that would be helpful for someone newly diagnosed with YOPD and for the physicians responsible for relaying the diagnosis and providing care. Participants will have the choice of face-to-face interview sessions taking place in their home, private lab space at the University of Western Ontario, or at a more convenient private location of their choosing. All initial interviews will be face-to-face, however, if barriers to face-to-face interviews exist, participants may also choose to complete the remaining interviews sessions over the phone. It is anticipated that each interview session will last between 45 and 60 minutes, for a total of 135-180 minutes over the 3 sessions.

For individuals taking part in a focus group, a member of the research team will present the research team’s developing understanding of the diagnostic process, information seeking, and information needs in YOPD. After this short presentation, you will be asked to relate the information presented to your own experience. Focus groups will be held at workshops hosted by the PSSO at locations across Southwestern Ontario. Each focus group will consist of up to 5 people who have also self-identified as being diagnosed with YOPD. Two members of the research team will help to facilitate the discussion between the focus group participants. It is anticipated that each focus group session will last approximately 60 minutes.

Both interview and focus group participants will be asked to complete a short questionnaire that asks for descriptive characteristics, such as age, marital status, employment status, type of residence, and highest level of education completed.

Participants may choose to participate in both the interview process and a focus group, but participants will not be able to participate in more than one focus group.

Interview and focus group participants will be invited to join a private online discussion board run through the PSSO website. In the process of joining the discussion board, participants will choose a pseudonym that will help the research team identify participants and also maintain anonymity among the participants. The research team will post discussion points to the board for participants to comment on as their understanding of the diagnostic process, information needs, and information seeking develops. The discussion board will also be a means by which participants can continue to interact and discuss topics relevant to the study. The
SUPPORT GROUPS
Brantford
Cambridge
Chatham-Kent
Goderich
Dunnville
Hanover
Kincardine
Kitchener
Leamington
London
Meaford
Orangeville
Owen Sound
Sarnia-Lambton
Simcoe
St. Thomas
Stratford
Strathroy
Tillsonburg
West Lorne
Windsor
Woodstock

discussion board will be set up so that any participant can send private messages to the research team if they do not want their responses seen by the other participants. Should any participant not wish to take part in the discussion board, or if they are unable to participate because of barriers, but they wish to provide ongoing input on the project, the research team can contact the individual by phone to provide updates and to solicit feedback. The discussion board will be launched during the first cycle of data collection and will close when data collection has finished.

Other Information about this Study:
In appreciation of your assistance with the study, the research team will reimburse travel and/or parking costs, or long distance charges you incur related to participation in this study.

How to Participate:
If you would like to participate in this study, have any questions about the study, or wish additional information you may contact Mr. Michael Ravenek by phone at

Thank you for your consideration,

Manager, Programs and Services
Parkinson Society Southwestern Ontario
Appendix H: Theory-Building Cycles – Information Letter and Consent Form

LETTER OF INFORMATION

Study Title: Development of a Framework for Information Needs and Information Seeking Following Diagnosis in Young-Onset Parkinson’s Disease

Research Team:

Dr. Sandi Spaulding, PhD  
Professor, School of Occupational Therapy  
University of Western Ontario

Mr. Michael Ravenek, PhD Candidate  
Health & Rehabilitation Sciences,  
University of Western Ontario

Dr. Mary Jenkins, MD  
Associate Professor, Movement Disorders Program, Clinical Neurological Sciences,  
University of Western Ontario

Dr. Debbie Laliberte Rudman, PhD  
Associate Professor, School of Occupational Therapy  
University of Western Ontario

You are invited to take part in a research study that aims to learn from people who have previously been diagnosed with Young-Onset Parkinson’s disease (YOPD). This is the term used to describe a diagnosis of Parkinson’s disease when individuals are diagnosed at a young age (i.e., in most cases under 55). We want to learn about your experience being diagnosed with YOPD, what information (if any) you sought out after being diagnosed, as well as when and how you located information. Reflecting on your own experience, we would also like you to think of advice that would be helpful for someone newly diagnosed with YOPD and for the physicians responsible for relaying the diagnosis and providing care to individuals with YOPD.

Approximately 48 people will be taking part in this study: 18 individuals will complete in-depth interviews and 30 individuals will participate in 1 of 6 focus groups. After participants take part in the interviews and/or a focus group, participants will also have the opportunity contribute to a private online discussion board to continue discussion related to this study with the research team and with other participants.

To participate in this study, you need to be 20 years of age or older, identify yourself as having been diagnosed with YOPD, and be able to engage in a conversation in English.
What will I have to do if I choose to take part?

For individuals taking part in interviews, you will be asked to complete 3 separate interview sessions. Each session will have a specific focus. The focus of Session 1 will be on understanding your diagnosis experience and your life surrounding the time of your diagnosis. The focus of Session 2 will be on understanding what information you have sought out as a result of being diagnosed with PD (if any), as well as when and how you sought out this information. The focus of Session 3 will be a reflection of the first 2 sessions, where you will be asked to think of advice that would be helpful for someone newly diagnosed with YOPD and for the physicians responsible for relaying the diagnosis and providing care. Participants will have the choice of face-to-face interview sessions taking place in their home, private lab space at the University of Western Ontario, or at a more convenient private location of their choosing. All initial interviews will be face-to-face, however, if barriers to face-to-face interviews exist, participants may also choose to complete the remaining interviews sessions over the phone. It is anticipated that each interview session will last between 45 and 60 minutes, for a total of 135-180 minutes over the 3 sessions.

For individuals taking part in a focus group, Mr. Michael Ravenek (PhD Candidate) will present the research team’s developing understanding of the diagnostic process, information seeking, and information needs in YOPD. After this short presentation, we will ask you to relate the information presented to your own experience. Focus groups will be held at conferences hosted by the Parkinson Society Southwestern Ontario at locations across Southwestern Ontario. Each focus group will consist of up to 5 people who have also self-identified as being diagnosed with YOPD. Two members of the research team will help to facilitate the discussion between the focus group participants. It is anticipated that each focus group session will last approximately 60 minutes.

Both interview and focus group participants will be asked to complete a short questionnaire that asks for descriptive characteristics, such as age, marital status, employment status, type of residence, and highest level of education completed.

Participants may choose to participate in both the interview process and a focus group, but participants will not be able to participate in more than one focus group. Please check the appropriate box in the consent form to indicate if you will be participating in the interviews, a focus group, or both.

Interview and focus group participants will be invited to join a private online discussion board run through the Parkinson Society Southwestern Ontario website. In the process of joining the discussion board, participants will choose a pseudonym that will help the research team identify participants and also maintain anonymity among the participants. The research team will post discussion points to the
board for participants to comment on as our understanding of the diagnostic process, information needs, and information seeking develops. The discussion board will also be a means by which participants can continue to interact and discuss topics relevant to the study. The discussion board will be set up so that any participant can send private messages to the research team if they do not want their responses seen by the other participants. Should any participant not wish to take part in the discussion board, or if they are unable to participate because of barriers, but they wish to provide ongoing input on the project, the research team can contact the individual by phone to provide updates and to solicit feedback. The discussion board will be launched during the first cycle of data collection and will close when data collection has finished.

*Please check the appropriate box in the consent form to indicate if you would like to participate in the online discussion board, or if you would like the research team to contact you by phone to provide updates on the project and to ask for your feedback.*

**Are there any risks or discomforts?**

There are no known risks associated with taking part in this research. Occasionally some people experience discomfort when they talk about health issues. You are free to choose what you will and will not discuss.

**What are the benefits of taking part?**

There are no known direct benefits associated with taking part in this research. More broadly, results of this study will help to direct the development of information materials for individuals with YOPD and physicians. Once developed these materials may help future individuals diagnosed with this condition in coping and adjustment, and may assist physicians to provide this population with appropriate support during and after diagnosis. Your first-hand experience of being diagnosed and living with YOPD, what information you have found useful or not useful, what sources you have used to acquire information, and your ability to reflect on your experiences now is very important information that only you can provide. Group settings and the opportunity to discuss these topics with the research team and others with YOPD in an ongoing manner may also aid in increasing your own knowledge about this disease.

**What happens to the information that I tell you?**

Focus group and interview sessions will be audio-recorded. What you say will be typed out. The only people who will listen to the recording and see the typed out data will be the researchers and a typist. All text from the private discussion board, private messages sent to the research team, and notes taken during telephone conversations

Participant Initials: ________

Page 3 of 4

Version A
will form the data set for the online discussion board. To protect your identity, a unique code will be used to identify recordings, text and written responses. Focus group members are asked to keep everything that they hear confidential and not to discuss it outside of the meeting. However, we cannot guarantee that confidentiality will be maintained by focus group members. Quotes from the interviews, focus groups, and discussion board will be included in future publications and presentations and will be identified using codes and pseudonyms (made up names). Any identifying information from the quotes, such as the names of other people, will be removed or changed prior to their use in publications or presentations. Information about the descriptive characteristics of the participants will be grouped to describe the group. All data will be locked in a secure place at the University of Western Ontario. Information will be erased and shredded/disposed of after 10 years.

Voluntary Participation:

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time. If you do drop out of the study, any information that you have provided may still be used as part of the findings. Being in this study or dropping out will not affect the services available to you through the Parkinson’s Society Southwestern Ontario or any other services you receive.

Other Information about this Study:

In appreciation of your assistance with the study, the research team will reimburse travel and/or parking costs, or long distance charges you incur related to participation in this study. We hope that you will participate in this important research. If you have any questions or wish additional information, you may contact: Mr. Michael Ravenek at [redacted] or Dr. Sandi Spaulding at [redacted]

If you have any questions about the conduct of this study or your rights as a research participant, you may contact: the Office of Research Ethics at the University of Western Ontario: [redacted]

Representatives of the University of Western Ontario Ethics Board may contact you or require access to your study related record to monitor the conduct of this research.

This letter is for you to keep.
Consent Form

Study Title: Development of a Framework for Information Needs and Information Seeking Following Diagnosis in Young-Onset Parkinson’s Disease

I have read the contents of the letter of information, I have had the nature of the study explained to me and I agree to participate. All of my questions have been answered to my satisfaction.

Please check only those activities to which you are consenting to participate:

I consent to participate in the 3 interview sessions

I consent to participate in a focus group

I consent to participate in the online discussion board

I consent to have the research team contact me to provide updates on the research and to solicit my feedback instead of participating in the online discussion board

________________________________________  ________________________________________  ________________
Signature of Research Participant                 Printed Name                           Date

________________________________________  ________________________________________  ________________
Signature of Person Obtaining Consent                 Printed Name                           Date
## Appendix I: Theory-Building Cycles – Descriptive Questionnaire

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<th>Age Diagnosed with Parkinson’s</th>
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<table>
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## Appendix J: Theory-Building Cycles – Sample Interview Questions

<table>
<thead>
<tr>
<th>Interview</th>
<th>Foci of Question</th>
<th>Sample Questions</th>
</tr>
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| 1         | Broad Overview  | • Could you describe for me the events that led up to your diagnosis of Parkinson’s disease?  
• What was going on in your life around the time of your diagnosis?  
• Could you describe for me your experience with physicians in the process of receiving your diagnosis?  
• What were your initial reactions after receiving your diagnosis? Did you disclose your diagnosis to anyone?  
• Could you tell me about how you have learned to handle your diagnosis?  
• Is there anything else you think I should know to better understand your experience being diagnosed with PD? |
| 2         | Health Information | • When you first received your diagnosis what, if anything, did you know about Parkinson’s disease?  
• After receiving your diagnosis what, if anything, did you want to know about Parkinson’s disease? Why was this important to you? What sources did you use to locate this information?  
• What, if anything, did you not want to know about Parkinson’s disease? Why didn’t you want to know this information?  
• Have you feels toward information about Parkinson’s disease changed since your diagnosis?  
• Who, or what, has been the most helpful to you since being diagnosed? How have they been helpful?  
• Is there anything else you think I should know to better understand your experience finding information related to Parkinson’s disease? |
| 3         | Summary          | • What positive changes, if any, have occurred in our life since being diagnosed with Parkinson’s disease?  
• Could you describe for me the most important life lessons you have learned through living with Parkinson’s disease?  
• Reflecting on your experience living with this disease, what advice would you give to someone newly diagnosed with YOPD? What advice would you give to a physician diagnosing and providing care to someone with YOPD?  
• Is there anything else you think I should know to better understand your experience living with YOPD?  
• Is there anything else you would like to ask me? |
### EXTANT TEXT DATA COLLECTION FORM

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<tr>
<td>Title</td>
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</tr>
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<td>Year</td>
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<tr>
<td>Type</td>
<td>Members of Residence</td>
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<td></td>
<td>Employment Status</td>
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<td></td>
<td>Highest Level of Education Completed</td>
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<td></td>
<td>Number of Children</td>
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### DIAGNOSIS INFORMATION

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<td>Number of Years Living with PD</td>
</tr>
<tr>
<td>Diagnosis Given By</td>
</tr>
<tr>
<td>Employment Status (when diagnosed)</td>
</tr>
<tr>
<td>Marital Status (when diagnosed)</td>
</tr>
<tr>
<td>Description of Diagnosis Experience</td>
</tr>
<tr>
<td>Other Relevant Information (e.g., Other health conditions, etc.)</td>
</tr>
<tr>
<td>LIFE AFTER DIAGNOSIS</td>
</tr>
<tr>
<td>-------------------------------------</td>
</tr>
<tr>
<td>Description of Emotional Adjustment</td>
</tr>
<tr>
<td>Supports In Life</td>
</tr>
<tr>
<td>Treatment(s) for PD</td>
</tr>
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<table>
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<th>INFORMATION</th>
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<td>References to Info Seeking/Needs</td>
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<td>Sources of Information</td>
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<td>Relationship Between Diagnosis and Info Seeking</td>
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<td>Reason for Writing Book</td>
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<tr>
<td>Creative Coping Strategies</td>
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<td>Memorable Quotes</td>
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Young-Onset Parkinson's Disease: Advice for Those Newly Diagnosed From Individuals Currently Living with YOPD

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Produced in London, Ontario, Canada

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ACKNOWLEDGEMENTS

First and foremost, I am indebted to the 39 people living with young-onset Parkinson’s disease (YOPD) who took part in this project, dedicating hours of their own time, inviting me into their lives and sharing their wisdom with me for others to read. Without all of you, the project and this booklet would not have been possible.

Beyond those who took part in this study, there is a mass of people that deserve thanks and acknowledgement for their contributions. My doctoral advisory committee, consisting of Dr. Sandi Spaulding, Dr. Mary Jenkins and Dr. Debbie Laliberte Rudman were instrumental in providing feedback on my research and this booklet as it progressed from an idea to a product.

I would also like to thank Dr. Soania Mathur for writing the foreword to this booklet and providing constructive feedback on the development of certain sections, including some of the tools provided at the end of this booklet. Lily Cappelletti at the Michael J Fox Foundation also deserve thanks for sharing some of the images that were included in this booklet.

Of course, I cannot end these acknowledgements without thanking my wife, Kelly, for her unwavering support and feedback on my research and this booklet as they moved through different stages of development.

Michael Ravenek,
PhD (Candidate)
A special thank you goes to the Parkinson Society Canada and the Canadian Institutes of Health Research who provided funding for my research in the form of a Doctoral Research Award. The staff at the Parkinson Society Southwestern Ontario were also instrumental in supporting my research, helping with recruitment and providing space at conferences to conduct some of my focus groups.
FOREWORD

You have young onset Parkinson’s disease” – words you were likely not expecting to hear and once spoken, are life changing. My diagnosis came at the age of 27 at the start of my career as a family physician and as I was expecting my first child. That was over fifteen years ago but I can still vividly recall that day and the shock, fear and confusion that followed; fear of the future, confusion about the present.

These are normal reactions to an overwhelming and unexpected life hurdle. And those of us living with the challenge of Parkinson’s disease have all been on the receiving end of this news. For many of us, the journey to taking charge of our disease has been a difficult one. It begins with first accepting what may seem an unfair twist in your life. For me it took close to a decade to recognize that although the diagnosis of Parkinson’s was not within my control, how I faced this challenge was mine to determine. For others in my Parkinson’s community, acceptance came much sooner. In my personal experience, only once you are able to accept your diagnosis, can you move beyond it and begin to take back some measure of control; to make the decisions and interventions that will optimize your health and help you to live well with this disease.

Experience has also shown me that you cannot be a passive bystander and expect to live well with Parkinson’s. You must play an active role in your own management. The suggestions presented in this booklet can serve as cornerstones for you to begin a journey of living well despite the daily challenges you face. Although it may initially seem like an insurmountable hurdle, there are things that you can do to empower yourself, to become an advocate in your own health, to remain productive and engaged, to maintain your quality of life.

It begins with education and becoming an informed patient. Having knowledge of our disease allows us to make sound decisions with our physicians regarding treatment options. This ultimately translates into better health outcomes.

We also need to surround ourselves with support and guidance. The effects of
Parkinson's disease are not simply physical. Its impact is pervasive, affecting every aspect of life – physical, social and emotional. We are often at the prime of our lives at the time of diagnosis, at the height of our careers, in the midst of parenting, and trying to build our financial futures. These issues are significant and are more easily confronted when you have a strong circle of support.

Then there is the practical management – keeping a logbook, tracking your symptoms, changes and medications, incorporating exercise into your self-care routine and considering being involved in clinical trials.

This advice and more is conveyed in this booklet by those that have experienced living with this disease first hand. People like you that at some point in time similarly faced this illness for the first time. Despite the fact that our physicians may serve as valuable resources, there is a vast amount of knowledge that can be learned from the experience of others facing the same challenge; insight which is invaluable.

I often think about what I would say to myself at the time I was initially diagnosed now that I've lived with Parkinson’s for so many years. I think that the most important piece of advice I would impart is that at some point you have to abandon your fear of the future in order to begin living your present. And with the right information, resources and a multi-faceted approach to management, including self-care, it is possible to live well with Parkinson’s.

Dr. Soania Mathur
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“I think when you get the diagnosis, your life sort of stops. I remember leaving the doctor’s office and I must have ran out because I remember his secretary saying ‘Don’t run.’ But there were some people in the waiting room and I just needed to blow. I needed to get out of there. I went into the hallway and I was pacing and I said ‘What does this mean? Now what?’ ... Because at that point you don’t really know what it means ... You have to deal with your kids, you have to deal with your job, you have to deal with getting up every day and all the things you’re supposed to do and then deal with this at the same time. And there’s no instruction book on how to do that. You don’t know where to turn.”

Shanna Mellins

As alluded to in the passage from Shanna above, the needs of those with young-onset Parkinson’s disease (YOPD) are unique. Being diagnosed with a chronic, progressive neurological condition in the prime of life is likely to be a very emotional experience. You may have children, you are likely still working and on top of these life stresses you now have YOPD. As a resource for those newly diagnosed, this booklet has been designed as one place to turn to after diagnosis. This booklet is full of advice for those newly diagnosed with YOPD from those who have been living with the disease and were willing to share reflections based on their own experiences.

As with advice you receive from any person, you need to weigh the value of the advice in relation to your own personal situation. As such, it is important to read this advice booklet as “suggestions” that may or may not work for you, but at the very least are topics to consider.
How Was This Booklet Developed?

This booklet is a product of the work completed by Mike Ravenek and the participants in his study investigating the experiences of individuals living with YOPD. Thirty-nine individuals who self-identified as living with YOPD, primarily from Southwestern Ontario, took part in the study over a two-year period from the fall of 2011 to the fall of 2013. To contribute to the study, participants had the option of participating in a series of interviews with Mike and engaging in online and/or in-person groups discussing issues related to their experiences and the evolving results of the study.

At the conclusion of the interviews in the early stages of data collection, participants were asked specifically what advice they would give to someone newly diagnosed with the disease, as well as what advice they would give to a diagnosing physician. Additionally, the focus group and interview participants in the later stages of this project reviewed the advice compiled and added to this knowledge base with their own thoughts and experiences. This booklet represents the collective voice of the participants and the advice they would relay to other individuals newly diagnosed with YOPD. Advice these individuals had for physicians, responsible for the diagnosis and treatment of individuals with YOPD, is presented in a separate booklet.
The specific passages included in this booklet were taken from participant interviews and group discussions, as they do a good job illustrating the main pieces of advice that were raised by all of those who took part in this study as a whole. Additionally, the passages represent responses from participants with a range of experience living with YOPD, from 1-year to 18-years post diagnosis. Brief demographic information about the participants whose advice was included in this booklet is provided below, along with pseudonyms (false names) to protect the identity of these participants.

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<td>Shanna Mellins</td>
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<td>Danny Pirie</td>
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<td>Suzanna Viles</td>
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INTRODUCTION

The advice dispensed by participants living with YOPD for others newly diagnosed focused primarily on the importance of being proactive in numerous facets of life; learning to now put your health and your concerns first above everything else. This mindset and the proactive strategies used, in essence, served to help manage the troubling emotions that can follow after receiving a diagnosis of YOPD. The idea of being proactive stems from the belief that it is up to each person that is diagnosed to make the best of the experience; that is, a sense of personal responsibility is perceived to be important. Given that we live in a society where independence is highly valued, it is not surprising individuals came to see that this responsibility ‘to take action’ falls on their own shoulders.

“Put yourself first. You gotta make sure you’re okay before you can do anything for anybody else. You are number one. Take care of yourself first and you will discover that everything else falls into place.”

 Joella Kline
Although it was believed that the initiative to make changes and be proactive falls on the person diagnosed, the journey of living with YOPD does not have to be one travelled alone. As we will see in the advice dispensed by those who took part in this project, many of the proactive strategies discussed served to increase the amount of support available to the person. Furthermore, the advice provided about the importance of being proactive did not just cover one specific life area; rather the participants believed that those who are newly diagnosed should become proactive in all areas of their life that can influence their health. The specific advice provided about being proactive is broken down into the sections that follow.

“I have as good a life as I can make it, but do I like having Parkinson’s? No. Does it negatively affect me? Yes. Now it’s up to me to make the best of it.”

Patti Bradner
GET INFORMED ABOUT PARKINSON'S DISEASE

One of the common ways that individuals spoke about being proactive was in trying to find out as much information about Parkinson's as they could, so that they had a better idea of what the disease entails as well as the supports and treatment options that were available. A lot of information that they desired in the weeks after receiving their diagnosis was not readily provided to them by physicians. Consequently, they believe that if you are going to become informed about Parkinson's disease, seeking this information on your own is often required and that you should not be afraid to ask questions when you are learning about the disease.

“Do the work to understand it and it will help you calm down. The more you know the more power you feel you have.”
Niels Kovitz
“Find out as much information as you can that you need for yourself. Any doctor can work with you, any group can work with you, but it has to be right for you, you as the person that’s got it …. I really didn’t have any other support to say please call this number or please – like I didn’t get the Society’s [information] until later on. I did that on my own. I found it ... It’s sad to think somebody is going through maybe six months or maybe a year of certainly a big question mark ... I would like to think that information is out there, but they gotta take the first step, and so I would encourage them to take that first step. In short, that would be the answer – take a step forward and find out about it.”

Danny Pirie
Once you start looking for information about Parkinson’s disease it can be overwhelming because of the wealth of knowledge that is available from a variety of print and online sources. Where does one start and where does one end this search? As alluded to by Danny in an earlier passage, the amount of information that a person will want to know after their diagnosis will vary from person to person. Numerous factors, such as the amount of knowledge a person has of Parkinson’s prior to their diagnosis, will influence this search for information. There is no set rule as to how much you have to know right away as learning is ongoing and will continue over time.

“Read as much as you can about your disease. You be the judge as far as that’s concerned too because sometimes people don’t want to know. But it helped me because I had several things that had gone awry ... So I would say try to find out everything about your disease for now. You know don’t go beyond a certain point. It’s hard not to know when to stop, but there’s just so much out there, there’s the internet, magazine studies, conferences, other people.”

Joella Kline
Related to acquiring information about YOPD, it is common to leave questions unasked and, therefore, unanswered. The participants firmly believed, in the spirit of being proactive about their health and becoming knowledgeable about their condition, the fear of asking questions has to be overcome.

“If you’ve got a question, it’s a legitimate question. I think sometimes a lot of people don’t want to ask because they don’t want to appear stupid ... I hear a lot of people feeling stupid or not feeling like they are given that opportunity to ask questions because you’re in and out in five minutes.”

Patti Bradner
As important as it is to become knowledgeable about YOPD, it is just as important to understand that some sources are more credible than others. A list of online resources with quality information has been provided at the end of this booklet. If you are ever concerned about the credibility of information you have heard or read, you can always check with your physician to get his/her opinion on the material. A few general rules for assessing the credibility of online information are provided on the next page, which has been previously published by Mike Ravenek in The Parkinson’s Update (Winter/Spring 2012, Issue 55, p. 10). This is a magazine published by the Parkinson Society Southwestern Ontario and the full article is available online at the Society’s website.
<table>
<thead>
<tr>
<th>The 3 “A’s” for Finding Information on the Internet</th>
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<tr>
<td><strong>1. Author</strong></td>
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<tr>
<td>Does the webpage have a clear author?</td>
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<tr>
<td>• A webpage should clearly state who has written the information, whether it be an individual or an organization.</td>
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<td>Are the authors of the webpage trying to sell something?</td>
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<tr>
<td>• Don’t be fooled by webpages where the authors are trying to sell you their products, including miracle treatments.</td>
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<td><strong>2. Age</strong></td>
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<td>Is the webpage current or has it been updated recently?</td>
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<td>• A webpage should have a date indicating when an article was written or when it was last updated. Older webpages and articles may not have the most current information.</td>
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<td><strong>3. Accuracy</strong></td>
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<td>Does the webpage cite references?</td>
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<td>• References are usually provided at the bottom of articles and list the sources the author(s) used to pull the information together. When references are not listed, it is impossible to know where the information is coming from and if the information provided is just opinion.</td>
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<td>If so, what types of references are cited?</td>
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<td>• Good webpages will list references, but it is also important to look at the references. Are the references from academic journals, (e.g., New England Journal of Medicine), or are they from more opinion-based sources? Can you locate the references yourself?</td>
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"You need to read everything with a grain of salt, and make sure that the sources are credible ... there’s a lot of bad information on the Internet.”

Derek Daumer
Putting the information you learn into perspective and focusing on the positive aspects of what you are learning was also deemed important by the participants. For example, when learning about YOPD, it is important to keep in mind that it is a chronic disease not a terminal disease. You also may not experience all of the symptoms that you read about. The disease can be very individual with great variability from one person to the next, so even though it is important to know what can occur so that you can recognize changes and can speak with your physician about those changes it does not mean you will experience all of the symptoms of Parkinson’s.
“I would want to have learned first of all that it’s – there are many different symptoms. Some which can be controlled medically. Some which can’t. Some which can be better controlled by diet or exercise of certain types. But the fact that everyone’s journey with Parkinson’s is basically an individual thing. That the symptoms, the combination of symptoms that one has are unique to you. Someone else may have the same particular symptoms but have them at different strengths or different times of the day or different stages along their life with Parkinson’s. So that’s the first thing to know that everybody’s journey is unique.”

Denis Bartoo

“Knowing that it wasn’t a life-ending condition; it was an uninvited guest that doesn’t go away. You learn that it’s possible to adjust your lifestyle and you explore potentials that you have that you never explored before ... If you have to have a disease, it’s a good one to have. It’s not deadly ... It’s not the end of the world.”

Jordan Chicholm
The importance of having a strong support system underneath you while learning to manage with YOPD cannot be understated. While the move to seek out and accept this support is proactive on the part of the person diagnosed, the support itself will help to ease the burden of living with a progressive neurological condition. In reference to specific types of supports, participants spoke about ‘YOPD-Specific’ supports as well as ‘Family and Friends’ as the most important components of their support systems. In some cases, individuals also found it beneficial to seek out the support of a ‘Family or Individual Counsellor’ to help navigate issues that arise, as well as supports related to ‘Employment and Finances.’
“Even though your journey is unique, you are not alone on the journey. There is a ton of people and resources out there to network with. And maybe you won’t run into someone who is walking the same journey as you because of the uniqueness of the symptoms. But there is somebody who can relate and especially can listen to your fears.”

Denis Bartoo.

“Get your supports. I think of the boardwalks at the beaches, and you go underneath. And they’ve got all these crisscross supports all over the place. And then on top is your public persona, but you’ve got all these little supports underneath that help you get out there and stay out there.”

Joella Kline
The Parkinson Society of Canada and its regional partners, like the Parkinson Society Southwestern Ontario, were often cited as being an important support specific to the disease for participants. Unfortunately, not everyone was referred to these societies after they became diagnosed, having to locate them on their own after starting a search for information about YOPD.

“Look for support. Because I didn’t know there was a Parkinson’s Society until I went searching for information and then oh, Parkinson’s Society of Canada. Whoa, what’s this? So that’s one nice thing about having the internet and computers, and all young people do.”

Patti Bradner
“I know the Society is there now. I know it now, but I didn’t know it then. That probably would have been a big help to call somebody . . . somebody who could be like ‘is there something I could find for you?’ – She’s there, she could send you some stuff.”

Danny Pirie

Among the many services offered by the Parkinson Societies in Canada are opportunities to meet and speak with other individuals living with the disease. This can occur through a number of venues, including conferences and workshops, support group referrals, and peer mentoring programs. Effectively, these societies act as a ‘gatekeeper’ for individuals to become more involved in the ‘Parkinson’s world.’

“Join a support group of people like you, but not just any support group, because right here is groups from a newspaper and you join in and it’s a bunch of 95-year-olds and above. That would not be advisable to a 49-year-old. So if they contacted the Parkinson Society of Canada or the regional offices they might be able to have a young-onset group or have a conference coming up soon that makes it easier for them to get into the Parkinson world.”

Jordan Chicholm
As alluded to by Jordan in a previous passage, there is a lot of value placed on the information and insight from other younger people living with the disease. This makes sense given that many of the issues, concerns and priorities are different for younger people living with Parkinson’s. The opportunity to speak with and get to know others who have lived with Parkinson’s from a younger age was described as an incredible support, even an anchor, for participants.

“I would say talk to people that have it. Just to get a feel of what is going to happen next or even from the mental side of things – There’s always the ‘what ifs.’ Those questions entered my mind, so I’m sure they enter everyone’s mind. So that person could say to them, ‘I went through those, here’s what I did.’ The doctor is going to give them the news, but that person is going to go home and the questions aren’t gonna come for the next 24 to 36 hours, but then they’re gonna flood in. So a mentor or a peer group, yeah, I think that’s the key.”

Danny Pirie

“When you talk to people who have never experienced it, they don’t really know ... they’re not living it. When you’ve never experienced it, I think it’s much harder for them to give advice.”

Shanna Mellins

“Sometimes the best resource is your support group or someone you know who has Parkinson’s.”

Joella Kline
Although face-to-face contacts were preferred by participants, those of you using popular social media outlets like Facebook, Google Groups and Twitter will also be able to find support from others with YOPD online. In many cases, Groups or Feeds have been set up specifically for those with YOPD. As with any online activity, it is always important to keep your own security at the forefront of your mind. Although these services can be used to communicate with others living with YOPD, you should never share personal information in a public online forum (e.g., your address, phone number, etc.).

Many national organizations, such as the Parkinson Society Canada, and regional organizations like the Parkinson Society Southwestern Ontario, have their own Facebook and Twitter accounts that can be joined and followed. This is a great way to keep up to date with information coming from these organizations, and the Parkinson's world more generally.
There are many factors that will influence the extent to which family members and friends will act as supports in a person’s life with YOPD. The closeness and openness of the relationships participants had with their family and friends prior to the diagnosis being among the more obvious factors. In order for family members or friends to become supports, however, the first step involves the person with YOPD disclosing their diagnosis to those closest to them.

“My wife went with me to the hospital, and then I got the kids together two or three nights later and just was like ‘hey guys – dad’s got this. We’re gonna fight it, and life goes on, but just wanted you to be aware that if you notice things this is why, or if you notice dad taking pills this is why he’s taking pills.’ We really didn’t have a hard time with it in our family, but I know there’s got to be some out there that even just to tell their wife or spouse. There’s gonna be a change – Your body is gonna be changing, and your demeanor is gonna be changing so they better know what’s happening to you or they may think you’ve become miserable – it could really put a stress on a marriage.”

Danny Pirie
On a practical level, there are a number of other reasons for disclosing your diagnosis and soliciting support from family members and close friends. First, after disclosing you will be able to share information that you learn about YOPD and doing so will help people come to better understand the disease and the implications it can have on the things you are able to do.

“...the fact to let them, include them, in what’s going on. Show them the websites. Talk to them a little bit about your fears. Again, everybody worries about how much do you want to dwell on it so that it gets to the point where that’s what your whole relationship’s about, but you have to say ‘hey, I’m trying to find this information and this is what’s out there and no I can’t do this because this is how I feel when I do it, but we can do this together because this works better now.’”

Patti Bradner
Second, disclosing will allow you to ask close friends or family members to go with you to medical appointments, which can be very overwhelming for some people. This is illustrated by the passages from participants below speaking about the initial appointment where individuals receive a diagnosis; however, it is still important for follow-up appointments over time as well because of the potential emotional nature of the appointments and the amount of information shared.

“I think if you’re going in to meet the doctor to get a diagnosis, I think you should take somebody else with you because I do believe that it’s pretty traumatic. It’s pretty traumatic finding what you’ve got. You might think you have a good idea, but when they say the words ‘we feel you’ve got Parkinson’s’ or ‘you’ve got Parkinson’s’ or however they word it, it’s pretty devastating news. And then when the doctor explains what you’re in store for, not everybody’s in tune I don’t think at that point.” Kalvin Giles

“I’d suggest that they ask if there’s some family member with you. I was all by myself. If there’s someone who could come in and be with you so that you’ve got two sets of ears, two sets of eyes because right after I think I probably would have been a wreck.” Joella Kline
Although disclosing your diagnosis to others will often open up additional supports for you, in the passage below Derek reminds us that you need to be personally ready to start disclosing outside of the group closest to you. This decision is obviously individual to each person’s own situation.

“Don’t tell everybody all at once. Don’t tell everybody until you are comfortable with yourself. You need to adjust to the news and know what it is before you start telling other people.”

Derek Daumer
Disclosure of your diagnosis to your family will also allow you to start to plan for potential implications on your employment and finances. Employment is a very important issue for younger people with PD, because of the impact the disease can have on the ability to continue to work over time. Setting up a discussion to talk about financial planning is, therefore, important to initiate after receiving the diagnosis. You may even wish to consult a financial planner or accountant to receive professional advice on planning your finances and to review insurance benefits you might have through your employer.

“Look closely at your financials – you just need to know what’s there and what isn’t and what you’re gonna do about it. A lot of people continue to work. They’re lucky they can continue to work. Or they can go on a disability. Especially young-onset because you could use your whole retirement up.” Joella Kline
Although employment rights for those with a disability have improved over time because of policy changes, such as the Ontarians with Disabilities Act, a number of problems can still occur in receiving workplace accommodation or a disability pension. Given the importance of being able to access these types of programs when you need them, it may be advantageous to seek out the advice of a legal expert for support when problems arise or to just know your rights ahead of time after your diagnosis.

"I would get information from a lawyer if there was one that was willing to help, like an employment lawyer who has dealt with it where people have lost their jobs. Because that's huge with young-onset ... I was fortunate because my employer was very accommodating. However, getting access to a disability pension was another story. You should have heard the way this case worker spoke to me. She brought me to tears. She brought more stress on me than the diagnosis ... they were really pressuring me to go back to work." Shanna Mellins
Family & Individual Counselling

Talking with your children about your diagnosis can be difficult, and depending on the age of your children it may be difficult for them to understand the implications of the diagnosis. If you do decide to disclose to your children soon after receiving your diagnosis, it will be important to always express hope and monitor their reactions over time. In some cases where difficulty arises, it is advisable to find a family counsellor who can help you and your family work through any issues that do develop.
“I ran into problems with my son because he didn’t want me to go to school with my cane. And he was just devastated because his dad left, and he was left with a sick mother. And he had a lot of trouble – I mean, he was fine at home; but he didn’t want any of his friends to know. So that was hard. That was really hard, and he wouldn’t even say the word ‘Parkinson’s.’ He said, ‘I don’t think you should come to my basketball games anymore.’ So that kind of surprised me. I thought how do I deal with this? And sometimes these things come right out of the blue. It’s like wow. I didn’t expect that to happen ... So you might want to think about getting someone who’s a counselor for your family, someone who knows about Parkinson’s and other movement disorders. They’re out there. You just have to scratch the surface a little bit.” Joella Kline

Although YOPD is a disease that affects the whole family, participants also spoke of the need to sometimes seek individual counselling to help navigate the feelings and emotions that can occur after receiving the diagnosis.

“Therapy is definitely a good alternative ... You can’t do it alone. You’re not thinking straight. Your thinking at the beginning of the future and what’s going to happen and how’s it going to affect me. Everything piles on you at once ... You need someone that’s separate, who isn’t emotionally attached ... someone to talk to outside of your immediate family ... to help you sort things out.” Shanna Mellins

It is very common for those living with a chronic illness to seek out some sort of counselling, so you should not be concerned about potential stigma in society. If you believe you stand to benefit from it, you should look into it. Depending on the type of counselling, some coverage may be provided by your provincial health coverage (e.g., OHIP) and some coverage may also be provided by supplementary health benefits for those that have them. If you think that you and/or your family would benefit from counselling, you should consult one of your physicians (family doctor or neurologist) for advice and a referral.
3. TRACK CHANGES AND QUESTIONS

One additional proactive strategy that participants spoke about was keeping a journal or a log of your experiences with medications, meals and exercise, specific questions that you have for your healthcare providers as well as main issues affecting your well-being. Examples of logs that can be used are provided at the end of this booklet. By logging your experiences, such as side effects and wearing off periods or unusual symptoms, your physician will be better able to manage changes in your medication. Given the long duration between appointments to see specialists, combined with the brevity of the appointments, it is easy to forget the questions you wanted to ask. Keeping a log of your questions will help to ensure your questions get answered.

“Take your medication as prescribed, but keep a log of your experiences so that the influences of diet and quantity of medication and timing of taking the medication can be looked at in retrospect and adjustments be made with quickness and accuracy to give you better results from the medications ... The combination of taking the drugs as prescribed and documenting the experience with those and the influence that the timing or the diet helps your quality of life along that early part of your journey.” — Denis Bartoo
“One thing is I think probably most people want all the answers all at once and you’re never gonna get all those answers at once. I think you just have to write down your questions.” Patti Bradner
4. KEEP ACTIVE

One of the most common pieces of advice given by those participating in this study was to stay active. Staying active was a way for people to help maintain their level of functioning over time, and there is certainly a body of research that supports the importance of regular exercise. The type of activity done by each individual will vary with their preferences, but the most important thing to do is to remain active and do things that you enjoy.

“Exercise, exercise, exercise. I can’t say that enough. Find something you like and just do it ... I’m always amazed at how I’m so much more positive when I exercise and I get up the next morning and just feel great. And it’s so unusual for a Parkinson’s person to – you know – feel great.” Joella Kline

“Exercise as much as you can ... if you asked me if I learned anything, is to keep active, to keep active and keep involved.” Kalvin Giles

“Exercise is my new drug for Parkinson’s. It has made such a difference for me.” Trevor Lyon
5. VOLUNTEER FOR RESEARCH ON PARKINSON’S

Described by a number of participants was the importance of volunteering for research studies that seek to improve clinical care and, more generally, the lives of those living with YOPD. This advice booklet, for example, would not have been possible without the time invested by participants. Unfortunately, many Parkinson’s studies have difficulty recruiting enough participants, despite the benefits that can result from the research.

“We need to support whatever research efforts are available ... it helps yourself and the cause in general. It can lead to empowerment and also increases your interaction with health professionals. It is hugely disappointing that 30% of clinical trials don’t even recruit a single patient and a greater percentage are being delayed because of trouble with recruitment.”

Suzanna Viles

“Clinical trials and other research are providing a lot of reason for hope.” Trevor Lyon

If you are interested in learning more about Parkinson’s research being done in your area, please use the resources on the next two pages. You may also contact the nearest university in your area, or ask your neurologist, to find more information about ongoing Parkinson’s research.
Parkinson Society Canada — Offers an excellent overview of terms used in clinical research as well as some studies currently seeking participants. To access this part of the site, click on “Research” then on the left side bar “Clinical Trials.” This will open an addition option for a page called “Studies Seeking Participants”
http://www.parkinson.ca/

Health Canada’s Clinical Trial Database — Acts as a searchable public database of ongoing clinical trials in Canada, largely involving pharmaceuticals and biological drugs. This site is not Parkinson’s-specific, so you will have to search using the word “Parkinson’s” in the search box in addition to other information to limit your search.

National Institutes of Health: Clinical Trials — Offers resources to learn more about clinical trials and also acts as a database of ongoing research needing participants and completed research. This site is not Parkinson’s-specific, so you will have to search using the word “Parkinson’s” in the search box in addition to other information to limit your search. Although the NIH is based in the US, many studies also have collaborators and data collection sites in different parts of Canada.
http://www.ClinicalTrials.gov
Fox Trial Finder – After creating an account, you will be able to search for Parkinson’s research in a number of different countries, including the US and Canada, searchable by postal code. Even those without Parkinson’s disease can create an account and participate in research.

PARTICIPATE IN RESEARCH.
BE AN AGENT OF CHANGE.

FOX TRIAL FINDER
THE MICHAEL J. FOX FOUNDATION FOR PARKINSON’S RESEARCH
WWW.FOXTRIALFINDER.ORG
6. WHAT NOT TO DO

Although the focus of this booklet has been on being proactive and the different strategies one can employ to help manage after receiving a diagnosis of YOPD, some participants also thought it was important to highlight specific things that you should not do after diagnosis.

On Making Changes

“You just found out that you got Parkinson’s. Don’t panic ... There is no need to rush into changing your life drastically. You already have to deal with uncertainty. So selling your house, resigning from your job, et cetera, will just make life more complicated ... I think it would probably be in everybody’s best interest to not get ahead of yourself. Like, just deal with what you’re dealing with now. If it’s just a bit of trembling in your fingers, or you’ve got a stiff neck just deal with that.” Joella Kline

On Struggles

“Don’t expect yourself to be optimistic all of the time ... Sometimes I get upset with myself after having a down day, but I have to recognize I’m only human and I’m going to have down days. Those down days are normal.” Suzanna Viles

“Don’t beat yourself up. And I’m not quite sure what that means totally, but I think take your time, give yourself a break every once in a while. You don’t have to be – not every little thing is a sign of bad things to come” Patti Bradner

“Don’t be hard on yourself as far as getting your life back together. It takes time, and it takes different amounts of time and different things that are going to make it right for people. It takes more time for some than others ... You have to give yourself time ... You need time to grieve and learning to cope with what you have ... It’s not a death sentence, it’s something you have to adapt to over time.” Shanna Mellins

And Most Importantly

“Don’t underestimate yourself.” Joella Kline
RESOURCES

Some Online Resources

The following is a list of some of the resources that participants in this study found useful to consult while becoming knowledgeable about YOPD and the supports that are available. This by no means represents all of the resources and supports available for those living with YOPD, and they will only continue to grow over time.

CANADA

- Parkinson Society Canada - [www.parkinson.ca](http://www.parkinson.ca)
- Regional Offices of the Parkinson Society Canada also have their own websites and resources, including the:
  - Parkinson Society British Columbia
    [www.parkinson.bc.ca](http://www.parkinson.bc.ca)
  - Parkinson Society Central & Northern Ontario
    [www.parkinsonCNO.ca](http://www.parkinsonCNO.ca)
  - Parkinson Society Southwestern Ontario
    [www.parkinsonsociety.ca](http://www.parkinsonsociety.ca)
  - Parkinson Society Ottawa
    [www.parkinsons.ca](http://www.parkinsons.ca)
  - Parkinson Society Quebec
    [www.parkinsonquebec.ca](http://www.parkinsonquebec.ca)
  - Parkinson Society Maritime Region
    [www.parkinsonmaritimes.ca](http://www.parkinsonmaritimes.ca)
  - Parkinson Society Newfoundland and Labrador
    [www.parkinsonnl.ca](http://www.parkinsonnl.ca)
- *E-ParkinsonPost: For Canadians Living with Parkinson’s*
  [http://parkinsonpost.com](http://parkinsonpost.com)
TO USE

USA

- American Parkinson Disease Association
  www.apdaparkinson.org
- National Young Onset Center
  www.youngparkinsons.org
- Davis Phinney Foundation for Parkinson’s
  http://www.davisphinneyfoundation.org/
- MedlinePlus
  http://www.nlm.nih.gov/medlineplus/
- Michael J Fox Foundation for Parkinson’s Research
  https://www.michaeljfox.org
- National Institute of Neurologic Disorders & Stroke
  www.ninds.nih.gov
- National Parkinson Foundation
  www.parkinson.org
- Parkinson’s Action Network
  www.parkinsonsaction.org
- Parkinson’s Disease Foundation
  www.pdf.org/

OTHER

Designing a Cure - http://www.designingacure.com/
European Parkinson’s Disease Association - http://www.epda.eu.com/en/
Parkinson’s UK - http://www.parkinsons.org.uk/
The Parkinson Hub - http://www.theparkinsonhub.com/
The Cure Parkinson’s Trust - http://www.cureparkinsons.org.uk/
World Parkinson Congress - http://www.worldpdcongress.org
World Parkinson Disease Association - http://www.wpda.org
**Daily Log for Medications, Meals & Exercise**

NAME: ____________________________  
DATE: _________ (Month) _________ (Day) _________ (Year)  
PAGE: ___ of ___

**NOTE:** It is not required to track every day between physician appointments as this would be too cumbersome. Try to track 2-3 times per week so that information on both 'good' and 'bad' days can be obtained.

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<thead>
<tr>
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<td>Describe the medication(s) taken and dosage(s), all food ingested, or the exercise completed at this time of day.</td>
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Questions for My Next Doctor's Appointment

NAME: _______________________
DATE OF MY NEXT APPOINTMENT: ________ (Month) ________ (Day) ________ (Year)

NOTE: Given that your time with your physician is sometimes limited, try to rate the importance of each of your questions so that you ask the most important questions first.

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Page 44
Young-Onset Parkinson's Disease: Advice for Physicians From Individuals Living With YOPD

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Produced in London, Ontario, Canada

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ACKNOWLEDGEMENTS

First and foremost, I am indebted to the 39 people living with young-onset Parkinson’s disease (YOPD) who took part in this project, dedicating hours of their own time, inviting me into their lives and sharing their wisdom with me for others to read. Without all of you, the project and this booklet would not have been possible.

Beyond those who took part in this study, there is a mass of people that deserve thanks and acknowledgement for their contributions. My doctoral advisory committee, consisting of Dr. Sandi Spaulding, Dr. Mary Jenkins and Dr. Debbie Laliberte Rudman were instrumental in providing feedback on my research and this booklet as it progressed from an idea to a product.

I would also like to thank Dr. Soania Mathur for writing the foreword to this booklet and providing constructive feedback on the development of certain sections, including some of the tools provided at the end of this booklet. Lily Cappelletti at the Michael J Fox Foundation also deserve thanks for sharing some of the images that were included in this booklet.

Of course, I cannot end these acknowledgements without thanking my wife, Kelly, for her unwavering support and feedback on my research and this booklet as they moved through different stages of development.

Michael Ravenek,
PhD (Candidate)
A special thank you goes to the Parkinson Society Canada and the Canadian Institutes of Health Research who provided funding for my research in the form of a Doctoral Research Award. The staff at the Parkinson Society Southwestern Ontario were also instrumental in supporting my research, helping with recruitment and providing space at conferences to conduct some of my focus groups.
FOREWORD

As physicians we are not immune to the burden of disease as I experienced at the age of 27 when what initially began as an intermittent, mild rest tremor evolved into a diagnosis of Young Onset Parkinson’s disease. Over the last 15 years I have not only come to accept this diagnosis but also to live well despite the daily challenges this disease presents. Having a medical background gives me a rather unique perspective on how chronic disease affects our life experience and what patients need to do in order to maintain their quality of life.

A diagnosis like young onset Parkinson’s disease, is usually met with a myriad of emotions, predominately anger, uncertainty and fear. As the bearers of this news, we in the medical profession are held to a certain level of expectation. Expectation that is also part of the modern version of the Hippocratic oath which states: “I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist’s drug.” a statement that the vast majority of physicians hold true. Although competent and complete care of the patient is paramount, it is this “art of medicine” that makes a significant impact on a patient’s ability to cope and move forward following a life altering diagnosis such as Parkinson’s.

And they must move forward. Patients cannot be passive bystanders and expect to live well with Parkinson’s. There are many interventions that motivated individuals can implement in order to lessen the physical, emotional and social impacts of this condition. And as physicians we play an integral role in this process. Likewise the effectiveness of a physician’s management strategy is enhanced by a patient’s involvement resulting in improved health outcomes.

By encouraging your patients to engage in self-care, setting goals and designing care plans, this disease can be better managed leading to an improvement in quality of life parameters. Because that is what is truly important – quality of life. Until a cure is found, we must do what we can to maintain our patients’ independence, productivity and positive life experience. We must empower them to take back some measure of
control in what may seem to them to be an uncontrollable situation.

To facilitate this level of involvement particularly in the newly diagnosed patient requires education, support and a multi-disciplinary approach. They are facing a progressive illness in the prime of their lives, at the height of their careers, while raising a sometimes young family and as they are building their financial security.

At the time of diagnosis, patients often look to the medical community to serve as a primary source for information and guidance, which although not unreasonable, is sometimes difficult due to time constraints and the number of vital clinical issues that need to be addressed in the time allotted. The testimonials in this booklet attest to the fact that patients do understand to some degree these limitations but feel dissatisfied with their clinical encounter if they leave with what they feel is insufficient information. So if there is not enough time within the appointment, then reliable and informative written material, community or online resources serve an important role.

We can learn a lot from patient narrative and from the input of those interviewed for this booklet, I am reminded of one important caveat - that although we may diagnose any number of patients with a chronic disease such as Parkinson's on a daily basis, for that particular patient and their family, it is the one and only diagnosis. We cannot underestimate the significant impact of those simple words "You have Parkinson’s Disease" and the feelings of fear and confusion that inevitably follow. This booklet and the testimonies herein are reminders of this important role we play in supporting our patients throughout this experience.

Dr. Soania Mathur
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BACKGROUND

“I think when you get the diagnosis, your life sort of stops. I remember leaving the doctor’s office and I must have ran out because I remember his secretary saying ‘Don’t run.’ But there were some people in the waiting room and I just needed to blow. I needed to get out of there. I went into the hallway and I was pacing and I said ‘What does this mean? Now what?’ ... Because at that point you don’t really know what it means ... You have to deal with your kids, you have to deal with your job, you have to deal with getting up every day and all the things you’re supposed to do and then deal with this at the same time. And there’s no instruction book on how to do that. You don’t know where to turn.”

Shanna Mellins

As alluded to in the passage from Shanna above, the needs of those with young-onset Parkinson’s disease (YOPD) are unique. Being diagnosed with a chronic, progressive neurological condition in the prime of life is likely to be a very emotional experience. They may have children, they are likely still working and on top of these life stresses they now have YOPD. As a resource for physicians, this booklet is full of advice from those who have been living with the disease and were willing to share their reflections based on their own experiences.
How Was This Booklet Developed?

This booklet is a product of the work completed by Mike Ravenek and the participants in his study investigating the experiences of individuals living with YOPD. Thirty-nine individuals who self-identified as living with YOPD, primarily from Southwestern Ontario, took part in the study over a two-year period from the fall of 2011 to the fall of 2013. To contribute to the study, participants had the option of participating in a series of interviews with Mike and engaging in online and/or in-person groups discussing issues related to their experiences and the evolving results of the study.

At the conclusion of the interviews in the early stages of data collection, participants were asked specifically what advice they would give to a physician responsible for diagnosing and treating a person with YOPD, as well as what advice they would give to someone newly diagnosed with the disease. Additionally, the focus group and interview participants in the later stages of this project reviewed the advice compiled and added to this knowledge base with their own thoughts and experiences. This booklet represents the collective voice of the participants and the advice they had for physicians in diagnosing and treating those with YOPD. Advice that participants wished to relay to others newly diagnosed with YOPD is presented in a separate booklet.
The specific passages included in this booklet were taken from participant interviews and group discussions, as they do a good job illustrating the main pieces of advice that were raised by all of those who took part in this study as a whole. Additionally, the passages represent responses from participants with a range of experience living with YOPD, from 1-year to 11-years post diagnosis. Brief demographic information about the participants whose advice was included in this booklet is provided below, along with pseudonyms (false names) to protect the identity of these participants.

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<th>Name</th>
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<th>Current Age</th>
<th>Years Living with YOPD</th>
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INTRODUCTION

This booklet is not intended to be prescriptive in how diagnostic encounters with young adults with PD should be handled, as every person and situation is unique. Information appropriate for one person may not be appropriate for another, as within YOPD there is great diversity of ages represented, as well as differences in life experiences, education, personalities, etc. Rather, the purpose of this booklet is to highlight specific areas of the physician-patient interaction that all physicians should consider in their encounters with individuals with YOPD. These areas were emphasized by individuals with YOPD who took part in this study, reflecting on their own experiences being diagnosed and living with the disease. The passage above from an interview with Denis captures the essence of this booklet and the advice that participants in this study had for physicians. That is, a diagnosis needs to be relayed with compassion and the information presented should provide hope and give the patient tools to manage with YOPD as they learn to adjust living with their condition. This booklet is organized into five sections, with each section building on the one previous to it, emphasizing this message.
“Physicians need to realize that they are a human just as the patient is, and they need to think about how they would like to have such a message delivered to themselves with a certain level of caring, a certain level of information, a certain level of professional distance being maintained, a certain level of hope to be instilled for there being resources to assist a person in their journey.”

Denis Bartoo
At the centre of the advice dispensed by participants was the need for physicians to better appreciate the emotional nature of the diagnosis experience for individuals with YOPD. The figure below is a creative representation of the most common words used by the participants who took part in this study to describe their diagnosis experiences.

Speaking of the appointment where she received her diagnosis, Joella recalls:

“I was a mess and I don’t think they realized that. I mean this is a totally life-changing thing for this person who you’re gonna tell they have Parkinson’s. So you’ve got to spend as much time – I would say at least half of the time not just doing the medical, you’ve gotta sit down and talk with them and just say, ‘you know these are some of the things you might want to think about and you might want to look into.’” Joella Kline
While acknowledging that physicians have a lot to deal with when delivering a diagnosis, Danny reiterates that the emotional part of caring for a patient with YOPD should never be overlooked.

“They’re inundated with all kinds of stuff that I think they tend to forget. They’ve given you the diagnosis; they started you on the pills, and they think, ‘okay this guy is as good as he can get now.’ Well, physically he probably is, but mentally I don’t think he is there. Don’t underestimate the issue of the emotional part because that can be huge, sometimes I think worse than the physical.” Danny Pirie

It was believed that one of the most important things that the physician can do after delivering a diagnosis of YOPD is to normalize the difficult and troubling emotions that patients are likely to experience.

“He did take his time with the diagnosis and he’s really great. But, yeah, it’s the aftermath – the aftermath, you know. Just say, ‘it’s okay to be panicking, it’s okay to be in shock, you know that’s normal.’” Joella Kline

A second strategy that will help patients to deal with the difficult emotions of a diagnosis is to provide them with information about the disease; and more specifically information that will foster hope and a belief in the ability to manage with YOPD. These points will be discussed in more detail in the sections that follow.
2. THE PHYSICIAN AS A HEALTH INFORMATION GATEKEEPER

Although many people access health information on the Internet, in many ways the physician is still seen as the main ‘gatekeeper’ of health information. People expect guidance from physicians on what to do and where to go for appropriate health information, and neglecting to provide this guidance will sometimes leave patients without the knowledge of where to go to find help.

“He’s the one that ultimately gives the diagnosis, provides the treatment and of course people rely on that and a lot of people too much so because they don’t have any other avenue to know where to look for information.”

Patti Bradner

Of course the most difficult question to answer is “how much information do I provide to a patient?” The participants of this study recognized the difficulty of this situation, as described in the passage below by Patti:

“You don’t want to flood them with information because the person may not be ready for it, but there’s got to be sort of a way of getting that information as they need it. I guess that’s the hard part.”

Patti Bradner
3. PROVIDING HOPE THROUGH INFORMATION

Upon receiving a diagnosis of YOPD, it is not uncommon for patients to have little or even no knowledge of the disease and, thus, what the future will hold. Often, these patients will think the worst and have concerns about their own mortality. It is important at the point of diagnosis, as described by the participants in the passages below, to inform the patient that YOPD is not fatal and that there are strategies that can be used to manage living with the disease.

“I guess maybe it would be it’s not a death sentence. You may think it is, but it’s not.” Joella Kline

“I think most people rely on their doctor to have the info. I think it’s important that the doctor not give the impression that there’s nothing you can do. Parkinson’s, there’s a lot you can do. Because I think people just think that it’s sort of a terminal stamp. I’m not gonna die, but I’ll be changed.” Patti Bradner

In addition to calming fears about mortality, it is also important to emphasize the heterogeneity of YOPD to try and reduce fear likely to arise when the patients learn about all of the potential symptoms of the disease and/or see others living in the later stages of the disease.

“One of the things that I hear about is that people are afraid to go to any Parkinson activities because they see older people and it scares them. It is scary if you think about being like that in ten years or so ... Some persons don’t go to a Parkinson conference until they realize that everybody is different. Always stress the fact that everybody is different, so they don’t waste their time thinking that they’ll be like that because you won’t be; you might be something completely different.” Jordan Chicholm
Providing Information About Ongoing Research & Clinical Trials

A nother way to provide hope to your patients with YOPD is to emphasize the extensive research being conducted to help improve clinical care and the lives of those living with YOPD.

“In order to generate a better outlook for a person newly diagnosed with YOPD, it would be good if the MD delivered a brief statement to the effect that a high volume of research into a better understanding of PD is underway worldwide and that a plethora of exciting and novel treatments are in development with the ultimate aim of finding a cure. Again, words such as this are of prime importance to a person newly diagnosed with YOPD since it will give them hope.”

Trevor Lyon

You may even wish to become familiar with the clinical trials and research being done on Parkinson’s in your area, so that you can help your patients get involved if they desire. The resources below will help you to locate research and clinical trials being completed in your area. You may also want to consult researchers at your local university to see what clinical trials are ongoing and recruiting participants.
Parkinson Society Canada – Offers an excellent overview of terms used in clinical research as well as some studies currently seeking participants. To access this part of the site, click on “Research” then on the left side bar “Clinical Trials.” This will open an addition option for a page called “Studies Seeking Participants”

http://www.parkinson.ca/

Health Canada’s Clinical Trial Database – Acts as a searchable public database of ongoing clinical trials in Canada, largely involving pharmaceuticals and biological drugs. This site is not Parkinson’s-specific, so you will have to search using the word “Parkinson’s” in the search box in addition to other information to limit your search.


National Institutes of Health: Clinical Trials – Offers resources to learn more about clinical trials and also acts as a database of ongoing research needing participants and completed research. This site is not Parkinson’s-specific, so you will have to search using the word “Parkinson’s” in the search box in addition to other information to limit your search. Although the NIH is based in the US, many studies also have collaborators and data collection sites in different parts of Canada.

http://www.ClinicalTrials.gov
Fox Trial Finder—After creating an account, you will be able to search for Parkinson’s research in a number of different countries, including the US and Canada, searchable by postal code. Even those without Parkinson’s disease can create an account and participate in research.

PARTICIPATE IN RESEARCH.
BE AN AGENT OF CHANGE.

FOX TRIAL FINDER
THE MICHAEL J. FOX FOUNDATION FOR PARKINSON’S RESEARCH
WWW.FOXTRIALFINDER.ORG
Providing an Information Booklet

There was a desire among the participants to leave the appointment, after being given the diagnosis, with tangible information, i.e. a booklet or package. Often this is because of the emotional nature of receiving the diagnosis and not being able to process everything immediately after being told the news. The provision of an information booklet or package was perceived by the participants as a way to ‘anchor’ them emotionally once they got home and started to process the news. Overwhelmingly, the participants desired a package with resources they can draw on for support, both emotional support and informational support, instead of a package filled with facts about the disease. With all of the participants, this was not something done for them when they were diagnosed. The companion booklet to this series, YOPD: Advice for the Newly Diagnosed, has been designed as a potential information package that can be provided to individuals newly diagnosed with YOPD.

“...It would have been nice if the doctor had been able to say, ‘here’s a little package’ — like a brochure, flyer, booklet or something that you could use to call a person and start that process to find information ... I would have liked to have seen more support early on. I did find some stuff myself, but there was a lot of time missed and a lot of loneliness, as I would call it. And again, the doctor was doing the best that he could, but he didn’t take it that step further. It would be nice to have that with all doctors. Just to know that you’re not alone, that there are people that you can talk to; that would have been huge in the first week. You do go through quite an emotional ride ... That would be something that would be nice if there was a structured thing saying, okay, once you are diagnosed, or at least strongly potentially diagnosed, ‘here’s a package.’” Danny Pirie
4. THE IMPORTANCE OF FOLLOWING-UP AFTER GIVING A DIAGNOSIS

Perhaps just as common as a belief in the importance of being provided an information booklet upon diagnosis was the belief that it would be invaluable for a physician, or the physician’s office, to follow-up with a patient after being given a diagnosis of YOPD. Again, the perceived value of this advice was recognized by participants of this study after going through the diagnosis experience and not receiving this type of support themselves.

“I would recommend the doctor schedule an appointment with the patient for a couple of days hence, maybe even a week, to call the patient again and say, ‘How are you doing? You’re not on this journey alone. How did you make out with contacting the Parkinson’s Society? ... That follow-up effort, I think, would be huge in its importance to the patient and it could be the nurse that does it.” Denis Bartoo
“There’s not one doctor I don’t think that doesn’t care about their patients, but I think it becomes – maybe over time they probably diagnose every day. It becomes like you and I having a cup of coffee. I don’t think they really totally realize the impact of what they just said to that patient at that moment in time. And it’s not that moment in time that bothers me; it’s the 24 to 36 hours after that. This person is going to have more issues after they leave the office than when they just sat down … I would suggest things like a follow-up visit a week later. It wasn’t done for me I can tell you that, but a week or so later just to follow-up and say okay, ‘it was pretty big news you just got a week ago, is there anything I can help you with? Do you have any questions?’ I wouldn’t leave it for three months after. Make time for that patient for another 10 minutes … I’m not saying overload the doctor more than they are now, but I honestly think that one extra visit for that 10-minute window would be huge for the patient, I really do.”  *Danny Pirie*  

Although it would be desirable for the diagnosing physician to be the person following up with the patient, the participants of this study recognized that there are time pressures facing physicians. In lieu of the physician, the medical office could have a dedicated support person to complete the follow-ups by answering questions and helping to provide initial support after diagnosis.

“It would be really nice if you could have a staff member sit down with you and give you some places that you could get information from and just get your feet on the ground a little bit. And sort of run past you what you should be thinking about right now.” *Joella Kline*
5. INSTILLING A PROACTIVE ATTITUDE

To help patients manage after the diagnosis, seeing that YOPD is manageable and not fatal, it is important to promote behaviors that will help your patients start to be proactive in managing their illness. The importance of developing a proactive approach was the main message in the companion booklet in this series, where individuals taking part in this study relayed advice they would give to those newly diagnosed with YOPD.

Simple things a physician can promote are the importance of exercise, participating in research, keeping a log of symptoms and medication side effects, and keeping track of their questions. Examples of logs that can be provided to patients are provided at the end of this booklet, and are also included in the companion booklet in this series.

“Knowing that it’s the Dopamine cell damage doesn’t help me cope with it. I can’t just babysit them and bring them back to life. That’s not the important information anyway, but how to manage symptoms by exercise or having therapy to be nimble and not atrophy and things like that. That’s more needed information. It's changing the quality of life of the person living with Parkinson’s.”

Jordan Chicholm
The following is a list of some of the resources that participants in this study found useful to consult while becoming knowledgeable about YOPD and the supports that are available. This by no means represents all of the resources and supports available for those living with YOPD, and they will only continue to grow over time.

**CANADA**

- Parkinson Society Canada - [www.parkinson.ca](http://www.parkinson.ca)
  - Regional Offices of the Parkinson Society Canada also have their own websites and resources, including the:
    - **Parkinson Society British Columbia**
      [www.parkinson.bc.ca](http://www.parkinson.bc.ca)
    - **Parkinson Society Central & Northern Ontario**
      [www.parkinsonCNO.ca](http://www.parkinsonCNO.ca)
    - **Parkinson Society Southwestern Ontario**
      [www.parkinsonsociety.ca](http://www.parkinsonsociety.ca)
    - **Parkinson Society Ottawa**
      [www.parkinsons.ca](http://www.parkinsons.ca)
    - **Parkinson Society Quebec**
      [www.parkinsonquebec.ca](http://www.parkinsonquebec.ca)
    - **Parkinson Society Maritime Region**
      [www.parkinsonmaritimes.ca](http://www.parkinsonmaritimes.ca)
    - **Parkinson Society Newfoundland and Labrador**
      [www.parkinsonnl.ca](http://www.parkinsonnl.ca)
  - **E-ParkinsonPost: For Canadians Living with Parkinson’s**
    [http://parkinsonpost.com](http://parkinsonpost.com)
TO USE

USA

- American Parkinson Disease Association
  www.apdaparkinson.org
- National Young Onset Center
  www.youngparkinsons.org
- Davis Phinney Foundation for Parkinson’s
  http://www.davisphinneyfoundation.org/
- MedlinePlus
  http://www.nlm.nih.gov/medlineplus/
- Michael J Fox Foundation for Parkinson’s Research
  https://www.michaeljfox.org
- National Institute of Neurologic Disorders & Stroke
  www.ninds.nih.gov
- National Parkinson Foundation
  www.parkinson.org
- Parkinson’s Action Network
  www.parkinsonsaction.org
- Parkinson’s Disease Foundation
  www.pdf.org/

OTHER

Designing a Cure - http://www.designingacure.com/
European Parkinson’s Disease Association - http://www.epda.eu.com/en/
Parkinson’s UK - http://www.parkinsons.org.uk/
The Parkinson Hub - http://www.theparkinsonhub.com/
The Cure Parkinson’s Trust - http://www.cureparkinsons.org.uk/
World Parkinson Congress - http://www.worldpdcongress.org
World Parkinson Disease Association - http://www.wpda.org
### Daily Log for Medications, Meals & Exercise

**NAME:**

**DATE:** _______ (Month) _______ (Day) _______ (Year)

**PAGE:** ___ of ___

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**NOTE:** It is not required to track every day between physician appointments as this would be too cumbersome. Try to track 2-3 times per week so that information on both ‘good’ and ‘bad’ days can be obtained.

<table>
<thead>
<tr>
<th>Time of Day</th>
<th>Activity (Check One)</th>
<th>Description of Activity</th>
<th>Did You Experience Unusual Symptoms or Side Effects After this Activity?</th>
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365
Questions for My Next Doctor’s Appointment

NAME: __________________________
DATE OF MY NEXT APPOINTMENT: ________ (Month) ________ (Day) _______ (Year)

NOTE: Given that your time with your physician is sometimes limited, try to rate the importance of each of your questions so that you ask the most important questions first.

<table>
<thead>
<tr>
<th>#</th>
<th>Question for Doctor</th>
<th>Level of Importance to Me (Check One)</th>
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</table>
Curriculum Vitae

Name: Michael J. Ravenek

Post-secondary Education and Degrees:

Wilfrid Laurier University
Waterloo, Ontario, Canada
2004-2008 Hon. B.A.

The University of Western Ontario
London, Ontario, Canada
2008-2010 M.Sc. (OT)

Western University
London, Ontario, Canada
2010-2014 Ph.D.

Honours and Awards:

Ontario Graduate Scholarship

Canadian Institutes of Health Research
Doctoral Research Award
2011-2014

Related Work Experience

Sessional Instructor
Western University, School of Occupational Therapy
Summer 2013

Sessional Instructor
Western University, School of Health Studies
Winter 2013

Executive Director
Canadian Society of Occupational Scientists
2010-2013

Programs and Services Assistant
Parkinson Society Southwestern Ontario
2011-2012
Publications:


LaDonna, K.A. & Ravenek, M.J. Challenges and strategies when conducting qualitative research with persons diagnosed with rare movement disorders. The Qualitative Report, In Press.


