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An intangible reality: the experience of uncertainty among intimate partners of persons with prodromal huntington disease

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AN INTANGIBLE REALITY: THE EXPERIENCE OF UNCERTAINTY AMONG INTIMATE PARTNERS OF PERSONS WITH PRODROMAL HUNTINGTON DISEASE

by

Meghan L. McGonigal-Kenney

An Abstract

Of a thesis submitted in partial fulfillment
of the requirements for the Doctor of
Philosophy degree in Nursing
in the Graduate College of
The University of Iowa

July 2011

Thesis Supervisor: Associate Professor Howard K. Butcher

ABSTRACT

Knowledge of genetic predisposition to future illness and disability creates uncertainties that shape and influence life decisions about reproduction, career, health behavior, and the need for care. Current research has not yet identified the meaning of the experience of feeling uncertain among intimate partners of persons who have received genetic information pertaining to future health status. The purpose of this phenomenological study was to understand the meaning of uncertainty as a lived experienced among intimate partners of persons who have tested positive for a mutation in the gene causing Huntington disease (HD) but have not yet been clinically diagnosed with HD. The specific aims were to create a rich, vivid description of uncertainty as experienced by this population and to present these findings within an existential phenomenological perspective. Using van Manen's hermeneutic-phenomenological methodology, experiential descriptions from 10 intimate partners of persons in the prodromal phase of HD were obtained. Thematic aspects of the lived experience of uncertainty were uncovered and isolated; essential themes were determined; and linguistic transformations were composed. The analysis revealed four essential themes, indicating that the meaning of the lived experience of uncertainty was 1) an *intangible reality* characterized by 2) *anticipating with ebbing and flowing disquietude* while feeling 3) *a weighty pull to dwell upon, towards inner turmoil* and 4) *a subdued presence with freeing possibilities*. The implications of these findings are that nurses need to ensure adequate opportunity is created in which the meaning of the lived experience of uncertainty can be ascertained and explored among persons who are on the cusp of the inevitable but not yet graspable. Continued research is needed to further address the implications of being situated in this potentially fracturing phase of the disease trajectory and to determine appropriate interventions.

Abstract Approved: ____________________________________

Thesis Supervisor

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Title and Department

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Iowa City, Iowa

CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph.D. thesis of

Meghan L. McGonigal-Kenney

has been approved by the Examining Committee
for the thesis requirement for the Doctor of Philosophy
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Toni Tripp-Reimer

To the people who participated in this study, for sharing their lived experiences with me

When we turn our lens on the human family, we are drawn more deeply into its richness and turmoil. Something of the other seeps into our lives, stakes its claim in the shafts of our conscience. Our questions deepen as we image life’s tragedies, focus on its terrors. How do I shoot to reveal the light?

Jan Phillips
God Is at Eye Level: Photography as a Healing Art

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ABSTRACT

Knowledge of genetic predisposition to future illness and disability creates uncertainties that shape and influence life decisions about reproduction, career, health behavior, and the need for care. Current research has not yet identified the meaning of the experience of feeling uncertain among intimate partners of persons who have received genetic information pertaining to future health status. The purpose of this phenomenological study was to understand the meaning of uncertainty as a lived experienced among intimate partners of persons who have tested positive for a mutation in the gene causing Huntington disease (HD) but have not yet been clinically diagnosed with HD. The specific aims were to create a rich, vivid description of uncertainty as experienced by this population and to present these findings within an existential phenomenological perspective. Using van Manen's hermeneutic-phenomenological methodology, experiential descriptions from 10 intimate partners of persons in the prodromal phase of HD were obtained. Thematic aspects of the lived experience of uncertainty were uncovered and isolated; essential themes were determined; and linguistic transformations were composed. The analysis revealed four essential themes, indicating that the meaning of the lived experience of uncertainty was 1) an *intangible reality* characterized by 2) *anticipating with ebbing and flowing disquietude* while feeling 3) *a weighty pull to dwell upon, towards inner turmoil* and 4) *a subdued presence with freeing possibilities*. The implications of these findings are that nurses need to ensure adequate opportunity is created in which the meaning of the lived experience of uncertainty can be ascertained and explored among persons who are on the cusp of the inevitable but not yet graspable. Continued research is needed to further address the implications of being situated in this potentially fracturing phase of the disease trajectory and to determine appropriate interventions.

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CHAPTER I

INTRODUCTION

Turning to the Nature of the Lived Experience of Uncertainty

Uncertainty is a universally-lived experience (Bunkers, 2007; Cohen, 1993; Morrow, 2010; Nelson, 1996; Penrod, 2001a, 2001b). Uncertainty reflects the experience of "feeling unsure" and "not knowing" (R.R. Parse, personal communication, February 28, 2004). All humans have an idea of what uncertainty and feeling uncertain means for them in everyday life. "Uncertain" is used to describe common situations, including everything from stock market fluctuations to whether a medical treatment is successful. While uncertainty may be considered a phenomenon that crosses vocation, gender, race, age, socioeconomic status, marital status, and any "status" or group humans use to organize themselves and identify with, the meaning ascribed to it may vary depending on one's personal experience.

Human science, or that which is concerned with mankind, particularly in relation to historical and social factors, can be traced to the works of Dilthey (The Oxford English Dictionary, 1989). Based on a synthesis of Dilthey's and Giorgi's philosophical views of human science, Mitchell and Cody (1992) define human science as one that 1) views humans as wholes, intentional and free-willed, and participants in the creation of reality; and 2) considers human experience to be preeminent and fundamental. Human science methods focus on meaning, values, and relationships within humanly lived experience. Lived experience is defined as humans' lifeworlds as they are immediately and pre-reflectively experienced (van Manen, 1990). The questions that concern and are of interest to those engaged in human science arise from human context and must be answered within that very context. However, it is the perspective of each, individual researcher that directs him or her to the particular topic of interest and the way it is approached. The questions that drive inquiry simultaneously reflect the real and present situations faced by humans (the researched) as well as the particular perspective espoused by the researcher. The researcher's perspective underpins and is intimately linked with the choice of question to be researched, methods used to answer it, and interpretation of findings (Mitchell & Cody, 1993). My perspective is informed by van Manen's hermeneutic-phenomenology (1990). According to van Manen, the researcher must first explicate how the researcher is oriented to the phenomenon under investigation. Then he or she makes explicit his or her assumptions and pre-understandings about the phenomenon and formulates the research question.

An Orientation to the Phenomenon of Interest

I am oriented to uncertainty as the phenomenon of interest in both professional and personal capacities. In the realm of healthcare, uncertainty is an experience common to both chronic and acute illness populations (Mishel, 1997, 1999). During times of diagnosis, treatment, and recovery, patients, family members, and/or family caregivers experience uncertainty (Brown & Powell-Cope, 1991). The stress and anxiety associated with uncertainty affects patients as well as their family members and/or family caregivers, beginning with the diagnosis of illness (Cohen, 1995a) to living with a chronic condition (Baier, 1995) and, lastly, to the end of life (Pelletier-Hibbert & Sohi, 2001). As an RN, I am oriented to uncertainty and its health implications for patients. As a nurse, I share an intimate connection with persons experiencing uncertainty across the lifespan and wellness-illness continuum. One instance providing a direct experience with persons feeling uncertain stems from being involved in research in which I heard and dwelled with the stories of family members of persons clinically-diagnosed with HD and those who had tested positive for a gene mutation associated with HD but had not yet been clinically diagnosed. Huntington disease (HD) is a chronic, progressive condition characterized by neuropsychiatric, cognitive, and motor dysfunction. When asked what their concerns were, family members described uncertainty as one of them.

My personal orientation to uncertainty also reflects my stance in the world as someone concerned with health. Recently, my own experience with a health crisis provided further opportunity to think about my orientation to uncertainty. It involved determining whether a detectable mass was malignant or benign. Searching for a diagnosis and undergoing both invasive and non-invasive procedures are inherently fraught with uncertainties. I did not know the practitioner that I was required to see very well. Questions I asked myself included: Do I trust her clinical judgment? How accurate is this particular test in detecting a problem? When one test reveals nothing significant, what is the rate of false negatives? These uncertainties did not play over and over in my mind as I went about my daily activities. What did creep into my mind and haunt me, however, were thoughts of dying. If the mass was malignant, I might not live, and then what would happen? I have responsibilities I must fulfill, especially for my young child. While I have always maintained that I am not fearful of death, the uncertainty felt intrusive and disturbing enough to force me to reconsider my stance. In sum, I did not think of uncertainty in terms of my risk for malignancy, how effective treatment would be, how I would respond to treatment, and so on. In those moments, I experienced existential uncertainty. My future self was threatened. I was uncertain whether the mass was malignant or not, whether I would live or die.

Explicating Assumptions and Pre-Understandings

My orientation to uncertainty leads me to consider the biases, assumptions, and pre-conceived notions I carry. These assumptions and pre-understandings are to be considered preliminary insights which may be naïve in nature, and, as such, were re-visited throughout the course of the study and revised as needed. Based on my personal health crisis and contemplation on uncertainty as lived experience and the things I react to while reading both lay and scientific literature and viewing cinematic productions, it appears that I tend to view uncertainty through an existential lens. For example, as I read the story “Finding a Heart” by Lisa Wolfe in the February 2008 edition of *O: The Oprah Magazine*, I see existential uncertainty. The non-fictional story portrays two mothers who find themselves on a pediatric inpatient unit, each with an infant son awaiting heart transplant surgery. The etiology of each boy’s condition is different, but the feeling of being uncertain is a shared experience. Although both had grown accustomed to spending time together, as each knew why the other was there, they had not yet shared the specifics in terms of what their boys’ conditions were. Upon this realization, the author writes it didn’t matter if “facts” remained unknown. It was “far more important to have someone with whom to share the feeling: the feeling of waiting with your child as he waited for a heart, not knowing whether he would live or die” (Wolfe, 2008, p. 150).

Formulating the Phenomenological Question

While serving as a graduate research assistant on a multi-phase investigation “Family Health After Predictive Huntington Disease (HD) Testing” (Williams, Paulsen, Schutte, & Tripp-Reimer, 2001), the phenomenological question driving my research began to emerge. The study was broadly focused on family members’ concerns and strategies used to address those concerns across the HD trajectory. HD is a progressive, incurable, autosomal dominant disorder affecting 1 in 10,000 people. It affects voluntary and involuntary motor capabilities, cognition, and affect. Clinical diagnosis is made upon the onset of motor symptoms. On average, symptom onset is around the age of 40, although it could occur anywhere between childhood and later life. Death typically occurs 15 years after clinical diagnosis. Predictive genetic testing, which allows persons with a known disease in the family to clarify his or her risk for developing the disease, is an option for individuals who are at-risk for HD based upon a positive family history but have not been clinically diagnosed. The process of predictive testing takes place within a context where other family members are at-risk and/or may be assuming caregiving roles. Results from testing for HD create a unique situation relative to other predictive tests. Predictive testing for HD provides information about an illness that will certainly develop in the future, barring unforeseen circumstances, while persons are either free from obvious signs and symptoms of disease or experience only very subtle disease-related changes and maintain daily functioning for an uncertain period of time; in other words, the certainty of having a disease-causing gene mutation is intermingled with uncertainties.

Participants in the Williams et al. (2001) study were family members of persons who had received 1) a positive result from predictive genetic testing for HD but had not yet been clinically diagnosed; 2) a clinical diagnosis of HD and lived in the home; and 3) a clinical diagnosis of HD and lived in a long-term care facility. The initial phase of the study used focus group methods to explore family members' common concerns and strategies used to manage those concerns. Among the most common concerns reported across the trajectory were those related to feeling uncertain. I became particularly interested in this phenomenon as experienced by intimate partners, as questions remained about the meaning of this experience as it was lived among this particular population. While the use of focus group methods in this study allowed for an increased understanding of general experiences of being a family member of someone with the gene mutation associated with HD (#1 above) or clinically diagnosed with HD (#2 and #3 above), it did not allow for in-depth examination of primary themes, such as uncertainty.

As I began to think more about uncertainty, I wondered what it meant for intimate partners of persons who had tested positive for the HD-causing gene mutation but had not yet received a clinical diagnosis. In other words, what is the meaning of uncertainty among a healthy, young to middle-aged adult group living with the certain knowledge of a progressive, incurable condition developing in their partners at some point in their futures? What is this lived experience like for a group who may be considering educational and/or career options, intimate partner commitment, future caregiving responsibilities, and reproduction?

Purpose of Research: Specific Aims and Research Question

The purpose of the research, therefore, is to understand the meaning of uncertainty experienced by intimate partners of persons who have tested positive for a mutation in the HD gene but have not yet been clinically diagnosed with HD. Several terms have been used to describe this time period, including: prodromal, preclinical, prediagnosed, pre-HD, asymptomatic, presymptomatic, and premanifest. Researchers have more recently referred to this time period as “prodromal,” to more accurately capture subtle changes that are detectable *prior* to the full manifestation of disease, when classic clinical signs and symptoms are clearly evident and the clinical diagnosis of HD is typically made (Nopoulos et al., 2011; Paulsen, 2010). For the purposes of this study, the term “prodromal” will be used to refer to the time period between post-predictive testing and the appearance of classic clinical symptoms and consequential diagnosis. “Manifest” will be used in referencing persons who demonstrate the classic signs and symptoms of HD and, therefore, have received a clinical diagnosis of HD.

Specific Aims

The specific aims are twofold: 1) to create a rich, vivid description of uncertainty as experienced by intimate partners of persons with prodromal HD and 2) to present these findings within an existential phenomenological perspective.

Research Question

The research question driving this inquiry is: What is the meaning of the lived experience of uncertainty among intimate partners of persons who have tested positive for the HD gene mutation but have not yet received a clinical diagnosis? “Uncertainty” and “feeling uncertain” are used interchangeably in the remainder of the text. From a phenomenological point of view, it is not the concept or word that is important, but rather the experience one is trying to describe (M. van Manen, personal communication, February 25, 2009).

Intimate Partners of Persons Testing Positive for HD as the Population of Study

Due to the unpredictable age of onset, magnitude of the disease, and progressive degeneration, intimate partners of persons in the prodromal phase of HD experience uncertainty (Kessler, 1993; Sobel & Cowan, 2003; Williams, et al., 2001). It is unknown, however, what the *meaning* of that lived experience is *among intimate partners* of persons who have undergone predictive genetic testing and tested positive for HD yet have not been clinically diagnosed and, therefore, are in the prodromal phase, or the phase precursory to the manifestation of full disease. Persons living with chronic illness, such as HD, "are not only dealing with a universal aspect of the uncertain human condition, but dealing with it in exaggerated form and with severely limited options" (Wiener & Dodd, 1993, p. 18). HD may, therefore, be considered an exemplar condition in which implied certainty invokes and intensifies uncertainty among such persons, providing a natural context in which to study uncertainty as an everyday, universally-lived experience.

Extant Literature Reveals Gaps in Knowledge

The literature is replete with definitions, discussions, and conceptualizations centered on and peripheral to uncertainty. Nursing and other health-related disciplines are interested in uncertainty in clinical situations in terms of illness-related tasks and experiences, such as diagnosis, treatment, transition, and caregiving. Theories and frameworks have been developed to understand uncertainty in such situations, and a significant body of research has revealed the highly complex nature of states of uncertainty, as well as the pervasiveness of the experience in the lives of patients and their families.

Despite a notable body of quantitative research and growing but substantive amount of qualitative research on uncertainty, the extant body of scientific literature points to the need for additional inquiry on the topic. Reasons include the following: 1) there are no studies of the lived experience of uncertainty among intimate partners of persons with prodromal HD; 2) while studies have shed light on families' experiences of uncertainty in chronic illness situations, many are predicated on frameworks used to understand uncertainty in illness. Such frameworks may not be suitable for examining uncertainty experienced during the *pre-illness* period. Additionally, 3) existential aspects of uncertainty have been identified and described in terms of their importance in better understanding persons whom nurses and other healthcare providers serve (e.g., Nelson, 1996 & Penrod, 2001a). Extant theories, however, fail to address these aspects. Researchers have examined uncertainty using frameworks that account for the existential notions of uncertainty, but to-date, 4) there have been no published studies examining uncertainty from a framework allowing for such existential notions from the perspectives of intimate partners of persons who have tested positive for the HD gene mutation but have not been diagnosed and are, therefore, facing the inevitability of disease development and its implications.

Significance of Study to Nursing Science

The increasing focus on expanding genetic knowledge forces consideration of this pre-illness or prodromal phase as a psychosocial element of the evolution of the disorder itself; it is in this phase that stress from uncertainty regarding disease onset and trajectory are most salient for the person genetically predisposed and for family caregivers (Rolland & Williams, 2005). Knowledge of genetic predisposition to future illness and disability creates uncertainties that will shape and influence life decisions about reproduction, career, health behavior, and eventual caregiving. A context is created upon receiving such knowledge wherein persons involved experience uncertainty in the face of a devastating certainty. Furthermore, when testing relatively young persons for late-onset conditions, “there is a potential for problems to arise resulting from the increased number of years that a person must live with confirmed genetic knowledge of a genetic condition in their future” (Chapman, 2002, p. 365).

Intimate partners of persons with prodromal HD experience uncertainty as they are confronted with managing changes from an uncertain origin, coping with the chronic nature of a progressive condition, and coming to terms with living with the anticipation terminal illness. Yet, it remains unknown 1) how the dynamic ebb and flow in states of sustained uncertainty is experienced; 2) which aspects of feeling uncertain are most problematic or debilitating; 3) which aspects of feeling uncertain are potentially positive in nature; and 4) how nurses can identify and describe these aspects. Intimate partners are assuming greater responsibilities during the prodromal phase of HD (Decruyenaere et al., 2004) but describe very few resources to use as support (Williams, et al., 2001). Nurses must not only understand their experiences, but also their struggles with uncertainty and how it affects these experiences.

The significance of the proposed research is that it will: enhance and expand understanding of aspects of uncertainty; add to the empirical and conceptual literature on areas of uncertainty and chronic, debilitating conditions with particular focus on the prodromal phase of illness; and contribute to the development of interventions designed to assist persons privy to genetic information pertaining to partners’ future health status to live with uncertainty. Furthermore, this research may serve as a model for other disorders as genetic testing becomes increasingly available. HD is often considered to be a model for studying other circumstances in which the impact of receiving genetic information is considered (Lilani, 2005; Williams & Schutte, 2000). Two other progressive conditions for which genetic testing is offered in clinical settings are early-onset Familial Alzheimer Disease (Bird, 2010) and Frontotemporal Dementia with Parkinsonism-17, or Familial Pick's Disease (van Swieten, Rosso, & Heutnik, 2010). Understanding uncertainty from the perspective of persons in the proposed study population may also have implications for families of persons in the early or prodromal stages of a progressive, debilitating condition; family members of persons with dementia (Nichols, 2001; Teel & Carson, 2003) and HIV (Brackis-Cott, Mellins, & Block, 2003) have also reported feelings of uncertainty.

Nursing is concerned with persons' unique experiences in health and illness (Munhall & Oiler, 1986). Hermeneutic-phenomenology offers a methodology leading to a systematic understanding of human experiences as meaningfully lived. van Manen's (1990) hermeneutic-phenomenological methodology will be used to answer the research question. The end product will be a "rich and thick description…exploring [the] phenomenon [of uncertainty] in all its experiential ramifications" (van Manen, 1990, p. 152). Understanding the meaning of the lived experience of intimate partners of persons with prodromal HD is necessary for nurses to be more mindfully present, facilitating human flourishing amidst vulnerability (Bunkers, 2010). By creating a rich, vivid description of the lived experience of uncertainty, nurses can have a pivotal role in empowering families to develop caregiver skills for future needs and enhance their coping abilities to safeguard their own health and quality of life (QOL). Additionally, understanding lived experience can facilitate the creation of strategies to support carers in their roles. Such strategies may potentially include, but are not limited to, cognitive re-framing, meaning-making, or problem-focused intervention. This study will provide knowledge that will aid in the 1) identification and description of aspects of uncertainty found to be problematic and facilitative of the meaning-making process and 2) eventual development and testing of nursing interventions tailored to reflect the unique needs of families in a particular developmental cohort and psychosocial life stage.

The proposed research aims to not only contribute to the development of science-based nursing practice but also to nursing science. Given the connection between this researcher's ontological and epistemological views and choice of methodology and claim that nursing science is human science (an assertion further discussed in Chapter III), interpreting the findings from an existential-phenomenological perspective will expand nursing science. van Manen's (1990) methodology for examining human phenomenon is well suited to human science paradigms. It is, therefore, relevant to "researchers in nursing, psychology, and other such professions (p. 1)…[whose interests are to study] 'persons,' or beings that have 'consciousness' and that 'act purposefully' in and on the world by creating objects of 'meaning' that are 'expressions' of how human beings exist in the world" (p. 4). The tenets and assumptions of existential-phenomenology are congruent with the methodology. Interpreting the findings through this perspective, therefore, aims to contribute to nursing's unique body of knowledge pertaining to the lived experience of uncertainty.

CHAPTER II

BACKGROUND AND SIGNIFICANCE

Introduction

The following review of the literature begins with an overview of Huntington disease, including a discussion of predictive genetic testing and signs and symptoms. A review of scientific literature pertaining to families living with HD will highlight the 1) impact of predictive testing on family relationships, 2) couples' perceptions of predictive testing, and 3) implications of HD and predictive testing for the intimate partner. This review will shed light on the context from which subsequent inquiry flows.

The review of literature will turn to an examination of how uncertainty is used in everyday, ordinary language, since the human language may be considered "a huge reservoir in which the incredible variety of richness of human experience is deposited" (van Manen, 1990, p. 61). Definitions, synonyms, etymological sources, idiomatic phrases, and selected references to non-scientific literature pertaining to uncertainty are presented to expose lay understandings of uncertainty.

The focus will then turn to a review of the scientific literature on uncertainty. A brief discussion of the philosophical implications of quantum physics and chaos theory will demonstrate how uncertainty is viewed within the natural sciences. A more detailed, in-depth discussion will demonstrate the state of the science on uncertainty within social and human sciences by specifically focusing on nursing literature. Specifically, extant theories and/or developing frameworks on uncertainty will be outlined followed by a critical review of the literature. Lastly, my personal conceptualization of uncertainty will be explicated; existential-phenomenology was the chosen lens or framework for this study. Concepts core to this perspective and a conceptualization of existential uncertainty will be offered.

Huntington Disease: An Overview

Huntington disease (HD), sometimes referred to as Huntington chorea (from the Greek “khorei” meaning “dance”) is an inherited disease characterized by a triad of features encompassing movement disturbances, cognitive deterioration, and neuropsychiatric changes (Brandt, Quaid, & Folstein, 1989; Folstein, 1989). While a myriad of symptoms are associated with HD, each affected individual does not necessarily experience all symptoms, and there is significant variability in the number and severity of symptoms between persons (Kent, 2004; Tost, Wendt, Schmitt, Heinz, & Braus, 2004). Among Caucasians, approximately 1 in 10,000 persons are affected with HD (Hayden, 1981) while prevalence is less in mixed-white populations and significantly less in Asians and Blacks (Harper & Jones, 2002; Jorde, Carey, Bamshad, & White, 2006). Disease onset is early, relative to other adult-onset disorders; symptoms appear, on average, around the age of 40 (Hayden, 1981), although onset can range between early childhood and later life (60 years of age and older) (Osborne, Munson, & Burman, 1982; The Huntington's Disease Collaborative Research Group, 1993). In general, the onset of signs and symptoms is subtle and disease progression is marked by gradual increases in symptom severity (Harper, 1996). Clinical diagnosis of adult-onset HD is made with the appearance of involuntary movement disorder (Folstein, 1989; Snell et al., 1993). Death typically occurs 15 years after clinical symptoms appear (Harper, 1996; Rosenblatt & Ranen, 1999) as a result of aspiration pneumonia, cardiorespiratory failure, or subdural hematoma as a result of head trauma. While there are clinical trials in progress (Huntington's Disease Society of America, 2011), there is currently no cure; treatment is palliative in nature and cannot prevent, delay, retard, or end disease progression (Harper, 1996; Kent, 2004). A multidisciplinary team approach in which nurses play a key role in symptom assessment and treatment, referral, education, and family support is crucial in successfully managing this highly complex disease.

HD is an autosomal dominant disorder, meaning the responsible gene is located on an autosome and the condition is expressed in persons who have inherited one copy of the gene mutation, which is an elongated CAG repeat in *HTT*, the gene that encodes huntingtin (OMIM, 2011). Each offspring of an affected individual has a 50% chance of inheriting the gene mutation. DNA markers linked to HD were found on chromosome 4, making HD one of the first autosomal dominant disorders for which predictive testing became available (Gusella et al., 1983; Wasmuth et al., 1988). In 1993, the gene mutation associated with HD was determined to be an unstable trinucleotide (CAG) repeat in the *huntingtin gene* (The Huntington's Disease Collaborative Research Group, 1993). A negative relationship exists between number of CAG repeats and age of onset of clinical symptoms, and estimates of penetrance may be made by considering age and repeat length (Langbehn, Brinkman, Falush, Paulsen, & Hayden, 2004). Penetrance is defined as the fraction of persons with a disease-causing genotype who have signs or symptoms of disease within a normal lifetime.

It is considered normal for persons to have 26 or fewer CAG repeats. Persons with repeats falling in the range of 27-35 are not at-risk to have HD themselves but are at-risk for having a child with an expanded allele in the HD-causing range. Persons with a CAG repeat length of 36 or more are considered at-risk of developing HD. Partial penetrance is evident among those whose CAG repeats fall in the range of 36-39 (Warby, Graham, & Hayden, 2010), meaning they may not show signs or symptoms during their lifetime (Kremer et al., 1994). Complete penetrance is evident among persons with 40 or more CAG repeats, meaning development of HD symptoms is nearly certain (Warby, et al., 2010), although there have been reports of persons with CAG repeats between 40 and 41 who did not show symptoms of HD within a normal expected life span (Brinkman, Mezei, Theilmann, Almqvist, & Hayden, 1997). When transmitted through the pedigree by an affected father, the disease appears to develop at an earlier age and with increased severity; this is called anticipation. Since other genetic and environmental factors likely contribute to the variance in age of onset (Langbehn, et al., 2004; Rosenblatt et al., 2001), however, individual predictions of age of onset cannot be made based solely on number of CAG repeats.

The discovery of the gene mutation allowed direct mutation detection methods to be applied resulting in highly accurate predictive testing with nearly 100% sensitivity and specificity. While the process of testing takes place within the context of family where other members are at-risk, the implications of HD and predictive testing for HD extend well beyond biological family members. Non-biological family members of persons who are positive for the HD gene mutation are confronted with future caregiving responsibilities and vulnerabilities, managing uncertainty in finances, (Dawson, Kristjanson, Toye, & Flett, 2004; Williams, et al., 2001), symptom onset and interpretation, difficulty identifying the meaning of changes in health, decisions regarding reproduction and career, and unknown coping abilities of other family members when such challenges arise (Williams, et al., 2001).

The following discussion begins with a description of the HD trajectory; the "trajectory" is defined as the time period post-predictive testing and ending with the late stages of HD. The description of predictive testing will include motivations for testing as well as psychological implications of testing on the proband (person serving as the starting point for the genetic study of a family). Signs and symptoms specific to the prodromal, early, middle, and late stages and those that are more globally experienced will be identified. The discussion will conclude with a review of the scientific literature, presenting what is currently known about families with and, more specifically, intimate partners of persons post-predictive testing (carriers and non-carriers) and diagnosed with HD. Specifically, the impact of testing on family relationships and couples' perceptions of distress post-predictive testing will be presented. Lastly, the review of literature will highlight the burden of HD and predictive testing on the proband's intimate partner, particularly in terms of loss and uncertainty.

Predictive Genetic Testing

Predictive testing for HD has profound implications for individuals being tested, their families, and society (Evers-Kiebooms, Welkenhuysen, Claes, Decruyenaere, & Denayer, 2000). Predictive testing allows prediagnostic and/or asymptomatic individuals who have a known genetic disease in their families to clarify their risk of developing it. Results from predictive HD testing are highly accurate, with nearly 100% sensitivity and specificity, creating a unique situation compared to genetic tests which offer risk estimates with less certainty. While it is possible to determine whether an individual carries the HD gene mutation, it is impossible to predict age of onset, symptoms, course of disease, or health care trajectory. The uncertainty of whether an individual carries the gene mutation for HD ends upon receiving test results while a realm of uncertainty persists and pervades family life.

With the advent of predictive testing in 1993 came a host of studies on motivations for testing, as well as the effects of predictive testing on those involved. Researchers examining motivations for testing demonstrate that individuals seeking predictive testing for HD do so to 1) obtain certainty (Tibben, Frets, van de Kamp, Niermeijer, Vegter-van der Vlis, Roos, van Ommen, et al., 1993) or relieve the uncertainty of not knowing their carrier status, 2) have an opportunity to plan future events (e.g., reproduction, career, finances), and 3) clarify the risk for existing children (Binedell, Soldan, & Harper, 1998; Bloch, Fahy, Fox, & Hayden, 1989; Evers-Keibooms & Decruyenaere, 1998; Evers-Keibooms, Swerts, Cassiman, & Van Den Berghe, 1989; Mattson & Almqvist, 1991; Richards, 2004; Tibben, Frets, van de Kamp, Niermeijer, Vegter-van der Vlis, Roos, van Ommen, et al., 1993; Tibben et al., 1992; Williams, Schutte, Holkup, Evers, & Muilenburg, 2000). These motivations, however, may carry different meaning depending on the life stage of the individual being tested. For example, an individual seeking testing to help transition into young adulthood through marriage may later find that testing complicates decisions about future children (Brouwer-DudokdeWit, Savenije, Zoeteweij, Maat-Kievit, & Tibben, 2002).

The International Huntington Association and The World Federation of Neurology Research Group on Huntington's Chorea (1994) developed a protocol for HD predictive testing which recommends involvement of a multidisciplinary team that includes genetic nurses and counselors, geneticists, neurologists, social workers, and psychologists. According to the protocol, persons under the age of 18 are not recommended to be tested. Additionally, the protocol outlines components to follow that ensure persons being tested maintain general well-being and receive optimal support. One component is a companion must accompany the proband, or the person at-risk for HD and seeking medical services, to clinic visits.

Ethical and moral dilemmas regarding predictive testing for HD have been explored (Clayton, 2003; Huggins et al., 1992), including the process of seeking informed consent for population-based genetics research (Beskow et al., 2001), genetic testing in children (American Academy of Pediatrics Committee on Bioethics, 2001; American Society of Human Genetics Board of Directors & American College of Medical Genetics Board of Directors, 1995; Davis, Krasnewich, & Puck, 2000; Lilani, 2005) the disclosure of familial genetic information by health care professionals (American Society of Human Genetics, 1998), and the potential for misuse of genetic information (Lapham, Kozma, & Weiss, 1996; Lilani, 2005). The latter has received increased focus because reports of genetic discrimination among HD populations have been described (Bombard et al., 2007; Bugermeister, 2003; Geller et al., 1996; Kenen & Schmidt, 1978).

As genetic technology continues to expand, more persons will receive information pertaining to their genetic susceptibility to a variety of diseases, including other adult-onset diseases (Burke, 2002; Saab et al., 2004; Wang, Gonzalez, & Merajver, 2004). Conditions for which predictive testing is currently available include early-onset Alzheimer disease, hypertrophic cardiomyopathy, Marfan syndrome, spinocerebellar ataxia, myotonic and muscular dystrophy, and thrombophilia. Uncertainties regarding risk will likely remain as incomplete penetrance, meaning the frequency of phenotypic expression is less than 100 percent, becomes the "norm for genes associated with common chronic diseases" (Welch & Burke, 1998, p. 1525). Despite the uncertainties involved with risk estimates of disease occurrence, persons may use probabilities as the basis from which they make health care decisions (Epstein, 2004). While having genetic information regarding future likelihood of disease allows an expanded understanding of future health, there are related uncertainties that arise from learning this information for the proband and family.

Researchers have sought to identify psychological implications of predictive testing for HD among probands and their families. Meiser and Dunn (2000) and Brouwer-DudokdeWit et al. (2002) present reviews of the literature on the impact of testing among those at-risk for HD. Broadstock, Michie, and Marteau (2000) conducted a systematic review and synthesis of the literature on the psychological consequences of predictive testing for HD and three other chronic health conditions. In short, among HD populations, adverse psychosocial outcomes have been reported in carriers and non-carriers (Codori & Brandt, 1994; Duncan et al., 2008; Huggins, et al., 1992; Sobel & Cowan, 2003; Williams, Schutte, Evers, & Holkup, 2000). Researchers have also reported benefits of having a family history of HD (Williams et al., 2010) or undergoing genetic testing for HD, such as improved or stable psychological functioning and increased knowledge and understanding, among individuals receiving both positive and negative results (Bloch, Adam, Wiggins, Huggins, & Hayden, 1992; Codori & Brandt, 1994; Decruyenaere et al., 1996; Duncan, et al., 2008; Huggins, et al., 1992; Lawson et al., 1996; Tibben et al., 1994; Tibben, Timman, Bannink, & Duivenvoorden, 1997; Wiggins et al., 1992; Williams, et al., 2010). These authors indicate that positive effects are typically associated with the short-term relief from uncertainty about carrier status, regardless of the nature of results. The test result itself is not inherently problematic.

Researchers find that HD test results most strongly interfere with the normal life cycle, through the changed expectations and possibilities that result from the information (Brouwer-DudokdeWit, et al., 2002).The impact of HD post-predictive testing on families and, in particular, intimate partners, will be discussed further in the review of scientific literature section below.

HD Signs and Symptoms

HD has traditionally been described in terms of early-, middle-, or late-stage features, with each stage lasting approximately 5 years (Hoffman, 1999; Kirkwood, Su, Conneally, & Foroud, 2001). More recently, researchers describe pre-manifest and manifest HD. Pauslen et al. (2005; 2001) and Conybeare (2005) indicate that changes in cognition and behavior frequently precede clinical diagnosis, which is made upon full manifestation of disease. In fact, such subtle changes can be detected 10-15 years prior to traditional clinical diagnosis (Paulsen et al., 2008). Specifically, increased irritability (Baxter et al., 1992; Berrios et al., 2001; Campodonico, Codori, & Brandt, 1996; Witjes-Ane, Zwinderman, Tibben, van Ommen, & Roos, 2002), moodiness (Berrios, et al., 2001), depressive symptoms (Folstein, Abbott, Chase, Jensen, & Folstein, 1983; Mindham, Steele, Folstein, & Lucas, 1985), including increased rates of suicidal ideation (Paulsen, Hoth, Nehl, & Stierman, 2005), lack of awareness (Duff et al., 2010), and memory difficulties (Hahn-Barma et al., 1998; Lemiere, Decruyenaere, Evers-Keibooms, Vandenbussche, & Dom, 2004) have been reported (Williams et al., 2007). Changes in functioning pertaining to finance management, work performance, driving, and social relationship engagement have also been noted (Beglinger et al., 2010; Williams, et al., 2007; Williams, Schutte, Holkup, et al., 2000). Walker (2007) provides a description of this prediagnostic, or premanifest, phase of HD, including clinical assessment, physical findings, and management.

Choreic movements, or involuntary movements consisting of irregular jerking and writhing, are considered the hallmark of clinical diagnosis of HD. Features of early disease progression include an abnormal gait pattern appearing as a wide, staggering gait; dysarthric speech whereby rate and rhythm are affected; clumsiness (Harper, 1996; Kirkwood, et al., 2001); and personality changes (Cummings, 1995; Harper, 1996; Hoffman, 1999; Kirkwood, et al., 2001). While persons in early stage HD are often able to independently maintain activities of daily living (ADLs), the marked onset of movement disorders leads to a predisposition to falls and other accidents. Mid-stage HD is marked by increased dependence on others for ADLs (Hoffman, 1999; Kirkwood, et al., 2001), increased clumsiness due to deterioration of voluntary movement, and the onset of sleep disturbances (Harper, 1996). Seizures may be present (Kirkwood, et al., 2001). Late-stage HD often requires the affected individual be admitted to a long-term care facility; most if not all ADLs require assistance and communication is near impossible due to worsened dysarthria, or a difficulty with the physical production of speech (Hoffman, 1999; Kirkwood, et al., 2001; Timman et al., 2005). Rigidity, dystonia (Harper, 1996; Kirkwood, et al., 2001), and aggression become more prominent, social-cognitive capabilities deteriorate (Timman, et al., 2005), and dementia is global (Hoffman, 1999; Kirkwood, et al., 2001). Additionally, persons often experience urinary and fecal incontinence and cachexia (Harper, 1996; Kirkwood, et al., 2001).

In addition, other signs and symptoms can appear at any point on the HD trajectory and worsen with disease progression, including: bradykinesia or akinesia; cerebellar abnormalities (e.g., tremors); dysphagia (Harper, 1996; Kirkwood, et al., 2001); impulsivity; depression; anxiety; mania; psychosis; delusion; bulimia; irritability to noise, excess stimuli, or when requests are not met (Cummings, 1995; Harper, 1996; Hoffman, 1999; Kirkwood, et al., 2001); abnormal eye movement, appearing as an inability to lift eyes up or establish and maintain eye contact (Harper, 1996; Kirkwood, et al., 2001; Seidman-Carlson & Wells, 1998); verbal and physical aggression; sexual disorders or altered sexual behavior (Cummings, 1995; Harper, 1996; Hoffman, 1999; Kirkwood, et al., 2001; Quarrell, 2002); memory problems (Cummings, 1995; Harper, 1996; Ho et al., 2003; Kirkwood, et al., 2001), particularly the retrieval of information (Ring & Serra-Mestres, 2002); deficits in attention and executive functioning (Ho, et al., 2003); apathy or loss of initiative (Hamilton et al., 2003; Quarrell, 2002); impaired learning and judgment; retarded thinking and responses; fixed or rigid thinking (Rosenblatt & Ranen, 1999); loss of visuospatial awareness (Bourne, Clayton, Murch, & Grant, 2006); and anosognosia (Rosenblatt & Ranen, 1999).

Scientific Literature Review: Families Living with HD

Huntington disease is a “prime example of a family disease;” it is estimated that for every affected person there are at least 10 more, including those biologically at-risk, intimate partners, and other family members, who “suffer from the far-reaching social consequences” of HD (Hayden, 1980, p. 201). Because the disease “begins during the time period when the family life-cycle is at its most complex, with childbearing, child-rearing, and career development all significant,” HD has a profound impact on family development and functioning (Vamos, Hambridge, Edwards, & Conaghan, 2007, p. 400). In an anthology of stories about how HD affects the lives of wives, husbands, mothers, fathers, sons, daughters, sisters, nieces, health care workers, and at-risk or affected persons, aptly titled “Faces of Huntington’s,” the editor, whose husband has HD, writes of her ever-increasing domestic and caregiving responsibilities: “The uncertainty of the future…is a panic which never leaves my mind” (Leal-Pock, 1998, p. 25).

In the following review of literature, the implications of HD and predictive testing for the family are presented, with particular focus on the proband’s intimate partner. The impact of testing on relationships and differences in perceptions of distress among couples are briefly discussed, followed by an identification of the burdens on the intimate partner, including experiences of loss and uncertainty. Rounding out the discussion on the impact of HD and predictive testing on the intimate partner is a brief mention of partner perception of the adequacy of support and guidance received from health care providers.

Predictive Testing: Impact on Family Relationships

Several researchers have examined the effects of predictive testing on the proband's family members. In general, families report a need to adjust to changes in family functioning as a result of predictive testing and find meaning for the existence of HD and the results of the test (Sobel & Cowan, 2000b). Descriptions of the effects of testing on couple and family relationships are mixed. While some intimate partners and other family members have reported no or minimal significant adverse effects in terms of relationship status or quality (Codori & Brandt, 1994; Codori, Slavney, Young, Miglioretti, & Brandt, 1997; Quaid & Wesson, 1995; Richards, 2004; Richards & Williams, 2004; Sobel & Cowan, 2000a, 2000b; Taylor & Myers, 1997; Tibben, Duivenvoorden, et al., 1993; Tibben, et al., 1997), others have described ill effects such as emotional distancing, marital dysfunction, separation, or divorce (Quaid & Wesson, 1995; Richards, 2004; Sobel & Cowan, 2000a; Taylor & Myers, 1997).

Couple Perceptions: Individual Differences

In contrast, descriptions of the impact of testing on individuals within couples are more consistent. For example, intimate partners and gene-positive partners (those testing positive for the gene mutation associated with HD) frequently report significantly different levels of distress, reflecting the very different perceptions each has post-predictive testing. In general, intimate partners have at least as much, if not more, difficulty adjusting to positive results as their gene-positive partners. Furthermore, intimate partners report being more depressed (Sobel & Cowan, 2000a) and pessimistic (Tibben, Frets, van de Kamp, Niermeijer, Vegter-van der Vlis, Roos, Rooymans, et al., 1993), having more feelings of anger, sadness, and despair (Quaid & Wesson, 1995; Tibben, Frets, van de Kamp, Niermeijer, Vegter-van der Vlis, Roos, Rooymans, et al., 1993; Tibben, et al., 1997; Tibben, et al., 1992), being more concerned about a future overshadowed by HD (Tibben, Frets, van de Kamp, Niermeijer, Vegter-van der Vlis, Roos, van Ommen, et al., 1993), having a poorer quality marriage (Decruyenaere et al., 2004), seeking less social support (Decruyenaere et al., 2005), and having lower levels of perceived disease controllability (Kaptein et al., 2007) than their gene-positive partners. While data collected for these studies occurred between 6 months and 5 years post-predictive testing, researchers examining the long-term effects of testing (7-10 years post predictive testing) describe how intimate partners experience as much hopelessness as their gene-positive partners (Timman, Maat-Kievit, Roos, & Tibben, 2004), corroborating findings which indicate intimate partners have a significantly difficult time adjusting to positive genetic test results.

The Intimate Partner: Implications of HD and Predictive Testing

The above-mentioned research findings warrant a more in-depth examination of what it might be like to be the intimate partner of persons who are 1) gene-positive but not yet clinically diagnosed and 2) clinically diagnosed with HD. To say that the intimate partner may experience difficulties as much or more than their partners is not a novel idea; the burden of HD on the intimate partner has long been recognized (Evers-Keibooms, Swerts, & Van Den Berghe, 1990; Hans & Koeppen, 1980; Hayden, 1980; Kessler, 1993; Tyler, Harper, Davies, & Newcome, 1983). In a report published nearly 30 years ago, Hayden (1980) describes how the strain of increasing responsibilities for finances, domestic chores, and caregiving among partners of persons with manifest HD is compounded by “inevitable isolation,…repeated social embarrassments, and rejection by old friends” (p. 202). Secrecy, an element common to many HD families (Sobel & Cowan, 2000a), further drives intimate partners and family members into isolating existences (Williams, et al., 2001) and failed relationships (Kessler, 1993). For those with partners who are gene positive and have not yet been clinically diagnosed with HD, secrecy may interfere with the ability to cope with and respond to changes within the gene-positive partner (Williams, et al., 2007).

In another early report, Hans and Koeppen (1980) interviewed 15 wives of persons with manifest HD in a study of the impact of HD on the intimate partner and described them as "suffer[ing] continuous trauma from [HD]" (p. 209). Intimate partners expressed feelings of hostility, regret, and ambivalence as they described the ways in which the disease permeated their 1) marriage, 2) financial responsibilities, 3) personal goals and lifestyle, and 4) roles as caregivers for both the affected spouse and children. Tyler (1983) described the significant strain intimate partners undergo as a result of being "sandwiched" by their dual caring responsibilities for both the partner with manifest HD and young offspring. Intimate partners may be further burdened as they contemplate their involvement in potentially transmitting HD to their children (Evers-Keibooms, et al., 1990; Hayden, 1980).

The symptoms of HD themselves are troubling to intimate partners. They may experience domestic violence as they become targets of aggressive and sometimes abusive attacks brought about either by symptoms of the disease or a response to it (Hayden, 1980; Williams, et al., 2001). Indeed, the behavioral changes are often much more troubling than the associated movement disorders (Anderson & Marshall, 2005). Researchers found behavioral problems (Tyler, et al., 1983), intellectual decline, and personality changes (Evers-Kiebooms et al., 1990) among persons with manifest HD were the primary sources of stress, anxiety, and tension among intimate partners.

Because of the genetic nature of HD and associated signs and symptoms, the intimate partners' caregiving role is quite unique relative to other family members serving as caregivers (Kessler, 1993). Juxtaposed to caregivers of persons with other chronic conditions, it is suggested that such caregivers in HD families may experience more intense problems due to the implications of HD (Aubeeluck, 2005). Specifically, family carers describe a heavy emotional burden characterized by a disintegration of their own lives, loss of life as it was, and the ever-present shadow of offspring's risk for developing HD (Williams et al., 2009). Relative to more well-known and –developed bodies of literature on caregiving among other chronic disease populations such as Alzheimer disease, research on understanding caregivers' experiences within HD families is limited. One author even describes the intimate partner as the "forgotten person in the [HD] family" (Kessler, 1993, p. 145). The extant body of literature on intimate partners as caregivers is even more limited when considering the prodromal period. During a time in which 1) the gene-positive partner is either free of obvious signs and symptoms or displaying very subtle changes and 2) families are young and largely focused on child-rearing and/or other activities commonly associated with their developmental cohort, caregiving preparations and activities may not considered.

Researchers have demonstrated, however, such preparations and activities must be considered during this time. In a study of concerns and psychosocial impact of predictive testing for HD on support persons, the majority of whom were intimate partners, researchers found they experienced caregiving problems after predictive testing and, in fact, expressed the need for caregiving information (Williams, Schutte, Holkup, et al., 2000). Partners report that, as a result of receiving positive test results, they prematurely assume greater care-taking activities and responsibilities even before the onset of symptoms (Decruyenaere et al., 2004). The researchers caution that this could lead to overprotection by the intimate partner, and, subsequently, create feelings of frustration and inferiority in the gene-positive partner, further complicating the situation.

Living with loss and uncertainty

Researchers using focus group methods to examine family health after predictive testing for HD, with a specific focus on family members' concerns for themselves and other family members, found that participants described a profound sense of loss and uncertainty across the HD trajectory (Williams, et al., 2001). The following quote from these researchers' study reflects loss and uncertainty experienced by a husband of a woman with manifest HD:

> I've had three very close family members die of cancer, and you go through it and you don't necessarily get over it, but you do get on with your life. There is support for the survivor, like for cancer. You know, with Huntington's, the time period is so long, and it's just this very slow walk down a very long road. Each day is just slightly worse than the day before. And there is no end to the tunnel, and you don't know what you're going to face, or the unpredictability. Where, you know, some other things, whether it be divorce or cancer or what have you, there is an end to it. And something new begins. You have the opportunity to start something over. But in this situation, you really don't.

Families with HD experience loss that "is magnified not only by a history of premature loss, but also by the knowledge, now available through DNA testing, of future loss" (Sobel & Cowan, 2000a, p. 56). Partners not only have the premature loss of life to anticipate, but also the personal losses, such as desired hopes, dreams, and aspirations, which may be replaced by caregiving responsibilities, and, relative to other chronic conditions, this occurs fairly early in their lives. One woman in a study by Dawson et al. (2004) described how her husband's increasing dependency increased her sense of loss, isolation, and helplessness: "Having a dependent who's no longer a husband…that's the saddest part and I miss the companionship…[it's] very lonely" (p. 127). Another woman described similar feelings, saying that personality changes, due to the disease, make her partner with manifest HD more like a child in a man's body, so she no longer feels able to talk with him about her concerns. Furthermore, intimate partners described the need to bolster their spirits to continue in their roles while feeling fearful of the future. These results suggest partners may find it difficult to pursue desired social activities, standards of living, and a "normal family life" amidst an uncertain future (Dawson, et al., 2004).

In a report on effects of predictive testing on the intimate partner, Kessler (1993, p. 149) posited that testing may be difficult for partners, as it challenges expectations for their futures.

> The prospect of finding out long in advance that one's mate will definitely become symptomatic is not very palatable…[upon receiving results], spouses may be confronted with a new life reality…their mate either will or will not become affected with HD. Previous ways of dealing with the uncertainty of not knowing may no longer be appropriate…requir[ing]…new ways of thinking and behaving for both partners.

Research has suggested that such new ways of thinking and adjusting to different expectations for their futures after predictive testing may be difficult for intimate partners. Role changes, particularly those anticipated in terms of future caregiving, increased stress on marriages and other family relationships, according to Sobel and Cowan (2000a). In another study, partners reported the following sentiment: "the thought that [Huntington's] was going to rob you of your future was robbing you of your present…you were living it every day…whether you consciously thought of it or not" (Richards, 2004, p. 176).

Researchers investigating the concerns of family members of persons with prodromal and manifest HD found that their experiences included feelings of uncertainty (Williams, et al., 2001). Partners of persons with prodromal HD are confronted with managing multiple uncertainties: finances; future caregiving responsibilities and vulnerabilities (Dawson, et al., 2004; Williams, et al., 2001; Williams, Schutte, Holkup, et al., 2000); symptom onset and interpretation of behavior (Williams, et al., 2001; Williams, Schutte, Holkup, et al., 2000); the meaning of changes in health, including what to attribute changes to (Downing, Williams, & Paulsen, 2010); the proband's functional abilities; treatment availability and outcomes; decisions regarding reproduction, career, and the pursuit of other life goals; and coping abilities of family members when such challenges arise (Williams, et al., 2001). One woman participating in the Williams et al. (2001) study described her and her spouse's decisions regarding reproduction: "[When] he had the [predictive] test done, we didn't have any children, and we chose to go ahead. We have two children now, but…I'll be thinking, (crying) was that the wrong thing to do?"

Families of persons who are 1) gene-positive and pre-clinical diagnosis and 2) post-clinical diagnosis also experience uncertainty as it relates to ambiguous loss (McGonigal-Kenney et al., 2005; Sobel & Cowan, 2003), defined by Boss (1999) as uncertain or unresolved loss. In the context of HD, ambiguous loss manifests as the person remains physically present but psychologically absent as cognitive and emotional symptoms appear and worsen. According to Sobel and Cowan (2003), families referred to members who had tested positive for HD but were asymptomatic as 'already in the grave,' "because of the uncertain status conferred [upon them]" (p. 50). One woman in the study explained 'You look at my sister. She's no different than five minutes before and all of a sudden, she's dying…we…started grieving immediately…like [living] the next fifteen years in those five minutes' (Sobel & Cowan, 2003, pp. 52-53).

Ambiguous loss has ramifications for family boundaries and belief systems as making meaning is complicated by the ambiguity. Families find it difficult to find meaning of symptoms and reorganize relationships and roles, discover there is a lack of social recognition and formal verification of losses, and experience exhaustion as a physical and psychological response to loss. One woman described the difficulty in finding meaning of health-related changes occurring prior to clinical diagnosis (McGonigal-Kenney, et al., 2005), stating

> I'm most concerned about the mental [symptoms of HD]…it's the big unknown…I don't know what to look for. He's a very forgetful person, but to me he's always been like that…I don't know. Was that just him? Or is that the disease?

Nurses: A resource for intimate partner support?

The difficulties faced by intimate partners of persons gene-positive and without clinical diagnosis of HD may be occurring in a context in which healthcare professionals appear indifferent or uninvolved (Hayden, 1980). Not only do persons testing gene positive report being dissatisfied with their healthcare practitioners' support post-predictive testing (Tibben, Frets, van de Kamp, Niermeijer, Vegtervan der Vlis, et al., 1993), but family members of persons who have tested gene positive but not received a clinical diagnosis as well as those who have received a clinical diagnosis of HD also describe a lack of professional health care resources to use as they cope with their situations (Williams et al., 2005). In one case study, an intimate partner of a man in the prodromal period felt neglected by health care providers as their care was frequently and solely focused on him (proband) (Williams et al., 2001), suggesting partners receive little assistance as they begin to navigate the healthcare system and anticipate a future for which they feel largely unprepared (Williams, Schutte, Holkup, et al., 2000). The impact of inadequate assistance and support from healthcare providers may be great, according to Rolland and Williams (2005), who suggest families may benefit from more consistent support during transitions across the disease trajectory, even for those occurring during the prodromal phase.

Summary

These studies represent the current literature on the impact of HD and predictive testing on families, with particular focus on intimate partners. The availability of predictive testing gives individuals the choice to know or not to know their genetic risk status; this decision has tremendous short- and long-term consequences for not only the proband, but also for his or her family. The process of seeking and completing predictive testing results in changes in the ways family members relate to each other (Williams, Schutte, Evers, et al., 2000). Families of persons who undergo testing and are positive for the HD gene mutation constitute a group of persons in which biologic offspring are at-risk, the age of disease onset is young relative to other chronic illnesses, assistance and support from health care providers is limited, and health care services tailored to meet their needs are scarce. Adjusting to the impact of HD may be challenging for the whole family. The proband’s intimate partner may, however, bear a particularly heavy burden. He or she faces increased responsibilities for wage-earning, childrearing, and caregiving, and the stress from these responsibilities is often compounded by secrecy and a growing sense of isolation. Issues specific to HD, such as the magnitude and breadth of symptom presentation and inheritance risk for offspring, further place intimate partners in less-than-desirable positions.

A review of scientific literature indicates that intimate partners experience overwhelming feelings of loss and anticipate a future filled with more of the same. Intimate partners of persons in the prodromal period, however, report that this sense of loss is more ambiguous, more uncertain. After all, are their loved ones really “sick” yet? Are their children affected by HD? Should they mourn the loss of a child that never came into being? Subtle changes are, at times, noted within the person gene-positive for HD which affect functioning, but does that mean intimate partners are now considered persons who provide care or oversight? As indicated by the research, partners may be assuming caretaking roles prior to the clinical diagnosis of HD. Can partners seek professional help as they cope with these role changes and feelings about their inevitable futures? Especially when, to the outside world, the appearance of normality and a supposed well-functioning family may lead others to fail to recognize and validate unnamed losses?

The majority of the studies included in the above review on intimate partners of persons who had tested positive for the gene mutation associated with HD were conducted using descriptive and/or correlational study designs with the couple as the unit of analysis. A smaller number of studies used qualitative modes of inquiry or mixed-methods and included couples and other family members in their samples. Fifteen years have passed since Kessler (1993) suggested the intimate partner was the “forgotten” member of the HD family, yet only a few recent studies focus on the experiences of the intimate partners, support persons, and/or other family members. Relative to the body of literature on the effects of predictive testing and HD on the couple dyad, there is little research examining the effects on the family. There is an even greater paucity of research on intimate partners and their experiences alone, without comparing and contrasting them with those of their partners who are gene positive. The extant body of literature provides a general landscape portrait of what intimate partners' experiences might be like. What remains to be done is a closer examination of aspects of this landscape, so that a richer, deeper understanding of their experiences may be ascertained. The aspect of their experiences chosen for the present inquiry is uncertainty.

This phenomenon of uncertainty has implications for families' coping mechanisms as they formulate new psychological identities and for health care professionals involved in their care (Evers-Kiebooms, et al., 2000). Knowledge of genetic predisposition to future illness and disability creates uncertainties that shape and influence life decisions about reproduction, career, health behavior, and eventual caregiving. Families facing such decisions, particularly those younger in age relative to late adult-onset disorders, are at-risk for experiencing effects of sustained uncertainty and associated stresses. Uncertainty is a salient experience in intimate partners of individuals positive for the HD gene mutation given current life-span development conceptualizations of adjustment to chronic illness.

Researchers, however, have not yet explored the meaning of the lived experience of uncertainty among intimate partners of persons with prodromal HD, after the testing process concludes. Furthermore, the extant literature previously described predominantly includes the family or couple as the unit of study; very few have solely examined the intimate partners' experiences during the earliest part of the HD trajectory: the prodromal period. The purpose of this study is to gain a deeper understanding of the meaning of the lived experience of uncertainty in this cohort.

While having knowledge about the likelihood of illness development prior to symptom onset may serve to challenge and complicate the lives of those involved, it also lends ample opportunities to plan for and coordinate supportive healthcare services. Gaining an in-depth understanding of uncertainty experienced by intimate partners of persons with heritable disorders will help those caring for such persons in: planning their lives; supporting abilities to maintain personal health; preparing for and assuming caregiving roles; and carrying out personal, family, and social tasks. Specifically, increasing nurses' and other health professionals' understanding of uncertainty will inform creation and implementation of strategies that support coping with negative emotional outcomes. Furthermore, understanding the potentially beneficial features of uncertainty will prompt the development and testing of interventions aimed at further facilitating positive health outcomes.

Lay Understandings of Uncertainty

To begin to acquire a deeper understanding of uncertainty, it is crucial to examine its use in the lay literature. A wealth of non-scientific literature abounds with definitions, synonyms, idiomatic phrases, etymologic descriptions, and conceptualizations related to uncertainty. van Manen (1990) indicates locating such literature is the initial step towards coming to a fuller understanding of human experience, taken once the investigator has oriented to the phenomenon, explicated assumptions and pre-understandings, and formulated the phenomenological question (as presented in Chapter 1).

Definitions

Dictionary definitions provide an initial overview of uncertainty. The Oxford English Dictionary (1989) defines uncertainty as the quality of being uncertain in respect of duration, continuance, occurrence, and so on. It is the condition of being in doubt (Morris, 1971). Uncertainty can range from a falling short of certainty to a nearly complete lack of conviction or knowledge, especially as it relates to an outcome or result (Merriam-Webster Inc., 2006; Morris, 1971). Uncertain is defined as indeterminate; not known; not having sure or certain knowledge (Merriam-Webster Inc., 2006; Morris, 1971) and indefinite; not certain to occur; not reliable; beyond doubt; not clearly identified or defined; not constant (Merriam-Webster Inc., 2006); questionable; doubtful; vague; undecided; variable; subject to change; unsteady; and fitful (Morris, 1971).

(Un)certain and (un)sure are often used interchangeably (Morris, 1971); in fact, unsure is one synonym most closely related to uncertain in terms of meaning (Lindberg, 2004). Defining “sure” and “unsure” may, therefore, help to shed light on the meaning of “certain” and “uncertain.” Unsure is defined as insecure or lacking in security or safety; not safe from danger or mishap; lacking confidence or assurance; uncertain; not having certain knowledge; not steadfast or stable; not reliable and untrustworthy; contingent or precarious; of doubtful or uncertain prospect; and archaic (Gove & Merriam-Webster Editorial Staff, 1993). To be “sure” is defined as incapable of being doubted or disputed; completely true; certain; not hesitating or wavering; confident of some future possibility; inevitable; having one’s course directed; destined; certain not to miss or err; worthy of being trusted or depended upon. How, then, do “(un)sure” and “(un)certain” differ then? Morris (1971) indicates that sure is the more subjective term whereas certain implies belief based on experience or established evidence.

Synonyms and Idiomatic Phrases

Uncertainty, doubt, dubiety, skepticism, suspiciousness, and mistrust all reflect a lack of sureness about someone or something (Merriam-Webster Inc., 2006). According to Lindberg (2004), unpredictability, doubt, dubiety, and hesitance are synonyms closest to uncertainty in meaning. Uncertainty is used as a general term, intended to indicate an unsureness about something and cover everything from a mere lack of absolute certainty to near complete lack of knowledge that makes it impossible to do little more than guess the outcome. Doubt implies uncertainty in addition to an inability to make decisions due to insufficient evidence. Dubiety is closer in meaning to uncertainty than doubt, as it stresses a lack of sureness instead of inability to make decisions. It is different from uncertainty because it reflects a wavering between two conclusions (Lindberg, 2004).

Other synonyms of uncertainty include: incertitude; bewilderment; capriciousness; unreliability; indeterminacy; untrustworthiness; fitfulness (Little Brown and Company, 1996); unsureness; vacillation; ambiguity; confusion; irresolution (Little Brown and Company, 1996; Sutherland, 1997); indefiniteness; vagueness; indecision; equivocation; perplexity; quandary; shilly-shally; chance; gamble; odds; and risk (Sutherland, 1997).

Synonyms closest in meaning to uncertain, aside from the previously mentioned "unsure" include: unknown; vague; changeable; and hesitant (Lindberg, 2004). Other synonyms are: not confident; dubious; not definite; speculative; unconfirmed; undecided; unpredictable; not known exactly; indistinct; hazy; obscure; not fixed; unsettled; in question; disputable; questionable; conjectural; variable; fluctuating; hesitant; doubtful; indeterminate; wavering; vacillating; unclear; nebulous; debatable; erratic; and fitful (Sutherland, 1997).

For the purpose of this review, an idiom is defined as a combination of two or more words that, when taken together as a unit, reflect a meaning different from the literal meanings of each word alone. "I don't know" is related to uncertain(ty); idioms reflective of this phrase include: it beats me; you've got me; I have no idea; your guess is as good as mine; and I haven't got a clue (Brenner, 2003). "Up in the air," "blow hot and cold," and "of two minds" are also idioms reflective of uncertain(ty). "Up in the air" is defined as "not settled," and "blow hot and cold" is defined as "changing one's mind," or "vacillating" (Ammer, 1997). Being "of two minds" means holding conflicting opinions or being undecided about someone or something (Spears, 2005). An idiom using the term uncertain in its phrase is "in no uncertain terms;" this means "in very specific and direct language" (Spears, 2000). Other idioms of uncertain(ty) are "in the balance," "up in the air," "iffy," "open to question," and "question mark" (Lindberg, 2004).

Etymology

"Uncertain" has etymologic ties with the Latin *incert-us* and originated as Scottish "uncert," which is now obsolete (The Oxford English Dictionary, 1989). "Un" is Old English, originating as a prefix added to verbs and meaning to do the reverse or opposite (Barnhart, 1995). "Certain" is Middle English, originating from old French and based on the Latin *certus* for "settled" or "sure" (Barnhart, 1995; Chantrell, 2002; Onions, 1966). Originally, certus was a variant of the past participle of *cernere*, meaning to separate, sift, distinguish, or decide (Barnhart, 1995; Onions, 1966). "Certainty" as noun was originally used around 1300 A.D. as *certeynte*, borrowed from Anglo-French *certainte* which comes from Old French "certain" plus "te." Upon brief examination of the origin of "sure," it is interesting to note its roots in Latin *securus* mean "free from care" (Chantrell, 2002; Morris, 1971).

Embracing Existential Uncertainty: A Sign of the Times?

Turning away from the dictionaries and thesauruses but remaining within the body of lay or non-scientific literature gives indication of how uncertainty may be viewed in current times. Within the investigator's existential-phenomenological perspective, uncertainty is a universally-lived experience. When attuned to its use in everyday language, including verbal and written media, its prevalence becomes quite noticeable. A simple search of "uncertainty" and "uncertain" within the online version of *The New York Times* reveals 13 separate articles spanning the weekend of April 4th-5th 2008 using one of the two terms. The content of the articles spans everything from politics to the economy to sports. Searching online at Amazon.com for books reveals an abundance of books with either "uncertain" or "uncertainty" contained in their titles. Examining just a fraction of a fraction of these is telling in terms of the ways in which humans are viewing and understanding uncertainty in their lives.

Maira Kalman (2007) in *The Principles of Uncertainty* sums up her seemingly random thoughts and observations about uncertainty in prose, photography, and illustration. The author includes an illustration of a woman wearing a pink hat, smiling and standing in a sea of pink and red petals which have fallen from a large bougainvillea plant which is portrayed behind the woman. The illustration is meant to represent a photo; the caption reads "I photograph my sister and think she looks so beautiful in her pink hat. What will happen to her? What will happen to us all?" (p. 81). She reveals the existential nature of contemplation when one views a photo and can't help but wonder about the person in the photo. Who is this person, really? Does this picture truly reflect what her life is like? How will the rest of her life story unfold? In her book, Kalman seems to capture the thoughts all humans carry at the core but rarely bring into everyday discourse.

Should one wish to learn how to deal or cope with uncertainty, there are several options available. For example, one may turn to the book *Coping with Uncertainty: 10 Simple Solutions*, by Eimer and Torem (2002). The authors define uncertainty as "a condition in which you lack knowledge or confidence about what will happen to you in your daily life as it relates to your job, financial security, health, wellness, shelter, family, and safety on a personal, family, and community level" (p. 1). Through a standard self-help format, the authors present ways to cope with uncertainty, based on the premise that the world is more uncertain than ever and the "perils" of uncertainty include: anxiety, fear, anger, grief, sadness, rage, helplessness, alienation, cynicism, and feelings of having no future. Some of the solutions offered are to accept uncertainty as a way of life; evaluate real risks; learn to forgive; restore inner harmony; and connect with others and create meaning. The authors seem to use "uncertainty," "change," and "anxiety" interchangeably. They also state that humans are driven to resolve uncertainty but indicate "all uncertainty is fruitful, as long as it is accompanied by the wish to understand" (p. 2). While the reader may find the blurring of terms confusing and conceptualization of uncertainty's nature conflicting, it is evident that, according to the authors, uncertainty is pervasive and tied with notions of angst, purpose, and meaning, perhaps all-at-once, and that humans have the capacity to effectively deal with or cope with this.

Susan Jeffers also considers meaning and purpose to be related to uncertainty. In her book *Embracing Uncertainty: Breakthrough Methods for Achieving Peace of Mind When Facing the Unknown*, an entire chapter is devoted to the discussion of the importance of finding meaning and purpose in one's life. The major theme is that a sense of meaning and purpose precludes humans' fears of the future, thereby rendering uncertainty as something to be embraced. Jeffers (2003) offers exercises for the reader who wishes to illuminate his or her purpose and meaning in life. With more than 40 of these exercises scattered throughout the book, it may read a little like a "how-to" manual for dealing with uncertainty; the flavor, however, is more positive and encouraging than the previously discussed "10 Simple Solutions" in terms of embracing the view that uncertainty is *the reason* for the good in life rather than how to have a good life *despite* uncertainty.

Another book resting on the shelves of giant, popular book-store chains is *Comfortable With Uncertainty*, written by Pema Chodron (2002), an American Buddhist nun and resident teacher at North America's first Tibetan monastery. Chodron offers a conceptualization of uncertainty from a Buddhist perspective. In general, the quest for spiritual awakening is considered a journey, and it is through this journey that humans fully explore and embrace the reality of insecurity, pain, and unpredictability. While human nature is frequently focused on seeking security and predictability in attempts at controlling the uncontrollable, or that which makes humans fearful, "the truth is that we can never avoid uncertainty. The not knowing is part of the adventure" (p. 5). The central question for a person taking this journey is how one should relate to discomfort rather than how one can avoid uncertainty and fear.

To question is to encourage doubt and acknowledge the unknown, thereby opening self up to experience unpredictability. Questioning “simultaneously reveals our limitations and our urge to go beyond them” (Batchelor, 1990, p. 37), thereby confronting the unknown. The approach humans take towards not knowing, or uncertainty, can create struggle or joy (Batchelor, 1990; Chodron, 2002). In sum, uncertainty creates a sense of groundlessness and discomfort, but a willingness to rest in the uncertainty ultimately teaches humans to relax in the midst of chaos (Chodron, 2002). Buddhist scholar Joanna Macy (2000) echoes these notions in her interpretation of the Shambhala prophecy, which asks humans to dwell with life uncertainty, thereby learning to be in an open place.

Review of Scientific Literature: Uncertainty in the Natural Sciences

A paradigmatic shift in the natural sciences has and is occurring from classical science’s view of reductionism to the “new” science’s view of wholeness (Briggs & Peat, 1989, 1999; Gleick, 1987). Scientists and philosophers have transcended disciplinary borders and joined this “growing movement that is reshaping the fabric of the scientific establishment (Gleick, 1987, p. 4). This movement is reflective of perspectives including chaos and complexity theories and notions of uncertainty, randomness, and unpredictability, pertaining to both micro (i.e., quantum physics) and macro levels. For example, considering the notion of “entropy” highlights the “inexorable tendency” of the universe or any of its systems to always be in movement towards a state of increasing disorder or randomness (Gleick, 1987, p. 257), while biological systems account for such randomness through stochastic approaches (Ullah & Wolkenhauer, 2010), or those which address that a system’s behavior is a product of genetics, environment, and chance events. A brief, non-exhaustive review of the literature on quantum mechanics and chaos and complexity theories demonstrates uncertainty’s role inherently found in nature and implications as an integral part of the universal fabric.

Quantum Mechanics: The Uncertainty Principle

German physicist Werner Heisenberg discovered the uncertainty principle in 1927. Also known as “Heisenberg’s uncertainty principle” and “principle of indeterminacy,” the uncertainty principle “captures the heart of quantum mechanics” (Greene, 1999, p. 116). It is defined as the principle that the product of uncertainties in the values of certain variables, such as the position and velocity of a particle (i.e., an electron), is greater than or equal to Planck’s constant (Morris, 1971). An inversely proportional relationship exists between these two variables so that it becomes impossible to know both with complete precision, despite equipment or procedure used to ascertain them. At the microscopic level, uncertain aspects of the world become increasingly uncertain as distance and time scales from which they are considered grow smaller and smaller (Greene, 1999).

The uncertainty principle is a sharp departure from the classical physics stance that, ultimately, an inability to capture the preciseness of both a particle’s position and velocity is reflective of human limitations. Unlike this view, the “new” quantum physics view of uncertainty indicates that humans are unable to ascertain the knowledge because it is unavailable to be ascertained (Greene, 1999). The universe is “a teeming, chaotic, frenzied arena on microscopic scales,” (p. 120) indicating nothing is ever at rest. Furthermore, the principle applies not only to micro-level particles but to “*all* constituents of nature” (p. 114). Perhaps the most significant implication of the uncertainty principle is the need to introduce the notion of probability (Briggs & Peat, 1989); all that can be concluded, based on the uncertainty principle, is that there is a probability of any given thing being here or there and that it has this or that velocity (Greene, 1999). On a larger scale, probability and human attempts at calculating it brings an awareness of the inescapability of the uncertainty and randomness surrounding all human efforts and endeavors (Kaplan & Kaplan, 2006).

Chaos and Uncertainty

Chaos is the interconnectedness underlying seemingly random events, and chaos science focuses on the nuance and pattern in attempts at understanding how the unpredictable leads to the new, including everything from forces of nature to bodily phenomena. As a scientific theory, chaos has evolved into a cultural metaphor, forcing humans to examine assumptions about reality and ways of life (Briggs & Peat, 1999). While chaos, uncertainty, and unpredictability have long-standing roots in ancient Eastern cultures, the “newness” of these ideas is based on Western civilizations’ tendency to seek, idealize, obsess about, and become addicted to control over chaos. Citing control as a primary theme of chaos, Briggs and Peat (1999) indicate “the predicament of all life is uncertainty and contingency” (p. 7).

One may wonder how it is possible to exist and function, particularly in terms of having any influence or impact on one’s world, in such an uncertain environment, always painfully aware of its presence and inescapability. Kaplan and Kaplan (2006) suggest that this inescapable fact of being human goes beyond existence and function by bringing fulfillment. While chaos theory highlights the integrality of uncertainty and unpredictability in the world, which may push some to the verge of despair, it also, somewhat paradoxically, “may hold comfort for anyone who feels his or her place in the cosmos is inconsequential [because] inconsequential things can have a huge effect in a nonlinear universe (Briggs & Peat, 1989, p. 75). In the context of chaos, complexity theory asserts that nature is not a mere collection of mechanical parts acting in isolation, but rather, is reflective of humans’ propensity towards interaction and self-organization, thereby resulting in highly resilient and adaptable life forms with boundless creative possibilities (Briggs & Peat 1989; 1999). At the crux of this growth and opportunity is the recognition of and reverence for uncertainty. Opening oneself up to uncertainty allows a discovery of the fine line between individual and universal. It is when humans act upon this discovery that opportunity for authentic creativity presents itself (Briggs & Peat, 1999). Chaos theory, therefore, implies that “instead of resisting life’s uncertainties, we should embrace them” (p. 8).

In sum, the quest for scientific understanding of what can be known (i.e., certainty) has become the quest to understand what cannot be known (i.e., uncertainty). As something considered to not only be a part of the fabric of the universe, uncertainty may be the very thread tying the universal fabric together, bringing a coherent unity and order to its chaotic, random nature. Based on this assumption, uncertainty cannot possibly be something to be eliminated but rather is something to be embodied in order to actualize full human potential.

Review of Scientific Nursing Literature on Uncertainty

Uncertainty is a concept which has long been of interest to not only the discipline of nursing but also to other social and human science and health disciplines (see Penrod 2001a and 2001b). In nursing research, the focus has centered on uncertainty in the illness experience, largely as a result of Mishel’s (1981; 1988; 1990) early works, including a description and re-conceptualization of an uncertainty in illness theory. Uncertainty plays a significant role in acute and chronic illness (Mishel, 1997, 1999). While the scientific literature is replete with studies on uncertainty in acute illness or events, these are not the focus of the present inquiry. More relevant to the study population in this research is the body of knowledge describing situations in which persons experience sustained uncertainty. The following review, therefore, includes studies largely pertaining only to persons and/or their families experiencing chronic conditions.

Selected frameworks in which uncertainty is the focus or identified as a significant part will be presented. The critical review of literature will commence with a brief discussion of literature reviews published thus far on uncertainty. In order to include the most current research on health-related uncertainty, a review of studies largely conducted after publication of the reviews will follow. This discussion is organized according to whether the researcher(s) used a quantitative or qualitative approach, as findings differ based on approach used. An in-depth presentation of findings from phenomenological research on uncertainty is included.

Extant Frameworks for Conceptualizing Uncertainty

Stress, Appraisal, and Coping

A cognitive theory of stress rooted in psychology, as proposed by Lazarus and Folkman (1984), provides one way of conceptualizing uncertainty. According to this theory, cognitive appraisal, defined as the process of categorizing a situation with respect to its significance for well-being, influences the experience of stress. Three types of cognitive appraisal are: primary, secondary, and reappraisal. The personal factors influencing the three types of appraisal are commitments and beliefs. A primary appraisal is made when the situation is categorized as irrelevant, benign-positive, or stressful. When judged to be stressful, the situation is appraised as a harm, loss, threat, or challenge. A secondary appraisal is made when one considers coping strategies and their effectiveness in the particular situation. A reappraisal is made after new information from the individual and/or the environment enters the situation. A reappraisal may be the result of cognitive coping efforts as well as the basis for ongoing coping efforts since coping is a continuous, dynamic process.

According to this theory, Lazarus and Folkman (1984) define uncertainty as the individual's "confusion about the meaning of the environmental configuration" (p. 103). Properties of situations influencing the potential for harm, loss, threat, or challenge are: event uncertainty; temporal uncertainty; and ambiguity. Event uncertainty is used to present how the likelihood of an event's occurrence affects appraisal. When appraised as stressful, event uncertainty has a paralyzing effect on anticipatory coping and causes mental confusion. Temporal uncertainty, defined as not knowing when an event will occur, is stressful in the presence of imminence, or when a threatening cue indicates that an event will happen. Temporal uncertainty stimulates coping efforts that diminish stress reactions. Ambiguity is defined as a lack of situational clarity; the environmental configuration is ambiguous as a result of unclear or insufficient information. Ambiguity plays a role in this model as a potential intensifier or minimizer of threat or potential harm.

In McCormick's (2002) concept analysis of uncertainty in illness, the author identifies factors often present in situations in which uncertainty is also present, including ambiguity, inconsistency, vagueness, unpredictability, and unfamiliarity. Each of these factors or characteristics, however, "are not attributes of uncertainty itself," as they are not always present simultaneously during states of uncertainty (p. 129). Probability, temporality, and perception are attributes that occur, either explicitly or implicitly, during states of uncertainty. She indicates probability is at "the core" of questions about diagnosis, treatment, and prognosis of an illness situation, for example. Regarding temporality, one's future becomes unclear and unpredictable in an uncertain situation, and the ability to plan is "taken away" (p. 130). Perception reflects that, for a situation to be uncertain, it must be perceived as such. Once perceived, uncertainty "enters" one's cognition and the search for predictability is initiated. Based on this concept analysis, McCormick asserts that in its purest form, uncertainty is a "neutral cognitive state" which should not be mistaken for its emotional outcomes" (p. 127).

Uncertainty in Illness Theory

Nursing scholars have also proposed conceptual frameworks from which uncertainty and its health implications may be understood. In general, the primary focus of uncertainty in these frameworks is on the illness experience or medicalized conditions (Mast, 1995). A key example is Mishel's (1988; 1990) Uncertainty in Illness Theory. Perceived uncertainty is a cognitive state occurring when a decision maker is unable to assign definite values to objects and events. He or she may also be unable to accurately predict outcomes because sufficient cues are lacking. In such a state, an inability to obtain a clear understanding and determine the meaning of such an event may result. A continuum of uncertainty/certainty exists, entailing various positive and negative emotional responses which change over time (Mishel, 1988).

According to this conceptualization, three antecedent categories lead to uncertainty: cognitive capacity, structure providers, and stimuli frame, with the latter being the primary preceding variable to uncertainty. The stimuli frame refers to the structure of perceived stimuli and includes three components: symptom pattern; event familiarity; and event congruence. All three have an inverse relationship to uncertainty. Cognitive capacity and structure providers influence these three stimuli frame components. Cognitive capacity refers to individual's information processing abilities. Limited cognitive capacity reduces the ability to perceive the three components in the stimuli frame. Structure providers reflect the resources available to assist the individual in interpreting the stimuli frame, and these can reduce uncertainty both directly and indirectly. Structure providers include: educational level, social support, and credible authority (Mishel, 1988, 1990).

When an illness-related event is perceived as uncertain, one of three things occurs: the event is not recognized; the event is recognized but not classified; or the event is recognized and classified incorrectly. Uncertainty is considered a neutral state open to many definitions until the individual determines personal implications. An appraisal is made via one of two processes, inference or illusion. Based on the appraisal, uncertainty is perceived as either a danger or an opportunity. Coping with danger involves mobilizing processes, such as information seeking and accessing social support mechanisms, or affect-management processes, such as wishful thinking, faith, and disengagement, to reduce the emotions generated by the appraisal. When uncertainty is perceived as an opportunity, buffering process, such as avoidance and selective ignoring, are used to support and maintain the uncertain state (Mishel, 1988, 1990). Adaptation is defined as a newly-constructed state characterized by growth outcomes; it occurs when the individual incorporates the experience of uncertainty into a new schema, thus contributing to a diverse, continually evolving state. Furthermore, uncertainty may be the impetus for an individual to transition during an illness experience from one perspective of life to a more complex, higher-order perspective (Mishel, 1990).

Shortly after the initial publication outlining Mishel's Uncertainty in Illness Theory (Mishel, 1988), Mishel reconceptualized the theory (Mishel, 1990) to account for uncertainty experienced in chronic illness. In essence, Mishel's reconceptualization espouses a more probabilistic view of uncertainty, rather than the mechanistic view that control and predictability are desirable and attainable states. This spurred Mishel to expand on the theory to include the potential that uncertainty may not be entirely reduced or eliminated, as in the case of those with chronic illnesses who may likely live with continual uncertainty.

Uncertainty and Health-Related Events

Other nursing scholars have offered a conceptualization of uncertainty within the context of response to a significant health threat (Morse & Penrod, 1999). Qualitative analyses of the affiliations among concepts of uncertainty, enduring, suffering, and hope have explicated the level of knowing, temporal perspective, goal, and route for each concept and determined links among concepts to better understand human responses to illness, injury, and catastrophic events. Uncertainty is conceptualized as the ability to recognize the event without full comprehension. A goal is identified yet a route or means of achieving it is not, leaving an individual in a state where an unattainable future makes the present uncomfortable and stressful. The researchers' conceptualization is largely congruent with Penrod's (2001b) analysis and concept refinement of uncertainty as "a dynamic state in which there is a perception of being unable to assign probabilities for outcomes that prompts a discomforting, uneasy sensation…affected through cognitive, emotive, or behavioural reactions, or by the passage of time and changes in the perception of circumstances…[uncertainty] is mediated by feelings of confidence and control that may be highly specific or more global" (p. 241).

Extant Reviews of Literature

Mast (1995) conducted a thorough review of nursing studies (N=38) examining the concept of uncertainty in illness published after 1980. Reports in which uncertainty was a predetermined focus of study or emerging variable were included. One study from this review included couples wherein one of the individuals had multiple sclerosis. The remaining studies largely included persons diagnosed with cancer, acute illness (e.g., myocardial infarction), or rheumatoid arthritis. The majority of the descriptive and/or correlational studies included in the review used Mishel's Uncertainty in Illness Theory (UIT) as a framework and the Mishel Uncertainty in Illness Scale (MUIS) to measure uncertainty. Mast, therefore, chose to present and discuss findings from this review according to categories consistent with Mishel's conceptualization, including antecedents to uncertainty, uncertainty appraisal, uncertainty and coping, and uncertainty and adaptation. Due to the "sheer scope and complexity of variables linked to uncertainty," comparison and generalization of study results are difficult. Mast points to a need for more qualitative research, since quantitative measures to describe a notion as contextually dependent and individually complex as uncertainty fall short. The author does conclude, however, that uncertainty is a "pervasive stressful accompaniment of illness and illness treatment that strongly influences patients' coping and adaptive behaviors" (p. 20).

In a more recent integrative literature review, Neville (2003) provides a discussion of studies examining uncertainty in illness, with an emphasis on orthopedic health conditions (N=5). Prior to the description of the studies, however, the author describes medical uncertainty, professional uncertainty, and Mishel's UIT. Medical uncertainty is the umbrella term for clinical uncertainty and functional uncertainty. While clinical uncertainty refers to uncertainty inherent in diagnostic and prognostic procedures, functional uncertainty is that which is based on providers' intentional decisions to communicate or not communicate certain health-related information. In a review of the variations of uncertainty's conceptualizations, Babrow, Kasch, and Ford (1998) provide a discussion of this type of uncertainty and indicate that language and discourse practices play a significant role in shaping health-related uncertainty.

Neville moves to a description of professional uncertainty, which is the term more frequently being used in recent literature to describe clinical uncertainty. While functional uncertainty can and should be minimized, professional uncertainty, or clinical uncertainty, is more likely to remain a constant in most, if not all, situations patients experience to some degree. While "the eventual discovery of new findings, rules, laws, methods, procedures, experiments, surveys, theories, standards of rationality and provisional truths" may make certain existing clinical uncertainties obsolete (Adamson, 1997, p. 135), others will arise and/or remain rendering "clinical uncertainty" in a continual state of flux.

Based on the notion that clinical uncertainty about symptoms, diagnosis, treatments, and prognosis are events likely to remain in patient situations, Neville turns to the discussion of Mishel's UIT, as the theory is predicated on this notion and these illness-related events. A description of nursing studies using this theory and MUIS among various patient populations spanning over a decade are mentioned. Only one study examined perceptions of uncertainty from the family's perspective. Based on the review, the author concludes that extant research indicates uncertainty has a significant influence on psychosocial outcomes of persons facing serious illness. Hilton (1992) echoes these notions based on her review of the literature on uncertainty, which included patient- and, to a lesser degree, family- or partner-focused studies. Hilton concludes that illness-related uncertainty is stressful for patients and families, and uncertainty may manifest as emotions and/or behaviors. Furthermore, uncertainty influences the adjustment to illness.

Mishel (1999) provides the most extensive and comprehensive literature review in terms of synthesis of findings from studies of chronic illness populations wherein uncertainty was a major topic of investigation or emerging theme reflected in findings. Included are studies published between 1975 and 1997 (N=47). Mishel included adults and parents of children diagnosed with chronic illnesses marked by acute phases (e.g., cancer), vacillation between stable and unstable periods (e.g., COPD), and remissions and exacerbations (e.g., AIDS). Similar to Mast's (1995) review, Mishel organizes the synthesis of findings according to the antecedents, nature, and management of and adjustment to uncertainty.

While only five family- or partner-focused studies are included, results consistently indicate that uncertainty is an issue for the family member, and that a family care provider dealing with uncertainty may not be available as a source for support for the affected family member. Mishel (1999) indicates one of most striking inconsistencies reported in findings is reflected in study design; an examination of quantitative studies revealed that uncertainty results in poor psychosocial adjustment, but qualitative studies have placed uncertainty in a more positive context, revealing that uncertainty changes over time and leads to new perceptions of the world. Like Mast (1995), Mishel concludes that qualitative designs are better suited to determine uncertainty's nonlinear, processual nature since "multiple interviews of the same individuals can be done to elicit the movement in the process" (p. 273) and "quantitative studies index a slice of time using a specific measure that may not reflect a process" (p. 289). Furthermore, she concludes that much focus has been on the ill adult, leaving a significant need to examine the family's experience of uncertainty.

Uncertainty: Quantitative Research

Since publication of the aforementioned literature reviews, researchers have continued to conduct correlational studies on uncertainty and its relationship with different variables among chronic illness adult populations. Researchers have demonstrated the following: a negative correlation exists between uncertainty and motivation to seek treatment among adults with insulin-dependent diabetes mellitus (IDDM) (Apostolo, Viveiros, Nunes, & Domingues, 2007), higher levels of uncertainty and decreased reliance on spirituality are associated with lower levels of psychosocial adaptation among persons with multiple sclerosis (McNulty, Livneh, & Wilson, 2004), high levels of uncertainty are associated with less social support and psychological well-being among high-risk pregnant women (Guirgescu, Penckofer, Maurer, & Bryant, 2006), uncertainty is positively correlated with post-traumatic stress and negatively correlated with health promotion behaviors among young adult childhood cancer survivors (Santacroce & Lee, 2006), uncertainty is positively correlated with fatigue and reduced functional status among patients with CHF (Falk, Swedberg, Gaston-Johansson, & Ekman, 2007), uncertainty is significantly associated with anxiety and negative affect and interacts with interpersonally stressful daily events in predicting reduced positive affect among persons with fibromylagia (Reich, Johnson, Zautra, & Davis, 2006), uncertainty is negatively correlated with education level among men undergoing watchful waiting for prostate cancer (Wallace, 2005), and uncertainty is associated with emotional distress among women with endometriosis (Lemaire, 2004).

With the exception of a few studies focusing on family uncertainty (as cited in the above-mentioned literature reviews), researchers have only recently demonstrated an increasing interest in examining illness uncertainty from perspectives of family members of those who are ill, with particular focus on intimate partners. Among couples in which one of the spouses had breast cancer (Northouse, Templin, & Mood, 2001) or colon cancer (Northouse, Mood, Templin, Mellon, & George, 2000), higher uncertainty is directly related to more role (e.g., work, family, and social) adjustment problems in both spouses 1 year after diagnosis. Researchers have demonstrated that in some instances, family caregivers report more concerns with uncertainty and other variables than their affected spouses. For example, among women with recurrent breast cancer and their family caregivers (59% were intimate partners), the family caregivers reported more uncertainty about the illness, less support, and less satisfaction with healthcare professionals (Northouse et al., 2002). Among couples in which husbands had prostate cancer, wives reported more uncertainty, lower levels of confidence in their illness management abilities, and less social support (Northouse et al., 2007).

In a study whereby researchers examined relationship satisfaction among persons with either fibromylagia or osteoarthritis and their intimate partners, low levels of partner supportiveness (as reported by the partner) and high levels of illness uncertainty (as reported by the patient) were associated with lower relationship satisfaction (as reported by the patient) (Reich, Olmsted, & van Puymbroeck, 2006). While this study did not directly assess intimate partner uncertainty or their own reports of relationship satisfaction, it revealed that the experiences of both partners are important in determining outcomes of importance to health status. Researchers studying the influence of psychological factors associated with chronic stress on caregivers' immune function found that "stressors perceived as unpredictable and uncontrollable" or uncertain may be "associated with elevated stress hormones" within the context of chronic stress (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002, p. 538). Thus, persons experiencing uncertainty as a psychological factor associated with adverse outcomes are at-risk for immunological dysregulation.

In sum, uncertainty is negatively associated with health promotion behaviors, positive affect, role adjustment, health care provider satisfaction, relationship satisfaction, and functional status, among other variables. This is of concern to nurses, particularly in light of research on the link between uncertainty and its effects on the immune system.

The most recent findings on uncertainty in illness corroborate Mishel's findings from her review of quantitative studies on uncertainty: uncertainty is associated with variables indicative of poor adjustment. Moreover, its nature is generally cast in a negative light. It is important to examine the findings of qualitative studies to perhaps gain a more complete picture of uncertainty.

Critique

Several of the previously discussed correlational studies used Mishel's UIT, which is based on a cognitive appraisal model to explain how persons construct meaning for illness-related events (Mishel, 1988, 1990), to conceptualize uncertainty and Mishel's Uncertainty in Illness Scale (MUIS) (Mishel, 1981) to measure uncertainty. The development of Mishel's Uncertainty in Illness Theory and MUIS is based on interviews with hospitalized patients (Mishel, 1981). Mishel used four illness-related classes of events to focus these interviews. The events included: the discomfort, incapacitation, and symptoms related to the illness; the management of treatment and its side effects; the health care environment and its technical, unfamiliar nature; and the assessment of future in terms of independence. Statements extracted from these interviews were included on the MUIS if judged to reflect one of eight dimensions of uncertainty, including: vagueness, lack of clarity, ambiguity, unpredictability, inconsistency, probability, multiple meanings, and lack of information.

Since the development of MUIS, Mishel has developed other scales for measuring uncertainty among 1) chronically ill individuals or families of chronically ill who are not hospitalized 2) parents of children who are ill, 3) and spouses, friends, or other relatives of an ill family member. While Mishel's (1990) reconceptualization and addition of various scale versions allow for an increased understanding of uncertainty among populations other than hospitalized adults, including family members of community-dwelling chronically ill persons, they are not appropriate for use in the conceptualization and measurement of uncertainty in the present study population for numerous reasons.

First, Mishel’s (1981) use of a semi-structured interview format solely based on questions about four illness-related tasks to elicit descriptions of uncertainty did not allow for an in-depth, rich, participant-grounded and -guided description of the meaning of uncertainty to unfold. This presents a serious limitation in the sense that findings from this initial inquiry were used to develop measurement scales and a theory on uncertainty. Ultimately, any inquiry based on this conceptualization of uncertainty will already be bounded by what it means to be uncertain according to the four, illness-related tasks.

Second, the proposed study involves persons who may or may not consider their pre-illness experiences to be illness events as defined by Mishel (1988, 1990) (e.g., diagnosis, hospitalization, treatment, recurrence) to serve as an impetus for a changed state of uncertainty. While the predictive genetic test for HD is clearly situated within a medical context, the focus of the proposed inquiry is not the uncertainty surrounding the unfamiliarity of the test or the healthcare environment in which the test is given, waiting for results, or accuracy of results (i.e., clinical uncertainty). Rather, the focus is on the time period after testing but before clinical diagnosis. It is unknown how partners of persons receiving genetic information about future illness development experience the time between testing and symptom onset and clinical diagnosis. On one end of the spectrum, all health- and illness-related experiences during that time may be colored by having the genetic information, and, therefore, become associated with “having” HD. On the other end of the spectrum, these experiences may be perceived as having nothing to do with illness since classic signs and symptoms are not evident and clinical diagnosis of HD has not yet been made. The current study aims to understand uncertainty during a time in which persons are not experiencing medically-related events and may or may not identify with experiencing illness- or HD-related events. In a similar manner, Morse and Penrod (1999) conceptualize uncertainty as a response to a significant threat to health in their model explicating relationships between enduring, uncertainty, suffering, and hope. It is unknown whether persons privy to genetic information during a state in which symptoms are either absent or subtle enough that attributing them to HD is difficult perceive the receipt of this information as a threat to health. Furthermore, uncertainty is one concept situated among others, rendering this model not appropriate for use in the present study.

Third, Mishel's conceptualization of uncertainty and measurement scales are rooted in a probabilistic paradigm and focus on and aim to capture the cognitive ways of knowing reflected in states of uncertainty. Similarly, the Lazarus and Folkman (1984) framework of stress and coping is rooted in cognitive appraisal. According to the probabilistic paradigm, strategies for reducing uncertainty depend on the availability of and ability to process information in order to determine probability prior to taking action. Researchers, however, have demonstrated there are modes of uncertainty for which a person is not able to process such information. Specifically, there are existential modes of uncertainty (Bunkers, 2007; Hilton, 1988; Nelson, 1996; Penrod, 2001a, 2007; Penrod & Hupcey, 2005) that hinge on pre-cognitive ways of knowing, and these are important in determining uncertainty states (Penrod, 2001a, 2007; Penrod & Hupcey, 2005).

In fact, Penrod (2007) reported that experiences with the type of "unknown" for which there are no conceivable probabilities are typically situated within existential issues, and it was this type that presented the prime sources of uncertainty among family caregivers. In sum, "probabilistic paradigms preclude existential and situational modes of uncertainty for which probabilities cannot be estimated or appreciated, [and their influence on] understanding states of uncertainty must not be underestimated" (Penrod, 2007, p. 665). It is the aim of the present study to gain an in-depth understanding of uncertainty; uncertainty must, therefore, be conceptualized and examined in a context broader than Mishel's Uncertainty in Illness Theory and related scales allow.

Other scales exist to measure illness-related uncertainty (Hilton, 1994) or the intolerance of uncertainty (Buhr & Dugas, 2002). Measuring the concept of uncertainty or tendency for considering “the possibility of a negative event occurring unacceptable,” (Carleton, Norton, & Asmundson, 2007, p. 105) however, does not provide a rich, in-depth understanding of the meaning of the experience. “The experience of uncertainty is highly personal and dynamic. One point-in-time measurement does not accommodate fluctuation, and aggregate group information does little to help us understand the unique experience of an individual” (Penrod, 2001b, p. 242). Extant measurement tools capture the cognitive ways of knowing reflected in states of uncertainty, as well as uncertainty’s situational, event-specific character. Researchers have, however, reported there are also 1) pre-cognitive ways of knowing, 2) existential modes of uncertainty, and 3) shifting types and modes of uncertainty (Penrod, 2001a, 2007; Penrod & Hupcey, 2005). These findings indicate uncertainty must be situated and examined in a context broader than existing measures currently allow. The present study will describe the experience of uncertainty in a population for which a point-in-time measurement would not capture participants’ voices. It is invaluable “to hear from even more of the participating voices than we currently do [by] turning[ing] directly to lived experience…and working with local discourses of caregiving” (Gubrium, 1995, p. 268).

Uncertainty: Qualitative Research

A smaller but substantive and growing body of literature examines uncertainty using qualitative methodologies. As in the body of quantitative research, qualitative researchers have largely focused on uncertainty in the context of illness and/or described its manifestations in illness situations. Similar to the previously mentioned correlational studies, family and/or intimate partner-focused research is not nearly as prevalent as “patient”-focused studies of uncertainty. Findings from a significant portion of qualitative research conducted on uncertainty in illness have been described and synthesized elsewhere (see Mast, Hilton, Neville, and Mishel for reviews); the remainder of the discussion, therefore, focuses on studies conducted more recently, since the publication of these reviews. The exception is the section on phenomenological studies of uncertainty. Since these are most relevant to the current inquiry and researcher's conceptualization of uncertainty, any and all studies examining uncertainty using this methodology are included in the description, regardless of publication date.

Brashers et al. (1999) conducted a study to examine uncertainty among persons with HIV or AIDS using focus group methods. Participants were asked to do the following: describe events and circumstances that made them feel uncertain since testing positive for HIV; describe how uncertainty affected their lives; and discuss methods used to manage uncertainty. Latent content analysis and constant comparative techniques revealed findings indicating that after a period of revival (a time when persons believe they can survive due to effective treatment), uncertainty and renegotiation involved feelings of hope, changing social roles, and changes in interpersonal relationships. Causes of uncertainty were medical, personal (e.g., complex, conflicting roles and unclear financial consequences), and social (e.g., unpredictable social reactions and unclear relational implications) in nature (Brashers et al., 2003). To manage uncertainty, persons used support systems to: assist them with information seeking and avoidance; validate knowledge, plans, or feelings; facilitate skill development; provide instrumental support; allow for ventilation; and encourage shifts in perspective. Seeking support from others, however, had drawbacks. While receiving support may be of benefit, it also diminished one's sense of personal control. Other circumstances, such as an incongruence between support provider and support receiver, served to interfere with uncertainty management strategies. In sum, the researchers found support networks to be important in managing uncertainty, but there are costs and complications involved (Brashers, Neidig, & Goldsmith, 2004).

Cohen (1993, 1995a, 1995b) used grounded theory methodology to explicate how uncertainty permeates and transforms family life when persons experience a disrupt discontinuation of past and present (i.e., child is diagnosed with a chronic, life-threatening illness). Findings revealed that the diagnosis "becomes an assault on previously held knowledge, beliefs, expectations, and values…[whereby] the taken-for-granted world abruptly ceases to exist" (Cohen, 1993, pp. 82-83). Families described moving from a world in which security and familiarity prevailed to one in which "ambiguous boundaries, unclear rules, probabilistic predictions, and sinister possibilities" became the norm (Cohen, 1993, p. 83). Specifically, parents found the diagnosis created a social distance from others who had not shared similar experiences, a sense that they could never be the same as they were before, feelings of vulnerability, and a hesitancy to think about the future. Findings explicate stages parents go through during the prediagnostic period, beginning with how they understand subtle illness cues and ending with a diagnosis (Cohen, 1995a). Uncertainty became a constant in their lives, however, even well after diagnosis when the disease was considered to be in remission or under control (Cohen, 1995b).

In line with the more recent interest in examining the perspectives of those more indirectly affected by illness (i.e., family and social support networks), researchers examined the issues faced by family and friends of persons with communication-debilitating illness or injury (CDI) (i.e., stroke, Alzheimer disease, multiple sclerosis, or traumatic brain injury). Researchers used semi-structured interviews to ask participants about such issues, including associated stresses and how communication was affected. Constant comparative and latent content analyses revealed that uncertainty emerged as a prominent theme. Specifically, they revealed sources of uncertainty (e.g., the condition itself and communication) and ways of managing uncertainty (e.g., information seeking and acceptance) (Donovan-Kicken & Bute, 2008). Findings are similar to those of prior family studies indicating uncertainty is, indeed, a central experience and pervades the lives of persons in relation with those who are ill.

Critique

Several qualitative studies point to a need to conceptualize uncertainty beyond Mishel's Uncertainty in Illness Theory, which uses the medical aspects of uncertainty in illness, to include non-medical aspects such as loss and dying, interpersonal relationships, personal identity, and transitioning to new life perspectives. A series of reports emanating from a study by Brashers and colleagues (1999, 2003, 2004) were presented in the above literature review. Due to the medical technology currently available whereby persons who are HIV-positive are largely able to remain in a stable, often symptom-free state, they are essentially living in an "at-risk" (for AIDS) state. Findings from this study may have relevance to the current study's population, whose partners may also be considered "at-risk" for future disease development. Brashers and colleagues, however, examined what uncertainty was like for such persons using Mishel's Uncertainty in Illness theory as a framework; findings, therefore, do not reveal an in-depth understanding of *what uncertainty is* from their perspectives, including how it flows over time.

Cohen's series of reports (1993, 1995a, 1995b) adds to the body of literature stating that sustained uncertainty is a source of psychosocial stress, and how families manage this stress has long-range implications for family health, well-being, and QOL. Cohen's report presenting the stages of the prediganostic period has potential relevance to the present study, considering the study population of interest includes intimate partners of persons who have not yet received a clinical diagnosis. There are differences, however, between receiving knowledge of future illness and receiving a diagnosis based on symptom presentation. In Cohen's research, parents described the uncertainty surrounding what it was like to experience sudden, dramatic events (e.g., a child's unexpected cancer diagnosis). The findings may not be applicable to families at-risk for

HD who are not only aware of risk potential prior to testing but have additional information about this risk after testing and, therefore, may not experience the event of clinical diagnosis as an abrupt discontinuation of past and present.

Furthermore, the sample consisted of families in which children had already been diagnosed, and interview questions were focused on getting retrospective accounts of what their experiences were prior to the diagnosis of their children's illness. The findings used to explicate the emerging theory on uncertainty in the prediagnostic period would be strengthened by theoretical sampling to include persons pre-diagnosis, particularly in light of the researcher's report that "above all, the experience [of having a child diagnosed with a life-threatening illness] made [the parents] certain that they can never return to being the same people they were before" (Cohen, 1993, p. 93). This leads the reader to wonder if the participants' accounts and recollections of the prediagnositc period are significantly different from what they might have been had they been collected prior to diagnosis.

Uncertainty: Phenomenological Research

Nurse researchers have sought to explicate the meaning of uncertainty from an existential perspective. Nelson (1996) examined uncertainty among women with breast cancer (BRCA); findings reflected 5 themes as an interwoven aspect of the uncertainty experience. The first, the *vicissitude of emotions*, involved feelings of fear, anxiety, and hope. Nelson described how the women made attempts at controlling the fear associated with uncertainty through suppression of emotions and/or distracting themselves. Anxiety was described as an undercurrent in which "awareness of the unpredictable nature of breast cancer [was] anchored" (p. 64). Hope was used to "[birth the women's] confidence in their unknown future[s]" (p. 64). The second theme, *relying on support*, reflects that the presence of support during times of uncertainty influenced women's perceptions and interpretations of their experiences.

Transitions: learning new ways of being in the world is the third theme from Nelson's (1996) study. As a result of contemplation with mortality, the women described finding new, valued ways of living in a world of uncertainty. An uncertain future was not viewed as a negative thing to be eliminated but rather a positive thing capable of allowing meaningful experience to unfold. The fourth theme, *reflections of self in the world*, involves the struggle between connecting with and separating from others; women often felt torn between wanting to offer support to other women with BRCA yet protect themselves in their own uncertainty. The fifth and final theme is *gaining understanding: putting uncertainty into life's perspective*. This reflects that the women embraced a more "cosmic view of life…in which they had not given up…but had reconciled to balancing their uncertain futures in a life perspective that had broadened within their uncertainty" (p. 72).

Penrod (2001a) examined uncertainty among informal family caregivers of older adults and reported 5 essences: *sensing control, sensing confidence, reading the situation, regaining a sense of normal, and shifting temporality*. Notions of enduring, suffering, hoping, normalization, and trust were found to be related or co-occuring concepts. Control and confidence were "two primary issues undergird[ing] the experience of uncertainty" (p. 137). *Sensing control* relates to the ability to influence the outcome of the situation. In this study, caregivers reported a general sense of a lack of control over events, although this was not particularly discomforting. Some, in fact, chose to surrender their control, "riding each wave of uncertainty" (p. 147). *Sensing confidence* relates to an ability to read a situation. Confidence was found to decrease the sense of uncertainty by reducing the doubt involved in determining meaning in a situation.

Reading the situation reflects a process in which persons assign meaning by processing evidence within their own analytic frames. This essential theme reflects that, upon self-examination in the context of personal situation, one's sense of existence or being in the world is challenged by uncertainty. *Regaining a sense of normal* is a comfortable state in which a “new sense of confidence in reading the situation and responding in order to control things” (p. 165) is actualized. In this state, growth may be experienced. Lastly, *shifting temporality* indicates states of uncertainty are temporally bound. Individual perception of time depended on the degree of uncertainty experienced. Furthermore, while uncertainty is largely present-focused, caregivers described glimpses of their futures during uncertain times.

Bunkers (2007) studied feeling unsure as an everyday lived experience related to health among women at end-of-life. She found feeling unsure is *disquieting apprehensiveness arising while pressing on with intimate sorrows*. *Disquieting apprehensiveness* reflects the discomfort one may have with uncertainty and includes “a pervasive hesitancy concerning what is possible” (p. 60). It involves feeling troubled and out of control when thinking of both present and future. A concept similar to disquieting apprehensiveness is “disturbing uneasiness.” *Pressing on* reflects the courage and perseverance to continue in living amidst struggle and uncertainty. It is the day-by-day living-dying process. The participants specifically described being “immersed in earnest endeavors, while fearing not having enough time to do” (p. 60). “Courage” and “deliberate persistence” are concepts related to pressing on. *Intimate sorrows* is paradoxical in nature, reflecting anguished yet cherished involvement with another. Sadness and mournfulness are present in anticipation of separating from valued connections with others.

Morrow (2010) described the structure of feeling unsure among community-dwelling persons living with chronic heart failure. She found the lived experience of feeling unsure is *discomforting trepidation with unassuredness-assuredness, as vigilantly anticipating with treasured alliances arises with moments of acquiescence*. The first core concept, *discomforting trepidation with unassuredness-assuredness,* is reflective of participants’ uneasiness, fear, and anxiety associated with doubt and uncertainty while simultaneously feeling confident. *Vigilantly anticipating*, the second core concept, is carefully watching, or "guardedly speculating and envisioning what lay ahead" (p. 320). Some participants described this as being "on edge." Participants described both confirming and not confirming cherished beliefs among important others in their lives, and this has bearing on the lived experience of feeling unsure; this core concept was described as *treasured alliances*. The last, *moments of acquiescence,* described participants' experiences of going with the flow and accepting feeling unsure. The acceptance was both an acceptance of what is and what is not-yet.

Critique

While nurse researchers have used an existential framework to guide inquiry on what the meaning of uncertainty is, thereby shedding light on non-medical aspects of uncertainty, a critical examination of these studies further supports the need for the present research. Methodological concerns arise from Nelson's (1996) study of uncertainty among women 2-6 years posttreatment for breast cancer. The researcher used van Manen's method of hermeneutic-phenomenological inquiry. Her first round of interviews with participants "focused on the women's descriptions of their uncertainty experiences" and the second round focused on their symbolic interpretations of uncertainty via photography. "All interviews were transcribed before analysis. Data from both interviews were combined for analysis" (p. 62). It appears, therefore, all data were collected prior to the start of data analysis. The concern is that the hermeneutic thrust may not have been fully realized and findings, therefore, compromised. van Manen (1990) indicates data analysis must occur in a more concurrent manner with data collection so that initial themes can be identified and serve as objects of reflection in any subsequent hermeneutic conversations.

> Both the researcher and the interviewee attempt to interpret the significance of the preliminary themes in the light of the original phenomenological question…[via] reflection on the text (transcripts) of previous interviews in order to aim for as much interpretive insight as possible (p. 99).

Penrod (2001a) also used van Manen’s method to guide her inquiry of uncertainty among 6 caregivers (mostly middle-aged and in non-spousal relationships with the care recipients) of older adults with the overarching intent of concept advancement. The aims of the study were threefold: 1) to derive universal essences of the lived experience of uncertainty among the study population; 2) to examine the utility of phenomenological findings in advancing uncertainty as a concept towards maturity; and 3) to propose an assessment guide for managing uncertainty. Sensing control, sensing confidence, reading the situation, regaining a sense of normal, and shifting temporality were identified as the essences of uncertainty, but “two primary essences, confidence and control, emerged as the strongest variants among several forms of uncertainty” (p. 173). In other words, “the balance of perceived confidence and control produces varied types of uncertainty” (Penrod, 2007, p. 661). While the study aims and purpose required the researcher to disentangle conceptual attributes from other concepts (e.g., hope, normalization, and enduring) that co-occured with the concept of uncertainty, the essences alone do not reflect the *experience* of uncertainty. van Manen indicates the description of the experience reflected in the study’s findings must be so powerful that it “reawakens our basic experience of the phenomenon it describes, and in such a manner that we experience the more foundational grounds of the experience” (p. 122). Based on the researcher’s findings, the two themes of confidence and control appear more “essential” to understanding uncertainty than the other themes. While these attributes are reported to be reflective of uncertainty and, may in fact, be the only two accurately identified thus far (J. Penrod, personal communication, October 10, 2005), there remains a need to produce a rich, animating, evocative description of the experience.

Bunkers (2007) and Morrow (2010) used Parse’s phenomenological-hermeneutic research method to uncover the structure of the lived experience of feeling unsure among 9 women at end-of-life and 10 persons with chronic heart failure, respectively. Findings from both reveal the existential aspects of uncertainty. *Disquieting apprehensiveness,* *discomforting trepidation with assuredness-assuredness,* and *moments of acquiescence,* for example, reflects existential conflict as one contemplates and/or accepts the freedom and responsibility for creating possibilities amidst a limited existence. As in the existential conflict faced upon consideration of death, the notions of *pressing on* and *vigilantly anticipating* imply one's choice to partake in meaningful endeavors or possibilities. The notions of *intimate sorrows* and *treasured alliances* mirrors that of the conflict faced upon confrontation with existential isolation; one makes an attempt at celebrating the intimate and prized connections with others while, at the same time, feels apart from them. While findings reveal the meaning of uncertainty experiences among women at end-of-life and persons with chronic heart failure, it remains unknown how persons experience uncertainty at the other end of the illness trajectory, during the prodromal period.

Taken together, these phenomenological studies on uncertainty shed light on its meaning among persons affected with illness and their caregivers during times of illness. It is important to gain an understanding of the existential aspects of uncertainty from the perspectives of intimate partners, who may serve as future caregivers, of persons in the prodromal phase of a chronic, progressive disease. Receiving genetic information about the future likelihood of disease development provides an ideal context to study uncertainty and situate the findings in an existential framework; intimate partners of persons in this early stage of the trajectory are not typically experiencing the aspects of uncertainty more heavily associated with medical procedures, tests, and treatments (i.e., clinical uncertainty). The more existential aspects of uncertainty, therefore, may be allowed to more fully emerge, be reflected upon, and be elucidated in a rich, evocative description of this lived experience.

Summary

The extant body of scientific literature on uncertainty reveals its highly complex nature, as evidenced by both non-scientific and scientific bodies of literature. Among the scientific body of nursing literature, uncertainty is considered pervasive in illness and illness events, influencing coping, health behaviors, and psychosocial and physiological outcomes. A smaller body of literature has indicated uncertainty includes or is relevant to aspects of loss, dying, and other existential notions. While the majority of research has focused on patient-centered experiences of uncertainty, a few studies have demonstrated that patients' families also experience uncertainty's pervasiveness and profound effects.

The critique of the quantitative and qualitative bodies of literature point to significant gaps in nursing's scientific understanding of uncertainty, thereby warranting the need for the current research: 1) Mishel's UIT cannot be applied to examine uncertainty among the present study's population. The present study involves persons who have received genetic information pertaining to their loved ones' future health but remain in the prodromal, or pre-illness, phase. It is unknown whether such persons experience this phase as an illness or health-related situation. Using extant frameworks centered on illness and/or health related events would, therefore, be inappropriate for examining and understanding their experiences; 2) more research involving intimate partners is needed. The scant amount of research involving family members of those who are ill indicates they, too, experience uncertainty and its health implications. Additionally, research has suggested that when family members experience uncertainty, they may not be available as a source of support for the ill family member. It is important to look outside of patients' perspectives to test/extend current frameworks for uncertainty and illness, since the majority of studies have focused on illness uncertainty from patients' perspectives; 3) further qualitative research is needed to expand nurses' understanding of uncertainty. Quantitative designs fall short when applied to the measurement of uncertainty. The majority of correlational and/or descriptive studies used

MUIS to measure clinical uncertainty; however, clinical uncertainty is in continual flux. How, then, is measuring this context-dependent variable useful in understanding uncertainty in all its complexity?; and 4) studies using existential frameworks for understanding uncertainty are needed. Existential modes of uncertainty hinge on pre-cognitive ways of knowing, and these are significant in determining states of uncertainty. While a few researchers have examined uncertainty from this perspective, their focus has been on uncertainty in times of illness. The present study includes intimate partners of persons in the prodromal phase, thereby aiming to capitalize on the presence of existential modes uncertainty, which are presumably more prominent during this phase than those in which clinical uncertainty is more prevalent.

In conclusion, studies emanating from the scientific body of nursing literature on uncertainty in chronic illness have largely focused on illnesses marked by 1) acute phases, 2) vacillation between stable and unstable periods, and/or 3) remissions and exacerbations. There is little understanding of the meaning of uncertainty as lived experience among persons in the prodromal phase of a disease marked by progressive deterioration, such as HD. It appears, however, that studies to determine how a person and/or his or her family members with a particular disease experience uncertainty could be conducted in a never-ending way. While the findings from such studies have and would no doubt continue to shed light on the experiences of persons faced with a specific illness, it is important to move beyond illness-based descriptions of uncertainty. For example, in research undertaken to determine how couples manage chronic illness, Corbin and Strauss (1988) found that participants' experiences with uncertainty were *not* rooted in illness, but rather were placed in a biographical context that melded past experiences with hopes and dreams of the future which had been disrupted or changed.

Furthermore, "findings [from a synthesis of the scientific literature on uncertainty] concerning the nature of the [disease] symptoms are consistent, even if the specific symptoms differ across illnesses" (Mishel, 1999, p. 288). While symptoms vary across illnesses, humans' interpretations of and responses to them fall within a range of universally-experienced feelings. These feelings, therefore, are the uniting commonality across illness. Nurses have long rejected the notion that persons are defined by their illnesses. The aim of the present study is, therefore, to place the study of human experience (i.e., uncertainty) in the forefront, with illness, or more accurately, predisposition to illness, serving as context.

While family members of persons with HD have described experiences similar to those in previously discussed studies, such as feelings of stress, vulnerability, and loss, the literature does not capture the complexity of living with uncertainty for family of those: in the prodromal phase; likely facing a certain development of progressive disease for which no prevention or treatment yet exists; younger in age relative to others with a chronic, progressive condition; and who may not experience the predictive testing as an abrupt discontinuation of past and present. Furthermore, the literature on caregiver uncertainty does not include the experiences of persons who may assume caregiving responsibilities in the future as a result of having genetic information about future health. The current study will address these gaps in knowledge by providing an enhanced understanding of uncertainty in all its complexity.

Explicating a Personal Conceptualization of Uncertainty

The proposed study is grounded in hermeneutics and phenomenology which is informed by existentialism. Existentialism is a philosophical stance centered on humans as they exist and emphasizes each human being as an emerging or becoming being (May, 1961). The challenge of existentialism is reflected in the following question: How do humans more fully realize that which remains undeveloped in human nature? (Bugental & Kleiner, 1993). Existentialism arose and developed in the 19th and 20th centuries in response to other orientations at the time that were largely reductionistic and deterministic in nature. As in the human science of nursing (Parse, 1998), existentialism views humans as whole, rather than parts, and irreducible in terms of pathology to be studied and cured. “Man supersedes the sum of his parts” (Bugental, 1965, p. 11).

Core Existential Concepts

The core concepts in existentialism are: death, freedom, and isolation. Each of these are considered a given in life; they are the ultimate concerns with which humans must deal. As long as humans are alive and pattern their lives based on these givens, these existential concerns must be confronted, and existential conflict arises from this confrontation (Yalom, 1980). According to Heidegger (1962), humans occupy one of two states of existence: the first, a state of forgetfulness of being, reflects immersion in everyday life and the way things are; the second, a higher state of mindfulness of being, reflects not only the *way* things are but *that* they are. In this second state, humans embrace possibilities and limitations posed by each of the ultimate concerns while experiencing a core, existential type of anxiety.

Existential anxiety is different from other emotions, according to May (1983), as it characterizes human nature and can never be completely eliminated. Ultimately, “anxiety is the experience of threat of imminent non-being” (May, 1983, p. 109). This existential anxiety cannot be understood and, therefore, not confronted, so feelings of continued anxiety and helplessness are generated (Kierkegaard, 1957). Persons attempt to deal with anxiety by seeking out certainties (Bugental & Kleiner, 1993). In general, humans respond by aiming to structure their worlds, providing order and limiting themselves to knowable proportions. In other words, fear of nothing is transformed to fear of something so that strategies may be employed to avoid or placate it (Kierkegaard, 1957).

The first given, death, carries such finality that it implies contingency, circumstance, and the chance for benefit or harm. Humans’ awareness that 1) all aspects of living are transitory and impermanent and 2) death is inescapable serves to create an inner, core conflict; humans desire to continue to *be* or *exist* while being aware of certain death (Bugental & Kleiner, 1993; Yalom, 1980). “The awareness of the certainty of one’s death coupled with the uncertainty as to when and in what manner that end will arrive colors experience powerfully” (Bugental & Kleiner, 1993, pp. 103-104). While an individual carries this core conflict in everyday life, it is not necessarily in the morbid sense. Heidegger (1962) posits that an individual’s awareness of death carries the potential to move him or her to the higher state of being of mindfulness. In this state of existence, humans are mindful of life’s fragility and that death is “the impossibility of farther possibility” (Heidegger, 1962, p. 310). Death may, therefore, be conceived as something which can positively contribute to life; it reminds humans that, as long as they live, there are possibilities, and without it, life’s intensity would likely be diminished.

The second given, or ultimate existential concern, is freedom. Heidegger’s (1962) reference to individual as “dasein” indicates he or she is *there* and constitutes, or is responsible for, *what* is there. This responsibility is inextricably linked to freedom. Each person can constitute the world in numerous ways, so these concepts of responsibility and freedom imply a creation of meaning or meaninglessness. Sartre (1956) emphasizes that each human is the uncontested and sole author of his or her life. Human awareness of this kind of responsibility and freedom carries much weight; while humans are free to create and claim responsibility for themselves, their destinies, and meaning in life, they may also create and must claim responsibility for their own suffering and meaninglessness. This awareness leads to a sense of groundlessness; nothing in the world carries significance except by virtue of each person’s creation (Yalom, 1980). Existential conflict arises from the tension between humans’ desire for structure and groundedness and their confrontation with groundlessness. Notions of dread and existential anxiety, therefore, ensue.

Isolation is the third given and has links with the former two, death and freedom. Heidegger (1962, p. 284) indicates death is ultimately the most isolating experience humans encounter; “No one can take the other’s death away from him.” Having freedom to carry the responsibility for being the sole author for one’s life reflects an isolated position (Heidegger, 1962). Bugental (1993) points out that humans live a paradox of being separate and engaged from and with others in the world; humans have a deep-seated need for connection to humankind yet want to remain separate individuals. Despite how close a human relationship may be, full and complete connection can never be attained, and this reality creates existential conflict and anxiety (Yalom, 1980). Dealing with this anxiety can be either harmful or growth producing. Kierkegaard (1954) indicates that the approach to eliminate isolation anxiety by sacrificing selfhood through immersion of self into another individual, cause, or pursuit leads to further despair. By not allowing oneself to become immersed or absorbed in worldly objects, however, the existential anxiety is allowed to lead humans back to full awareness, or a higher, mindful state of being (Heidegger, 1962). Confronting the existential isolation and anxiety, therefore, allows humans to more fully engage with others and the world on a deeper, more meaningful level.

Defining Existential Uncertainty

From an existential perspective, uncertainty is inherently linked with existential anxiety. Gordon (2003) defines uncertainty as “an inherent cosmic expression, deeply embedded within the core of reality” (p. 96), and this uncertainty “is a source of primal anxiety” (p. 107). In other words, uncertainty is an inherent state of the world simultaneous with anxiety while anxiety is an inherent state of being human simultaneous with uncertainty. As humans become aware that their existence is inherently uncertain, they embody this awareness in anxiety. In the medical encounter, existential uncertainty is that which is experienced at a personal, private level upon the realization that “the future life of his or her mind, body, and self is in jeopardy” (Adamson, 1997, p. 134). “The awareness of the certainty of one’s death coupled with the uncertainty as to when and in what manner that end will arrive colors experience powerfully" (Bugental & Kleiner, 1993, pp. 103-104). While the finality of death implies impossibility of being, it also reminds humans of their freedom to create possibilities during an existence which is open and undetermined. There is, therefore, a fundamental uncertainty to life; "existence is inexorably free and, thus, uncertain" (Yalom, 1980, p. 26).

Based on the assumption that the three, existential concepts in life of death, freedom, and isolation are givens, or universally experienced, uncertainty is also a universally-lived experience. Kleinman (2006) states: "Underneath the huge varieties of cultural meanings, social experiences, and subjectivity, there is a shared condition of being human that centers on experiences of loss, threat, and uncertainty" (p. 231). Just as existential anxiety cannot be avoided or eliminated, uncertainty cannot be avoided or eliminated. When one becomes aware of and confronts existential conflict upon contemplation of an existential concern, what does one do with ensuing uncertainty and anxiety? One may either embrace it and constitute the higher, more mindful state of existence or attempt to avoid or placate it, constituting the lower, more forgetful state of being reflected in immersion in everyday objects.

From an existential perspective, uncertainty is, therefore, conceptualized as a state in which meaning and growth are either cultivated or suppressed. Gordon (2003) asserts that amidst an uncertain universe, or that which is "comprised of interdependent, interpenetrating networks of relationship," systems with a greater degree of uncertainty actually have greater creative potential (p. 104). Choices arising from boundless possibilities come from uncertainty, which is inextricably linked with creativity, authenticity, and anxiety. In other words, creativity and authenticity are not possible without uncertainty and anxiety; in fact, without the latter two, humans face a life devoid of meaningful experience (Gordon, 2003). When human response is, therefore, focused on embracing uncertainty, the potential for enhanced creativity, possibility, meaning, and authenticity are realized.

Humans may also, however, demonstrate responses aimed at avoiding or placating uncertainty by attempting to create certainty, structure, and limits to contain feelings of groundlessness, isolation, and fear. This human resistance to anxiety and struggle to create order and certainty may open the way for pathology. Uncertainty and its "child," anxiety, however, are not pathological in-and-of themselves. Kleinman (2006) supports this notion, describing the dangers in medicalizing existential angst and uncertainty by turning it into disordered anxiety. Doing so, Kleinman asserts, dehumanizes the natural, "deep mixture of often contradictory emotions and values whose untidy uniqueness defines the existential core of the individual as human being" (p. 10). Kleinman notes that confronting, rather than quelling, the uncertainty inherent in the human condition may prove to be liberating, as it prepares humans to find new ways of being with self, other, and world:

> Coming to terms with the dangers and uncertainties of our lives is the existential responsibility we owe our humanity to craft a moral life that is not simply the mechanical reaction of a cog in the machine but reflects the human potential for self-knowledge and collective refashioning of who we are and where we are headed (p. 122).

In the book *Man's Search for Meaning* (2006), Victor Frankl describes three years of his life spent in Nazi death camps and how he managed to find meaning in his experiences despite the ever-looming uncertainties associated with fear, threat, and danger. One of his anecdotes highlights how existential uncertainty may be embraced to create meaning out of even the most unconscionable situations. As Frankl toiled in a camp, working in harsh, abusive conditions, he realized he was uncertain whether his pregnant wife, with whom he had been separated from at an earlier point, was still alive. He knew he had no way of even finding out, of being certain of her existence. He realized, however, that it did not matter. He let go of his need to cling to an "other" and, rather, decided to embrace the uncertainty. Frankl stated "There was no need for me to know; nothing could touch the strength of my love, my thoughts, and the image of my beloved" (p. 39). In other words, deceased or alive, the meaning his wife gave to him was all he needed. It superseded any need, or even desire, to know the outcome thereby quelling the uncertainty.

Existential Phenomenology

Existential phenomenology is largely concerned with meanings and values; it reflects existentialism's emphasis on life conduct and phenomenology's emphasis on meaning and knowledge (Lawrence & O'Connor, 1967). Heidegger initiated the exisitential-phenomenological movement by merging these two perspectives. Based on the prior discussion of the three givens or ultimate concerns of existentialism, death, freedom, and isolation, an elucidation of the major tenets and concepts of existential-phenomenology reveals the connection between the two perspectives.

Husserl is credited for being the "father" of descriptive phenomenology (Polkinghorne, 1983), while Kirkegaard is considered the founder of existentialism (Yalom, 1980). Based on Husserl's idea of a human-world unity, the first tenet of existential phenomenology is intentionality. Intentionality reflects that humans act as intentional beings and are involved with and open to their worlds (Heidegger, 1962). Humans' inherent freedom to create or not create possibilities is enacted through a merging of historical and present connections with those yet to be realized. This tenet, therefore, is the foundation for the concepts of coexistence and situated freedom.

Coexistence emphasizes human connection with others. This is connected to the existential concept of isolation. Despite humans' inability to ever be truly connected to another, it is through personal connections that humans are aware of their own existence. In other words, coexistence denotes existence and the human potential to transcend any given situation (Merleau-Ponty, 1974). Situated freedom emphasizes each human's personal choice in any given situation. This is connected to the existential concept of freedom. The foundation for each choice is provided by prior experiences and personal situatedness in the world. For example, humans have innate capacities to be in a world with meaning for the self, and as time passes, the human learns cultural and habitual meanings allowing him or her to perceive the situation according to past experience (Benner & Wrubel, 1989). Humans may also pre-reflectively participate in choosing situations; background meaning, or that which a culture, subculture, and family give a person from birth, includes that which is taken in by a person prior to having reflective consciousness (Benner & Wrubel, 1989). While meaning is ascribed both reflectively and pre-reflectively to experience, it changes over time as one continually bears the freedom and responsibility to live one's values through choice.

The second basic tenet of existential phenomenology, human subjectivity, is based on Kierkegaard's idea of human as subject. This tenet reflects that humans exist in and are engaged with their world via a dialectical relationship (Heidegger, 1962), thereby co-creating and ascribing meaning to personal situation and lived value priorities. This tenet is the foundation for the concept of co-constitution, which refers to any ascribed meaning in a situation and reflects the constituents of that situation. Because of humans' mutual relationship with their world, including its inhabitants, possibilities are always co-created (Heidegger, 1962). The notion of death and existential conflict arising from human awareness that death is certain while having the desire to exist is connected with this and the other existential-phenomenological concepts. Because the conflict carries potential to move humans to the higher, more mindful state of being as described by Heidegger, humans are able to more fully co-exist, co-constitute, and bear freedom in the creation of possibilities, thereby living valued priorities and ascribing meaning to situations.

Conclusion

To conclude, the review of literature indicates that uncertainty is universal and HD serves as a prototype for studying uncertainty during the prodromal period, as the experience of feeling uncertain is heightened during this time. There is little understanding what the meaning of that lived experience is among intimate partners of persons who 1) have undergone predictive genetic testing for HD and tested positive for the gene mutation, meaning they have a near-certain likelihood of developing HD at some point in their lives and 2) are in the prodromal, or pre-illness, phase, meaning they have not yet experienced the classic signs and symptoms of HD and, subsequently, been clinically diagnosed. The purpose of this study is to understand the meaning of the lived experience of uncertainty among intimate partners of persons who have tested positive for the mutation in the Huntington disease (HD) gene and will almost certainly develop signs and symptoms of HD in their futures.

To answer the research question, an existential-phenomenological framework will be used to interpret findings from the proposed inquiry. Methodologically, it follows that phenomenology as human science be employed; as “the study of lived or existential meanings, [phenomenology] attempts to describe and interpret these meanings to a certain degree of depth and richness” (van Manen, 1990, p. 11). Nursing, as human science, requires human science methods as a means of developing knowledge relevant to guide practice. Hermeneutic-phenomenology offers a methodology leading to a systematic understanding of human experience. van Manen’s (1990) hermeneutic-phenomenological methodology will be employed to answer the research question.

CHAPTER III

METHODOLOGY

Uncertainty is a universally lived experience; it may, however, be heightened in certain situations. Intimate partners of persons who have tested positive for the HD gene mutation but have not yet been clinically diagnosed find themselves in such situations. The meaning of the lived experience of uncertainty among this group is not, however, well-understood. An hermeneutic-phenomenological strategy was used to enhance understanding of the meaning of uncertainty among intimate partners of persons in the prodromal stage of the HD trajectory.

Phenomenology is an approach to inductive research used to understand the nature or meaning of humans' everyday, universally-lived experiences (Parse, 2001; van Manen, 1990). The goal of phenomenology is to describe human experiences as they are lived (Merleau-Ponty, 1964). Along with uncertainty, examples of everyday, universally-lived experiences include inner strength (Rose, 1990), caring (Beck, 1991; Clarke & Wheeler, 1992; Forrest, 1989; D. Riemen, 1986), grieving (Sowell, Bramlett, Gueldner, Gritzmacher, & Martin, 1991), meaning-making (Trice, 1990), being understood (van Kaam, 1959), feeling misunderstood (Giorgi, 1970), and loving (Ray, 1994). Hermeneutics is the "theory and practice of interpretation" (van Manen, 1990, p. 179). The hermeneutic-phenomenologic tradition "is ontologic, a way of being in the social-historical world where the fundamental dimension of all human consciousness is historical and sociocultural and is expressed through language (text)" (Ray, 1994, p. 118). Hermeneutic-phenomenology, therefore, reflects a cyclical pattern whereby interpretive depth of understanding is expanded and re-shaped simultaneous with life world interaction; Bishop and Scudder (1991) call this the hermeneutic spiral. It is both descriptive and interpretive and assumes lived experience is already meaningfully experienced.

Nursing as Human Science

Human science requires human science methods as a means of developing knowledge relevant to guide nursing practice; hermeneutic-phenomenology offers a methodology leading to a systematic understanding of human experiences and human science paradigms (van Manen, 1990), which are well suited to nursing (Beck, 1994; Benner, 1985; Bishop & Scudder, 1991; Lynch-Sauer, 1985; Munhall & Oiler, 1986; Oiler, 1982; Omery, 1983; Parse, 2001; Paterson & Zderad, 1988; Porter, 1994; Ray, 1985; Walton & Madjar, 1999). To defend this claim, it is essential to first establish nursing as human science. Parse (1987, 1998) defines nursing as human science, which views humans as indivisible wholes, intentional and free-willed, and in continuous relationship with their social and historical worlds. As such, nursing has its own body of distinct knowledge. Parse (1998) asserts that nursing's unique approach to working with and studying humans should, therefore, focus on humans' unitary patterns rather than their "parts;" this is what distinguishes nursing from other health-related disciplines. Nursing, as human science, therefore requires the application of human science methods to study its phenomena of interest. Other nurses have explicated frameworks in which beliefs congruent with human science are prominent (Newman, 1986, 1990; Paterson & Zderad, 1988; Watson, 1985); they emphasize the wholeness of human beings, the significance of subjective experience, and the creation of reality as something co-created between humans and their worlds (Mitchell & Cody, 1992).

Omery (1983) echoes the notion of applying human science methods to nursing: "The nursing profession is proud of its identification as a humanistic discipline…[its] values and beliefs include a view that the human phenomenon is holistic and meaningful. The phenomenological methods share such values and beliefs" (p. 62). Quantitative methods, situated within logical positivism, do not consider certain aspects of life such as feelings and intuition in order to remain objective. These aspects, however, are "vitally important to nursing" (Beck, 1994, p. 501) in both research and clinical domains. Oiler

(1982) describes the fit between phenomenological approaches and assumptions of the nursing profession, highlighting the importance of interpersonal technique, empathy, holism, and support of patient autonomy that both share.

Beck (1994) describes the linkages between phenomenology and clinical nursing practice, saying “both emphasize observing, interviewing, and interacting with clients so that a deeper understanding of the client’s perspective can be grasped” (p. 501). In the domain of research, this takes form as the “drama [or] interactive involvement of both the ‘researcher’ and ‘researched’” (p. 55), according to Bergum (1991). Beck also points out the similarity between use of self as data collection instrument in phenomenological research and therapeutic use of self in practice. Furthermore, in both practice and research the subject as object is not viewed as meaningful; the social nature of nursing (i.e., client/participant and practitioner/researcher co-constitute the situation) is thus realized in both. Activities which are intrinsic to nursing practice (e.g., understanding meaning of individual experience with health and illness) are “an excellent fit with the phenomenological approach” (p. 501). Examples of seminal phenomenological research contributing to nursing research and practice domains include Benner’s (1984) “From Novice to Expert;” Riemen’s (1986) “Essential Structure of a Caring Interaction;” and Parse’s, Coyne’s and Smith’s (1985) “The Lived Experience of Health.”

Methodology Choice and Rationale

“Phenomenology aims at gaining a deeper understanding of the nature or meaning of everyday experiences” (van Manen, 1990, p. 9). This approach is best used when the aim is to gain an insightful description of the way persons experience a phenomenon pre-reflectively, without attempts to classify, abstract, or taxonomize such descriptions (van Manen, 1990). This is consistent with the aims of the study. Using van Manen’s methodology, I conducted a systematic inquiry to uncover and describe the essential meaning of the everyday lived experience of uncertainty among intimate partners of persons with prodromal HD.

van Manen’s human science approach (1990) “is avowedly phenomenological, hermeneutic, and semiotic or language oriented” (p. 2); he indicates its use is for those engaging in human science research who have “a prior interest of, for example…a nurse” (p. 1) and that it is not used for those pursuing research for the sake of research. van Manen’s methodology, which is based in the Dutch phenomenology of the Utrecht school, draws on the strengths of both interpretive and descriptive phenomenology (Cohen & Omery, 1994; van Manen, 1990) to create a vivid, experiential description of a phenomenon in which meaning is inherent (van Manen, 1997). van Manen espouses “’engaged’ [rather than ‘theoretical’ or ‘philosophical’] phenomenology conducted by professionals in education, pedagogy, health science, medicine, and psychology” (1997, p. 350) to enhance their reflective understanding of the meaning and significance of everyday experiences.

Researchers practicing from the perspective of Dutch phenomenology of the Utrecht School have the goal of understanding humans not only to know how they are, but to understand them in order to know how to act competently; “nursing, as a science, has a goal to understand those individuals being cared for in order to know how to care for them” (Lynch-Sauer, 1985, p. 106). Examples of nurse researchers using van Manen’s methodology to examine uncertainty include Penrod’s (2001a) study of uncertainty among caregivers of older adults and Nelson’s (1996) study of uncertainty among women living with breast cancer.

The outcome of hermeneutic-phenomenology is an interpretive description depicting the lived world in symbolic form (i.e., language). This is inevitably an interpretive process. The results of this inquiry are intended to be an “animating, evocative description” of uncertainty in the form of text of participants’ actions, behaviors, intentions, and experiences as they are lived (van Manen, 1990, p. 19), allowing an enhanced understanding of the significance or deeper meaning of aspects of the human experience (van Manen, 1984) of uncertainty among intimate partners of persons with prodromal HD. Phenomenology reveals patterns in the human predicament that are needed to develop practice wisdom, thereby providing care in a more thoughtful, tactful, and careful way (Walton & Madjar, 1999).

Research Procedures

The following description of research procedures begins with a detailed presentation of recruitment efforts. Proceedings thereafter are explained within a discussion of van Manen's (1990) four methodological themes. A section on the consideration of data saturation and strategies used to address scientific rigor conclude the description of the research procedures for this phenomenological inquiry.

Recruitment of Informants

Prior to initiating recruitment efforts, The University of Iowa Institutional Review Board (IRB-01) processed and approved my request to use human subjects in this phenomenological study. Appendix B includes all IRB-approved forms used. I sought a purposive sample for this study. According to the criterion-based approach (Kuzel, 1999), I recruited persons meeting the following inclusion criteria:

1) intimate partners of persons who had tested positive for the HD gene mutation and who had not received a clinical diagnosis;

2) persons aged 18 years or older;

3) English-speaking persons;

4) persons who identified with the experience of uncertainty, feeling uncertain, and/or feeling unsure; and

5) persons who were willing and able to talk about their experiences of uncertainty, feeling uncertain, and/or feeling unsure.

Participants were recruited at two sites within a large, mid-western medical facility. One site was the HD Society of America Center of Excellence (HDSA-CE) at the University of Iowa, through which a larger study (PREDICT-HD) (Paulsen et al., 2006) was underway. The second site was through UIHC's Division of Medical Genetics Regional Genetic Consultation Service (RGCS). I received letters demonstrating support in recruitment efforts from contacts at both the HD Center of Excellence (contact: Jane Paulsen, PhD; PI: PREDICT-HD) and the Division of Medical Genetics (contact: Catherine Evers, RN, MA; Genetic Nurse Consultant) (Appendix A). Approximately one quarter of a million Americans have HD or are at-risk (HDSA Center of Excellence at Hennepin County Medical Center, n.d.). Among those at-risk, 10-20% seek predictive HD testing (Meiser & Dunn, 2000).

At the RGCS, approximately 12-20 individuals receive presymptomatic HD testing per year. All persons who seek presymptomatic HD testing are encouraged to have a support person accompany them; approximately 75% of these support persons are intimate partners. Ms. Evers (Genetic Nurse Consultant, UIHC) searched the UI Medical Genetics Division database to identify persons that had received presymptomatic HD testing and tested positive no more than 5 years prior to the start of recruitment (January, 2009). Based on this search, Ms. Evers identified medical charts to review to determine contact information and verify that persons tested had an intimate partner. From this search, Ms. Evers identified 19 persons; she proceeded by mailing a recruitment packet (Appendix B) addressed to the person whose medical record was reviewed (the proband). The packet included a cover letter, an information sheet describing the study and inviting participation, and a contact information sheet. The study information sheet indicated persons could choose to share study information with their intimate partners (potential participants) who could either contact me by phone or return the contact information sheet to me, if interested.

At the HDSA-CE, there were approximately 240 gene-positive persons living in the Midwest (Iowa, Illinois, Missouri, Nebraska, South Dakota, Minnesota, and Wisconsin) listed in the UI HD registry at the start of study recruitment. Ten to twenty percent of these persons were pre-diagnosis. Anne Leserman, MSW, LISW (HD Center of Excellence Coordinator) searched the UI HD registry to identify persons who were gene positive and had not yet received a clinical diagnosis. From this search, Ms. Leserman identified 38 persons to whom she sent recruitment packets.

In response to Ms. Evers's and Ms. Leserman's mailings, 10 persons total responded in approximately 2 months. Two persons indicated they were not interested via the contact information sheet; one person indicated that his or her partner had been diagnosed and, therefore, was ineligible via the contact information sheet; two persons phoned indicating interest; and five persons indicated interest via the contact information sheet. Based on this lower-than-desired response rate at the end of this two-month time period, I requested that Ms. Evers and Ms. Leserman send follow-up packets to persons eligible and who had not yet responded. The follow-up packets included the same materials as before, but the original cover letter was changed to reflect that it was a reminder notice. For this second round of mailings, Ms. Evers sent 13 packets and Ms. Leserman sent 26 packets. In an approximately 1-month time period, 7 total persons responded. Three persons indicated they were not interested and three indicated they were interested via the contact information sheet; and one person indicated interest by phone.

For all persons indicating interest in study participation, I spoke with them by phone to review the study purpose and procedures, verify eligibility, and answer any questions (see Appendix B for screening log). For those continuing to express interest, I arranged with the participant to meet at a mutually-agreed upon time and private location. Additionally, I mailed an informed consent to the potential participant prior to the meeting date.

Methodological Themes and Their Application

van Manen (1984, 1990) outlines four methodological themes which collectively reflect research procedures. Each theme consists of one or more procedural dimensions. While van Manen clearly lays forth procedures in an attempt at offering “practical approaches that may be helpful in hermeneutic phenomenological [inquiry]” (p. 30), he emphasizes the need to resist adopting the notion of “procedure” as a step-wise, mechanistic approach to human science methods. Rather, there is a dynamic interplay between themes as well as dimensions within themes, as no one particular activity is performed in isolation of another. The researcher “may work at various aspects [of the research process] intermittently or simultaneously” (p. 34), ultimately relying on his or her own “interpretive sensitivity, inventive thoughtfulness, scholarly tact, and writing talent” (p. 34) more than procedural activity during critical junctures of the inquiry (van Manen, 1990).

Prior to the current study, I completed a research practicum in which I gained experience under Dr. Butcher’s supervision in applying van Manen’s methodology to describe the meaning of dispiritedness among 11 older adults (Butcher & McGonigal-Kenney, 2010). The following section outlines and discusses the four methodological themes, their associated procedural dimensions, and the ways in which I applied the principles of these throughout the current study. Figure 1 outlines the hermeneutic-phenomenological method used (van Manen, 1984; 1990). While the themes and associated procedural dimensions are presented in what may appear to be sequential order due to the use of letters and numbers, the letters and numbers are used only to clarify and highlight differences between the themes and procedures.

A. Turning to the Nature of the Lived Experience

Lived experience is experienced in a person’s lifeworld before he or she has reflected upon that experience; it is pre-reflective. To grasp the lived experience, however, requires a retrospective, reflective view of the experience. This grasping entails an assignment of meaning, thereby revealing its interpretive nature. Phenomenological research begins in a person's lifeworld, as inquiry is derived from lived experience, or the empirical data. Phenomenological research also ends in lived experience, in the form of textual description. Since lived experience is expressed through a variety of ways, including art, science, and principally language, van Manen (1990) asserts lived experience itself has a linguistic structure. The outcome of hermeneutic phenomenological inquiry must be thorough elucidation of lived experience via text; van Manen (1990) indicates a good textual description "is collected by lived experience and recollects lived experience [and] is validated by lived experience and it validates lived experience" (p. 27).

Three procedural dimensions are involved:

1. Orienting to the Phenomenon

This procedural dimension involves identifying the researcher's deep interest in an experience human beings live through. To orient to this lived experience or phenomenon is to approach it with the interest of whichever vantage point the researcher possesses, moving beyond simple recollection of experiences with it towards recollection in a way in which its essences, or meaning structures as lived, are illuminated in phenomenological research and writing (van Manen, 1990).

As stated in Chapter 1, my orientation to the lifeworld is as a nurse. As an RN, I am oriented to the phenomenon of uncertainty and its health implications for clientele. I have also been involved in collecting and analyzing data from family members of persons with HD in prodromal and manifest phases; I have heard their stories, which included expressions of uncertainty (Williams, et al., 2001). Throughout the study, I recorded these and other ways that I was oriented to the phenomenon of uncertainty in a journal and in field notes.

2. Formulating the Phenomenological Question

This procedural dimension requires the researcher to not only pose an existential question, but also to hold steadfast to this question of lived experience the remainder of the phenomenological inquiry. To do this, the researcher must clarify, understand, and live the experience being studied; "to truly question something is to interrogate something from the heart of our existence, from the center of our being" (van Manen, 1990, p. 43). In other words, the questions we ask about the lives of others (i.e., how another experiences something) must be connected to our own lives (i.e., how we experience that very thing). I can only genuinely question the nature of uncertainty for persons carrying knowledge of future illness because I am interested in uncertainty in my daily existence as person and as nurse.

The phenomenological question driving this research came to fruition during my participation in a multi-phase investigation titled "Family Health After Predictive Huntington Disease (HD) Testing" (Williams, et al., 2001). The study was broadly focused on family members' major concerns across disease trajectory, including family of persons who 1) had received a positive result from predictive genetic testing for HD but had not yet been clinically diagnosed; 2) had received a clinical diagnosis of HD and lived in the home; and 3) had received a clinical diagnosis of HD and lived in a long-term care facility.

The initial phase of the study used focus group methods to determine family members' common concerns and strategies used to manage those concerns. Among the most common and concerning issues reported across the trajectory were notions of uncertainty. I became particularly interested in this phenomenon, and began to wonder what it was like for those family members of persons who had received a positive result from predictive testing but had not yet received clinical diagnosis. In other words, what is uncertainty like for a healthy, young- to middle-aged adult group living with the certain knowledge of a progressive, incurable condition most likely developing at some point in their futures? What is the nature of uncertainty among a group likely considering educational and/or career options, intimate partner commitment, reproduction, and future caregiving responsibilities? *What is the meaning of their lived experience of uncertainty?*

As the researcher proceeds through scholarly inquiry and “lives” with his or her phenomenological question, van Manen (1990) issues a reminder to resist the urge to develop and/or rely on positivistic paradigms, models, or frameworks of knowledge to shed light on the lived experience. Rather, the researcher must direct his or her questioning back to the lifeworlds of humans, for they bring these frameworks into being.

3. Explicating Assumptions and Pre-Understandings

A third procedural dimension of the methodological theme “turning to the nature of lived experience” involves articulating and bringing into direct consciousness the researcher’s assumptions and pre-understandings of the phenomenon. van Manen (1984) states the researcher must “make explicit [his/her] understandings, beliefs, biases, assumptions, presuppositions, and theories [not to forget them], but rather to turn this knowledge against itself…exposing its shallow or concealing character” (p. 46). This view takes into account the importance of not allowing everyday and scientific constructions of the phenomenon to conceal the true meaning of the lived experience under investigation. Unlike phenomenological approaches which espouse a bracketing of assumptions, however, this view posits that the researcher is unable to bracket and forget his or her assumptions fully, as they will inevitably and persistently make their way back into reflective thought.

There is a significant amount of literature to be found on the topic of uncertainty. From lay literature, I can find a “how-to” book titled “Coping with Uncertainty: 10 Simple Solutions” (Eimer & Torem, 2002) and from the scientific literature, I can find a book titled “Key Aspects of Caring for the Chronically Ill: Hospital and Home,” featuring a chapter on chronic illness and uncertainty (Mishel, 1993). I can certainly peruse these texts to learn something about uncertainty, but I must, however, continually ask myself: Do they bring me closer to a *deep understanding of the lived experience* of uncertainty? Making explicit my understandings and biases about uncertainty means setting aside my attempt to discover, construct, name, or identify the experience. Instead, revealing the lived experience of uncertainty involves an attempt to "recapture something…it must be brought back, recalled, or recollected from original experience" (van Manen, 1990, p. 50). My initial pre-understandings and assumptions were presented in Chapter 1. These and other assumptions, beliefs, and biases regarding uncertainty that arose during the study were recorded in a reflective journal and periodically re-read, thereby bringing them back into direct consciousness and making them explicit.

B. Investigating Experience as We Live It

This methodological theme signifies the process of data collection, or gathering experiential description. van Manen alludes to the idea that this process can be quite challenging for the phenomenological researcher. The data collected, including oral and written accounts and descriptions of lived experience, will never be identical to the lived experience itself. In other words, every piece of data I gathered on uncertainty was already a transformation of the experience of uncertainty. To cope with this, van Manen (1990) eloquently states the researcher must "find access to life's living dimensions while realizing that the meanings [brought] to the surface from the depths of life's oceans have already lost the natural quiver of their undisturbed existence" (p. 54). There are four procedural dimensions suggesting possible avenues in which the researcher can find access and search his or her lifeworld for lived experience material, which may shed light on its fundamental nature.

1. Using Personal Experience as a Starting Point

van Manen (1990) suggests the researcher create a personal description of the lived experience under investigation without providing interpretation, generalization, or explanation. The aim of conducting a personal description is to bring into the researcher's awareness the structure of his or her own experience with the phenomenon. This not only orients him or her to the phenomenon itself but also to the remaining phenomenological research activities. On a broad level, this awareness reflects that the phenomenological description has a universal character; in other words, my own experiences of uncertainty could also be the possible experience of others and vice versa. It is, therefore, vital to use the personal description of lived experience as a starting point in an attempt to begin to grasp and be reflectively aware of experiential meaning. I created a personal description of uncertainty, focusing on a specific event, which served as a starting point from which I proceeded.

2. Tracing Etymological Sources

Current, everyday use of language is permeated with words which we easily identify with and assign common meaning to. This often happens, however, in an automatic, superficial sense that renders us without full understanding or comprehension of the power and true essence behind a particular word. van Manen (1990) illustrates this point with a discussion of the word "care." The word is used quite liberally; we use it to describe what we do and feel, what we do not want to do and feel, how we want to behave (or not) towards another person, the type of setting or professional rendering a service, and so on. Despite its many uses, however, it could be argued that none truly reflect its original meaning. For example, what is a "health care professional?" If I am a professional of any sort, and I "care" about health in general, can I define myself in this way? Regardless of our initial supposed understanding of the word, we are often left with a murky grasp of what "care" truly means.

Hence, the aim of studying the origin of the words related to the lived experience, including how their meanings have changed throughout history, is to "put us in touch with an original form of life where the terms still had living ties to the lived experiences from which they originally sprang" (van Manen, 1990, p. 59). This does not imply that the etymological analysis leads us to the essence of the experience. Rather, it gives "meaning clues" with respect to a language once used and more deeply lived. I traced the etymological sources of "uncertain" to uncover its origin, and this work was presented in Chapter 2.

3. Searching Idiomatic Phrases

Locating and reflecting upon common expressions of uncertainty is the third procedural dimension. Idiomatic phrases often come out of lived experience; the researcher must, therefore, engage with and reflect upon them as to elucidate their interpretive significance. In other words, the researcher must look beyond a mere description or literal definition of the phrase to something meaningful revealed by the expression. I searched idiomatic phrases of uncertainty asking myself: what expression(s) may be of help as I reflect on uncertainty, the lived experience from which the expression(s) derives its meaning? Examples of phrases found were "blow hot and cold;" "of two minds;" and "up in the air." Participants also offered idioms to express their experiences of feeling uncertain, and reflecting upon these and understanding the ways they were used were included in the process of hermeneutic-phenomenological reflection and writing.

4. Obtaining Experiential Descriptions from Others

To come to a better understanding of lived experience, the researcher "borrows" others' experiences and reflections on that phenomenon "in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole human experience" (van Manen, 1990, p. 62). van Manen suggests numerous approaches to gathering experiential descriptions from others. Since language, whether verbal or non-verbal, is the vehicle of experiential description, the phenomenological researcher may look to the following for data repositories: 1) interviewing; 2) creating a personal protocol; 3) observing; 4) lay literature, including but not limited to novels, poetry, biographies, autobiographies, and personal life histories; 5) diaries, journals, and logs; 6) art, including but not limited to film, music, painting, and sculpture; and 7) phenomenological literature. Regardless of selected means of gathering experiential descriptions, the thrust of phenomenological research must reflect the question: What is the nature of the phenomenon (uncertainty) as an essentially human experience? This drives both data gathering and data analyzing, which are largely conceptualized as inseparable processes.

Interviewing

The conversational interview serves two functions in hermeneutic-phenomenological inquiry: to 1) collect or gather lived-experience material and 2) reflect with the "other" on the topic under study. The latter reflects the hermeneutic nature of inquiry; the participant becomes less of an interviewee and more of a partner or collaborator as researcher-participant develop a conversational relation about the meaning of the lived experience. The function that largely predominates at any point depends upon the stage of inquiry.

van Manen (1990) suggests using an interview schedule only in the sense that the researcher be strongly oriented to his or her question in an attempt at preventing an interview with no clear focus as well as one which is too narrowly focused. He suggests beginning the interview by 1) asking the participant to think of a specific situation, person, event, or instance reflective of the phenomenon under investigation, then 2) exploring the whole experience to the fullest. He asserts it is not possible to pose pre-determined questions. The researcher flows, rather, with participant in the interview context, using patience, silence, repetition to remind participant of the last thought, and/or questions like "what do you mean?" and "can you give me an example?" when conversation is too narrow or generalized, respectively.

van Manen indicates the following four, fundamental lifeworld existentials may serve as a guide to reflection and interpretation to be used during the interview: lived space, or spatiality; lived body, or corporeality; lived time, or temporality; and lived human relation, or relationality. The use of these to guide reflection is based on the assumptions that 1) all phenomenological inquiry is exploration of the human lifeworld structure, or the "lived world as experienced in everyday situations and relations" (p. 101) and 2) the above four existentials pervade humans' lifeworlds despite historical, cultural, or social situatedness (van Manen, 1990). In other words, there is a universality found among these four existentials which may prove helpful as guides for data collection and interpretation during the research process; it is difficult to imagine any situation in which one cannot ask fundamental questions associated with these fundamental existentials.

Lived space is felt space; it refers to a world or landscape in which humans move and find themselves at home. Similar to the way another is often asked about his or her profession (work space), where he or she is from (birth and childhood space), and so on in order to better understand that person, it is useful to ask the research participant about his or her lived space when he/she experiences the phenomenon under study. Lived body reflects that humans are always bodily in the world, revealing-concealing something about themselves simultaneously. Lived time is subjective in nature. Again, if one is interested in knowing another, one will likely ask about his or her past, present, and future; these "constitute the horizons of a person's temporal landscape" (p. 104). Lived other is lived relation we have with others in the space we share with them. This fourth, fundamental existential reflects that humans often search for purpose and meaning through the other, or more specifically, through relationships with the others (van Manen, 1990).

For this phenomenological study, I applied the interview as the primary method to gather lived experience descriptions and reflect upon those descriptions, as van Manen indicates person-to-person conversations, or interviews, tend to be richer sources than other lived experience descriptions, such as those found in sources mentioned above (e.g. protocol writing, consulting phenomenological literature, or art). Consistent with van Manen’s (1990) methodology, I used an informal, open-ended conversational interview style to foster spontaneous generation of questions and engage each participant in the interview as a means of gathering a personal life story of living with uncertainty as well as reflecting upon the lived experience. Unstructured interviewing facilitates the establishment of openness, trust, rapport, and genuineness, thereby creating an atmosphere of the flexibility and creativity necessary for in-depth self-disclosure (Patton, 1990). I sought depth and clarity of the experience by taking the role of facilitator, clarifier, and evoker of descriptions of uncertainty. Interviews were aimed toward encouraging expression, elucidation, and disclosure of participants’ uncertainty experiences. A conversational relationship such as this allows meaning to emerge as researcher and participant co-create the meaning of the experience (Carson, 1986).

van Manen (1990) points to the hermeneutic interview as one, essential guide to enhance reflection and interpretation. The two functions of the hermeneutic phenomenological interview (to gather lived-experience material and to reflect with the “other” on the topic under study) frequently co-occur within a single interview. Anticipating that I would interview each participant up to three times, I created three interview schedules. The first interview schedule reflects my intent to use the initial interview as the primary source of gathering lived experiences of uncertainty while subsequent interview schedules reflect my intent to use second and/or third interviews as the primary source of reflecting upon and interpreting the lived experience of uncertainty (see Appendix B). Detailed descriptions of initial interviews and subsequent interviews are as follows:

Initial interview

Prior to the first interview, I obtained informed consent from each participant (Appendix B). This took place at the time and location arranged. I verbally presented the consent document in its entirety to the participant and answered any questions. Two copies were signed; I kept one and gave the other to the participant. The interview commenced only after the consent was signed. In total, 10 persons consented to participant in this study. All initial interviews were conducted in person. Interviews lasted between 60 minutes and 100 minutes, with the average interview lasting 78 minutes. Interviews took place at mutually-agreed upon times and locations where only the participant and researcher were present, such as the participant's home or a room with a door in a public library. Six initial interviews occurred in participants' homes and four occurred in public libraries. Interviews were audio recorded, and I transcribed all interviews verbatim for purposes of data analysis. Demographic information was collected during the initial interview (Appendix B).

I initially planned the opening interview question would be: Tell me what it has been like for you since your partner/wife/husband received his/her positive test result for Huntington disease. Upon using this for the first interview and finding it awkward and not fruitful, I changed the opening question to: Can you tell me about how you and your partner/wife/husband met and got together? Participants responded well to this, and the information I wanted from the original question was either offered spontaneously by the participant or elicited by me later in the interview. I asked participants to think of a time they felt uncertain and describe the event or situation to me. Focused inquiry into uncertainty flowed from these descriptions. I asked participants questions pertaining to the four, lifeworld existentials, such as "What happens to your sense of time when you feel uncertain?" and " Do your connections with others change when you feel uncertain? If so, how do they change?" If it was necessary, I asked questions to elicit depth of meaning and used probes to clarify participant descriptions.

Participants were invited to provide other expressions of their lived experiences of uncertainty; I indicated in the informed consent (which participants received prior to the first interview) they had the option of bringing written or artistic expressions to the interview to talk about. No participants chose to do this. At the end of the initial interview, I reminded them they would have the option of providing other expressions during the subsequent interview(s). Towards the end of the initial interview, participants were given hand-held audio recorders and instructions for creating their personal protocols. Appendix B includes the guide used for creating the personal protocol, and further discussion on protocols as a data source is included below. We reviewed the instructions together, and I ensured the participant was comfortable using the audio recorder prior to ending the initial meeting.

Subsequent interviews

Upon transcription of initial researcher-participant interviews, I uncovered thematic aspects and isolated thematic statements, the first steps in conducting thematic analysis. These themes guided the creation of anecdotal narratives; both the themes and narratives became the object of reflection in second, follow-up interviews (the procedures used for conducting thematic analysis and creating anecdotal narratives are elaborated upon in the section “Conducting Thematic Analysis” below). Subsequent interviews were conducted over the phone, unless the participant and I deemed it feasible to meet in-person at a mutually-agreed upon, private location such as that used for the initial interview. Out of 10 subsequent interviews, 3 were conducted over the phone and the remainder either in participants’ homes or a library room. Subsequent interviews lasted between 21 minutes and 100 minutes, with the average interview lasting 48 minutes.

Six participants did not complete all three interviews. Reasons for this included difficulties in arranging subsequent interviews (2nd or 3rd), such as an inability to contact participants and/or geographical distance between myself and participants. To address these issues, I attempted to contact participants by phone and/or email (if participant had provided this to me) on several occasions throughout the course of the study and also offered to travel any required distance in order to conduct the interview. In one instance, a participant indicated he had forgotten about our arranged meeting. Although I called participants several days in advance of a scheduled interview as a reminder, he was out of town and did not receive this message prior to our arranged meeting. Another participant agreed to a third interview as we concluded the second, but when I attempted to schedule the third interview, he did not return my phone calls. Another participant cited reasons of being “too busy” to continue study participation according to my research protocol (in-person meetings for 1st and 2nd interview), saying he could continue via email.

As previously described, the follow-up interviews were more collaborative in nature than the initial interview. Second follow-up interviews typically began by presenting the anecdotal narrative to participants and asking “how does the content in the narrative fit or not fit with your experience of feeling uncertain?” I encouraged them to pay attention to any words, phrases, or ideas in general that resonated with them in any way. I indicated my intent was for them to expand or revise in any way they chose so that the narrative would be an accurate reflection of their experiences of feeling uncertain. Additionally, I inquired about any other written or artistic expressions of feeling uncertain the participants wanted to offer; some referred to a photo, a visual analogy or metaphor, a song, or a painted quotation on a bedroom wall. In reference to these expressions, I asked, for example, what meaning the item had and what sort of feelings it evoked. I showed a photograph I had taken to participants as a symbolic representation of my experience of feeling uncertain. The participant and I viewed it and talked about it together, much in the same way we viewed their own written and artistic expressions. Participants returned their protocols to me at the second interview. I transcribed audio protocols verbatim and performed first-level analysis. Third follow-up interviews began with a discussion of the personal protocol. I asked participants if my understanding of their experience in terms of codes applied rang true or not. I also used the third interview as an opportunity to clarify and expand upon themes and insights gleaned from prior interviews. In all subsequent interviews, I asked questions to elicit depth of meaning and used probes to clarify participant descriptions. The interviews ended when the participant and I were “silenced by the stillness of reflection” (p. 99).

Data collected from subsequent interviews were treated in the same manner as initial interviews; all subsequent interviews were audio taped, I transcribed them verbatim, and transcripts, anecdotal narratives, personal protocols and digital photographs of expressions of feeling uncertain were imported into NVivo (QSR NUD*IST NVivo, 1999) and coded (see steps on uncovering thematic analysis and isolating thematic statements, under “Conducting Thematic Analysis” section below). Participants received $45 gift cards (each was given a choice between Target or Wal-Mart) as compensation based on their involvement in the interviews; compensation was pro-rated for early withdrawal (withdrawal between first and second or second and third interviews) and was not dependent on completion of the personal protocol.

Creating a personal protocol

This method is the generation of original text on which the researcher works. van Manen (1990) has suggested guidelines for creating a protocol: avoid causal explanations, generalizations, and abstract interpretations; include feelings, moods, and emotions experienced; focus on a specific event or incident of the object of experience; choose an event which “stands out” for its vividness, as if one could experience it again for the first time; include bodily sensations, including sounds, smells, sights, etc.; and avoid florid terminology. He issues a word of caution, however, when asking participants to generate their protocols. Despite the above suggestions, particularly that which emphasizes the direct elucidation of experience as lived without explanations, generalizations, and interpretations, writing tends to place the author in a reflective stance. This serves as a potential constraint on the free gathering of lived experience description. To cope with this, the researcher must be attuned to the author's tendency to intermingle explanation and interpretation with description.

At the conclusion of the first interview, participants were given hand-held audio recorders and instructions aiding them in producing their lived-experience descriptions of uncertainty. Specifically, they were asked to audio-record a direct account of a personal experience (i.e., event or situation) of feeling uncertain, being sure to describe feelings, moods, sensations, and emotions experienced. In total, three participants created audio protocols, and one participant said he would prefer to create a written protocol. Subsequent participants were given the option of doing either an oral or written protocol. One person specifically indicated having a difficult time creating his oral protocol and opted not to do so. Upon exploration of this in the second interview, the participant said as he thought about the particular event he had chosen to speak about, he felt more "emotional" about it than he felt comfortable with. He preferred to speak about the event during our second, follow-up interview, indicating it was easier to recount the event with another person present as opposed to being alone and doing so. The remaining participants did not offer specific reasons for not creating a personal protocol.

Observing

To closely observe is another method aimed at gathering experiential material. To do this, the researcher must enter participants' lifeworlds and act as observer-participant simultaneously as to hold to the hermeneutic purpose of doing so. The data gathered is in the form of anecdote, or brief story told about the incident and/or person involved. I recorded observational remarks about the interview meetings as field notes. These notes included types of information gleaned outside of participant-researcher verbal communication, including but not limited to: the environmental configuration; how the environment helped or hindered the flow of conversation; the ease at which the participant spoke; the tone of the interview (e.g., Was participant tearful? Hesitant to speak? Relieved or anxious to share his or her story?); and non-verbal communication.

Lay literature, diaries, journals, logs, and art

The researcher may turn to lay literature, such as novels, poetry, biographies, autobiographies, and personal life histories, to enhance phenomenological insight. Depending on the author's perceptiveness and intuitive sensitivity, he or she may be able to experience some aspect of the phenomenon in a way not experienced before in a way that enriches understanding of human experience. van Manen (1990) indicates that, because of this, a good story may allow us to "broaden the horizons of our normal existential landscape" (p. 70) and to detail the unique and particular features of life while transcending particularities. The primary thrust behind examining such literature is not to gain individual or private meaning, as told by biography, for example, but rather existential meaning. In other words, text should be examined not because of personal interest in a particular person's life, but rather for what it can tell us about possible experience for ourselves and others.

The intention of keeping a diary, journal, or log is to assist an individual to reflect on significant aspects of his or her life, whether for educational, research, religious, or therapeutic purposes. van Manen (1990) states that because of these reflective accounts, diaries, journals, and logs could contain accounts of the human experience that are of phenomenological value and, therefore, worth exploring as yet another source of experiential description.

In addition to the verbal (written and oral) data repositories described above, there are multiple non-verbal mediums through which the researcher may find phenomenological data, such as through painting, music, photography, sculpture, and film. Researchers may turn to these sources because "artists are involved in giving shape to their lived experience…[so the product of art are themselves] lived experiences transformed into transcended configurations" (van Manen, 1990, p. 74). As previously described, participants were invited both prior to the first interview and before the second to bring such expressions of feeling uncertain to the interview for discussion. I offered the options of using literature, diaries, journals, logs, and/or art, as described above, as examples. Additionally, I brought a photograph to the second interview and used it as a method of launching further discussion.

Phenomenological literature

van Manen (1990) asserts that the researcher not remain blind to the phenomenological literature on his or her topic of interest. The researcher must familiarize himself or herself and come into dialogue with this literature as to avoid "ignor[ing] the insights of others who may have already maintained a conversational relation with that same phenomenon" (p. 75). The researcher should lend a critical yet deeply reflective eye to the literature; others' insights are not necessarily integrated into the researcher's frame, but they may allow the researcher to "challenge and stretch [his or her] own descriptive or interpretive sensibilities" (p. 76) as well as learn of innovative methodological approaches to research. Ultimately, these things aid the researcher in framing his or her overall purpose of contributing to human science tradition.

van Manen does not dictate when the researcher should consult, or enter into "conversational partnership," with phenomenological literature; he does, however, indicate it may be more difficult to suspend interpretive understanding of the phenomenon if the researcher studies the literature on his or her topic at the very beginning of inquiry. He further states "it is sound practice to attempt to address the phenomenological meaning of a phenomenon on one's own first" (van Manen, 1990, p. 76). While I conducted a precursory examination of other phenomenological studies on uncertainty, my goal was more focused on gathering a collective sense of the state of the science and conducting a critical review rather than entering into conversational partnership with the literature. I did, however, enter into dialogue with the phenomenological literature on uncertainty throughout reflection and writing, after attempting to address the phenomenological meaning of uncertainty on my own.

C. Hermeneutic Phenomenological Reflection on Essential Themes

Data analysis begins with the third methodological theme, hermeneutic phenomenological reflection (van Manen, 1990). The purpose is to attempt to grasp the essential meaning of the phenomenon under study. To grasp something's essence, however, is difficult, as there are pre-reflective and reflective understandings of the meaning and the lived experiential meaning, respectively. In other words, it is easy to identify with feeling "uncertain," but as soon as it is brought into reflective awareness, it is more difficult to clarify and make explicit the meaning of the lived experience of feeling "uncertain."

van Manen essentially offers two ways to cope with this challenge. The first entails holding a strong orientation toward the phenomenon, approaching it with the interest of whichever vantage point the researcher possesses. As previously discussed in the section "turning to the nature of the lived experience of uncertainty: orienting to the phenomenon," I am oriented to the phenomenon of uncertainty as a nurse. I am also oriented to uncertainty as a human who has had experiences of feeling unsure, being in doubt, not knowing, and so on. Reflecting on the lived experience of uncertainty from these vantage points brings me into a more direct contact with the experience; I want to grasp the meaning of uncertainty according to the perspectives of persons encountered in the health care system so I can live my life as a nurse (and human) with clients more fully.

The second approach van Manen offers to cope with the challenge hermeneutic reflection holds is to think of the phenomenon described in text in terms of meaning units, structures, or themes. The remainder of this section explicates how I conducted thematic analysis, the primary procedural dimension under this methodological theme. Conducting thematic analysis is comprised of three parts: 1) uncovering thematic aspects and isolating thematic statements; 2) composing linguistic transformations; and 3) determining incidental and essential themes. van Manen presents the use of the research seminar/group for collaborative analysis as a guide to reflection and interpretation. Prior to the discussions on using collaboration as a guide for reflection and interpretation and conducting thematic analysis is a brief description of the notion of "theme," as used in van Manen's method.

Theme

Theme is defined as the experience of focus, meaning, and point. As the researcher attempts to capture the phenomenon he or she seeks to understand, it is captured it in the form of theme. Theme may, therefore, be seen as the means or tool to get at the notion under study. As I read and reflected upon the data, I asked: What is the meaning or the point of this? The answer comes in the form of a theme. van Manen indicates that, at its best, theme is a simplification or a reduction of the notion under study; even with an extensive listing of themes, I cannot and will not ever get at the full meaning of uncertainty. Since its meaning is multi-dimensional and multi-layered, it can never be fully grasped with even the most well-constructed definition. On the other hand, theme should "touch the core of the notion we are trying to understand," thereby giving "shape to the shapeless" (van Manen, 1990, p. 88).

While van Manen (1990) indicates the use of theme in human science research is not to be mistaken for a mechanistic, clear-cut process of labeling or counting items in text, he does provide some indication of how to arrive at theme. Because the researcher approaches the text with a particular interest and vantage point, he or she approaches it with a desire for understanding and finding meaning; theme, therefore, may be arrived at through this deep need to make sense of something. As meaning is attached to something revealed in the text, a symbolic representation, or theme, is the outcome, and this is possible only by having an openness to the notion embedded in lived experience. Taken together, these indications of how theme is arrived at reflect that “theme is the process of insightful invention, discovery, and disclosure” (p. 88).

Collaboration as hermeneutic guide

Collaborative analysis may be used as a guide to reflection and interpretation (van Manen, 1990). The researcher may seek collaborative assistance as he or she reflects in the form of conversational relation with advisors, consultants, reviewers, colleagues, or friends. I shared text of participant descriptions of uncertainty and themes uncovered and isolated with Dr. Butcher, my dissertation chair. Specifically, I shared my initial, first level of thematic analysis (i.e., codes resulting from uncovering thematic aspects and isolating thematic statements) and participants’ anecdotal narratives. I also shared insights gained from subsequent participant interviews and how these insights translated into the evolving process of subsequent analysis (i.e., composing linguistic transformations and determining incidental and essential themes) and writing. The goal of this collaboration was to “strengthen what is weak in human science text…allowing [me] to see the limits of [my] present vision and to transcend those limits” (p. 101). The nature of collaboration with Dr. Butcher reflected a hermeneutic conversation rather than an attempt to correct or change any initial insights. This, in essence, served to protect the essential meanings found in participants’ stories.

Conducting Thematic Analysis

The first part in conducting thematic analysis is to uncover thematic aspects and isolate thematic statements (van Manen, 1990). To uncover a thematic aspect of lived experience is to allude to or point to an aspect of the phenomenon. A group of thematic aspects is like a group of “knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes" (p. 90). They must first, therefore, be isolated from the lived experience description found in text.

I applied both a selective, or highlighting, approach and detailed, or line-by-line, approach to coding text (i.e., text from transcripts and personal protocols resulting from initial and subsequent interviews). After listening to the audio recording on at least two occasions (I transcribed each interview and verified my transcription) and reading the transcribed text several times, the question "What statements seem essential or revealing about uncertainty?" drove the selection of passages to highlight and code. At times, a more discrete view of a sentence was required, as I asked "What does this sentence reveal about uncertainty?" Coding was performed using the NVivo software program. Table 1 summarizes the dates on which I interviewed participants and performed first-level analysis.

After conducting this first level of analysis on transcripts from initial interviews, I created an anecdotal narrative for each participant. An anecdotal narrative is a common rhetoric device in phenomenological writing espoused by van Manen (1990). The anecdotal narrative reflected each participant's personal story, using concrete descriptions and participants' words to "stay close to experience as lived" (van Manen, 1990, p. 67). In other words, each narrative became a condensed version of what was shared with me during the initial interview, consisting largely of participants' own words.

The creation of the anecdotal narrative involved "sensitive editing of the lived experience descriptions" that I obtained during the initial interview (M. van Manen, personal communication, July 15, 2009). I reviewed thematic headings applied to a sentence or passage and extracted verbatim those words or groups of words associated with the thematic heading and synthesized the statements to create a story. While each narrative is largely reflective of participants' own words, there was some amount of interpretation required of me as I chose the order in which to present themes and used discretion in choosing what to include and what not to include.

Composing linguistic transformations, the second part of conducting thematic analysis, is highly intertwined with the third and final part, determining incidental and essential themes (van Manen, 1990). The former reflects the transformation of themes and thematic statements into more phenomenologically-sensitive text while the latter serves as a means of capturing the thematic statements into phenomenologically-sensitive text. To determine incidental and essential themes, van Manen suggests using the method of free imaginative variation. This is the explicit questioning of whether the phenomenon is still the same if a theme is imaginatively changed or deleted. Upon examination of a particular theme, for example, I asked myself: Does uncertainty lose its fundamental or essential meaning without this theme? The goal is to ultimately discover only those aspects which make uncertainty what it is and without which uncertainty could not be what it is. Prior to composing linguistic transformations, I had arrived at nearly 100 codes as a result of conducting thematic analysis and uncovering thematic aspects. To begin the process of linguistic transformation and identifying incidental and essential themes, I methodically reviewed each code and respective data supporting it. I examined the passages as a whole, considered the definition and its synonyms, and determined whether the code applied was most accurate or needed to be revised. Incidental themes were deleted entirely, as they were not deemed to be essential in describing the phenomenon.

During the process of reviewing each code in this manner, I created notes detailing decisions made and rationales for those decisions. After careful review of each code, I often was led to think of other codes that may be similar enough in theme that synthesizing codes was possible. For example, among the initial codes was the code “being a gentle presence.” After reviewing passages here, I recalled another existing code, “graceful.” I reviewed passages subsumed under both codes, collectively, and decided all reflected an element of compassion. I, therefore, collapsed these two and created a new name, “compassionate presence.” I continued this process and arrived at 35 such groupings, or subthemes.

Upon arriving at 35 subthemes, I carefully examined each subtheme, asking myself "what is the common thread, or essence, that connects these? At this stage, as I began to have a sense of how the subthemes might congeal, I continued to refer to transcripts, annotations, field notes, and the notes made during the above-mentioned process of identifying the 35 subthemes. I printed each subtheme on a piece of paper and began grouping those I felt would belong together. After considerable dwelling, the 35 subthemes coalesced into four essential themes. I created a name for each theme by, once again, considering the whole of all subthemes subsumed under each essential theme. Each word chosen for each essential theme abstractly represents one or more subthemes.

D. Hermeneutic Phenomenological Writing

The fourth and final methodological theme is hermeneutic phenomenological writing (van Manen, 1990). There is one procedural dimension, attending to the speaking of language; this requires researcher sensitivity to language's subtle undertones to create an authentic acquaintance with the participants' descriptions. Attending to the speaking of language subsumes three methods involved in hermeneutic phenomenological writing to produce the final product of scientific inquiry. Prior to presenting these methodological devices, a brief discussion of writing itself as the method of hermeneutic-phenomenological is warranted.

Writing

van Manen asserts that hermeneutic-phenomenological writing is not merely an outcome of inquiry in which the report is conceived of as something distinct and separate from the inquiry itself. Rather, "writing is closely fused into the research activity and reflection itself" (p. 125). In other words, questioning and reflection continue as the researcher writes; writing, therefore serves as both method and outcome (van Manen, 1990). The outcome of hermeneutic phenomenological inquiry arises out of a complex process of writing and rewriting in order to "do justice to the fullness and ambiguity of the experience of the lifeworld" (p. 131). To get at the complexity and depth of the phenomenon under study, the researcher must return to his or her writing to re-think, re-flect, and re-cognize, creating a text with layer upon layer of meaning. As the researcher moves between the parts and the whole and the particulars and the universals, text becomes a "finely crafted piece that often reflects the personal 'signature' of the [researcher]" (p. 132).

The product of phenomenological writing and, in a sense, the final product of this hermeneutic-phenomenological inquiry as a whole, is a textual description of the essential nature or meaning of uncertainty as lived experience among intimate partners of persons with prodromal HD. van Manen suggests five ways of structuring this final presentation: thematically, analytically, exemplificatively, exegetically, and existentially. None are exhaustive or mutually exclusive of each other; the researcher chooses the way(s) that best relates to the fundamental structure of the phenomenon. I largely structured the presentation of findings thematically, including a detailed presentation of essential themes, the subthemes that are subsumed under each essential theme, and exemplar participant quotes supporting each subtheme description. I also structured the presentation of findings analytically, reflected in the presentation of the anecdotal narratives.

Attending to the Speaking of the Language

Attending to the speaking of language subsumes three methods involved in hermeneutic phenomenological writing, including the use of silence, anecdote, and varying examples.

Silence

To assist the researcher in attending to the speaking of language, van Manen suggests the use of silence as one method. He outlines three categories of silence which operate in hermeneutic phenomenology: 1) literal silence; 2) epistemological silence and 3) ontological silence.

Literal silence is an absence of speaking; it is the type of silence used during an interview, for example, to allow for a deeper, more reflective response than what my come when one tries to fill space with mere words in attempts at avoiding silence. Using a similar rationale, van Manen (1990) warns against writing too much, or at least more than what is necessary, when creating text.

Epistemological silence is that which is experienced when one is facing the unspeakable. It is the "silent gap" between what we know or feel on one level yet are unable to put into words. To cope with this, van Manen (1990) suggests: 1) borrowing the words of another, whether those words are found in poetry, fiction, or other type of literature; 2) phenomenologically reflecting upon artistic forms, such as film and music; and 3) patience. In the same manner in which one may experience a sudden, unexpected "burst" of writing after intentional and/or unintentional contemplation on a topic, the researcher may experience the ability to capture into writing what was, only moments ago, unspeakable.

Ontological silence is experienced when "we meet the realization of our fundamental predicament of always returning to silence" (p. 114). The researcher can recognize this type of silence as that which "fulfills and yet craves fulfillment;" in other words, there is a recognition of meaningful insight after reading or hearing something, for example, which "speaks" for itself without actually speaking anything.

Anecdote

A second methodological device van Manen suggests using is the anecdote. Similar to the way that narrative or story is used to present aspects of human research in general, the anecdote serves to make understandable a notion that otherwise easily escapes understanding. For this reason, the value of anecdote is reflected in its ability to do the following: compel, transform, personally involve, inspire reflection, and measure one's own interpretive sense. Ultimately, the type of anecdote to be used in hermeneutic-phenomenological writing is more "like a poetic narrative which describes a universal truth" (p. 119) rather than a mere account of factual-empirical and factual-historical content (van Manen, 1990). When creating the anecdotal narrative, the researcher must, therefore, be aware of the tension between particularity and universality. In sum, as the researcher writes, he or she has the goal of conveying a certain truth with underlying tones of universality while using concrete, particulars to make apparent what is otherwise difficult to grasp in language.

Varying the example

According to van Manen (1990), "a phenomenological description is an example composed of examples" (p. 122). The third and final method van Manen presents for use in hermeneutic phenomenological writing is to vary the example to create a phenomenologically powerful description. It is the researcher's goal to present the structural features in the form of textual description of the phenomenon under study in a way that bears its essence. This description should, according to van Manen, be so powerful that it "reawakens our basic experience of the phenomenon it describes, and in such a manner that we experience the more foundational grounds of the experience" (p. 122). The researcher does this through careful attention to themes identified during reflection (analysis) and to the exemplary descriptions created to support each theme. Varying the example comes into play as the researcher addresses each theme in a way that those features of the phenomenon which are unchanging are brought to the surface.

Data Saturation

Data analysis commenced after the initial interview from participant #1 and was ongoing throughout the remainder of data collection. Participants were recruited and further interviews conducted (i.e., more than one interview per person) while keeping the notion of data saturation, or “the point of redundancy…when no new information is forthcoming from new sampled units” (Lincoln & Guba, 1985, p. 202), in mind. Morse (1995) defines saturation as ‘data adequacy.’ She indicates “investigator proclamation” and evaluation of the “adequacy and comprehensiveness of the results” are signals of saturation (p. 147). The goal is to achieve variation in occurrences as opposed to quantity or frequency. The researcher must, therefore, be sure to not discard any data during the initial stages of analysis, giving “all data equal consideration in the analytic coding procedures” (p. 147). Furthermore, Morse indicates the importance of paying close attention to the implicit or “infrequent gem” contributing to the richness, fullness, and completeness of data.

As previously described, I performed the first level of thematic analysis, uncovering thematic aspects and isolating thematic statements, after transcribing each participant interview. The codes resulting from this first level of analysis reflected participants’ words and phrases as much as possible. For example, participant #1 described feeling uncertain as having to keep her antennas up. A code “keeping antennas up” was, therefore, created. With subsequent participants who described a similar notion but used different words, codes were created to reflect the differences (e.g., “being alert” and “awareness”). Coding continued in this manner until it became apparent to the researcher that codes with similar notions or themes could, eventually, be collapsed. I instituted caution during this process to avoid prematurely placing codes together. For example, after having completed 11 interviews with 6 participants and first-level analysis for 6 transcripts, I had 55 codes and began to recognize how some could collapse (e.g., “desiring explanation,” “making sense of situation,” and “need to understand”), but I did not do so at that time.

I started to become aware of not only how codes might collapse into subthemes but also of the possible connections between the subthemes after completing 17 interviews with 10 participants and first-level analysis for 10 transcripts. It was at this point I recognized there were, for example, themes indicating that feeling uncertain was both a projecting into the future and not projecting into the future, and these were characterized by an ebb and flow. Three additional interviews were completed and all data analyzed at the first level. As subsequent analysis and writing continued, four essential themes were identified, as a result of merging approximately 100 codes.

Even towards the end of the process of analyzing and writing, I held a stance of being open to variation, continually questioning the adequacy and comprehensiveness of data supporting the four essential themes. I did not eliminate codes or themes based upon whether an arbitrary minimum number of participants spoke to the code or theme, thereby retaining the "infrequent gems" which add to the richness and fullness of the findings. Upon feeling confident that data saturation had been reached and having my dissertation chair (Dr. Butcher) review my notebook of codes, subthemes, and emerging essential themes and concurring that it was reached, I concluded data collection.

Scientific Rigor

Several researchers have proposed criteria and/or specific strategies to enhance rigor in qualitative research (Burns, 1989; Lincoln & Guba, 1985; Oiler, 1982; Sandelowski, 1986) (see Table 1). Sandelowski (1986) and Walters (1995) have commented that due to the diversity in qualitative methods and phenomenological methods, respectively, it is clear that no one, single set of criteria for rigor can be applied to all methods. For example, the conceptualization and use of bracketing one's assumptions as a means of enhancing scientific rigor varies depending upon philosophical underpinnings of phenomenological methodology. Subsequently, a set of criteria for the critical appraisal of rigor in interpretive phenomenological nursing has recently been laid forth (de Witt & Ploeg, 2006).

It may be argued, however, that hermeneutic-phenomenology as method has built-in mechanisms whereby strategies for achieving scientific rigor are incorporated.

"[Human science's] claim to validity as a method of demonstrating truth would be by virtue of itself as method, as having satisfied certain steps or stages" (van Manen, 1990, p. 173). van Manen's hermeneutic-phenomenological method contains such mechanisms, and these were adhered to throughout this study, thereby addressing criteria required for the establishment of scientific rigor.

> Human science operates with its own criteria for precision, exactness, and rigor…human science strives for precision and exactness by aiming for interpretive descriptions that exact fullness and completeness of detail, and that explore to a degree of perfection the fundamental nature of the notion being addressed in the text (van Manen, 1990, p. 17)

To best illustrate how van Manen's method largely meets the criteria for scientific rigor, in and of itself, Lincoln's and Guba's criteria for establishing trustworthiness will be described and the components of van Manen's method which coordinate with these established criteria will be identified. Other nurse researchers conducting phenomenological studies have incorporated these criteria to establish rigor (Hayes, 1997; Maputle, 2006; Taylor-Walton, 1989; Turner, 1999). The remainder of this section aims to demonstrate how the criteria laid forth by Guba and Lincoln are already a part of van Manen's method with the exception of the audit trail; therefore, following van Manen's method and demonstrating this via an audit trail implies criteria for scientific rigor (as outlined by Guba and Lincoln) have been met.

Procedures for Establishing Scientific Rigor

There are four criteria for establishing trustworthiness: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Each criterion will be described in terms of various techniques employed; however, Lincoln and Guba suggest one technique which can contribute to all of the four criteria: the reflexive journal. The researcher makes entries on a regular, frequent basis on the use of self as instrument for inquiry as well as reflections on decisions made throughout the inquiry. I kept a reflexive journal to enhance credibility, transferability, dependability, and confirmability. I included the following in my accounts: the daily schedule and study logistics, insights and reflection on how personal values and interests were evolving, and rationales for methodological decisions.

Credibility

Three techniques used to establish credibility as outlined by Lincoln and Guba will be outlined. The first involves activities (*prolonged engagement; persistent observation; and triangulation*) aimed to increase the probability that credible findings will be produced. *Prolonged engagement* requires the researcher to be sufficiently oriented to the situation or context from which the data are derived in order to 1) appreciate the nuances of that context, 2) enhance awareness of the possibility of distortions arising from either the researcher's a priori values and biases or the participant's desire to produce socially acceptable answers, and 3) build trust and rapport.

Prolonged engagement is addressed in van Manen's research procedure "Turning to the Nature of the Lived Experience" and includes the following procedural dimensions: orienting to the phenomenon; formulating the phenomenological question; and explicating assumptions and pre-understandings. Aside from orienting myself to the phenomenon of interest and documenting this in my reflexive journal, I oriented myself to what it might be like to be a family member of a person at-risk for HD. Much of this orientation has occurred in prior work on Dr. Williams's study, as I've heard (as focus group assistant and transcriptionist) and analyzed (as research team member) the stories of families who have relatives with prodromal or manifest HD. My a priori values and biases were made explicit in my reflective journal. By making explicit the researcher's biases, assumptions, understandings, and theories, the researcher's knowledge is turned against itself (van Manen, 1990), thereby prompting the researcher to discount premature conclusions from data. To facilitate the building of trust and rapport with participants, I assured them that their confidences would not be used against them, participation in the study would not influence health care received, their interests would be honored, and they would influence the inquiry process as I sought their input as collaborators. Furthermore, I met with participants on more than one occasion for interviewing purposes, when possible, thereby increasing the amount of time available to establish and build upon a sense of trust and rapport.

Persistent observation requires the researcher to "continuously engage in tentative labeling of what are taken as salient factors and then exploring them in detail" and to thoroughly describe how this is carried out (Lincoln & Guba, 1985, p. 304). This technique is reflected in van Manen's research procedures "Hermeneutic Phenomenological Reflection on Essential Themes" (procedural dimension: conducting thematic analysis), "Investigating Experience as We Live It" (procedural dimension: obtaining experiential description from others), and "Hermeneutic Phenomenological Writing." Throughout data analysis, I identified incidental and essential themes, according to van Manen's (1990) method of free imaginative variation. Via the hermeneutic process whereby themes were identified, explored, and reflected upon through subsequent interviews and made explicit in writing, irrelevancies were sorted out and characteristics or elements particular to the phenomenon were focused on in detail. A record of this process was kept.

Triangulation requires the researcher to use one or more modes to determine congruence of findings among them; in this inquiry, I triangulated across data sources. This is reflected in van Manen's research procedure "Investigating Experience as We Live It", through the procedural dimension obtaining experiential description from others. van Manen suggests not only the interview as a means of coming to a deeper understanding of the phenomenon under investigation but also other sources of data. Aside from the interview, I gave participants the option of referring to other sources (e.g., written protocol, art forms, literature) to express experiences with uncertainty. Audio-recorded discussions of these other sources were transcribed and analyzed.

The second technique used to establish credibility, peer debriefing, provides an external check on the inquiry process. This debriefing occurred according to the collaborative analysis procedures (subsumed under research procedure “Hermeneutic Phenomenological Reflection on Essential Themes) previously outlined; through honest discussions, Dr. Butcher challenged biases I held and explored rationales behind decisions (at both the process and content levels) in order to clarify the basis for any interpretations made.

The third technique, member checking, provides for the direct test of interpretations and findings with the human sources from which they were drawn. It is the “most crucial technique for establishing credibility,” according to Lincoln and Guba (1985, p. 314). This technique is reflected in van Manen’s research procedure “Investigating Experience as We Live It” and procedural dimension obtaining experiential descriptions from others. I presented each participant’s anecdotal narrative and preliminary findings in a second interview (among those who participated in second interviews). This provided each participant with the opportunity to further reflect upon, clarify, and explore the meaning of uncertainty. For those who completed initial interviews only (and, therefore, not having the opportunity to review their anecdotal narratives), I presented opportunities throughout the first interview (as well as subsequent interviews, when applicable) for participants to volunteer additional information and challenge my interpretations. There were several instances participants corrected how I was understanding their experiences.

Transferability

Implementing the transferability criterion of trustworthiness involves the provision of a thick description to give indication of the time and context from which data were collected and in which interpretations were made. The aim of this is to enable the reader of the inquiry report to decide whether findings are transferable. The description should include all that the reader would need in order to understand how the findings were arrived at. The two primary items which must be thoroughly detailed in the thick description are: the context in which the study took place; and the transactions or processes observed in that context.

These are addressed in the above, wherein credibility is established by tending to the nuances of the context. This was done via "Turning to the Nature of the Lived Experience" and its related procedural dimensions. Additionally, these were addressed during procedural dimension "obtaining experiential descriptions from others." During interviews, observational notes were recorded and field notes made. In order to address the notion of transferability, I attempted to not only be aware of and document study context and processes observed, but continually expand upon and provide enough detail in the documentation and presentation of research procedures and findings so that the reader may make transferability judgments.

Dependability and Confirmability

The final two criteria, dependability and confirmability, are attended to by creation of an audit trail. The researcher must include in the audit trail the *process* of the inquiry (this addresses dependability) as well as the *product*, including data, findings, interpretations, and recommendations (this addresses confirmability). I created a decision trail from the study's conception to its end. Specifically, I included the following: methods used to collect data, including length of and chosen setting for data collection; all data, including transcripts, observational and field notes, and reflective journal entries; data reduction and analysis products, including any summaries or write-ups created to document working thoughts on emerging themes; data reconstruction and synthesis products, including subthemes, essential themes, and their definitions and relationships; process notes, including those on procedures and their rationale, trustworthiness notes, and audit trail notes themselves; materials related to intentions, including the study proposal and any personal notes kept in a reflective journal on biases and motivations; and instrument development information, including proposed interview schedules and any notes on the interrelationship between researcher-participant.

The auditor should have expertise pertaining to both methodological and substantive arenas. Dr. Butcher served as auditor in determining dependability and confirmability. For the former, the auditor examined the appropriateness of inquiry decisions and methodological shifts as well as any evidence of researcher bias, as it carries the potential for premature closure. For the latter, the auditor examined the audit trail linkages to determine whether 1) findings are grounded in the data, 2) findings are logical, and 3) the researcher implemented strategies to ensure credibility.

Human Subjects Protections

Risks to persons participating in this study were considered minimal. Emotional or psychological risks included feeling embarrassment or pressure that there were right or wrong answers to questions. Participants were at-risk for feeling distressed, uncomfortable, or upset when asked to think about and describe their situations in detail. Financial risks included costs required to meet for interviews, if meeting at participants' homes was not feasible. There were no legal or social risks.

I minimized risk by telling participants that, at any time during their involvement in the study, they had the option of not answering a question or stopping the interview. I inquired at the conclusion of each interview and upon study completion whether the participants had any questions or concerns. For those who did have questions and concerns, I referred them to Anne Leserman who fielded them. Anne and I maintained communication about the issues, ensuring that participants' questions or concerns were adequately and appropriately addressed. I attempted to minimize financial risks (i.e., those associated with travel and parking) by choosing a mutually-agreed upon location for each interview which was most convenient for the participant. For example, 5 participants lived between 180 and 260 miles from my home, so I traveled to their homes to minimize travel costs and time away from work, if applicable. Participants were told they may not find personal benefit from participating in this study. Participants generally reported, however, that they found participating in this study to be a positive experience.

As mentioned in the procedures above, interviews were held in a private setting. Efforts were made to interview participants in private, when possible. In public locations (i.e., libraries), I arranged to meet participants in a private room where only participant and I were present and doors available. In participants' homes, there were times other family members were present in the home. When this was the case, I asked if there was a quiet location where we could speak. For phone interviews, I assured participants I was in a private location in my home. Since these interviews were scheduled prior to the actual interview, participants had sole discretion over where they chose to speak on the phone and whether others were present in their homes at the time.

I collected hard copies and created and maintained electronic forms of data and other study materials. All contact information sheets received were stored in a locked filing cabinet. All materials gathered at interviews were transported from the interview location via briefcase to my home where they were stored. Upon enrolling each participant, I created a folder in which the informed consent and demographic questionnaire were stored in a locked file cabinet. I assigned each participant a code which was used to label folders. Audio recordings were uploaded to my personal (non-network) computer and remained in my sole control. Data was and will not be shared with recruitment sites in a way that would be personally identifiable to participants. Electronic records (i.e., transcripts, digital photos, field notes, and personal journal entries) were stored on my personal computer, under my sole control, at my home address. All proper names were changed to pseudonyms. Persons involved in recruitment (Ms. Evers and Ms. Leserman) maintained electronic records required for identifying eligible persons; these records were stored as a document in password-protected files. All materials containing identifiers will be destroyed upon conclusion of the study.

Figure 1 Hermeneutic-Phenomenological Method

A. Turning to the Nature of the Lived Experience
    1. Orienting to the Phenomenon
    2. Formulating the Phenomenological Question
    3. Explicating Assumptions and Pre-Understandings
B. Investigating Experience as We Live It
    1. Using Personal Experience as a Starting Point
    2. Tracing Etymological Sources
    3. Searching Idiomatic Phrases
    4. Obtaining Experiential Descriptions from Others
C. Hermeneutic Phenomenological Reflection on Essential Themes
    1. Conducting Thematic Analysis
D. Hermeneutic Phenomenological Writing
    1. Attending to the Speaking of Language

Table 1 Interview and first-level analysis completion dates

Participant	Interview 1	Analysis	Interview 2	Analysis	Interview 3	Analysis
1	2/20/09	3/12/09	3/13/09	7/12/09	5/3/09	7/18/09
2	3/2/09	3/22/09	3/26/09	7/19/09	7/29/09	8/23/09
3	3/25/09	5/14/09	5/15/09	10/24/09	11/23/09	1/10/10
4	4/3/09	4/28/09	5/2/09	2/6/10	2/13/10	2/18/10
5	5/2/09	2/21/10				
6	7/7/09	2/27/10	3/26/10	4/10/10		
7	8/9/09	4/24/10				
8	8/28/09	9/12/10				
9	9/14/09	10/2/10				
10	9/25/09	5/20/10	6/3/10	7/22/10		

CHAPTER IV

PRESENTATION OF FINDINGS

The research question driving this inquiry was: What is the meaning of the lived experience of uncertainty among intimate partners of persons who have tested positive for the HD gene mutation but have not yet received a clinical diagnosis? The following presentation of findings includes a description of participant characteristics and a textual description of the essential meaning of uncertainty as experienced by intimate partners of persons who are positive for the HD gene mutation yet have not been clinically diagnosed. A detailed presentation of essential themes, subthemes subsumed under each theme, and exemplar participant quotes demonstrate support of the meaning of the lived experience of uncertainty as described by participants.

Participant Characteristics

Ten persons participated in this study. Information pertaining to their gender, age, marital status, amount of time in current relationship, highest level of education completed, and race were obtained via questionnaire. Additionally, participants were asked to report on how many children from their current relationship they had, how long they knew their partners were at-risk for having HD before their partners had the predictive genetic test, and how long it had been since their partners received results from the predictive test. Participant characteristics are reported below and summarized in Table 2. All participants’ actual names have been changed to pseudonyms to ensure anonymity. The researcher created anecdotal narratives after each participant completed the first interview. These are presented in Appendix C. Persons participating in more than one interview reviewed anecdotal narratives during the second interview and were offered the opportunity to change their stories, as needed, so that they were true descriptions of their experiences with feeling uncertain. Words or phrases participants wanted to delete appear as having a strike-through, while any words, phrases, or ideas participated wanted to add appear in italics.

Participant #1

Karen was a 66-year old female. She had been in her current intimate relationship for 7 years and was not married. She had completed high school and is Caucasian. She and her current partner had no children together. Her partner received predictive genetic testing results 15 years prior to our initial interview. Karen completed three interviews; the first two were in her home on 2/20/09 and 3/13/09, respectively, and the third in a public library on 5/3/09. Karen did not create a personal protocol. She did not refer to any written or artistic forms of feeling uncertain during our conversations. Karen offered additions and deletions in her anecdotal narrative.

Participant #2

George was a 42-year old male. He had been in his current intimate relationship for 10 years and was married. He completed his high school education and is American Indian. He has one child with his current partner. He reported that his partner was tested 4 years prior to our initial interview, and he knew 3 months prior to that she was at-risk. George completed three interviews. The first two, completed 3/2/09 and 3/26/09, took place in a public library. The third interview occurred 7/29/09 over the phone. George created a personal protocol using the audio recorder. He did not offer other written or artistic expressions of feeling uncertain. George offered additions in his anecdotal narrative.

Participant #3

Madison was a 34-year old female. She was married and had been in her current relationship for 12 years. She had completed her baccalaureate studies. She is Caucasian. Madison and her current partner have no children together. Her partner tested 4 years prior to our initial interview, and she knew 1 month prior to testing of his at-risk status. Madison completed the first interview on 3/25/09 and the second interview on 5/15/09. Both took place in her home. The third interview, which was done 11/23/09, occurred over the phone. Madison created a personal protocol using the audio recorder and provided a photograph as an artistic expression of feeling uncertain. Madison provided additions to and deletions from her anecdotal narrative.

Participant #4

Karl was a 38-year old male. He had been in his intimate relationship for 33 months and was unmarried. He had completed his high school education. Karl is Caucasian. He had no children with his partner. His partner tested 7 years prior to our initial interview. Karl completed three interviews; the interviews took place on 4/3/09, 5/2/09, and 2/13/10. The first two were in his home and the third over the phone. Karl did not create a personal protocol. He referred to a song during the second interview as an expression of feeling uncertain. Karl indicated he would add a story, which he recounted during the second interview, to his anecdotal narrative to more accurately reflect his experience of feeling uncertain.

Participant #5

Ryan was a 29-year old male. He was unmarried and had been in his current relationship for 6 years. He received his Bachelor’s degree. He is Hispanic and had no children from his current relationship. His partner had tested 7 years prior to our initial interview. Ryan completed one interview, on 5/2/09, in his home. He did not create a personal protocol, and he did not offer written or artistic expressions of feeling uncertain.

Participant #6

Brian was a 51-year old male who was married and had been in his current relationship for 26 years. He had completed his doctoral education. Brian is Caucasian and had two children from his relationship. His partner tested 10 years prior to our initial interview, and he knew 5 years prior to that she was at-risk for developing HD. Brian participated in two interviews. The first took place on 7/7/09 in a public library, and the second took place on 3/26/10 in a public library and fast-food restaurant; we were required to change locations due to unforeseen circumstances. Brian indicated a preference to create a written personal protocol as opposed to an audio protocol. He sent his protocol via email. Brian did not refer to other written or artistic expressions of feeling uncertain, and he had no additions or deletions to make upon reviewing his anecdotal narrative.

Participant #7

Joe was a 52-year old male. He had been in his current relationship for 33 years and was married. He completed his high school education. Joe is Caucasian and has 4 children with his current partner. She was tested 6 years prior to our initial interview, and he knew of her at-risk status 2 years prior to that. Joe participated in one interview, which took place on 8/9/09 at a public library. Joe did not create a personal protocol and did not have written or artistic expressions of his feelings of uncertainty.

Participant #8

Ellen was a 51-year old female. She had been in her current relationship for 29 years and was married. She had received her Bachelor’s degree. Ellen is Caucasian and has one adopted child with her current partner. She knew her partner was at-risk for the HD gene mutation 16 years before he tested, and he tested 10.5 years prior to our initial interview. Ellen completed one interview, on 8/28/09, at a public library. Ellen did not create a personal protocol or have any written or artistic expressions of feeling uncertain.

Participant #9

Angie was a 26-year old female. She was married and had been in her current relationship for 5.5 years. She completed her high school education and some post-secondary education. Angie is Caucasian and had two children with her current partner. Her partner received the predictive genetic test 2 years prior to our initial interview. Angie participated in one interview, which occurred on 9/14/09 in her home. She referred to a quote painted on her bedroom wall as an expression of feeling uncertain. She did not create a personal protocol.

Participant #10

Laura was a 44-year old female. She was married and had been in her current relationship for 16 years. She completed baccalaureate studies and is Caucasian. She has one child with her current partner who tested 4 years prior to our initial interview. She reported knowing 5 months prior to testing of his at-risk status. Laura participated in two interviews, both of which took place in her home on 9/25/09 and 6/3/10.

Essential Themes, Subthemes, and Supporting Data

Four essential themes arose from this scientific inquiry to uncover the meaning of uncertainty as lived experienced among intimate partners with prodromal HD. The essential themes are as follows: Intangible Reality; Anticipating with Ebbing and Flowing Disquietude; A Weighty Pull to Dwell Upon, Towards Inner Turmoil; and A Subdued Presence With Freeing Possibilities. The lived experience of uncertainty among intimate partners of persons who have tested positive for the Huntington disease gene mutation yet have not been clinically-diagnosed is an *intangible reality* characterized by *anticipating with ebbing and flowing disquietude* while feeling *a weighty pull to dwell upon, towards inner turmoil* and *a subdued presence with freeing possibilities*. The essential theme "intangible reality" encompasses the others. "Anticipating with ebbing and flowing disquietude" is always a part of the experience of feeling uncertain. The ebbing and flowing nature of the disquietude is apparent as “as weighty pull to dwell upon, towards inner turmoil” and “a subdued presence with freeing possibilities.” Each essential theme is defined and a detailed description of subthemes reflective of each theme and supporting data for each subtheme is presented. Table 3 includes the four, essential themes and respective subthemes.

Intangible Reality

Intimate partners of persons with prodromal HD describe feeling uncertain as an intangible reality. “Intangible reality” is defined as a thing experienced or existing in fact that is not definite or clear. It is something that is there, but it is vague, elusive, and unable to be touched or grasped. Three subthemes reflect this essential theme: knowing creates questions, thoughts, feelings and ways of being; strange; and anyone, anywhere, anytime with form.

Knowing Creates Questions, Thoughts, Feelings, and Ways of Being

Upon receiving the information about their partners’ gene status, a new context emerges from which questions, thoughts, feelings, and ways of beings arise. In other words, knowing creates questions, thoughts, feelings and ways of being. Participants know something will happen and that there will be significant change and loss in their futures, but they don’t know, specifically, what will happen, when it will happen, what to do, how to be, and how to find meaning amidst these unknowns. For example, it is because Brian knows his wife will someday be ill that he wonders when it will happen and what his response will be: “[It] will happen. The question is when will she go off the plateau and go to a deeper level and you’ve gotta be there to help…it’s just one of those things that you think about.”

Ryan spoke of how his ways of being have changed as a result of knowing about HD and not knowing when it will affect him and his partner, saying “The uncertainty of not knowing when this is really going to affect him caused us to travel a lot more… If he did not have Huntington's, I think we would not have done a lot of things." Similarly, Angie indicated she is doing things differently now because of knowing: "Knowing definitely has changed how we perceive the future and what we're doing now to benefit things in the long-run." Joe described how his view of the future with his wife changed because of the test result:

> Most people go south for the winter…or they travel or something like that. [T]hat's something that we won't have together. What are we going to have together? Nobody can answer that question…I think of my wife down the line, and I think of no future and it just makes work some place where I go to get money. I don't think of it as a livelihood or something I can look forward to…My future, I feel, is not a bright and happy one. It's like my wife died when she got the results of the Huntington's test. [There's] no sense of finding any enjoyment whatsoever.

He anticipates his retirement years to be something different from before, changing the meaning of what he does now as well as the way in which he views his future, even though his wife is not yet ill. At the same time, however, he acknowledges that questions and unknowns remain. In other words, his reality now includes the expectation that his future will not be normal or bright, yet he does not know what it will be. It is an intangible reality. Laura described how knowing the information about her partner's gene-positive status changed her perceptions, specifically the ways in which she tries to find meaning for his behavior:

> Our printer started acting very strange. I turned it off. Then my husband came home and just blew up and said what did you do to this printer?! Was swearing…He just seems to have these temper flare-ups that he never had when I first met him. Maybe it's me knowing this information, this knowledge…it's making me have a different perception. Maybe it's the fact my husband's 54-years old and has a 4-year old son that he wasn't so enthused about to begin with…Maybe it is the Huntington's. He was just a gentle, kind person with an even personality. I fell in love with him because he was so kind.

Knowing the information is a new lens that changes participants' vision and sets the stage for thinking and wondering in ways they hadn't prior to knowing. Laura juxtaposes what feeling uncertain might be like had her partner not been tested with what it is like now that she does know:

> Just knowing that it's in the family, I think I would assume 'oh, he's positive.' But then I would be having all this turmoil 'oh, is he or isn't he?' But [because I know], my turmoil is 'are these signs and symptoms…are we going down this path?'"

She likens this to a Pandora's Box because "now it's out there." In sum, knowing the test result presents a reality that reveals a new layer of unknowns. The reality or known fact is that, barring any unforeseen events, participants' partners will be ill from the effects of HD at some point in their futures. The uncertainties revolve around this reality. For Ryan, "It's like a tree effect, because there's the thing. There's the Huntington's disease and what direction is this going to take? What direction is *that* going to take? What direction is *that* going to take? You really don't know." The knowledge that participants' intimate partners are gene-positive for HD points to thinking and wondering in a way that is more specified than their thinking and wondering was before. It is because of the knowing that the unknowns have shape. Ellen succinctly captures this notion, saying "There's so many unknowns but there's enough known that it gives the unknowns a direction." The not knowing with a direction is, alternatively, a knowing without clarity, or a reality that is intangible.

Strange

Participants describe this intangible reality as not being able to see, visualize, or grasp something they know is there. Karl offers a visual of this, as he says feeling uncertain is like a hallway where you know other hallways are connected to it but you can't see them:

> [P]icture something like a long hallway. And it'd kind of come to an end with a whole bunch of other long hallways shooting off from it. And [you're] just not sure where they're going. Not that one was necessarily the right road or the wrong road, but I feel like that's…in one way the uncertainty of HD and everything…[the hallway] goes into a shadow where you don't

> really see. You know eventually you're going to go some different way. You just don't know where or when that is.

It is a circumstance which is difficult, if not impossible, to define or understand, as it is not definite or clear to the mind. It is as if one is viewing something while wearing a veil, creating a blurred, hazy view and rendering what one knows is there unknowable. George indicated "You can see the picture and you know what it is, but it's distorted. It's a visual. You know but it's not clear." Participants described this experience as strange, or being outside of their experience, not previously seen, visited, or encountered. It is unusual in a way that is unsettling or hard to understand. They used words and phrases like "weird," "bizarre," "not normal," "hard to grasp," "unreal," "can't picture," and "can't wrap your head around" to describe the strangeness implied in the intangible reality. For example, Ryan said there is a "weirdness and uncertainty" that comes from resolving that he will someday find another intimate partner while, at the same time, feeling "madly in love" with his current partner, adding "in any other situation, if you don't think your relationship is going to last the rest of your life, you would just end it there." Karl described his difficulty in imagining and grasping anticipated changes in his spouse and their relationship:

> It's still hard to sometimes grasp that someday something may change in her drastically that might be beyond our control, because there's no symptoms whatsoever right now. 'Cause I've read a lot of things about that, where the closest person really gets hurt the most. Not just because it's happening, but maybe verbal abuse and things like that. I just can't picture these things, because it's so far away from how we are with each other now.

Participants describing the strangeness of their experience indicated it is not normal. Laura, for example, said she thinks about things in a way that is not typical:

> The whole uncertainty of knowing…I kind of have an imagination too, and it just runs…when you're laying there at night trying to sleep, things just play out and maybe the normal typical person wouldn't have these fanciful thoughts that I'm having… I think 'oh, should we build a house?' But then we'd probably be in debt. And then would my husband be out of work? Would we be able to afford this handicapped-type one-level house? Should we do that? Because we do have this land and our

> thought was to build a house out there, but now I'm thinking 'oh, maybe that's not a good plan.'"

Angie described an abnormal mix of excitement and wondering, as she thinks about places she and her partner would like to travel to. "It's a bizarre thing…you have excitement, thinking this will be really cool. But I'll have that thought in the back of my mind…what if it doesn't happen? Am I going to have to go on this trip by myself?" It is the knowing about, or the reality of, something which will likely happen in the future that is there, in her mind, from which questions arise that are not normally or typically there. Karl shared how, upon finding out his then-girlfriend was gene-positive, he sought his father's advice on whether to proceed in the relationship:

> My mom passed away several years ago from cancer, and I said to my dad well, if you met Mom 50 years ago and if she would've told you 'hey I'm going to, by the way, get cancer and pass away only in my mid-50s.' Would you leave? Like, if she already knew that was going to happen? Obviously he said oh no, of course not. Love is over-riding, that's all that matters.

It is not commonplace to know about a partner's future health status and, subsequently, wonder whether one should proceed in the relationship.

Anyone, Anywhere, Anytime with Form

Many people anticipate and look forward to things, such as retiring, traveling, or simply living out their lives with loved ones by their sides. What many don't do, however, is to frequently wonder if it will *actually* happen or carry much doubt that it *will* happen. At the same time, there is a reality that all humans face: things happen along that way that are surprising, unexpected, and tragic. "Like if somebody just all of a sudden finds out they have cancer, one day out of nowhere…or have a car accident and they get hurt that way. Things can happen at any old time," said Karl. It's a knowing that anything can happen to anyone, anywhere, and anytime. The futures of all humans are, ultimately, uncertain and unforeseeable.

While this is this case for everyone, the element of having information pertaining to future health status and events gives the unknown form for these participants. It reveals unknowns in a way that is different from what the general population might consider to be unknown. All humans have thoughts of the future, but the nature of these thoughts is different for these participants. Several participants make note of this, commenting on how while no one knows what the future holds, including themselves, they know *something* that gives their futures a direction. Angie, for example, created a vision board to include what she wanted to come into her life. She described how what she plans and hopes for now, as opposed to before knowing her partner's positive gene status, is "different because of the uncertainty, of (intimate partner's name) getting sick, of not knowing what our future holds. Granted, nobody knows what the future holds, but we know there's something negative that could be a part of our future." Ryan described how he, like anyone else, knows that disease and death of a loved one is an inevitable reality, but knowing something more about what is in his future brings this reality closer to home. "[E]veryone's going to have to deal with death and disease. So why should we be so upset? It's just that being able to name it makes it more of a reality."

The intangible reality experienced by these participants is different from the uncertainties surrounding the possibility of unexpected tragedy or a diagnosis of a condition. Karl described how thinking about HD as a future certainty is different from thinking about the certainties that other illnesses and death present:

> It was almost 20 years ago when [my mom] and my dad let us know she had cancer. She already had it. I didn't have to deal with this whole thing years before, knowing that someday it was going to happen…I guess things can happen to anybody. It's certain probably amongst myself and all my lifelong friends that somebody's going to have something bad come their way too in the future. More likely, it's just a fact of life. What's weird is I don't dwell on those kind of certainties. I don't worry about [them]. I don't worry about death or being very old and in a hospital or about to die.

He acknowledged the reality that "something bad" can come into anyone's life, but he doesn't worry about or dwell in this reality. It is the "whole thing" of knowing about and dealing with the idea of HD and its implications before it happens that is strange.

Madison echoes this notion, describing how her experience is unlike others who face illness:

> I [am] compassionate with (intimate partner's name) but at the same time, it's hard because it's not like he has it. That's what's so hard about HD. It's so hard to explain and so hard to deal with because it's like this unknown somewhere out here. Somewhere on (intimate partner's name)'s lifeline it will occur if he lives long enough…And that's so difficult. Where when you have cancer or Alzheimer's or whatever, you see it right away. You know here's the stuff we're gonna take, here's what we see, here's the medical things we can do for you. With HD it's totally not like that. It's you tested positive, you will get it in some period of time. How is a normal person supposed to deal with that?…It's kind of like being diagnosed but not. You just don't know.

Like other participants, Madison described the difficulty in "being diagnosed but not," or knowing about something that has not yet manifested. Things are fine now in the sense that her partner is not yet affected with symptoms but she knows that, unless something affects him before HD does, he will get symptoms. It is difficult to comprehend, as it is something that is there but at the same time it's not.

In sum, upon receiving information that their partners are positive for the gene mutation causing HD, participants ask questions, and have thoughts, feelings, and ways of being that are different from before. They are viewing what lies before them through a new lens and cannot return to the ways in which they viewed the unknowns before. This new lens is always there. Karl said "it's always in the back of my mind a little bit, about HD, the not knowing and uncertain part…it's always, always there," and Ryan also conveyed this notion, saying "It exists. It's while we're having all this fun…in the back of our heads, it's always there." What is always there is the reality is that participants' intimate partners are gene positive and the possible implications of this. Ellen tearfully said the following:

> [T]he predictive test is weird. Knowing the future is not a good thing, not a good thing, *(said in a whisper)* not a good thing. 'Cause if we think about or guess too much, you can't function very well. Clearly, everybody's going to die. Who knows when, who knows how. But knowing that at some point it's just going to be miserable for him and miserable for me…I don't know. I don't

> know. There's not a lot of support out there because people just don't understand. I don't think most people really even think about the possibilities very much.

Knowing gives form to the possibilities, or unknowns, all humans face. This is a strange experience considered to be unusual, elusive, and ungraspable, as the form is a presence only; it cannot be fully seen, felt, heard, or touched. Participants' experience of uncertainty is an intangible reality.

Anticipating with Ebbing and Flowing Disquietude

Anticipating with ebbing and flowing disquietude is the second essential theme describing participants' experiences of feeling uncertain. It is defined as a thinking, speaking, acting, or feeling in advance which is characterized by a changing sense of worry and unease. The disquieting anticipation is always present, but its intensity changes in a way that can be likened to a recurrent or rhythmical pattern of fading away and advancing, or lessening and rising. There are 10 subthemes comprising this essential theme, including: attentive sensitivity; worrying and feeling afraid; when will the anticipated happen; what will happen; considering what to do and how to be; contemplating relationship changes and loss; a desire to find meaning; trying to prepare; uncomfortable; and changing intensity of emotion and thought.

Attentive Sensitivity

Participants described being quick to detect or respond to slight changes and paying close attention to their partners' behaviors which may or may not be symptoms of HD. They describe this attentive sensitivity as being "alert," "on guard," and "watchful," having "awareness," and keeping your "antennas" or "radar" up for the changes. For example, George said "I do look at her more closely" as his partner reaches the age when the development of symptoms becomes more likely.

The attentive sensitivity is like being on edge, waiting for something to happen. Participants described the unsettling features of this attentive sensitivity. "Knowing that he has this, I’m watching him and just thinking ‘oh, is this the beginning? Is he becoming symptomatic *(crying)*?’ It’s hard to know…I guess knowledge can be powerful, but it can also be disturbing,” said Laura. Karen said “[We] keep our antennas up for anything that might happen…I react when his memory isn’t good…it just feels like a concern that I need to stay aware of...I get tense about it.” Similarly, Angie described the subtleties she picks up on and ensuing sense of alarm.

> He’s supposedly pre-symptomatic but he’ll have a leg twitch at night and I’ll think ‘oh my gosh, is that an early sign?’…Or he’ll blink an eye, so I’m like, are you blinking your eye ‘cause your contact itches or is that uncontrollable, is that an early sign that something’s starting?

Brian says the watching is parental in nature, particularly as he wonders when the time will come where his partner is putting someone else at risk due to involuntary motor movements and loss of voluntary motor control. He indicates that, in the meantime, he “monitors [and is] more tentative to watching her movements…It’s like a dysfunctional child…you start moving more into a parental-type activity, in terms of watching.”

Worrying and Feeling Afraid

Participants indicated that worry, fear, anxiety, and dread characterize their feeling of being uncertain. Ellen, for example, said “I’ve had a real hard time over the years with anxiety…I’m thinking I should not have ever *(pause; speaking in near-whisper)* had this uncertainty all the time,” while Laura said “I just have these worries…I feel a sense of dread thinking about the future…I have a lot of anxiety about just the unknown…I’m afraid, I don’t know.” Karl “kind of want[s] to worry” about HD and its unknowns, saying “it’s part of her life, my life, our life together. It’s going to affect it some way.“

Some of the words participants used to describe this worrying and feeling afraid include: “stewing,” “wondering,” “panic,” “scary,” “frightening,” “cold,” and “concerning.” Karl likened worrying to “questions [that] race in your head that you can’t really answer." Laura said fear feels like being "gripped" and "just tense…closing yourself like tunnel vision, almost. You just can't even see the whole picture." Ellen said the worry is "always there" while Karen indicated it is "hidden…down there somewhere." Laura provided other poignant features of feeling worried and afraid, as she told a story about seeing her partner respond in a "very upsetting" way to both their young child and family pet and not knowing what would ensue.

> These things really make me feel very worried *(said in a near-whisper and with trepidation).* I feel sick to my stomach. This is not the man I married. It's hard. I feel like what is my son learning from this? Is this going to continue? Are these situations going to get more and more escalated? It's very, very worrisome. I feel like I'm shaking, I feel so upset *(sighs).*

Participants were worried and felt afraid of many things as they anticipated certain things happening in their futures. Ryan, for example, was worried about transitioning out of his relationship while his partner was still living but near the end of life and what others would think of him. Madison said the possibility that her partner might contemplate suicide was an "unknown that a little bit scares" her, one that she "always worries about." Ellen said she worried about seeing changes in her partner, thinking they meant that the expected (HD) had arrived. She describes this in a palpable way:

> Sometime *(voice trembling)* the silliest things would make me think about it and worry about it, like…I'd see a change in how he is, or a twitch or something…it would just be automatic…the sensory stuff would go in and I would be panicked…Thinking the worst…catastrophizing, [feeling] panic, dread…I mean, he'd do something that was like, I don't know…drop a glass, or something that people just do sometimes. [It'd] just be like 'oh my God.'

When Will the Anticipated Happen

Participants know their partners are likely to develop HD and this will affect their partner' as well as their own lives. They do not, however, know *when* this will occur. Several participants anticipate HD-related changes: Brian straight-forwardly stated "You know they're going to happen. It's a matter of when they do;" Laura said "I know that these things are going to happen. But I just don't know…when;" and Madison indicated "I think about it understanding that there will be stuff, but at this point there's really nothing to do. 'Cause I don't know when all that's going to happen." Some described the difficulty in not knowing when the anticipated would happen. George said "It's kind of hard. [T]he not knowing when it's going to take place is really the one big thing." Karl concurred, saying "not knowing when it is…is the bad part."

In some instances, participants asked the question in more specific terms, beyond wondering when "things" or "it" would happen. They asked "When is the progression moving forward?" "Is it going to happen soon? Will it happen in 5 years or 10 or 20 or 30? When [will things] start getting bad or tough?" "Will the romantic relationship end when he's 30, when he's 35, or when he's 40, or somewhere in between?" "When [will] she get to that point where she can't work no more?" Brian thought about a hypothetical situation and how he wouldn't know when it would be serious enough to become involved: "When is this all a real, you know…her forgetfulness of leaving the groceries at the store or something. When is that…'ok, now I need to go with you to the grocery store,' type of thing. When is it serious?" Ellen commented on HD's slow progression and insidious nature, asking "When does the person…when do you know for sure that they actually have it?"

Several participants used metaphors to describe what it is like to feel uncertain about when the anticipated would happen. George said "the time-frame, waiting, wondering…it is a 'waiting game.'" Karl described it as a "guessing game" as he tries to figure out in his head when something might happen. Laura likened it to a time bomb: "[I]t's almost like a bomb, a ticking bomb. When is it going to go off?…How much time do we have until he starts having problems?" Brian doesn't know when the "drop-off" to a "deeper level" will happen. In this last description of feeling uncertain about when the anticipated will occur, Ellen says "My attitude was always 'oh, I know this is going to happen. I know this is going to happen. I just don't know when.' It's like waiting for the other shoe to drop, like all the time."

What Will Happen

Akin to wondering when the anticipated will happen, participants know something will happen but they don't *what* will happen. Joe said "You don't know what's going to happen," while Laura described how she lays in bed at night, "just wondering what's the future is going to hold...how will things unfold?" Karl knows he will "do a good job" as a husband, supporter, and caregiver, but then doubt enters his mind as he wonders what will happen: "It's easy for that little voice to pop in there and say 'are you so sure? It's going to be tough, you're not going to like it. You don't know what's going to happen.'…no one really knows how it's going to happen."

Aside from the general questions about what will happen, participants think about specific possibilities. Several participants wondered about the nature of the anticipated changes. George said "With Huntington's…she could shake all of the time, or she could just …be a little stiff and rigid. I guess the thing of it is, is she going to become more stiff or rigid?" Brian doesn't know if the changes will be gradual or sharp. Similarly, Karl doesn't know "How fast will it take hold? Or how slow will it go?...What it's all going to encompass? How severe will it be for her?" Some pondered whether their partners will be affected in a manner similar to other family members. Karl asked "How is she going to change?...Is she going to be like her one uncle [where] it was more of just an annoying thing that he had?" while Laura considered the possibility that "Maybe it will be just a very gentle, easy course. Maybe he'll be older like his father [when symptoms develop]." Madison gives shape to the question of what will happen as she envisions her future:

> I'm scared of…just the whole 'how will it manifest?' What will it look like for him to be at his worst, and needing [me] to be taking care of him and living life? What will that look like? I don't know.

Participants also wondered what will happen specifically in terms of friendships, family structure, support, and others who could possibly be affected by their partners' disabilities. Ryan thought about what will happen and what the implications are for his friendships when the "reality" of the disease sets in. "What's going to happen? How's it going to happen?...How are other people going to react…if they have to face that sort of reality, will they still be our friends?" As Laura thought of her future with her partner, she said "I don't know what's going happen and how our family structure will be…are we going to turn into this dysfunctional group?" Madison wondered how supportive her partner's and her family will be. "What are [our families] going to be like? Are they going to be supportive at all? Or is it really just me?" Both Ryan and Brian felt unsure about what might happen as they considered the safety of others. "How [will] his disease affect…the situation? Am I going to have to worry about him holding the child with the chorea?" asked Ryan, while Brian said "What is going to happen with that child [she is holding]?…[I have a] fear of what her actions are going to lead to."

Considering What to Do and How to Be

Participants described feeling uncertain about how they should be and what to do. They wondered how they'll react in the future, in response to HD-related events, as well as what to do now. This subtheme reflects a wondering about one's own behavior, both now and in the future, based upon knowing what the future likely holds. Madison wondered "how am I going to deal with this…[thing that will happen]?" Karl said "you know it's going to happen, it's been chosen for you…you just don't know really what to do about it." He elaborated on this, describing feeling a certain way as he thinks about his future but, at the same time, how that feeling is not tied to anything specific or concrete yet. "[I was]…crying out of, a little bit of anger a little bit…not really like sad, like I totally feel weak about it, because…you almost don't know what to feel weak about yet." Laura described how she anticipates and has no answer to the questions about what she'll do as her partner develops symptoms. “If he starts displaying signs of this disease, how will I deal with it?…Would [we] need to take action?” Karl reflected on his personal capabilities, feeling uncertain about whether he can do what needs to be done when the time comes.

> One of the things I’ll think about the most is I don’t know how I’m going to be at the time when things start turning for the worse. I just don’t know what I’ll be able to do …how much strength I’m going to need or what’s going to be asked of me [during those] trying times.

Several participants contemplated what to do and how to be in relation to their partners, both now and in the future, as they noticed differences in their partners’ behaviors. Karen described how her partner reacted to her concerns about memory loss in a way that was unexpected and out of the norm. She felt uncertain about how to discuss topics of concern with her partner: “How should I interact with him from now on, to let his stress dissipate, to not aggravate it?” Brian described not knowing whether to take the role of spouse or caregiver as he interacts with his wife: “Which role do you choose?... [T]he whole decision is when do you reach out and help and when are you helping too much?” Joe described how his partner has been acting differently in social situations and wondered how to approach and “deal with” her.

> How am I supposed to deal with her when those situations come up?…How will I be able to deal with it in the future? You know, with (intimate partner’s name) as a person, as a human being, how am I going to deal with her? Is she going to go around and put me in embarrassing positions because of her Huntington’s?

Similarly, Madison described instances where her spouse was acting out of character, displaying more of a temper than usual, and how she felt uncertain about what to do and how to be.

> I remember…feeling really close to just [being] in that place where you’re emotionally charged, feeling very ‘what am I supposed to do?’…[T]he biggest most uncertain times I have are usually when something has happened, and you’re like, as a person, what am I supposed to do with this?...How do I handle it?...What am I going to do with him?

Contemplating Relationship Changes and Loss

Participants think at great length and in a profound manner about the ways in which they anticipate relationship changes and loss. They wonder what the implications for their relationships and futures together are, knowing that: HD symptoms can severely affect neuropsychiatric functioning and cognitive and physical abilities; they will likely become caregivers for their partners, and, ultimately; they will lose their partners, either physically or mentally or both. Karl described what it feels like to consider the possibility that the love he and his partner feel for each other now may be "taken away" by HD:

> (Intimate partner's name) sing[s] *"You are my Sunshine"* to me sometimes…And it's a very nice, happy song, really. But…the words…'don't take my sunshine away' really get to me. They put me in that uncertain spot. I think about her…[and how the sunshine is being taken away from] us together. *(crying)* I think…about how much we love each other along with thinking maybe the reverse might happen.

As participants considered specific HD-related features, such as dementia, personality changes, and even motor symptoms, they wondered what the implications might be for their relationship. Karen said "My fear…it's about losing him, or him losing some of his cognitive ability. Which would change our relationship a lot." Similarly, Laura said "I wonder, is he going to be the same person that I fell in love with? How much time [will we] have together?...It is kind of terrifying just thinking of that person slipping away from you (crying)." Karl asked "[What] if her mind totally flips to a spot where she doesn't want to be around me…I don't know if I'll be able to handle that…or say well, that's the disease and you gotta deal with it." Others thought about how the disease would alter the spousal relationship as they became caregivers: "When do I need to step in and all of a sudden you're no longer a spouse, but you become a caregiver?" asked Brian. Laura tearfully anticipated what it would be like to become a caregiver and lose the spousal relationship: "That's the part that just really bothers me…just shifting in that relationship. You know, losing your partner. It's not like your partner anymore."

Participants contemplated the unknowns surrounding the eventual mental and physical loss of their intimate partners as they consider their futures, the desire to move into another intimate relationship, and the seeming futility of building a life with another person knowing there is a significant likelihood of "having to go through it alone." George described doubt over whether he and his wife will have a future previously hoped for and expected. "[Thinking] that we'd both be old and gray, watching the great-grandkids grow up, or whatever…I don't know if it'd get that far." Laura conveyed a similar sentiment, saying:

> Before any of this happened…we got this land…I thought we'll just grow old and we'll watch these beautiful trees and we'll have a little garden. This could be his retirement. He'll be out here puttering about. And now I'm just thinking will he have the motor skills to be able to do this? I just don't know.

Ryan described feeling uncertain as he anticipates the end of the relationship and finding another partner: "I don't know where or when our relationship will end…I don't know when I'm going to have to make the decision, you know, he's in the hospital…it's time for me to start seeing other people." Meanwhile, he described how he is holding on to what he can of his current partner. I'm grasping for every little bit of [him] that I can get." Angie wondered if her efforts to create a life with her partner are going to, ultimately, be fruitless.

> Are we going to build this life together and then one day it's going to abruptly just be me? And then here I am, we have all these memories together and these kids, and then what happens if the kids get sick? Then I'll really be alone….[T]hen what happens?...I don't want to build my life and then all of a sudden it's just me.

A Desire to Find Meaning

This subtheme is reflected in participants' statements about making sense of the unknowns, wondering why things happen, needing to understand, wanting an explanation, and finding a reason. They expressed a desire to know the cause or purpose behind something unknown, using phrases such as "I wonder what's causing the change;"

“I need to understand;” “What is going on?” “I try to make sense of it;” “I’m trying to think of an answer;” and “I have no reason why.” Brian characterized his attempts at finding solutions to things that don’t make sense as an “obnoxious persistency [to] keeping digging and keeping turning rock.” Laura described the difficulty inherent in the process of identifying a “cause” for her spouse’s behavior, despite knowing her partner’s gene-positive status, saying she is “trying to put things neatly in place…it is tricky to sort it out even when you know this information, you don’t always know you’re attributing it to the right cause or not.”

Participants wondered “why” things happened, almost in disbelief, as they try to find meaning. Karl asked “Why [did] this happen? Why her? Why me? Why us? Why does it exist? Why [do] these types of things happen to people?...It just doesn’t seem right that this stuff happens.” Similarly, George asked, upon receiving his partner’s predictive test results, “Why does it have to happen…why does this have to happen now?” Ryan and George described the difficulty in making sense of how a disease so debilitating could alter their partners’ capabilities in the future: “Having seen where people have full-on symptoms, and knowing him…it’s just kind of impossible to see that. He has a genius IQ. He has a physics degree…just one of the most together people you could possibly meet,” said Ryan. George asked “How it could happen to somebody who is such a smart, intelligent, personable person. [T]hat’s kind of a hard part…As we know, this has nothing to do with how the person is, it’s genetics.”

Participants sought to find answers to unknown circumstances by considering various possible solutions. Several described being concerned about changes in their spouses, such as memory difficulties, uncontrolled motor movements, mood and personality changes, and behavior changes. They sought to find meaning for these changes, often trying to determine if the change was HD-related or not. Several participants searched for the meaning behind their partner’s “shakes” or “jerking” when falling asleep. For example, upon seeing her husband “twitch” at night, Angie wondered what the reason is, asking does it happen “every night? Is it nights that we go to bed late? Is it nights that he had beer? [I’m] trying to think of an answer and figure out…is it a normal twitch or is it because of Huntington’s?” Brian asked questions in order to “explain” changes in his partner’s behavior. He’s noticed her moving away from activities she used to enjoy, becoming more child-like as she seeks out fun, and appearing less responsible. He “wonder[s] what’s causing some of the change,” asking is it HD-related dementia, aging, just the way she is, or stress?

Joe has difficulty understanding his spouse’s behavior. He told a story about how she “self-isolates,” avoiding joining the family for dinner, and he doesn’t know why this is happening. “Sometimes I think she does it on purpose. But then I try to understand it, well maybe she’s not doing it on purpose. Maybe it’s part of Huntington’s, I don’t know…I have no reason why she does that.” Ellen, who was in the midst of a divorce with her spouse, tried to make sense of her spouse’s behaviors and his unexpected request for a divorce. “Is it a mid-life crisis? The symptoms are very similar to the early neuropsych symptoms of Huntington’s disease…I have no idea. Is it the Huntington’s? Is it a mid-life crisis? Is it all me that did it *(laughs)*?” George described his desire to know why his spouse has mood swings, wondering if they’re from Huntington’s, the stress of everyday life, or because of her family history of bipolar disorder. Karen indicated that, when she noticed her partner having some changes in memory, she wondered if it was HD, aging, dementia, or something stressful going on at work causing the changes. She indicated she spoke with a therapist out of a need to understand what was going on.

Madison wonders “who are you?” in relation to her husband, when he’s “not quite himself.” She wonders why he does things he didn’t used to do, considering stress or HD as possible causes. Laura similarly described how she has noticed her spouse acting “very out of character.” She asks “Where did this come from?” as she tries to ”make sense of it and figure it out.” She considered possible explanations, saying

> Maybe he's just kind of dragged down because my son has all this clutter all over our house…And you know, he's in his 50s. His body could be slowing down. [Maybe] it's just me and my perceptions are off…Maybe it is the Huntington's.

Laura also describes her desire to know the meaning behind her son's concerning behaviors, whom she knows carries a 50% risk of developing HD. "I wonder is (son's name)'s problem autism? Is it ADHD? Is it both? Or is it juvenile HD? I want to kind of differentiate out why he is having these behavioral issues…what's causing it?"

Some participants expressed their desire to find meaning as an identified purpose despite the unknowns. Madison expressed that "this HD thing" prompts her to ask "who do I want to be and what do I want to be known for?" Its purpose is to serve as an opportunity for growth or preparation, to be "the best version of me that God wants." George described his new faith as a Christian as he identified a reason or purpose for the unknown: "God has a purpose for everything…whatever happens, happens for a reason." He used to ask the questions and feel dreadful about what lies ahead, but now he sees those situations as having meaning. "If something happens that's bad, it happens for a reason now…it means it's a test to see how you handle that situation."

Trying to Prepare

Participants described ways in which they were trying to prepare for what lies ahead. They worried and asked questions in the name of preparing or planning. Angie said she and her spouse are "hoping for the best and planning for the worst…we still plan and have these big goals, [like building our dream home] and things that we're going to do, but then I'll [wonder] is that really going to happen?" She describes the planning as a doubt or a question about whether her desire to build their dream home will actually happen. In other words, "planning for the worst" *is* asking the question "is that really going to happen?" Karl said he engages in worrying, in addition to educating himself, in order to be ready for the anticipated. "If you can be ready somehow, or prepare mentally, or be educated about it the best you can be so that if something happens, you're ready…I kind of want to worry about it."

Participants commented on how their efforts to plan would only go so far, rendering their ideal notion of "preparation" elusive. Laura raised questions and worries in an attempt to plan. She asked herself:

> What is my future? I don't know. I'm just trying to put in place how would I deal with this. What would I do? I don't know. I don't have answers yet. Sometimes my worrying I think can be very productive. Because I can think of plans of action and what would I do? But right now I'm not, it's just kind of fruitless worrying.

She said the worrying can be productive as she thinks of an action plan or what she would do, yet when she asks herself that very question, she responds with "I don't know. I don't have answers yet." Madison said "I wonder about it," as she asks what her life would look like if and when something happened to her spouse. She said "I think about it because I'm a planner," yet she says "you can't really plan for it…there's not a whole lot we can do." Laura's dialogue is demonstrative of the pull between trying to plan and prepare and realizing attempts to do so are difficult if not impossible:

> I just want to try to plan things out. But it's really hard. I mean in life, you just can't plan. You can to some extent. I mean…you just don't know. But I'm just trying to cover potential problems. But it's just hard because I just don't know…I guess I shouldn't think of the worst case scenarios but that's what I'm trying to think of because I'm trying to deal with that and trying to prepare myself. But I don't know, how do you prepare yourself? I don't know.

Similarly, Karl said

> In those moments [of feeling uncertain], I'm trying to think of mentally how I'm going to handle the hard parts of what might be in store. You can't prepare for it. Other than…knowing that at some point it will happen. But I always try to find answers…[but] it's never going to happen.

In sum, participants asked questions such as "what will I do?" and "what will happen?" in order to achieve a sense of readiness, or make themselves ready to deal with anticipated changes. They asked these questions, which they often called "worrying," to prepare for something they know is likely to occur. Despite the worrying and wondering, however, many described their efforts at preparing unavailing as they came back full circle to the unknowns.

Uncomfortable

Feeling uncertain is characterized by unease and discomfort. It is a bothersome, upsetting, and unpleasant state. For example, Karl said it is “kind of upsetting” to not know when the anticipated will happen or what to do about it. He “doesn’t like” that there are no clear answers to the questions he asks, and he describes this as being bothersome: “The things I don’t have control over or not knowing how something’s going to work out or uncertainty…that bothers me.” Similarly, as Laura considered questions about what will happen and what to do, she commented that these unknowns are “uncomfortable,” “not pleasant, ” and “not fun” things to think about; the not knowing is “not a good feeling.” Joe expressed feeling uncomfortable when he doesn’t have the answers in a clear, specified way. “I’m the guy that likes to have it in writing, on a contract…I want the answers and I want it down, kind of in an iron-clad thing. It’s the way it is.” Karl provided a detailed description of the discomfort inherent in feeling uncertain, saying:

> It’s uncomfortable ‘cause it’s like…I don’t notice what time it is…you kind of don’t care about anything else…there’s nothing comforting going on in my head at the time, or around me…I might be sitting here or in my computer room or somewhere else and normally I’d be very…feeling ok and comfy in that regard. But…I could be sitting on a rock or a couch and it wouldn’t matter. It doesn’t feel good either way.

Changing Intensity of Emotion and Thought

Participants described how their emotions and thoughts surrounding the uncertain changed. Specifically, the intensity of the emotions and thoughts characterizing their feelings of unease, worry, and anxiety varied and did so in a rhythmical or ebbing and flowing manner. Participants’ phrases and words reflected the changing intensity of these thoughts and feelings: “things hit me more;” “sudden rush of emotions;” “thinking about all sorts of things at once;” “attacking;” “being beside myself;” “overwhelmed;” “crummy;” “tougher;” “letting it get the better of me;” “height of the moment;” “comes to the front of my mind;” and “breakdown.”

Joe described his changing levels of unease, saying “you could have a small portion…then you can pile onto that, then it reaches that point” where intensity is strong, or “extreme,” while Karl said his unease is “sometimes heavier than others…and at times it’s a lot lighter.” Madison described this varying intensity using a storm as an analogy: “[Uncertainty] is like a storm…just in the level of intensity…We have the spitting rain and we have the boom boom boom thunder and lighting, like you feel your house is going to come down.” Participants described the rhythmical nature of their unease and worry: Brian said it “comes and goes;” George said it “goes back and forth;” Karl indicated it wears off, comes back, and goes away again; and Madison described it as an “in and out, up and down. Valleys and high points…prevalent some days, others not.”

While the worry and anticipation rise and fall, they are always present. Participants indicated this, often by saying they are always in the “backs of their minds,” becoming more intense at times as they come to the forefront of their minds. Angie described having a doubt “in the back of [her] mind” about whether she and her husband will be able to travel together in the future. The intensity is such that it is a thought which remains in the background as opposed to the forefront. It becomes more intense as she considers other unknown circumstances. “Being afraid like ‘oh my gosh, is that twitch the beginning?’ is more emotion-evoking” than considering whether they will take a trip. Ellen described how “the worry was just always there,” and “sometimes it seems like it might be worse, sometimes it seems like it might be better.” She indicated that, as her spouse got closer to the age when symptoms were expected to develop, her feelings of stress increased in intensity. Madison said her concern is “there somewhere in the back of [her] mind,” and it “comes to mind” when she sees her partner acting out of character and doesn't know why. Karen's concerns are "underneath…the surface," but they rise as she "react[s] more strongly [when she sees] something that could possibly be a symptom."

Some participants shed light on the process behind this shift from being in the background to the foreground. Karl, for example, described how a doubt begins in the back of his mind and comes to the forefront and seems opportunistic in nature:

> I don't know how I'm going to handle stuff …there's this little voice in the back of [my] head that says…'are you sure [you can]?' It's easy for that 1% of doubt to creep in and start doing its thing if you're down about stuff…if I had a bad week at work, or if I had a droopy day…where you might be melancholy in general…that's when I get into the whole worrying about well why, or how, or when…it can bother you a little bit more…[Uncertainty] seems to be able to find that moment to zap you…it seems to have like an open door to kind of come in.

Laura thinks about things as she wonders about her future, but she indicated that the thinking can become more intense if she gets "side-tracked and dragged down," feeling "dread[ful] and panic[ked]." Brian said that when he "was trying to find an explanation and couldn't" for changes in his partner's behavior that didn't make sense, he felt an "increas[ing] intensity" to find a solution, which "caused more tension."

A Weighty Pull to Dwell Upon, Towards Inner Turmoil

Participants described feeling uncertain as a weighty pull to dwell upon, towards inner turmoil. This third essential theme is defined as a serious and burdensome force or influence drawing one into: thinking at length and with persistence about sources of discontent and anxiety; and an internal state of great confusion, agitation, and disturbance. Subthemes reflective of this essential theme include the following: feeling the weight of the situation; feeling down and sad; stuck; feeling powerless; lost; exasperating; confusing; a disconnect from others; not obviously noticeable to others; and time feels distorted.

Feeling the Weight of the Situation

At times, participants' worries, fears, and sadness were laden with expressions of seriousness, gravity, and strain. Reflecting on her situation, Ellen conveyed a tone of solemnity:

> It's really a unique circumstance…it's sort of one of the newest predictive tests, and because it's a dominant gene, it [is] very clear-cut. You have the gene, sooner or later, you're going to get it, probably. And people don't always understand what that really means.

Ryan elaborated on what knowing about his partner's gene status "really means." Ryan said his friends "don't understand" and "can't wrap their heads around" the fact that he gives thought right now to dating other people when his current relationship ends. He described how they are "much more capable of living in denial" than he could ever be, for they are "in relationships that they can fantasize about lasting until they're 80 or 90 years old," and "they don't have to deal with or think about [their relationships ending] because they're comfortable in that uncertainty of an ending." Ryan called the demand for such careful consideration a "burden." Similarly, Karl indicated how he has worries and questions in a way that is different from "someone who doesn't have [this] scenario in their lives," saying he wasn't in a state of "trying to figure things out" before his partner told him about HD. Now, according to Karl, knowing "it's certain that something will happen at some point…thinking about it seems hard for me…it feels like a burden."

Participants referred to the "stress" they experienced as they worried and wondered about their futures. Worrying about the development of symptoms "caused a lot of stress" and "stress-related illnesses" for Ellen; trying to figure out how she will care for her spouse in the future is "a lot of stress" for Angie; and the not knowing when things are going to get worse places "more strain [and] more stress" on Brian and his relationship with his spouse. George stated that, despite his belief that "things happen for a reason…I still *(pause; takes deep breath)* [feel] worried…uncertain of what is going to happen…it feels stressful." Ellen described experiencing "a lot of bad feelings [and] terrible stress" when she witnessed her partner's unusual behaviors, not knowing if they were reflective of the onset of HD or not.

Other words participants used to describe how they felt the weight of the situation were "heavy," "drained," "overwhelmed," "gravity," "serious," and "weight." Ryan provided an analogy to the "weight of the reality of this disease," saying it is a ticking clock with an alarm that will go off, reminding him that he can "see an ending where a lot of people can't." Madison likened her feeling of not knowing how she'll get through the "challenging" times that lie ahead to a mountain. She said that, as they get closer to the onset of symptoms, the question of "'how am I going to deal with this?…hits [her] head-on." Ellen similarly described being "hit" with somber thoughts when she considered that her partner's change in behaviors could be indicative of disease onset: "When he obviously hasn't showered for who knows how long…it's like death hits me again. And it's like, oh, this is what's going on…the future is now."

In sum, participants expressed that their feelings of uncertainty were, at times, grave and solemn in nature. Thinking about HD and its implications, particularly as they considered the unknowns surrounding it, feels serious, heavy, and burdensome. Brian said "it really isn't [just] her disease, it's ours because it affects both of us. It affects her physically but it affects my life." Karl understands the profound implications on his life as well. "It's serious and severe and can be very taxing on our lives and how we are with each other and with the world and everything." For some, feeling the weight was most keenly conveyed through their tone and way of speaking. Ellen pensively said "I've had a real hard time over the years…I'm thinking I should not have ever *(pause)* had this uncertainty all the time because I think it was really stressful for me *(speaking in near-whisper)*."

Feeling Down and Sad

Participants expressed feeling down, sad, depressed, disappointed, and regretful. These feelings were connected with the unknowns surrounding HD and the likelihood their partners would develop symptoms of this disease in their futures. Ryan eloquently captured this, saying

> Sadness is borne out of uncertainty, as well as certainty. I guess I shouldn't even say that because it's all uncertainty. We don't know when his onset's coming, how severe it'll be…[or] when a cure is going to be found…So sadness is borne out of the uncertainty of not knowing what's going to happen.

Echoing this notion, Karl indicated "the not knowing type of thing…I just don't know what is going to be…so I can get a little bit down thinking of that." Joe feels "very sad" as he asks himself questions for which there are no answers.

Participants were down and sad as they contemplated potential future losses, such as a hoped-for retirement or dream house and time together with their partners, as well as personal choices made in the past. Both Brian and Joe felt unhappy that they will likely not have the kind of retirement they'd planned for. Brian said he'd prefer to "work hard [and] save money so in retirement you can do a lot of fun things," but his wife wants to "do [the fun things] now," thinking she'll be unable to do them in the future, and this feels "disappointing" to him. Joe expressed "sadness" as he lamented that he and his spouse won't be able to have a "normal" retirement after working for so long in order to have one. Angie felt "kind of sad" to think about the possibility that she and her husband may not get to build their dream home. When Karl thinks about his future with his partner and "the way [they're] used to spending [their] life together" he cries and feels "a little bit sad."

Some participants expressed regret about choices they had made. "Why was I so irresponsible with decisions I made when I was younger,…when I first met (intimate partner's name), that led me to this point?" asked Angie, continuing on by saying "I would be lying if I said there wasn't days that I thought it would just be easier if I wasn't with him…it makes me sad to think about being alone.” Ellen stated “I always felt like I had to take the stress off him…[do the] housework, pay the bills, everything…And who cares about me? I’ll sit here and support him…I could’ve accomplished a lot more in my life.” Laura reflected on her choice to have a child, as well as unspoken possibilities, before knowing her partner’s risk status: “If I would’ve known this diagnosis, I wouldn’t…don’t want to say wouldn’t have had our son, but I would’ve made different choices.”

Participants used an array of words, phrases, and visuals to describe feeling down and sad. Ellen, Joe, and Laura indicated they had “depression.” Ellen has “been depressed for a lot of years,” and sometimes she “felt more than depressed, [feeling] despair.” Joe said “I’ve been depressed twice,” and Laura said she’s having “a lot of depression,…sleep issues, [and not] good energy…in dealing with some of these things.” Madison said she can “feel low,” while Karl can feel “bad and down.” Ryan said he expresses sadness outwardly as he eyes become “very focused and angled down.” Joe provided a vivid description, saying feeling down and sad is feeling like “a guy floating in space. Nobody around. Nothing there. Dark. Isolated. Not being able to breathe. Cold. That’s sadness.”

Stuck

Participants described the persistency of their thoughts, particularly those that were worrisome in nature, to the point of feeling “fixed” in a static condition or unable to move. Karl indicated if he “start[s] worrying about the future of what might happen” or thinks too much about the unknowns that “you’re never going to be able to solve,” he gets “stuck in that little worry.” He used a metaphor to describe what it feels like to be “thinking about it so much,” saying it’s like being “submerged in thoughts…stuck there and needing to break out…up to the surface again, to get above where there’s actually some good to think about.”

Laura described how her thinking and worrying can be characterized as "perseverating" and "ruminating." To think and feel with such persistency is like "feeling gripped with just your own inability to open up…closing yourself like tunnel vision [where] you can't see the whole picture." She described that, when she's not "just sitting here," or feeling "gripped," she feels an ability to "do something" or be "empowered." Similarly, Karl indicated that "brewing" renders him unable to "move on."

Feeling Powerless

Participants described an inability to produce or act, indicating they felt a sense of helplessness and loss of control. They described feeling unable to "do," as their choices and possibilities seem to have been taken away or limited by knowing of what might come and the unknowns surrounding that. Karl expressed how knowing his partner's gene-positive status and ensuing feelings of uncertainty leave him feeling powerless, as he is blocked, helpless, unable to do something, and not in control of his own choices.

> That choice has already been chosen for me…it's going to happen at a time to be determined…[Y]ou just don't know really what to do about it. And that's upsetting…I don't like not being able to answer something or decide or pick something…I like to think I somewhat can kind of choose what is going on,…[but] the uncertainty somewhat blocks the path...[T]here doesn't seem to be a direction or any clear routes to choose from…you definitely feel helpless.

Karen described what the feeling of not being in control was like, saying "being uncertain is not being in control...it's floating around in the ice and the water...It [feels] very cold [and] scary."

Joe, Madison, and Ellen contrast what it is like to know about HD with knowing about other illnesses and the helplessness they feel as they attempt to "do" something or "deal" with it. Joe said that, unlike other persons with conditions that carry visible features of illness or disability, such as a wheelchair or hair lost from chemotherapy, his wife is "sick" but "nobody sees it." He is attempting "to learn to live to deal with [that]," but finds himself unable to do so, concluding "there's nothing really I can do to help."

Madison said finding out is like getting a diagnosis but not, rendering her in a state where "you just don't know [and] there's nothing you can do." Ellen said that knowing her own pathology results indicative of a malignancy was "better to know" that knowing her partner's gene-positive status and not knowing "oh, is it happening now?" She stated simply "when you know, there are things you can really do…not knowing is a helplessness."

Participants described efforts aimed at "doing" or controlling something, such as solving the unknowns, while recognizing these efforts were often futile. "I'm kind of a control freak…but this is something that you just can't control," said Laura. Madison felt "There's just not anything you can do…(Intimate partner's name)'s doing all the things he can do, but it doesn't mean anything...it's inevitable. It's going to happen...[T]here's nothing in my control I can do." Karl described "wanting to know 'why?'…Why isn't there something more that can be done?" and how this question with no answer could "lead to being a little bit helpless about stuff. Feeling like you can't quite do anything about it yourself." He described the futility in trying to "figure out how to handle it and what to do," saying he realizes he's "not going to get anywhere."

Lost

Some participants described being lost, or deeply absorbed in thought and without a clear idea of purpose, as they worry about the unknowns. Joe said he thinks about the future, having a precursor right now of what it might be like, as tensions between he and his wife escalate. He doesn't feel able to deal with it now, and wonders how he will deal with it as her symptoms appear and worsen. He has no answers to his questions, and describes this as feeling "kind of lost." He alludes to the intensity of this feeling, adding "that's why I hope I die before [she does]." Karl felt lost as well as he searchers for answers to the unknowns. He described the process by which his thoughts mounted into a worry and ensuing sense of feeling lost in that worry:

> [I] start thinking about stuff in the future, like 'ok, is there gonna be a day where…like what would the first symptom be?'…I'll worry about the HD a little more. And I'll start thinking about that sort of thing. You can think it forever, you're not going to be able to solve it in your head…or answer it. But when you're kind of stuck in that little worry, kind of being down about things in general, it's easy to kind of get lost in that.

Exasperating

Feeling uncertain is exasperating. Participants expressed frustration, irritability, impatience, and anger as a result of being unable to answer their questions. Laura felt "very frustrated a lot;" Karen "tend[s] to get angry…irritable…and impatient;" and Joe was "mad…really deep down inside" during times of uncertainty. As Brian sees a change in his wife's behavior and cannot find an explanation for it, he "respond[s] to it with somewhat irritability, anger, that type of thing as an uncertainty." George finds it frustrating to not know why his partner has mood swings, saying "she can be great and then all of a sudden can just snap…it's frustrating. I don't know, it could be stress from her day, her life, or it [could be] Huntington's…you just want to pull your hair out." When Madison finds herself questioning how to "deal with" her partner's behavior, she finds herself in "the biggest, most uncertain times." She described feeling "frustrated" and ready to "blow up" when faced with the question 'what am I supposed to do with this?" Karl said as he tries to come up with "answers" and can't, it drives him crazy and his worry turns "into a bit of anger."

Participants' exasperation ranged in intensity, from feeling irritated and mildly annoyed to feeling angry and outraged. Consequently, their outward displays of exasperation varied. George said "I don't really express [my anger with] any physical outbursts." Ryan "listens more intently." Joe said that, while he might occasionally raise his voice, he typically "swallows" his anger as he silently shakes his fist at his spouse behind her or says something under his breath. Karen says she "blows up." Karl recalled "yelling outloud…slamming [his] down on his bed and just [being] beside [him]self" when he was overcome with anger as he put himself in "that uncertain future spot, thinking [he] might not be able to take it." Ellen described how her "screaming and yelling" intensified the closer her spouse was getting to the age of 50, when they anticipated his symptoms developing. Joe provided a powerful image capturing the range of his anger. He likened his rage to a "vicious animal ripping and tearing at some kind of helpless animal, like a bear clawing up something with its claws, just non-stop." At a lesser extreme would be "the feeling the bear has when he's just about ready to swipe at the flesh…maybe he swings and he misses."

Confusing

Participants felt a sense of bewilderment over the things they felt uncertain about. It is confusing to be in a state of knowing something will happen yet not knowing the details surrounding it, such as when it will happen or what it will look like. It's like being in the middle of something, between two clearer, more distinct ends. George said it is "confusing…like a haziness or blurriness" to be in this state of "know[ing] it's there [but] you can't make it out." He doesn't know whether to attribute his partner's behaviors to the type of day she had or the Huntington's, saying "I'm just confused about what it actually is." He elaborated with an example:

> You know that poster you sometimes see in the doctor's office, [with the] cartoon faces? There's days that remind me of that poster, where it's like 'what face am I going to see today?…it's just hard for me to put it all into words sometimes because I just don't know of it's the Huntington's or if it's [something else]…it's just one, big huge mess.

Similarly, Brian indicated not knowing whether his wife's "child-like" behavior is a form of dementia or simply an expression of her desire to seek out enjoyable, fun things is "one of the things that's really confusing right now." Karl described his feelings of being perplexed as "the whole mystery," while Laura said she is in "turmoil," not "know[ing] what to think and trying to figure it out."

A Disconnect from Others

Participants experienced a disconnect from others during moments of uncertainty. They expressed this as a lack of desired or usual connection with people that would be there otherwise. Ellen and Laura, for example, both described a self-imposed isolation: Ellen said “in those moments, I isolate big time. I just stay away from people,” while Laura said “I’m putting up walls…I feel kind of isolated from [people around me].” Ryan and Karl become less talkative when uncertain. A “shift” happens for Ryan, where he “will just shut up and won’t talk at all,” saying “I don’t communicate for a little bit, in an attempt to analyze what’s going on in my own head.” Karl indicated “I’d probably talk less…[and] be quieter.”

This disconnect from others was felt in participants’ relationships with their partners, family, friends, and society at-large. Brian indicated his partner was not receptive to his concerns, particularly as he’d try to involve her in making sense of her behavior. Additionally, feeling that he’s “right on the edge of just moving into [being a caregiver]” implies a disconnect in the spousal relationship as he feels more “parental.” Joe expressed a lack of relating to his wife in situations where “somebody’s mad because of something she did.” He tries to relate to others moreso than his wife because he “might need them in [his] future.” When Madison found herself in an uncertain moment, wondering why her spouse was acting a certain way or how she would handle the situation, she described how her relationship with her spouse reflected a disconnect: “It felt like we were two people living in the same house…like we were brother and sister…I didn’t even know him. I didn’t know what he was doing. We didn’t talk…[he] and I kept to our own.”

Aside from feeling a disconnect in their spousal relationships, participants told of ways they experienced a disconnect in their relationships with family, friends, and society. Ryan experiences a “judgment” from his friends that happens when he explains to them that he thinks about what it will be like to date other people while his current partner is at end-of-life. He also described a disconnect that happens as his friends try to comfort him or offer words of encouragement, saying "everything's going to be fine…think positively," feeling "frustrated with that cookie-cutter response." Madison expressed discontent with her family's approach to being supportive, or lack thereof, saying "they just don't care…they don't realize what I'm going through…it'd be nice once in awhile [for them to say] hey, I was just thinking about you." Nobody in Laura's family knows that her spouse is gene positive because she's kept it a "big secret," not wanting to "put [this] on them." Ellen described feeling "not a lot of support out there because people just don't understand." Joe described similar feelings of being disconnected from society in general, saying "I don't talk to anybody…nobody really gives a crap…they [don't] really understand anything about being a caregiver."

Some participants shared how they felt alone and isolated. Karl said "at that moment where it's very challenging and if I have uncertain moments…[I feel] alone, think[ing] about myself, like 'geez, I'm a man and I can't handle this? What's the problem here'?" He continued on, describing how "those kind of thoughts can kind of creep in" and you feel like you're "by yourself with [them]." Madison indicated a Kelly Clarkson song, entitled 'If No One Will Listen,' conveyed her sense of being without someone to relate or listen to her. For Joe, his disconnect from others is like being "in isolation in space," with nobody around and nothing there.

Not Obviously Noticeable to Others

Most participants indicated that, during moments of feeling uncertain, others wouldn't necessarily know they are experiencing these moments. Some try to hide it or choose not to express it, while others said that those closest to them might notice if paying attention to subtle cues. It is not, however, blatantly apparent to others. Angie said it's "probably not" apparent to an observer when she's feeling uncertain, as she doesn't act differently and keeps her thoughts to herself. Ellen didn't think an onlooker would know, “unless it went on for a long time or I told them or I was crying,” because she’s “able to hide it [and] stuff it.” George said “I don’t think I show any kinds of signs of worry or stress about it…I don’t think you could tell.” Karen also reported it “wouldn’t be that noticeable,” even to her friends whom she sees weekly for lunch dates. “I know there have been times when I’ve been upset [when out with my friends]…if there was a visible change they would certainly notice. And that’s never happened.”

Other participants said persons in their lives closest to them and who knew them well might notice a subtle, visible change in their behavior or expression indicating they were in a moment of feeling uncertain. “If you knew me,” said Brian, “you probably would [know something’s going on].” He told a story about being at a party where his partner was holding an infant and he felt the need to monitor the situation to ensure the child’s safety. In this case, an onlooker might notice as he “watch[es] closely” and gently persuades her to put the child down. Laura said her “evading behavior [and] evading responses” to her sister’s “probing” might give her sister indication that she’s in a place of trying to figure things out, thinking through the unknowns, but others wouldn’t “necessarily” know. Karl said he would wear a more “serious” facial expression and “be quieter” when he’s thinking about the unknowns, and his partner and closest friends would be able to pick up on these cues. Ryan indicated that he would appear more focused and quiet, with eyes looking downward.

Time Feels Distorted

Participants described a distorted sense of time during moments of uncertainty. They largely reported how time seems to slow down: George reported his sense of time seems to “go slow;” Karl said “time just slows down, I don’t notice what time it is;” and Ryan said it “seems to go slower. Everything comes to an abrupt stop.” Some participants described projecting into their futures as they try to think of possible scenarios in anticipation of what it might be like to have a partner affected by HD and how this changes their sense of time. Laura asks herself “what is going to happen here?” but says “It’s just hard to think in the future like that, try[ing] to see where you’ll be.” Doing so makes her sense of time “get a little distorted.” Ellen also described projecting herself into the future and how this takes her out of the present moment.

> I’m totally out of the present. It’s like life has speeded up somehow. It’s sped up and I’ve gone past the, I’ve gone right to the really bad part. I think about his mom’s symptoms and his sister’s… I just see that and it’s hard for me to separate that from ok, this is your life now.

She feels like she’s sped up to the anticipated, as though her future is being lived in the now. In sum, participants’ awareness of the present moment is distorted in terms of time. Karl elaborated how his thought process changes his sense of time, drawing his focus away from the present moment:

> Even though right now there’s nothing wrong at all, I put myself in that uncertain future spot, thinking that I might not be able to take it…I might be thinking about things so much that I’m not really paying attention to what’s being said or happening around me as much…it might seem like a long time…just because it’s my own thoughts kind of going over and over again.

A Subdued Presence With Freeing Possibilities

Participants described how feeling uncertain was a subdued presence with freeing possibilities. It is something that is there, existing, but its intensity can be quieted or softened. As its vividness and force are toned down, its liberating nature becomes less impeded, giving way to other potentials and states of being. Eleven subthemes are reflective of this fourth essential theme, including: keeping HD and what-ifs in check; not dwelling; letting go; using distraction to snap out of it; reorienting towards the good and the now; not projecting into the future; feeling capable of doing something; making a connection; compassionate presence; acknowledging its presence; and considering possibilities.

Keeping HD and What-Ifs in Check

Participants indicated that they influenced and, at times, suppressed their thoughts of HD and its surrounding uncertainties. Karl said "I'm just trying to keep it in a spot, checked, where it doesn't come too far front yet I don't bury it…not tucking it too far away but not letting it intrude too much." Laura described visiting an online forum for family members of persons with HD, saying it's a way to control the amount of time she spends thinking about HD and the unknowns: I just go on there…it's my time to think about it and then I can be done. Let's just put it out of our mind now, we've had our little time to think about this. It's a controlled thing." Madison described her ideal form of support from friends and family as something that's there but not too much:

> I just want them to say 'hey, is everything ok?' That's really all I need…with something like this you don't want to be asked all the time because then it brings it to the forefront of your mind, leav[ing] you in not a very good place.

Participants described not letting their thoughts of HD and feelings of being unsure consume or define them and their lives. "It's something you can very easily let eat at you…I try not to make it consume my future and things that I see for my future," explained Angie. Laura said "I try not to think about it too much…my brain has needed as rest about it. It helps me cope better to just not be so consumed." Ryan said he doesn't let thoughts of HD and feelings of being unsure "weigh [him] down." Madison refuses to define her spouse as "an HD person" or allow it to guide how they live everyday. She said "it's not that we don't think about it. It's just not a huge deal." Karl indicated how he "go[es] on the other side of the coin" of "feeling bad" to thinking about the other things going on in his life, such as his upcoming vacation with his partner. Laura echoes this notion of not letting HD be all that is going for her by "trying to be involved outside of this just a little bit. Just step[ping] outside and away from it."

Participants recalled that there are other things in life that are possible, taking the sole focus or the spotlight off of HD and its potentials, thereby rendering them not as powerful. Angie said “People get cancer. People die in car accidents. Horrible things can happen to people every single day. So is this the worst thing in the world?” Similarly, Ryan said “everyone’s going to have to deal with death and disease, so why should we be so upset?...let’s embrace that…[and] live for this moment.” Karl describes shifting the focus off HD as he considers no one’s life to be perfect. “Thinking about it seems hard for me sometimes…but at the same time I go over with myself ‘ok, this is just life. Nobody’s lives are perfect.’” Madison leveled her feelings of being uncertain about HD with the fact that all humans face uncertainties. “We can be certain that life is full of uncertainty. You may not have this particular thing happening in your family, but there’s all kinds of things.”

Participants are aware that, if they do not keep HD and its what-ifs in check, they will be unable to live in the ways they desire to live. Ryan said that he and his partner use discretion in terms of how much they think or talk about HD and its unknowns with the awareness that “it can’t be the best life possible if we’re talking about it all the time.” Madison described how, upon finding out her partner’s gene-positive status, he made the decision to not have children. Madison felt he was unfairly “taking [the choice] from [her],” giving too much power to the possibility of HD and its potential to affect a child and not considering other possibilities. Karl eloquently stated:

> You know, bad things can happen to anyone at anytime. No one really knows what’s going to happen to themselves anyway in the future. If you’re going to worry about that, then you’re just going to be constantly in a state of worry and that’s no way to live.

In sum, participants kept HD and its what-ifs in check. Their concerns and worries surrounding the unknown were curbed or restrained. They remained, but were made less powerful or overwhelming. Ultimately, they were subdued enough that participants could continue on in hopes of living the lives they wanted. Madison provided a symbolic representation of this, referring to a photograph of an African savannah landscape. The photo simultaneously captures a storm on its left side, showing dark gray clouds from which heavy rain is falling, and the clearing on its right side, where golden sunlight is shining through a cloud, brightly illuminating its edges. In the center are giraffes and a cluster of trees. Madison pointed out how specific features of one of the trees represented how HD and its unknowns are there but so is a life to be lived, even as one anticipates a "storm."

> It's all green and pretty [on one side] and on [the other] side it's all dead. You can choose to be that half of the tree *(referring to the dead half)* and die off and be miserable and not function, or you can choose to be this side where yeah, you're going to have to confront this stuff and its going to pass and you gotta work through it *(referring to the storm)*, but you can still be growing and green.

Not Dwelling

Feeling uncertain, according to the participants, was a feeling they didn't dwell or linger in. They described not thinking or worrying about HD and its surrounding uncertainties very much and, when they did, the time they spent doing so wasn't long. Upon being concerned about changes in her partner's memory and wondering why they were happening, Karen said "it's just a thought…it's not something I chew on…it's not like I spend the rest of the day worrying." George said, as he wonders what will happen in terms of the types of symptoms his wife *will* develop, that he doesn't think about it much, falling into a wallow. "You can't sit and just dwell on the what-ifs, you know, what's going to happen next, so on and so forth…I don't make it an everyday part of my life." Laura describes the dwelling as "obsessing," indicating she tries not to think about things much.

Ryan has questions and thoughts that *do* "pop" into his head, but they "don't *always* pop into [his] head." He elaborated, saying "we don't typically think about it or dwell in it," and when it is thought about, he said "the amount of time I spend…is not a huge amount." Karl said he doesn't "stew" over things for "long periods of times." "I could be [stuck] in that place for a couple of hours…it's not like days on end." Like others, he tries not to "dwell on it too much" or "worry about it too much." Angie indicated she might have a concern about a twitch and its cause, but it's not "something that would follow [her] all day." Both she and Madison described not living every day with the thought that their husbands are defined by HD. Madison described not dwelling as not "get[ting] down in the mire" and not living [in the unknowns] very much. She contemplates what might happen upon her partner's death, but adds "I don't spend a lot of time there because you don't know." In sum, participants described moments of feeling uncertain, but they indicated that these moments, at times, did not amount to a dwelling upon or lingering over.

Letting Go

Participants described embracing or acknowledging the fact that not everything can be controlled or known. Some described a "letting go" upon this realization, others described a "release" that happens. Laura said it is the opposite of being "gripped" or "holding on;" it is an opening up. Angie described journaling her thoughts and feelings as a way to "let go of" and not "mull it over and over and over" in her head the concerns and worries about the unknowns. She also described how she's included HD and its potentials in her vision for the future, and this "allows [her] to release it and not harbor it." Madison expanded on this feature of feeling uncertain the most. Letting go, according to Madison, is akin to not trying to control what is beyond control. "For me, it's that release…I set it out here *(makes a fist with hands, holds them out at arms' length)* and drop it *(opens hands out wide)*. She was taught that, if you love something so much, "you take it, go ahead and hold it, and open it, and drop it *(demonstrating holding on, making fist, then opening and letting go)…*understanding that it's out of my control and I'm just going to let it be."

Using Distraction to Snap Out of It

Participants spoke of distracting themselves away from thoughts of HD and the unknown. George, for example, found that “if you’re doing something else, [like going] into the garage [to] do something,” the thoughts “just go away.” Laura described how her dog helps her to “just step outside and step away from it.” Karl described how, earlier on and shortly after finding out about his partner’s gene-positive status, he’d intentionally put his mind on something or actively do something, like going for a jog, in order to “get rid of” the thoughts of “all the bad stuff that might happen in the future.” He indicated that now, he finds that he uses distraction less intentionally, indicating that doing simple, everyday things with his partner, such as eating dinner or exercising together helps him to come out of his thoughts.

> If I get to that place…I can kind of snap out of it because we do things together…[or] it might just be (intimate partner’s name) walking through the door, smiling, giving me a kiss, and I’ll [think] ‘hey, Karl, life’s not that bad. It’s ok.’

Reorienting Towards the Good and the Now

When feeling uncertain, participants recounted the ways that they intentionally re-oriented their focus on the good and the now. They described living life fully, feeling blessed, helping others, and being positive, present-focused, and hopeful. Angie, for example, described shifting her thoughts fraught with fear and negativity towards those more focused on the good and now, referring to a painting on her bedroom wall.

> I have on the wall ‘Enjoy this moment for this moment is your life.’ It’s something I remind myself every day…there may be things that are unhappy or negative that happen in the future, but right now, today, it was awesome…while the thought of Huntington’s is scary…I think about how good things are now.

While Brian felt pained that HD is a part of his and his spouse’s lives, he also sees the good coming from their lives together, saying “I wish [she] wouldn’t have brought it into the marriage, you know, but look at all the other things she brought *(crying)*…all the other gifts our children receive from her.” Karl described this re-orienting as a “trying to turn it around," as he considers his efforts to help others through research participation and donating money. Furthermore, he described trying to "focus on positive things" and "realize there's a lot of good out there."

Ryan also spoke of ways that he re-orients, recounting the ways in which he feels blessed. "[I] focus on everything that is good, that is now. I'm doing extremely well. We're both employed in this economy. We're planning a vacation." Laura similarly described feeling blessed, saying "I feel fortunate. There's people that have far worse circumstances…I've had a good life so far…I feel really lucky that I have, hopefully a lot of time left here." Karen indicated that, because of HD, she is "considerably more aware of how blessed [she] is," and that she and her partner "feel so blessed that at this time in our life we've found each other…it's a real treasure."

Participants described efforts at being present-focused and living full lives. "I think kids keep you more in the present…so when I experience love for my daughter, it's kind of the opposite of worrying," said Ellen. Ryan said "I rest with [the uncertainty] by just focusing on the positives, on where we are right now in our lives…let's live for this moment." He described that, because of knowing he and his partner don't "have forever to get everything done," they are motivated to "really live for the moment…making much more out of our lives" than his friends who don't have the "incentive" to do so. In a similar vein, Madison described how knowing about HD is a motivator to be more aware of the present. "I'm really grateful for every day. You just start noticing things more and taking time and not rushing…I don't know that you can do that until something smacks you in the face."

Participants felt hopeful for a treatment or cure for HD and for a good scenario or outcome. "We are always optimistic for a cure," said Ryan; Karl stated "I'm betting on…hav[ing] as much fun as we can and try not to worry about it too much. There could be a cure in a couple years, or tomorrow, or five years or ten, who knows;" and Angie said they had children with the hope that "by the time our children would potentially have to worry about it, there will be a treatment or cure…we have our fingers crossed, hoping for the best.” Both Madison and Laura described hoping for the best possible outcome: “Hopefully he ends up dying of some other natural cause,” said Madison of her partner, since she “can’t think of anything worse” than having both “your physical body [and] mental person ailing you.” Laura is hopeful that her spouse will be able to control his anger and avoid becoming abusive. “My husband is just a really, a very good man and I just hope that things continue to be ok. It’s hard to just know what the future holds.”

Participants made efforts to extend their help to others as a way to re-orient towards the good and now. Participants described participating in HD-related research studies and leading HD support groups. George indicated how he tries to “do what I can do…to better somebody else, to try and make the world a better place.” Participants also talked about re-orienting their attitude or perspective away from the negative, towards the positive. While Madison doesn’t attend any HD support groups, she indicated that if she did, she would want it to be about “moving forward in a positive way…not sitting there, delving into all your crap…it’s the whole sunshine, joy, find the good in a situation versus ‘oh, let’s find out what’s wrong.’” Laura said her desire is to “treasure [her] time with her partner [and] just try to focus on the happy things.”

Not Projecting into the Future

Participants indicated how they chose to take one day at time, or not project into the future. This is slightly different from the connotation that choosing to be present-focused carries in the sense that it is a choice not to worry about something that hasn’t happened yet and take things day-by-day as opposed to a more deliberate choice to be present-oriented. Madison said “I just don’t worry about stuff until it gets here” and “we just take one day at a time…you don’t know what’s going to happen tomorrow.” She elaborated, saying

> In today’s world where I am, there’s not anything to do because he lives a normal life…I don’t want to dig deep as far as

> what am I going to do [in the future]. All I can do is live today…I'm not going to do the if's, and's, and but's today because I don't know.

Joe said he and his partner "live it day-by-day because [they] don't know what's going to happen," while George said he tries to "just take it day-by-day" and not "look at it as being a death sentence." Brian described how he doesn't project into the future, taking things as they come and making adjustments along the way. He wondered about his spouse's functioning, whether it required serious attention yet or not, and concluded that all he can do in response is to continue to give it attention and "make adjustments as you go." Karen stated "I've never projected into the future, what it would be like to live with someone with HD."

Feeling Capable of Doing Something

Participants felt capable of doing something, and this was expressed through having a sense of confidence, knowing what to do, not feeling paralyzed, gathering information, and not giving up. Brian described how "uncertainty is just another hill or mountain to climb to find a solution" and that, for him, if he can be persistent and "dig deep enough," he can "always find a solution." During a very difficult moment fraught with the uncertainty of not knowing whether he could handle what might be coming in his future, Karl recognized he had an "inner strength" to draw upon as he talked himself through the moment. He described "turning the corner," recognizing "I *can* deal with it." [I'll] just find a way." Madison similarly described her sense of confidence in knowing what to do.

> When I feel very uncertain, there comes a point where I experience great peace…understanding that while I don't understand what's going to happen and how things are all going to lay out and happen in my life, [I feel peace knowing] I have the capacity to deal with that.

Participants indicated how their feelings of uncertainty did not render them paralyzed, stuck, or in a mode of giving up. Brian said "nothing is too big to overwhelm…I don't know that there's an uncertainty that would immobilize me," while

Karen said her uncertainty about whether her partner's memory issues were from HD or something else "certainly [did] not have a hold on me." Ryan described that, even though he knew HD would be "the thing that reared its ugly head someday," he "just dove in" to his intimate relationship. Likewise, he indicated he intends to "move forward" with plans to have and raise a child together, feeling confident that they will be "amazing parents" despite the "uncertainties that come along with making a decision like that." Karl said the following about how he feels capable of doing something rather than feeling stuck:

> As far as looking at the uncertain part itself, I wouldn't say I feel constrained…in a straight-jacket or something and can't do anything about it. I can do some good about it, whether it's speaking with you or taking part in surveys or talking with (intimate partner's name) or friends about it. So I don't feel stuck.

Angie strives to be active in "what could happen" in her life, saying "I don't just have the dialogue of thinking what if, what if, what if. I actually try to take steps to resolve those what-if's." She gathers information from HD-related websites, identifies persons locally who could serve as resources, and participates in research. Madison, Ryan, and Laura also described "doing" these types of activities in order to "at least know what's going on," to "just learn what the symptoms are," and to "try to get some support." Laura also added how she's ordered supplements for her spouse, which makes her feel like she has the power to do something as opposed to "just sitting here." In sum, feeling capable of doing is about not getting too overwhelmed or immobilized by the unknowns. It's a feeling of being certain about one's abilities "to do" amidst an uncertain situation.

Making a Connection

Participants sought a connection or re-affirmed their connection with others, including their partners, other family members, and friends. Angie and Karen described sharing their concerns and feelings with their partners when feeling uncertain about the cause of an unusual behavior. "I'll force myself to talk to (intimate partner's name) about it so we really make that team…then the communication is better and I feel better about it and he knows so it's not like I'm going through it alone," said Angie. Karen said "I think it was important to discuss…it put me closer in touch with his feelings." Karl described that, in moments of uncertainty, he feels alone initially but later connects with his partner through his thoughts. "If I have uncertain moments, I definitely can't help but think about myself initially…eventually, I start thinking more about me and (intimate partner's name) together…I kind of find her, and we find a way to deal with it."

Karl and Ryan both talked with their families initially, upon hearing of their partners' gene-positive status, wondering whether to continue in the relationship. Karl described how, as a result, he felt they were "behind what [he's] doing," in terms of moving forward. He also described the difficulty in talking with friends at first, but after having done so, he felt able to "solve" something, as he "got confirmation" that they would give their "support and love in different kinds of ways than usual." Madison indicated she's sought a connection with her friends who have become like family. Laura sought a connection with others via an HD-related online forum. "It's like a support group…it feels nice to be in this community…just being anonymous, you can just type whatever you're feeling and usually you get pretty good responses."

Some found a connection with non-human entities, such as a higher power, a pet, or a meditative practice. Madison said "although I'm uncertain, I'm certain of where my truth lies…I have a very, very, very strong, firm foundation, faith [in God]." Similarly, George and Joe indicated that above all else, you "put your trust in God." When Joe doesn't have answers to his questions, he "just pray[s] that [God will] answer them." Laura had found a connection with her dog, with whom she enjoys being outside and in nature with. "He just gives me unconditional love." Ellen connected with mindfulness meditation, saying "it's the best thing…[it] keeps you out of the ruminating about the past and worrying about the future."

Compassionate Presence

Participants expressed feeling compassion or a sympathetic concern for their partners and others. Some described this as being graceful while others said they carry a gentler or softer approach. Brian told of an early experience with his spouse, characterized by confrontation and anger, when he expressed his concerns about not knowing why she was behaving a particular way. He juxtaposed this to now, saying his "uncertainty is expressed [more] as a caring." Ryan said he's assumed a role where it is his "job" to "tak[e] away [his intimate partner's] work stress and stress from the disease as well…to just love [him]." Karen said she's "more aware and gentle with people," describing efforts to "try to be there and listen." Madison also takes a softer approach during times of feeling uncertain about the meaning of her spouse's behaviors. "I just try to have a little bit more measure of grace than maybe I did before…HD has made me more compassionate towards him." Fueling this compassion is her understanding that to "be the husband, the provider, feeling like he has something that he can't control in his life" must be difficult for him.

Acknowledging its Presence

Participants expressed an acceptance or recognition of what is known; they acknowledged HD and the uncertainties surrounding it. It's an acknowledgement of what is there. "It's acknowledging that it will happen," said Brian; "It's not swept under the rug…we're not in denial," said Ryan; "It's [not] really pushed away," said Karl; and "you don't want to totally ignore it," said Laura. Several participants referred to its presence as something that is "there" in the "back of their minds." Karl said "it's always in the back of my mind…about HD, the not knowing and uncertain part. It's always, always there." Ryan echoed this notion, saying "it's there. It exists…in the back of our head[s], it's always there." He expanded on how its presence is a "silent motivator," saying "it has been acknowledged that before we take a trip or do something fun that we are living life while we can."

Many described how they have come to tolerate or submit to the unpleasant and undesired. Karl, for example, said "for me it's learning how to deal with the fact that the choice is already made. How can I work with that and what can I do now?" He said of his approach to HD and its unknowns that he wants to "acknowledge it…tackling it head-on." Madison described accepting the "inevitable," saying she will "deal with it when I get [to it]." Brian said "we just approach it as an acceptance. It's there…you just take [it] and move forward as you can." Laura characterized her acceptance as a resignation: "I'm just getting more resigned…it's not a pleasant thought to think of these things happening but…I'll find ways to deal with it."

Some participants described this acknowledgement as an understanding, indicating it is a knowing that "what happens is what happens." For George, it is "a way of life…we've come to accept [God's plans for us]…I know what to expect. You can't change it…whatever happens happens." Karl describes coming to an "understanding about it," realizing "things do happen, whether you like it or not." Similarly, Madison said "I think about it understanding there will be stuff." She recognized that there is nothing to do now and, when it "gets here," there's still "only so much you can do…it's just a matter of whatever happens."

Considering Possibilities

Feeling uncertain is a consideration of possibilities. Some participants expressed their wonderment of certain possibilities as they assessed "chances," "risks," and "probabilities." Some expressed it as a staying open to the possible. "I know…it could go various ways," said George. Brian was open to the possibility that perhaps his spouse's personality changes, specifically those appearing more juvenile in terms of irresponsibility might actually be fun to experience, to be around someone more "child-like." Karl described envisioning different "pathways" that he will come upon in the future, and the way that he ends up going "could be good or bad." Madison similarly expressed her consideration of the possible, saying "Whether [whatever happens is] good or bad…no matter how my life proceeds, I want to feel it either way."

Participants described considering the risk in having children who may or may not be gene-positive for HD; Angie told about taking the "chance" of having children, knowing her partner was at-risk with the first child and knowing her partner carried a gene-positive status with the second. Madison knows her potential offspring would have a 50% chance of being gene-positive, but emphasizes "this is a 50-50 shot. They may or may not even have it. And if they have it, they may never exhibit the symptoms." Participants also considered possibilities for age of onset based on the number of their partners' CAG repeats: Karen considered her partner's repeats, saying he's not in a "risky" range, and "there's a good chance" he won't develop HD; and Ellen said "He has 42 CAG repeats…it sort of points towards around late 40s, age 50.

For participants, considering possibilities is not settling on one thing or one possibility, as it reflects a neutral awareness that there are others. This differs from their attempts to find meaning or reason and the feelings that go along with their inability to do so. For example, Angie conveyed nonchalance upon considering the notion that perhaps her spouse's twitches aren't due to HD. "I think everybody twitches when they're falling asleep…who's to say it's because of the Huntington's? I mean, maybe it is, maybe it's not." Ryan said "things naturally come up with aging in anyone…I don't want to be paranoid about natural personality traits and changes that come with aging." Laura said of her spouse's unusual behavior "I don't want to say that 'oh I think it is HD.' I don't know…there's other possibilities." Karen also expressed an indifference upon considering possible reasons for her partner's changes in memory. "I didn't say 'oh, this is HD.' I just thought this is an issue. It could be aging, it could be HD, it could be dementia." In sum, considering the possibilities carries a tone of freedom and movement;

it's not settling on or attempting to identify one reason or possibility in order to achieve a sense of certainty. Brian succinctly captures this, saying "I don't get to certainty…life is kind of always moving."

Concluding Thoughts on the Essential Nature of Uncertainty

The lived experience of uncertainty among intimate partners of persons who have tested positive for the Huntington disease gene mutation yet have not been clinically-diagnosed is an *intangible reality* characterized by *anticipating with ebbing and flowing disquietude* while feeling *a weighty pull to dwell upon, towards inner turmoil* and *a subdued presence with freeing possibilities*.

Anything tragic and unplanned for can happen to anyone, anytime, anywhere. The uncertainty of this reality faces all humankind. What is unique for the intimate partners of persons who have tested positive for the gene mutation causing Huntington disease but who have not yet been clinically diagnosed is that this reality has been given more shape. The unknowns have a direction. It is a not knowing with direction, or a knowing without clarity. It is an ever-present questioning and anticipating beyond that which is considered natural. It is an ungraspable, intangible reality. This intangible reality is anticipating with an ebbing and flowing disquietude. As the disquietude flows, it is a weighty pull that ensnares a person into dwelling and inner turmoil. At it ebbs, it is a subdued presence that allows for the consideration of freeing possibilities. The intangible reality for persons with intimate partners who are gene-positive yet have not been diagnosed is a feeling of being in the balance. They are in a place of holding a sort of tension between two sides of the same coin: the anticipating with disquietude is always there, but it is experienced as both a weighty pull to dwell upon, into inner turmoil *and* a subdued presence with freeing possibilities. It is like a fist that tightly grips and opens to release. It is like a heart with both its pumping and resting, two different and seemingly opposing motions but one theme. The intangible reality is not clearly one or the other; it is both. It is, at its most basic, a thinking about the future while staying in the present. It is trying to find a balance between not holding on too tightly and not letting go completely or, perhaps, trying to maintain a loose hold. This is a remarkable and distinctive circumstance. It is like an eddy whose turbulence varies. What remains constant is that it is something contrary to mainstream yet still a part of the river flowing.

Table 2 Participant characteristics

Characteristics of Participants (N=10)	n
Age	
20-29	2
30-39	2
40-49	2
50-59	3
60-69	1
Gender	
Women	5
Men	5
Marital status	
Married	7
Unmarried	3
Amount of time in intimate relationship (years)	
0-5	2
6-10	3
11-15	1
16-20	1
21-25	0
26-30	2
31-35	1
Education completed	
High school	5
Baccalaureate	4
Doctoral	1
Race	
Caucasian	8
American Indian	1
Hispanic	1
Children from intimate relationship	
0	4
1	3 (1 child adopted)
2	2
3	0
4	1
Amount of time since tested	

(years)	
0-3	1
4-6	4
7-9	2
10-12	2
13-15	1
Amount of time prior to testing at-risk status known (years)	
N/A	4
0-2	4
3-5	1
6-8	0
9-11	0
12-14	0
15-17	1

Table 3 Essential themes and subthemes

Essential Themes	**Subthemes**
Intangible Reality	Knowing creates questions, thoughts, feelings, and ways of being Strange Anyone, anywhere, anytime with form
Anticipating With Ebbing and Flowing Disquietude	Attentive sensitivity Worrying and feeling afraid When will the anticipated happen What will happen Considering what to do and how to be Contemplating relationship changes and loss A desire to find meaning Trying to prepare Uncomfortable Changing intensity of emotion and thought
A Weighty Pull to Dwell Upon, Towards Inner Turmoil	Feeling the weight of the situation Feeling down and sad Stuck Feeling powerless Lost Exasperating Confusing A disconnect from others Not obviously noticeable to others Time feels distorted
A Subdued Presence with Freeing Possibilities	Keeping HD and what-ifs in check Not dwelling Letting go Using distraction to snap out of it Reorienting towards the good and the now Not projecting into the future Feeling capable of doing something Making a connection Compassionate presence

	Acknowledging its presence Considering possibilities

CHAPTER V

DISCUSSION OF FINDINGS

The purpose of this hermeneutic-phenomenological study was to understand the meaning of the lived experience of uncertainty among intimate partners of persons who had tested positive for a mutation in the gene associated with Huntington disease but had not yet been clinically diagnosed with HD. The specific aims were to create a rich, vivid description of uncertainty as experienced by intimate partners of persons with prodromal HD and to present the findings within an existential-phenomenological perspective. The lived experience of uncertainty among intimate partners of persons who have tested positive for the Huntington disease gene mutation yet have not been clinically-diagnosed is an *intangible reality* characterized by *anticipating with ebbing and flowing disquietude* while feeling *a weighty pull to dwell upon, towards inner turmoil* and *a subdued presence with freeing possibilities*. This chapter presents a discussion of the findings reported in Chapter IV. Limitations of the study will be addressed. Implications of the study will include those pertaining to clinical practice and future research.

Discussion of Themes

Feeling "uncertain" as described in the present study coincides with definitions presented in Chapter II, but emphasis on one of its features should be made. Uncertain is defined as questionable, not determinate or fixed, doubtful, undecided, not clearly defined, and with no regular shape (The Oxford English Dictionary, 1989). Vagueness was a prominent feature of "intangible reality," as it highlights something not clear or definite in thought, understanding, or expression. Implied in this definition is that for something to be unclear, something must be *there*. The vagueness renders one able to know without fully knowing. The consideration of possibilities was another feature described as participants' uncertainty experience. Chodron (2002) indicated uncertainty is unavoidable and, moreso, "part of the adventure," capable of teaching humans to rest and relax in the uncertainty (p. 5). While most participants in the present study did not indicate feeling “relaxed” or “restful” amidst their uncertainty, they did describe moments of opening themselves to fully experiencing the unknown. The review of literature on uncertainty in the natural sciences (e.g., quantum mechanics and chaos theory) revealed the assumption that uncertainty cannot possibly be eliminated and should be embodied in order to actualize humans’ full potential. Indeed, participants in the present study described ways they could “have,” or acknowledge, HD and its unknowns while also remaining open to the possible. According to Batchelor (1990), this opening up is an acknowledging that simultaneously reveals personal limitations while pushing humans to move beyond them.

The following discussion turns to the four, essential themes described in the present study. This discussion will focus on how these findings relate to prior literature capturing phenomenological descriptions of the lived experience of uncertainty as well as studies examining intimate partners’ experiences post-predictive testing and prior to clinical diagnosis. Several studies in the extant literature include “families members” of persons tested who may or may not be gene positive. Furthermore, some include the family or couple as the unit of study. Only those for which experiences of intimate partners of persons who are gene positive can be clearly identified will be included in this discussion.

Intangible Reality

In the current study, intimate partners of persons who had tested positive for the gene mutation associated with HD but had not yet been diagnosed described the receipt of predictive genetic testing results as a circumstance that changed their ways of being, the ways in which they asked questions, thought, and felt. In Nelson’s (1996) hermeneutic-phenomenological study of women with breast cancer, participants similarly described their uncertainty experience as “transitions: learning new ways of being in the world." The breast cancer diagnosis and subsequent disease-related events served as impetuses for life transitions, and the uncertainty of their futures "challenged them" to learn new ways of being in the world (p. 67). Nelson defined "transition" as change taking place after an upheaval; in her study, it was the time period surrounding breast cancer diagnosis.

Nelson (1996) described another theme: "reflections of self in the world." This theme arose as participants connected with other women with breast cancer. Seeing others' vulnerabilities highlighted participants' own sense of vulnerability; they recognized how life can be taken away so quickly after others' recurrences of breast cancer and that they, too, could be subject to such a fate. This theme is similar to the notion of "anyone, anywhere, anytime with form" described in the current study. As in Nelson's study, participants in the present study were keenly aware of the surprising, unexpected nature of illness, tragedy, disability, and death. They knew that, like all humans, they were vulnerable to this.

In the review of the literature, found in Chapter II, it was presented that the extant frameworks and body of literature used to understand uncertainty and examine uncertainty, respectively, do so in a way that an illness event (e.g., diagnosis, treatment, and waiting for test results) or significant threat to health (e.g., signs or symptoms of illness) serves as an impetus for a different state of uncertainty. In the current study, the receipt of information pertaining to partners' genetic status was, indeed, considered an upheaval creating a new state of uncertainty, according to participants.

The information pertaining to participants' intimate partners' future health status was not, however, considered an illness event or health threat in the ways previously defined. It was a vague, impalpable circumstance in which a new known and surrounding unknowns emerged but remained elusive and ungraspable, "like being diagnosed but not," according to one participant. This circumstance places participants in a context where they no longer experience the every-day uncertainties in the ways they did prior to receiving the information, but they do not yet experience the uncertainties arising upon clinical diagnosis of disease, which often center around more tangible uncertainties (e.g., questions pertaining to symptoms, treatment, care options, and prognosis). Knowing their partners' gene-positive status propels participants towards the throes of disease-related uncertainties, but the disease has not even been clinically-diagnosed, and obvious signs and symptoms of illness are not evident.

Contrary to the way in which participants in Nelson's (1996) study described vulnerability, participants in the current study described the vulnerability inherent in uncertainty as having form, or shape and direction. They described knowing *something* about their futures while also acknowledging that, ultimately, their futures were unknown. While women diagnosed with breast cancer may face an increased likelihood that their experiences could, eventually, mirror those of others,' participants in this study must consider such vulnerabilities before being confronted by them in a way that brings them closer to home. In other words, the "reality" of disease and death were brought closer to their awareness although the diagnosis of their partners' disease, much less the sequelae of it, had not yet happened. The participants in the present study compared the things they felt unsure about *prior to knowing* their partners were gene-positive to the things they felt unsure about *after knowing* their partners were gene-positive. Participants felt that, because of the reality of knowing of future illness, the things they considered unknown before now have more shape, but not in a way that is clearer or more tangible, as in the case for persons experiencing illness or illness-related events.

Participants in the present study indicated that the nature of their uncertainty experience was strange, defined as being outside of one's experience and unusual in a way that is disturbing and difficult to understand. The strangeness was conveyed as they described attempts at comprehending or "wrapping their heads around" something which has not yet occurred but is expected to. One participant pointed out the "weirdness" in knowing he will likely seek out another intimate partner someday, when his current partner is rendered physically and/or mentally absent by the disease, while *at the same time* feeling satisfied and committed in his current relationship. Participants indicated that, compared to other circumstances surrounding illness, tragedy, disability, or death, their circumstances were “unreal,” “different,” “not normal,” and “hard to grasp.” These notions were not described in the extant literature on the lived experience of feeling uncertain or studies examining intimate partners’ experiences post-predictive testing.

Anticipating with Ebbing and Flowing Disquietude

Similar to the current study, findings from other studies have revealed that “anticipating” is part of the experience of feeling uncertain. Morrow (2010) conducted a phenomenological-hermeneutic study of “feeling unsure” among community-dwelling persons with chronic heart failure. The researcher described the core concept of “vigilantly anticipating” as a finding, indicating it is a careful watching, or “guardedly speculating and envisioning what lay ahead” (p. 320). As in the current study, participants in Morrow’s study indicated feelings of being on edge. In Nelson’s (1996) presentation of her findings, she indicated part of the theme “reflections of self in the world” was characterized by anticipation of what was to come. The anticipation was described as a curiosity or intrigue of both the positive and negative. Partners of persons with prodromal HD indicated a general anticipation of possible effects of disease in the future as well as its effects on family life (Tibben, Frets, van de Kamp, Niermeijer, Vegter-van der Vlis, Roos, Rooymans, et al., 1993).

In the current study, participants described a desire to find meaning, which was expressed in the context of knowing something pertaining to their partners’ future health status and, subsequently, wondering about or anticipating what will likely be to come. In other studies of uncertainty, researchers similarly indicated that participants sought meaning in their situations. Nelson (1996) indicated there was one, unifying aspect of the women’s uncertainty experience: struggling to gain meaning. She indicates the women found it difficult, at times, to find meaning in their emotions. At other times, they found meaning as they discovered what they valued in life. In Penrod's (2001a) hermeneutic-phenomenological study of uncertainty, informal caregivers of older adults attempted to "assign meaning" to their situations as part of one essential theme, "reading the situation" (p. 150). According to Penrod, uncertainty "peaks…[upon] an inability to assign meaning" and, as solutions are discovered, so is meaning (p. 148). Williams et al. (2007) sought to describe family members' (most of whom were intimate partners) perceptions of changes in persons with prodromal HD. One finding was "attempting to understand changes." Similarly, Downing et al. (2010) identified how intimate partners and those with prodromal HD felt uncertain about "how to make attributions for noticed changes" (p. 348).

There were also similarities between results of the present study and those of others regarding the things anticipated, such as losses and what to do. Bunkers (2007) applied a phenomenological-hermeneutic method to examine "feeling unsure" among women at end-of-life. One core concept, "intimate sorrows," reflected how women anticipated leaving the "cherished presence of close others" (p. 61). Nelson (1996) similarly described how women with breast cancer considered losses, expressed as grief over both real and imagined losses. They considered possible losses, or things that might not take place if their lives were cut short, and actual losses related to disease progression. Penrod (2001a) indicated how family caregivers anticipated losses in the future (e.g., the loss of a meaningful mother-daughter relationship). Sobel and Cowan (2003) indicated partners of persons testing positive for the HD gene mutation experienced a loss of a future that was expected, based on the normal life cycle. Additionally, women in Bunkers's study described not knowing what to do as they questioned how long their lives would be. Penrod revealed that one of participants' biggest uncertainties revolved around what to do, specifically in terms of making decisions on behalf of the care recipient.

The present study indicates disquietude, defined as uneasiness, anxiety, and worry, is a feature always present in participants' experiences of feeling uncertain. Other researchers examining this phenomenon presented similar findings. Nelson (1996) described an "undercurrent of anxiety" and fear as part of the theme "vicissitude of emotions," indicating these were always "uncomfortable sensation[s]" (p. 64). Penrod (2001a) described fear or "being afraid" as features of uncertainty and indicated feelings of discomfort are present, and she attributed the discomfort inherent in uncertainty to not being sure of the meaning of the situation. Bunkers (2007) described one of the three core concepts of feeling unsure as "disquieting apprehensiveness." She defines this as an "unsettling foreboding" wherein feelings of uncomfortableness accompany uncertainty (p. 60). According to Morrow (2010), one of the core concepts of feeling unsure was "discomforting trepidation with unassuredness-assuredness." This is defined as "uneasiness and anxiety associated with the doubt and uncertainty and the all-at-once confidence and certainty in feeling unsure" (p. 319). As in the current study and others, Morrow indicated fear is a feature of feeling unsure. Researchers examining distress among intimate partners of persons with prodromal HD found they were "very anxious" about anticipated expectations (e.g., becoming a caregiver in the future) (Decruyenaere et al., 2004, p. 28) and had feelings of being afraid (Decruyenaere et al., 2005).

As previously described in Chapter IV, the disquieting anticipation, while always present, changes in intensity in an ebbing and flowing way. Nelson (1996) described one aspect of uncertainty as a "vicissitude of emotions," defined as a change or a succession from one state to another in terms of emotions women experienced post-diagnostically for breast cancer. As in the current study, Nelson described how uncertainty was characterized by anxiety with changing intensity. This theme reflected how emotions were characterized by a waxing and waning, "ups and downs," and an "ebb and flow" (p. 63). Penrod (2001a) also described a changing intensity in the feelings of uncertainty;

specifically, she indicated how changes in feeling control and confidence were dynamic, having a back-and-forth or up-and-down nature.

In the extant literature, some notions related to “anticipating with ebbing and flowing disquietude” as presented in the current study were not evident. These notions were “trying to prepare” and “when will the anticipated happen.” These are connected with the *anticipating* described in this essential theme. It is, therefore, imperative to carefully consider the way in which this word is used. As indicated above, Morrow (2010) described feeling unsure as “vigilantly anticipating” and Nelson (1996) indicated women with breast cancer considered the “mystery of what was to come,” and this created a sense of anticipation (p. 71). These researchers indicated participants watched, speculated, and wondered about their futures. While these features are also evident in the current study’s findings, anticipating as it is defined in this study describes how such ways of thinking, speaking, acting, or feeling are done *in advance of something expected*. In the current literature, the “expected” is not made as explicit as it is in the present study. Intimate partners of persons gene-positive for the mutation associated with HD are anticipating something sure to happen, barring unforeseen circumstances.

Knowing something about their partners’ health status led participants in this study towards efforts at preparing or planning for something. As described in the above discussion of “intangible reality,” this *something* is there but remains unable to be fully grasped and understood. Participants in the present study wondered and worried in an attempt to visualize or imagine possible HD-related scenarios in the name of trying to prepare, but found it difficult, if not impossible, to do. Participants’ ideal notions of preparation remained an elusive, unattainable goal. In another study, nearly 60% of partners describing the impact of receiving test results indicated the information allowed them to better plan for their families’ and their own futures (Tibben, Frets, van de Kamp, Niermeijer, Vegter-van der Vlis, Roos, Rooymans, et al., 1993). Descriptions of the ways in which they planned were not collected. Furthermore, it is unclear in the Tibben et al.

report whether these are references to “planning a family” (i.e., making reproductive decisions based on information learned through testing).

Nelson (1996) indicated women diagnosed with breast cancer changed the ways they planned their day-to-day schedules as well as their lives, and this depended largely on whether they were currently seeking treatment. Women with disease progression, for example, felt little control and hence, were hesitant to plan too much. Penrod (2001a) described how participant caregivers “built up a ‘bag of resources’ to prepare for the inevitable, yet uncertain, future of the older adult” (care recipient). For example, the caregivers solicited practical advice pertaining to care approaches from others, and this “made the caregivers feel better prepared” (p. 144). These examples of planning (or not planning) in the midst of uncertainty highlights how, for persons experiencing illness and illness-related events, planning and preparing clearly carry different connotations than they do in the current study.

Participants in the present study asked “when will the anticipated happen?” Specifically, they wondered when HD-related changes and ensuing effects would occur. This kind of wondering reflects and highlights that which is unique to this group of participants; existing studies of uncertainty examine the lived experience among persons *who have already experienced* symptoms of disease and their effects (either personally or as a caregiver). The participants in the present study have not yet experienced the ramifications of being the intimate partner of one who is displaying obvious HD-related signs and symptoms. While participants describing their experiences of uncertainty in other studies wondered about the possibility of a shortened life span, for example, perhaps as they contemplated when death might occur, thinking about or even anticipating this sort of “expected” is different from that described in the current study. In the present study, “when will the anticipated happen” implies a more imminent anticipation, one that is always hanging over-head. One participant said “it’s like waiting for the other shoe to drop, all the time,” while another said it is like a ticking time bomb.

Several mentioned this being one of the most difficult aspects of their uncertainty experience.

Furthermore, while the above discussion of “a desire to find meaning” indicated that other researchers also identified this as a major finding, a noteworthy difference warrants further discussion. Researchers described not only *that* participants found meaning in their experiences but also *how* they found meaning. For example, Penrod (2001a) said “As solutions are discovered and decisions regarding a plan of action are made, confidence begins to grow because meaning is discovered,” which decreased participants’ sense of uncertainty (p. 148). Nelson (1996) said “women in this study were able to assign meaning to their uncertainty experiences,” (p. 74) which came from helping others or tapping into supportive relationships (i.e., those conducive to uncovering meaning). In the present study, however, only 2 out of 10 participants explicitly indicated they had discovered or identified meaning and how this was done. Specifically, both participants indicated it was their belief in a higher power that provided the context from which purpose and meaning sprang forth.

A Weighty Pull to Dwell Upon, Towards Inner Turmoil

In the current study, participants described feeling uncertain as feeling the weight of the situation and its pull, and this was characterized by being down, sad, and stressed. The participants in Nelson’s (1996) study similarly expressed feelings of sadness, feeling grief upon considering possible losses. She identified “depression” as one emotion experienced as part of the “vicissitude of emotions.” Bunkers’s (2007) theme “intimate sorrows,” one of the core concepts of feeling unsure, reflected that participants felt sad as they anticipated leaving the “cherished presence of close others” (p. 61). Researchers describing emotional responses of partners post-predictive testing indicated they experienced depression (Decruyenaere et al., 2004; Sobel & Cowan 2000a; Quaid & Wesson, 1995), sadness (Decruyenaere et al., 2005), and “intense sorrow, anger, and despair about a future that would be overshadowed by HD" (Tibben et al., 1992, p. 97). Within Penrod's (2001a) description of the essential theme "regaining a sense of normal," some participants indicated they did not want to be caregivers again when their current caregiving experience ends, saying that it is too stressful and weighs very heavily on a person. In addition to feelings of being down, sad, and stressed, the "weighty pull" described by participants in the present study was characterized by the subtheme "time feels distorted," which reflects the ways in which more intense uncertainty pulls one away from the present time. One researcher described a theme similar to the notion of "time feels distorted:" Penrod presented the essential theme "shifting temporality." During times of extreme uncertainty, "time collapsed," where there was no future or past, just an unbearable present (p. 169).

"Dwelling upon," as described in the current study, features notions of being stuck and feeling powerless and lost. Other researchers described themes similar to this. Penrod (2001a) defines "extreme uncertainty" as having "complete loss of control over the situation…[and] over life's destiny" (p. 137). For example, Penrod described times of extreme uncertainty as being capable of immobilization; participants in her study felt immobilized by a sense of doubt and unable to take action…getting "stuck in the throes of uncertainty" (p. 162). Furthermore, participant caregivers felt lost, as they were unable to read the person (care recipient). Women in Nelson's (1996) study described feelings of not being in control, particularly when waiting for test results or because their lives revolved around treatments. When fear was most intense, the women "felt controlled by their uncertain futures" (p. 63). As part of the "vicissitude of emotions," Nelson described how one woman's depression was likened to a feeling of helplessness. Decruyenaere et al. (2005) reported that partners of persons with prodromal HD felt incompetent.

Participants in the current study described how, at its most intense, uncertainty was an inner turmoil. This is defined as a state of great disturbance, confusion, and exasperation which is not obvious, as it is situated within or "inner" to one's experience.

Intimate partners indicated feeling disconnected from others and that, during times of feeling intensely uncertain, their experiences would not be obviously noticeable to others. In a similar way, Penrod (2001a) said that, in times of “extreme uncertainty,” participants were in a “state of personal turmoil” (p. 157), characterized by feelings of being frustrated. Decruyenaere et al. (2005) found partners of persons who were gene-positive experienced feelings of being angry post-predictive testing. Nelson (1996) described how frustration and anger “over the blows being dealt by their uncertainty,” were emotions experienced as part of the “vicissitude of emotions” (p. 65). Participants largely directed these emotions towards a perception of a lack of progress related to treatment or cure. Nelson’s “reflections of self in the world” theme indicated how, upon being faced with other women’s vulnerabilities to cancer and subsequently their own, the women felt unsettled and avoided spending time with their friends despite wanting to support them, as they felt their “reflection was too close to her own reality” (p. 70). Researchers studying the impact of predictive testing on intimate partners indicated some felt lonelier (Decruyenaere et al., 2004). In another study, nearly half (N=20) of partners indicated they “missed the support of others with whom they could share their feelings” post-predictive testing (Tibben, Frets, van de Kamp, Niermeijer, Vegter-van der Vlis, Roos, Rooymans, et al., 1993, p. 106).

Certain aspects of “a weighty pull to dwell upon, towards inner turmoil” were not previously described. Although Penrod (2001a) described how participants’ caregiving experiences were characterized by stress that weighs heavily, participants in the current study described the subtheme “feeling the weight of the situation” as something laden with seriousness and gravity. They spoke of how they felt they were in a unique situation, one which was not only burdensome but so somber in nature that they found it difficult to describe. At best, participants said how others don’t understand what it “really means” to know something so “clear-cut” about their partners’ future health status and carry the worries and uncertain implications surrounding that. Considering the gravity of the situation in this way reveals and emphasizes uncertainty's capability to pull, exerting its influence and force.

In the present study, participants described ways in which notions pertaining to lifeworld existentials characterized their experiences of being uncertain. These subthemes were either not explicated or were described in a different way in the existing literature. For example, Penrod (2001a) found one essential theme of the lived experience of uncertainty to be "shifting temporality." During "times of overwhelming uncertainty," the shifting temporality was a collapsing of time with no future or past, just a present where all participants could do was take things as they came, moment-by-moment (p. 169). Penrod additionally described caregiver participants' experience of slowed time, and this was a result of an actual prolongation of the time it took to assist the care recipient in completing activities of daily living. Contrary to this, the subtheme "time feels distorted" described in the current study reflected how participants felt they were *not* in the present moment during their most uncertain times. Some described it as feeling sped up to or projecting into the future. One participant said that as she feels uncertain, worrying and feeling afraid of her future, she often finds it difficult to separate her thoughts of the future from her present awareness. Others described a slowing of time. Again, this was different from Penrod's description of slowed time; participants in the current study indicated that "time just slows down." This slowed sense of time is not connected with anything, as it is in Penrod's study.

Two other notions reflective of lifeworld existentials, a "disconnect from others" and "not obviously noticeable to others," were described in the present study. While Nelson (1996) indicated participants avoided connections with other women, as they felt their realities came too close to their own, participants in the current study did not describe a particular reason for isolating themselves or discontinuing to communicate with others during moments of intense uncertainty. Participants in the current study also described how others wouldn't necessarily know they were experiencing feeling uncertain. Some indicated there might be behavioral cues (e.g., evading responses to questions or a "serious" facial expression) while others said they showed no "signs." Furthermore, some said their close relations might pick up on subtle cues while others said their close relations would not be able to do so. These features have been previously described in the literature.

A Subdued Presence With Freeing Possibilities

Several themes described in other studies resonate with aspects of the essential theme "a subdued presence with freeing possibilities." Participants in the current study described the presence of both the knowns and the unknowns pertaining to HD, and this presence was acknowledged or accepted. Similarly, Morrow's (2010) theme "moments of acquiescence" reflected how participants accepted both the known and unknown. Penrod (2001a) also indicated that, as part of the essential theme "sensing control," amidst facing the inevitable of their loved ones' decline and subsequent feelings of no control, participants described an acceptance.

While HD and the "what-ifs" were a constant presence, according to intimate partners of persons testing positive for the HD gene mutation, they were subdued. Participants described efforts at suppressing their thoughts, or keeping them in-check. For example, some shifted the focus off of HD and its potentials by focusing on the other things in life that are possible, thereby rendering the former less powerful. Similarly, in Penrod's study (2001a), informal family caregivers of older adults found that amidst unfolding events beyond control, they were able to exercise some control as a strategy to minimize uncertainty's effects. Results from Nelson's (1996) study indicated that, as part of the theme "vicissitude of emotions," women "suppressed thoughts related to their uncertain futures just to control the overwhelming spectrum of emotions" (p. 63). Specifically, they used distraction. They also described balancing an uncertain future with a broadened life perspective. Having a different understanding or perspective of the "overall picture of life" (p. 71), the women saw certain worries as less significant and carrying less meaning than before. In Richards's (2004) study of couples' experiences with living with a gene-positive test result, one partner described questioning 'why us?' in relation to HD but then re-focusing on other tragic events that have occurred and from which she feels she and her spouse have escaped.

Researchers examining the lived experience of uncertainty also described aspects similar to the notion of "freeing possibilities," as described in the present study. "Feeling capable of doing something," for example, reflected participants' descriptions of confidence, knowing what to do, not feeling paralyzed, gathering information, and not giving up. Penrod (2001a) described confidence as one of the primary essential themes and how, when participants felt they were doing something as opposed to doing nothing, they found comfort in their situations. Bunkers (2007) described participants' attempts at continuing on in the pursuit of life endeavors and trying to keep going as part of the theme "pressing on." In Nelson's (1996) study, one aspect of "transitions: learning new ways of being in the world" was that, upon diagnosis, the women learned to take a more "proactive stance" in how they chose to live out the rest of their lives (p. 69).

"Reorienting towards the good and now" was another subtheme arising from the present study. Other researchers have similarly indicated that the lived experience of uncertainty is characterized by feeling hopeful, living life fully, being positive, and focusing on the present moment. Bunkers's (2007) finding "pressing on" included notions of hope and living a full life. Nelson (1996) described how women tended to cherish their lives with a newly-found passion, as part of "gaining understanding: putting uncertainty into life's perspective." The women also spoke of hope; hope from within and encouragement from others (e.g., spouses and healthcare providers) fostered confidence. The amount of information provided by others pertaining to disease trajectory (e.g., prognosis and treatment options) influenced whether women felt hopeful or hopeless. Despite the ups and downs of their emotions, women in Nelson's study "struggled to keep an optimistic view of their uncertain future" (p. 65). One aspect of "transitions: learning new ways of being in the world" was that, upon diagnosis, the women described living for the present as they considered the amount of time they had left to achieve life goals. Another change or transition occurred for one of the women: she described viewing the loss of a breast from treatment more of a "positive" than "negative" thing that happened. For her, it was a re-focusing toward a goal of living instead of "focusing on the negative aspects of her uncertainty" (p. 68). In sum, the transition meant not always viewing an uncertain future in a negative way; the women in Nelson's study tried staying positive and hopeful in order to "allow for a future within uncertainty" (p. 66). In Richards's (2004) study of couples' experiences after predictive genetic testing, one partner described a philosophical attitude of enjoying life. In another study, partners similarly reported intentions to make the most of life, 6-months post-predictive testing (Tibben, Frets, van de Kamp, Niermeijer, Vegter-van der Vlis, Roos, Rooymans, et al., 1993).

In the present study, another aspect of "freeing possibilities" was "making a connection." Participants sought or re-affirmed their connections with their intimate partners, family, friends, as well as non-human entities. Nelson (1996) similarly described how women felt supported by others, including family, friends, healthcare providers, and spiritual beliefs, as part of the theme "relying on support through relationships." Another theme presented in her study, "reflections of self in the world," indicated that, as the women reflected on themselves, "uncertainty introduced a dynamic interaction of possibilities" in their lives (p. 71). Upon seeing other women who had survived breast cancer, participants described efforts at fostering connections with them. Morrow's (2010) theme of "treasured alliances" illustrates how participants sought out connections with others when feeling unsure, and Penrod (2001a) consistently described how participants connected with others, and this feature cuts across themes.

Notions related to “compassionate presence” and “letting go,” as described in the present study, were also found in other phenomenological descriptions of uncertainty. Pertaining to the former (compassionate presence) and as part of the theme “relying on support through relationships,” Nelson (1996) indicated a “loving presence” was critical in helping participants feel comforted, as was “resting in the trust” of others, namely healthcare providers. Pertaining to the latter (letting go), Morrow’s (2010) theme “moments of acquiescence” reflected how participants experienced going with the flow in feeling unsure, using phrases like “letting go” to describe the experience. In times of “overwhelming uncertainty,” the participants in Penrod’s (2001a) study surrendered control. Some described the surrender as going “with the flow of the disease” (p. 179). Penrod interpreted this surrendering as a respite, enabling the individual to restore their own integrity in the world and “begin the onerous task before them (p. 147). In other words, it’s considered a “short-lived” strategy.

The subtheme “considering possibilities” was described in the present study as an assessment of chances, risks, and probabilities, as well as a staying open to the possible. Although participants often indicated a desire to find meaning, especially as they attempted to identify a reason or cause for their partners’ behaviors, they also described times in which they were not set on finding meaning, being open to various reasons or causes. “Considering possibilities” is characterized by freedom and movement, as participants’ efforts are directed towards entertaining the possible as opposed to narrowing the possible. In the existing, relevant literature, such a notion has not yet been described. In Nelson’s (1996) discussion of “struggling to gain meaning,” an aspect unifying the other aspects of the uncertainty experience, she indicated how, through the struggle, the women were taken through a range of experiences. For example, the “wide spectrum of emotions” women experienced meant that they sometimes found it difficult to find meaning in their emotions, while at other times, their emotions enabled them to discover their life values (p. 72). While the notion of discovering may be similar to that of opening to the possible, Nelson indicates that the experience overall is still one in which "the women struggled to find meaning and gain understanding in their uncertainty" (p. 73). This is not the case in the current study; "considering possibilities" was not described as a struggle to find meaning, but rather it was more of an indifference towards or an embracing of not finding meaning.

While findings from both the present study and extant studies similarly report that participants sought out or re-affirmed their connections with others, notable differences in the nature of the connection exist. Participants in Nelson's (1996) and Penrod's (2001a) studies described connections with healthcare professionals as well as persons who could relate. In general, through participant-provider interaction wherein information was exchanged, participants' uncertainty experiences were influenced. For example, the women with cancer described relying on healthcare professionals' support, receiving hope as health care professionals offered "both positive and negative possibilities in the women's uncertainty" (p. 66). Alternatively, the women did not feel supported upon receiving conflicting information among healthcare professionals. Nelson also indicated that supportive connections with others, including healthcare professionals, was vital in fostering participants' sense of confidence and hopefulness. Furthermore, the women in her study reported the necessity of support from others as their uncertainty both ebbed and flowed. Penrod indicated that, for participants in her study, the "ability to relate through common experiences was especially helpful in decreasing the caregivers' uncertainty" (p. 154). In the current study, participants did not describe many supportive connections with healthcare professionals or peers, outside of occasional contact with personnel associated with research endeavors, family members' therapists, or a select few who were able to relate to or understand them.

Summary

Findings from the current study largely echo those presented in extant phenomenological literature examining uncertainty and those reporting on intimate partners' experiences post-predictive testing, but notable exceptions exist. What is different between findings from the present study and those of others may best be captured by considering "disease trajectory" and the way it is conceptualized. Obvious changes in health status, much less a clinical diagnosis of HD, have not yet occurred among participants' intimate partners. Participants described that their experience of feeling uncertain had more form, shape, or direction than before learning of their partners' gene-positive status, but they still found themselves without the tangibles associated with illness-related events. *Being in this place, where one knows about, anticipates, and tries to cope with and prepare for an illness and its implications before it happens, was described as a strange experience.* Participants described it as something that is there, but at the same time, it is not; it is something outside of their experience, which had not previously been seen, visited, or encountered. One participant described knowing it (HD) would happen, but not knowing what to do or feel about it. He said he felt anger, sadness, and weakness, but at the same time, not *really* angry, sad, or weak since he did not yet know where to direct those feelings. It is like being "in limbo," defined in the colloquial sense as an unknown place between two others and characterized by feeling "on edge" and that little can be done until something else happens.

While receiving results from predictive genetic testing about their partners' likelihood of developing HD in their futures was certainly considered an upheaval among participants, it was not necessarily considered an illness event or health threat in ways previously defined. The knowing about future health status and ensuing ways of being, thinking, and feeling created an uncertainty experience difficult understand, and this felt akin to a gravitational pull. This "pull" was highlighted by an expanded understanding of the ways participants' lived space, lived body, lived time, and lived human relations were experienced when feeling uncertain. Furthermore, anticipating was a feeling of imminence, often characterized by feelings of dread. Planning and preparing were difficult or impossible to do in the ways participants desired. Finding meaning was largely described as a desire as opposed to something achieved, with the exception of two participants who identified their faith in a higher power as a source of meaning. *Not* finding meaning was viewed with indifference, or, at times, even embraced as participants considered possibilities. During most intense uncertainty, participants experienced a distortion of time which took them from the present moment. While participants described seeking and re-affirming their connections with others, they also described fractured connections. In general, participants experienced a disconnect from family, friends, and society at-large during moments of intense uncertainty. A frequent reason participants cited for this disconnect was the difficulty others had in relating to or understanding them. There was also a notable lack of connections with healthcare professionals. All participants in the present study had partners enrolled in a larger, ongoing research project, and they described turning to the project coordinator as a resource. In sum, these are the findings which differ from others' descriptions of the lived experience of uncertainty or impact of predictive testing. Together, they reflect a heightened experience of sustained uncertainty which is uniquely experienced by persons on the cusp of that which is inevitable but not yet graspable.

Limitations

Two or three interviews per person were anticipated, but due to difficulties in scheduling multiple interviews with each person, some participants completed only the first interview. These persons did not have the opportunity to clarify, add to, or revise their anecdotal narratives, which were intended to be shared with participants in follow-up interviews. It is possible, therefore, that those who did not participate in reviewing their narratives could have found inaccuracies in what was identified from first-level analysis. Six out of ten persons participated in second interviews and, therefore, did have the opportunity to review their anecdotal narratives. While these participants provided content which served to elaborate upon what had been shared during first interviews, none of their revisions reflected gross inaccuracies in first-level analysis.

Implications for Practice

Knowledge gained from this study points to ways in which practitioners can provide nursing care with enhanced mindfulness and tactfulness. Specifically, findings from this study shed light on the meaning of the lived experience of feeling uncertain, and this understanding provides the context in which nurse-client interactions are based. With enhanced understanding, nurses are adept at watching, listening, and picking up on expressions of feeling uncertain. For example, with an increased awareness of existential modes of uncertainty, nurses caring for intimate partners post-predictive testing possess an increased ability to recognize possible verbal and non-verbal expressions of disconnecting during intense uncertainty (e.g., gaze turned downward, evasive behavior, and “putting up walls”) as well as the desire to connect in a meaningful, supportive way with others. Based on findings from this study, nurses should respect clients’ need to go inward while gently facilitating awareness of present-moment connections that provide a sense of being understood and relatedness. Participants in this study indicated such connections were found in present-focused meditation, spiritual and religious practices, and online forums wherein “talking” with peers remained anonymous and could be controlled (i.e., time and energy devoted to participating could easily be self-regulated).

Based on findings from the present study, the clinical *diagnosis* of HD is a matter requiring consideration. Implications regarding the matter of clinical diagnosis of HD have been discussed (e.g., Paulsen, 2010 & Williams et al, 2007), and researchers have pointed out the significance of diagnosis on the experience of uncertainty. For example, Penrod (2001a) described one woman's efforts to get a diagnosis for her spouse, and until she did, she described feelings of being lost, without confidence, not knowing what to do, and this led to a "profound from of uncertainty" (p. 178). Upon getting a diagnosis, she attained a greater sense of confidence and control. Similarly, Evers-Kiebooms et al. (1990) reported that intimate partners of persons who had tested positive for the HD gene mutation found it easier to cope with their problems upon their partners' clinical diagnosis, when behavior changes could be attributed to organic causes.

"Diagnosis" is a distinct phenomenon of the illness experience that "calls for particular considerations of 'care,'" according to Hayne (2003, p. 722). In her study on being diagnosed, she describes it as "a knowledge that knows;" an indisputable illness or "absolute knowing" that disrupts one's sensibilities, often creating a sense of not knowing anything at all. It is "sharply penetrating news…a power that impacts directly to the centre of one's being." (p. 725). Furthermore, receiving a diagnosis is "making visible the invisible," bringing hope and healing to light. For participants in Hayne's study, "what had been invisible was now manageable because it could be 'seen' and dealt with" (p. 727). Building on this is the theme "knowledge made knowledgeable." When diagnosis was relayed to participants in Hayne's study, so was information or "knowledge." For the diagnosis to be a healing or "life-giving" experience, though, meant that the knowledge needed to leave participants feeling more knowledgeable about ways leading to improved functioning. For some participants, the diagnosis carried "tremendous explanatory power," allowing them to take ownership of what was going on and move to a healthier way of living (p. 727). Participants described a sense of affirmation, feeling the diagnosis confirmed the "'non-normal' happenings…[and] the reality of sickness." Haynes eloquently summarized this finding, saying that moving from non-diagnosis to diagnosis "evolves knowledgeable knowledge, a means to make possible the reinterpreting of self and life and reorganizing one's world. Knowledge is meaningful because it rescues and guides the way to wholeness again." (p. 727).

Intimate partners of persons who have tested positive for the HD gene mutation but have not been clinically diagnosed experienced the receipt of genetic information as a diagnosis but not, creating an intangible reality. It is an onerous task to balance the implications of being in such a position, wherein the knowing creates a not knowing that may be considered “sharply penetrating,” as Haynes describes the diagnosis experience to be (2003, p. 725), simultaneous with *not* having the invisible made *fully* visible or knowledge made *fully* knowledgeable. For clients experiencing uncertainty as an intangible reality, validating this experience, helping them to identify and name it, and discussing ways in which it is unique relative to situations more familiar or commonly experienced may help in making the intangible more tangible.

If such aspects of the diagnosis experience are, indeed, critical for creating wholeness again, one must consider the fracturing potential receiving genetic information carries for intimate partners. Based on findings from the present study, “trying to prepare,” for example, was described as something participants strived towards, predicated on a notion that it would be possible, due to having information pertaining to their partners’ future health status. At the same time, their ideal notions of preparing could not be actualized, since preparations ultimately hinged upon what remained uncertain. Nurses play an important role in bearing witness to this struggle, recognizing clients’ unique circumstance of being in a “fractured” place. Nurses can facilitate the application of stress-reduction techniques while providing anticipatory guidance, thereby creating a space in which the client can mentally prepare for the possible while minimizing undue stress and feelings of powerlessness. Additionally, nurses must screen for mood disturbances (e.g., depression and anxiety) and treat accordingly or provide referral to a mental healthcare professional. If possible, nurses should assist clients in identifying a therapist who specializes in or has knowledge of health conditions such as HD (i.e., one who is aware of not only disease manifestations but also potential complicating factors such as secrecy, discrimination, and family history).

Another potentially fracturing circumstance was revealed as participants described ways they intentionally subdued HD and its unknowns, allowing it to be a presence in their minds while not allowing it to consume. Nurses can facilitate this balance of acceptance while simultaneously moving forward towards a full life. Participants indicated ways they used discretion and how they would want others to do the same, acknowledging HD and its implications but not dwelling in them. Nurses can explore the extent to which each client chooses to do this, as well as the ways in which he or she prefers to re-orient to the present. For example, discussing with the client the ways in which uncertainty, as experienced in the present moment, can be freeing may help to re-frame uncertainty as something necessary for movement and freedom. One participant described feeling fearful in anticipation of his wife's expected cognitive decline, not knowing when it would happen or how he would be in response. The same person also described making the most of the fact he *was* experiencing uncertainty, as this allowed him to consider the possibility that some of the child-like behaviors resulting from her cognitive decline might actually be fun and enjoyable. Another participant similarly recognized the inevitable and its unknowns as an acceptance but also described how those very things acted to propel him and his partner forward. For this participant, living in the moment and doing "positive" things now as opposed to later were predicated on the notion that they were uncertain as to when and to what extent they would no longer be able to do these things. In sum, nurses can assist clients in viewing HD and its surrounding uncertainties as a silent motivator.

Facilitating discussions of the meaning of intimate partners' uncertainty experiences throughout nurse-client interactions will continue to add to nurses' understanding of what it is like to feel uncertain as an intimate partner of someone with prodromal HD. Furthermore, persons in similar circumstances may also describe similar experiences of uncertainty (i.e., intimate partners of persons who have received genetic information pertaining to future health status). Of primary concern, however, is the paucity of opportunity to foster such nurse-client interactions. According to Rolland and Williams (2005), the prediagnostic phase of illness (in the present study, this is the prodromal phase) is characterized by a crisis phase, which includes the test and early posttest period and is situated within a long-term adaptation phase. In the case of HD, the long-term adaptation phase may subsume years or decades. Paulsen (2010) suggests this phase be seized as an opportunity for better care provision and education for HD families. Living with uncertainty is one of the several developmental challenges families face during this phase, according to Rolland and Williams (2005). Subsequently, the authors suggest periodic assessment and evaluation by a healthcare provider during these phases, including support groups created based on specific typologies of genomic conditions or preventive check-ups with primary care providers. Participants in the present study did not, however, express desired or actual connections with such services. Furthermore, participants expressed that they did not feel understood and others appeared to have an inability to relate and how these served as a “disconnect” between themselves and others.

An opportunity for facilitating this connection may best be operationalized within the post-genetic testing counseling process wherein a multidisciplinary team is available to both the proband and his or her intimate partner. Presently, post-test counseling is to be arranged between the proband and counselor, but such opportunities are often lost due to refusal to schedule or follow-up (Tibben, 2007), with the proband possessing the right to modify the schedule at any given time. While self-determination and autonomy of persons seeking genetic testing should be preserved, the right of the intimate partner to take advantage of such an opportunity, with or without the partner, must be considered and made explicit.

Implications for Research

Findings from the current study add to the existing body of literature on uncertainty supporting the need to examine and understand uncertainty in an expanded way, beyond that which frameworks such as Mishel's Uncertainty in Illness Theory (1988; 1990) or Lazarus and Folkman's (1984) conceptualization of uncertainty offer. Mishel's UIT allows for focused inquiry of uncertainty surrounding the illness experience or medicalized conditions. Participants' experiences of feeling uncertain were not firmly and exclusively situated within the context of HD- or illness-related events. While predictive genetic testing for HD is situated within a medical context, the present inquiry did not aim to focus on the uncertainty surrounding the test or the healthcare environment in which counseling and exchange of information take place. Based on findings from this study, the time period between predictive testing and diagnosis is a time wherein health- and illness-experiences are both colored by and not colored by having the genetic information. In other words, what ensued upon receiving the test results was always considered in the context of HD, but definitive conclusions were rarely drawn, allowing the consideration of possibilities to remain as part of this context. The findings from this study stretch beyond illness-based descriptions of uncertainty. Furthermore, existential modes of uncertainty were not only identified but also highlighted in terms of their significance in the current study. Mishel's UIT and Lazarus and Folkman's conceptualization are rooted in cognitive appraisal and aim to capture cognitive ways of knowing wherein availability and ability to process information is paramount. Other modes of uncertainty exist in which persons cannot process such information, and results from this study add the body of literature supporting existential modes of uncertainty as significant aspects of the experience (Bunkers 2007; Morrow, 2010; Nelson, 1996; & Penrod, 2001a).

Possibilities for further investigation stem from the essential themes that emerged from the present study. For example, "anticipating with ebbing and flowing disquietude" could lead to future research on "anticipating the inevitable" or "trying to prepare," while "a subdued presence with freeing possibilities" could lead to research on "considering possibilities." Research on these phenomena may enhance understanding of the lived experience of uncertainty. Additionally, future research including intimate partners of persons receiving genetic information pertaining to expected changes in health status may further elucidate experiences of being uncertain. The interplay of certainty of disease development and surrounding uncertainties warrants further examination, as results from predictive genetic testing provide varying levels of certainty-uncertainty in terms of risk, possibly creating nuanced differences in the uncertainty experience.

Rolland and Williams (2005) present the Family Systems Genetic Illness (FSGI) model to construct a psychosocial typology of genomic disorders based on four variables: timing of clinical onset; whether treatment can alter onset or progression; likelihood of development; and clinical severity. Importantly, this model expands traditional notions of disease trajectory to include the time prior to clinical diagnosis and possible influences of genetic information on the family. Other disorders for which predictive genetic testing is available may be chosen as the context in which uncertainty is examined based on one or more of the above variables in order to determine similarities and differences. Based on this model, both HD and early-onset familial Alzheimer disease are considered typologically similar: a high likelihood of development exists (gene mutation is in the highly-penetrant range); early- to mid-adult onset is evident; no treatment to alter onset or progression is currently available; and high clinical severity characterizes each condition. A different subset of Alzheimer's, which is APOE e4allele linked, carries a lower likelihood of development than the two above-mentioned conditions but is similar on the other 3 variables. Rolland and Williams suggest that "with lower-penetrance mutations, living with more ongoing uncertainty about whether the disorder will occur becomes a salient adaptational challenge" (p. 9). Based on findings from the present study, however, ongoing uncertainty amidst a high likelihood of disease development (as a result of the highly-penetrant HD gene mutation) was, at times, more than a challenge; it was described as a turmoil. Understanding how differences in likelihood of disease development play a role in the uncertainty experience would provide further insight into the experiences of intimate partners of persons who have received genetic information.

Conclusions

This study is the first to elucidate the experience of feeling uncertain among intimate partners of persons with prodromal HD. *Their lived experience of uncertainty was described as an intangible reality in which they anticipated HD and its surrounding unknowns with ebbing and flowing disquietude while feeling a weighty pull to dwell upon, towards inner turmoil and a subdued presence with freeing possibilities*. Nurses showing mindful interest in understanding the meaning of feeling uncertain as lived experience can illuminate the pathway to further conversation about what is creating the turmoil or fostering the possibilities that are freeing. According to Fromm (1947), “meaning does not imply certainty; indeed, the quest for certainty blocks the search for meaning. Uncertainty is the very condition to impel man to unfold his powers” (p. 45).

APPENDIX A: LETTERS OF SUPPORT

SITE #1 LETTER

November 10, 2008

Dear Ms. McGonigal-Kenney:

The Huntington's Disease Center of Excellence at the University of Iowa is pleased to be a recruitment site for your research study titled "The Lived Experience of Living with Uncertainty Among Intimate Partners of Persons Who Have Tested Positive for Huntington Disease." We have access to partners (same- and opposite-sex, married/unmarried) of persons who have tested positive for the Huntington's disease (HD) gene mutation and have not yet received a clinical diagnosis.

We currently have 480 gene-positive persons in our HD database and approximately half are located in the geographical region you plan to recruit from (Midwestern states). I am aware that Ms. Anne Leserman, HD Center of Excellence Coordinator, will be assisting you with your recruitment efforts. She will review the database to identify registrants to whom your recruitment packet will be mailed. If the registrants so choose, they may share this information with their intimate partners who will contact you if interested in your study.

We will be able to assist in your efforts to recruit potential participants and work with you to facilitate data collection throughout the study period. We look forward to working with you throughout the duration of your study.

Sincerely,

Jane S Paulsen

Jane S. Paulsen, Ph.D.
Professor of Psychiatry, Neurology and Psychology
Roy J. and Lucille A. Carver College of Medicine
1-305 Medical Education Building
Iowa City, IA 52242

319-353-4551 Office
319-353-3007 Aecretary
319-353-3003 FAX
jane-paulsen@uiowa.edu
April 28, 2008

SITE #2 LETTER

Meghan L. McGonigal-Kenney, PhD(c), MSN, RN
(PI address removed)

Dear Ms. McGonigal-Kenney

The Division of Medical Genetics, University of Iowa Hospitals and Clinics, is pleased to be a recruitment site for your research study entitled “The Lived Experience of Uncertainty Among Intimate Partners of Persons Who Have Tested Positive for Huntington Disease.” Through our outreach and university outpatient genetics clinics we have access to partners (same- and opposite-sex, married/unmarried) of persons who have tested positive for the HD gene mutation and have not yet received a clinical diagnosis.

On average, 100 patients are seen per month in the University of Iowa Genetics and the Regional Genetic Consultation Service (held in 12 cities throughout Iowa) outpatient clinics. This includes approximately 12-20 individuals per year who are scheduled for presymptomatic Huntington’s Disease counseling and testing. All individuals who seek presymptomatic HD testing are encouraged to have a support person accompany them for their 3 counseling sessions. The majority of support persons are partners of the persons being tested.

Our staff will be able to assist in your efforts to recruit potential subjects from our outpatient clinics, and we will work with you to facilitate data collection throughout the study period.

Sincerely,

Catherine A. Evers

Catherine A. Evers, R.N., M.A.
Division of Medical Genetics
The University of Iowa
200 Hawkins Drive, W121GH
Iowa City, Iowa 52242-1083
319-356-3347 Fax
800-260-2065 Toll Free
cathy-evers@uiowa.edu

APPENDIX B: IRB APPROVED FORMS

APPORVAL MEMO (IRB ISSUED)

IRB ID #:	200809722
To:	Meghan McGonigal-Kenney
From:	IRB-01 DHHS Registration # IRB00000099, Univ of Iowa, DHHS Federalwide Assurance # FWA00003007
Re:	The Lived Experience of Living With Uncertainty Among Intimate Partners of Persons Who Have Tested Positive for Huntington Disease

Protocol Number:
Protocol Version:
Protocol Date:
Amendment Number/Date(s):

Approval Date: 12/08/08

Next IRB Approval Due Before: 11/20/09

Type of Application:	**Type of Application Review:**	**Approved for Populations:**
☒ New Project ☐ Continuing Review ☐ Modification	☒ Full Board: Meeting Date: 11/20/08 ☐ Expedited ☐ Exempt	☐ Children ☐ Prisoners ☐ Pregnant Women, Fetuses, Neonates

Source of Support:

Investigational New Drug/Biologic Name:
Investigational New Drug/Biologic Number:
Name of Sponsor who holds IND:

Investigational Device Name:
Investigational Device Number:
Sponsor who holds IDE:

This approval has been electronically signed by IRB Chair:
J. Andrew Bertolatus, BA, MD
12/08/08 0949

IRB Approval: IRB approval indicates that this project meets the regulatory requirements for the protection of human subjects. IRB approval does not absolve the principal investigator from complying with other institutional, collegiate, or departmental policies or procedures.

Agency Notification: If this is a New Project or Continuing Review application and the project is funded by an external government or non-profit agency, the original HHS 310 form, "Protection of Human Subjects Assurance Identification/IRB Certification/Declaration of Exemption," has been forwarded to the UI Division of Sponsored Programs, 100 Gilmore Hall, for appropriate action. You will receive a signed copy from Sponsored Programs.

Recruitment/Consent: Your IRB application has been approved for recruitment of subjects not to exceed the number indicated on your application form. If you are using written informed consent, the IRB-approved and stamped Informed Consent Document(s) are attached. Please make copies from the attached "masters" for subjects to sign when agreeing to participate. The original signed Informed Consent Document should be placed in your research files. A copy of the Informed Consent Document should be given to the subject. (A copy of the *signed* Informed Consent Document should be given to the subject if your Consent contains a HIPAA authorization section.) If hospital/clinic patients are being enrolled, a copy of the signed Informed Consent Document should be placed in the subject's chart, unless a Record of Consent form was approved by the IRB.

Continuing Review: Federal regulations require that the IRB re-approve research projects at intervals appropriate to the degree of risk, but no less than once per year. This process is called "continuing review." Continuing review for non-exempt research is required to occur as long as the research remains active for long-term follow-up of research subjects, even when the research is permanently closed to enrollment of new subjects and all subjects have completed all research-related interventions and to occur when the remaining research activities are limited to collection of private identifiable information. Your project "expires" at 12:01 AM on the date indicated on the preceding page ("Next IRB Approval Due on or Before"). You must obtain your next IRB approval of this project on or before that expiration date. You are responsible for submitting a Continuing Review application in sufficient time for approval before the expiration date, however the HSO will send a reminder notice approximately 60 and 30 days prior to the expiration date.

Modifications: Any change in this research project or materials must be submitted on a Modification application to the IRB for prior review and approval, except when a change is necessary to eliminate apparent immediate hazards to subjects. The investigator is required to promptly notify the IRB of any changes made without IRB approval to eliminate apparent immediate hazards to subjects using the Modification/Update Form. Modifications requiring the prior review and approval of the IRB include but are not limited to: changing the protocol or study procedures, changing investigators or funding sources, changing the Informed Consent Document, increasing the anticipated total number of subjects from what was originally approved, or adding any new materials (e.g., letters to subjects, ads, questionnaires).

Unanticipated Problems Involving Risks: You must promptly report to the IRB any serious and/or unexpected adverse experience, as defined in the UI Investigator's Guide, and any other unanticipated problems involving risks to subjects or others. The Reportable Events Form (REF) should be used for reporting to the IRB.

Audits/Record-Keeping: Your research records may be audited at any time during or after the implementation of your project. Federal and University policies require that all research records be maintained for a period of three (3) years following the close of the research project. For research that involves drugs or devices seeking FDA approval, the research records must be kept for a period of three years after the FDA has taken final action on the marketing application.

Additional Information: Complete information regarding research involving human subjects at The University of Iowa is available in the "Investigator's Guide to Human Subjects Research." Research investigators are expected to comply with these policies and procedures, and to be familiar with the University's Federalwide Assurance, the Belmont Report, 45CFR46, and other applicable regulations prior to conducting the research. These documents and IRB application and related forms are available on the Human Subjects Office website or are available by calling 335-6564.

PARTIAL HIPAA WAIVER (IRB ISSUED)

IRB ID #: 200809722
To: Meghan McGonigal-Kenney
From: IRB-01 DHHS Registration # IRB00000099,
Univ of Iowa DHHS Federalwide Assurance #FWA00003007
Re: The Lived Experience of Living With Uncertainty Among Intimate Partners of Persons Who Have Tested Positive for Huntington Disease
Protocol Number:
Protocol Version:
Protocol Date:
Amendment Number/Date(s):

Approval Date: 12/08/08 (Full Board)

This project has been granted a partial waiver of HIPAA Authorization based on the documentation provided by the researcher in the HawkIRB application Section VII.D and the assurance document signed by the Principal Investigator.

This partial waiver of authorization for recruitment purposes satisfies the following criteria:

(1) The use or disclosure of the requested information involves no more than a minimal risk to the privacy of individuals based on, at least, the presence of the following elements:

(a) An adequate plan to protect the identifiers from improper use and disclosure

(b) An adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention is otherwise required by law; and

(c) Adequate written assurances that the requested information will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of the requested information would be permitted by the Privacy Rule;

(2) The research could not practicably be conducted without the waiver or alteration; and

(3) The research could not practicably be conducted without access to and use of the requested information.

This approval has been electronically signed by IRB Chair:
J. Andrew Bertolatus, BA, MD
12/08/08 0949

COVER LETTER

Site Heading to Appear Here

Date

Dear Ms./Mr.:

I am writing to let you know of a research study being conducted by Meghan McGonigal-Kenney, a nurse and doctoral student at the University of Iowa, College of Nursing. Ms. McGonigal-Kenney is looking for spouses and intimate partners of persons who have tested positive for the Huntington disease (HD) gene mutation to participate in her research study. The purpose of this study is to understand what it is like to feel uncertain or unsure when a spouse or intimate partner has tested positive for HD.

Because I cannot release your name or contact information without your permission, the researcher is not able to contact you or your intimate partner directly. If you choose to pass the information about this study along to your partner, and he or she is interested in hearing more about this study, there are two options:

1) He or she can fill out the top portion of the enclosed “Study Interest Indication Sheet” and mail it to Ms. McGonigal-Kenney. A self-addressed, stamped envelope has been included for convenience; or

2) He or she may call Ms. McGonigal-Kenney at (PI phone number removed).

If he or she is not interested in the study, he or she can fill out the bottom portion of the “Study Interest Indication Sheet” and return it in the self-addressed, stamped envelope. If you would like to speak to Meghan about the study, you may contact her at (insert PI phone number). Please leave a message if she is unavailable

Taking part in this research study is voluntary. It is not part of or associated with your healthcare at the University of Iowa Division of Medical Genetics, any other services you receive, and/or studies you may participate in through the U of I HD Center of Excellence. Your spouse’s or intimate partner’s decision on whether to participate will not change any part of your involvement there. If you choose not to share this information with your spouse or intimate partner, you may throw this information away. Please feel free to contact me if you and/or your intimate partner have questions or concerns. Thank you very much for your consideration.

Sincerely,

(Signature, name, credentials, and contact information of either Cathy Evers or Anne Leserman to appear here)

REMINDER COVER LETTER

Site Heading to Appear Here

Date

Dear Ms./Mr.:

I hope that you have received a letter in the mail describing a study in which your spouse or intimate partner may be eligible to participate. The “Living With Uncertainty Study” is being conducted by Meghan McGonigal-Kenney from the University of Iowa, College of Nursing.

This is a reminder letter about the opportunity for your intimate partner (married or unmarried; in opposite-sex or same-sex relationships) to participate in this research study. The purpose of the study is to understand what it is like to live with feeling unsure or uncertain related to having an intimate partner who has tested positive for the Huntington disease gene mutation but who has not yet been diagnosed. We hope that information gained from this study will assist nurses and other health care providers in providing care and supportive services to intimate partners. I have again included further information about the study.

Because I cannot release your name or contact information without your permission, the researcher is not able to contact you or your intimate partner directly. If you choose to pass the information about this study along to your partner, and he or she is interested in hearing more about this study, there are two options:

1) He or she can fill out the top portion of the enclosed “Study Interest Indication Sheet” and mail it to Ms. McGonigal-Kenney. A self-addressed, stamped envelope has been included for convenience; or

2) He or she may call Ms. McGonigal-Kenney at (PI phone number removed).

If he or she is not interested in the study, he or she can fill out the bottom portion of the “Study Interest Indication Sheet” and return it in the self-addressed, stamped envelope. If you would like to speak to Meghan about the study, you may contact her at (insert PI phone number). Please leave a message if she is unavailable.

Taking part in this research study is voluntary. It is not part of or associated with your healthcare at the University of Iowa Division of Medical Genetics, any other services you receive, and/or studies you may participate in through the U of I HD Center of Excellence. Your spouse’s or intimate partner’s decision on whether to participate will not change any part of your involvement there. If you choose not to share this information with your spouse or intimate partner, you may throw this information away. Please feel free to contact me if you and/or your intimate partner have questions or concerns. Thank you very much for your consideration.

Sincerely,

(Signature, name, credentials, and contact information of either Cathy Evers or Anne Leserman to appear here)

STUDY INFORMATION SHEET

"Living with Uncertainty:" Research Study Information

Meghan McGonigal-Kenney, a nurse and doctoral student at the University of Iowa (UI), College of Nursing, is looking for intimate partners (married or unmarried; in opposite-sex or same-sex relationships) whose partners have tested positive for the Huntington disease (HD) gene mutation but who have not yet been diagnosed with HD. The *purpose* of the study is *to understand what it is like to live with feeling unsure or uncertain* related to having an intimate partner who has tested positive for the HD gene mutation but who has not yet been diagnosed. It is hoped that information gained from this study will assist nurses and other health care professionals in providing care and supportive services to intimate partners.

You are receiving this information because of one or more of the following reasons: you either are currently receiving or have received services in the past from the UI Regional Genetic Consultation Service (RGCS) and/or the Division of Medical Genetics; and/or you have chosen to be listed on the University of Iowa HD Registry. Dr. Jane Paulsen, Anne Leserman, Cathy Evers, and other staff at the U of I who may be familiar to you are working closely with Meghan to help her identify persons who may be interested in this study. Your intimate partner may be eligible to participate in this study. Persons participating in the study must be 1) able to identify with the experience of uncertainty, not knowing, and/or feeling unsure, 2) willing and able to talk about these experiences, 3) English-speaking, and 4) 18 years of age or older.

Estimated time commitment: If your intimate partner is eligible and agrees to participate, he or she will be asked to talk about his or her experiences of uncertainty in 3 interviews. Each interview will last about 1 hour and will occur over an approximately 8 month time period. The interviews will be done by Meghan at a convenient location and time. Your intimate partner will also be asked to audio record his or her experiences with feeling unsure or uncertain to help the researcher to better understand what his or her uncertainty experiences are like. Your intimate partner will be paid for his or her time and effort.

IMPORTANT: You are free to either share or not share the information in this letter with him or her at this time. If you do, and he or she is interested in learning more about the study, there are two options:
1) He or she can fill out the top portion of the enclosed "Study Interest Indication Sheet" and mail it to Meghan in the self-addressed, stamped envelope; or
2) He or she may call Meghan at **(PI phone number removed)** Please leave a message if she is unavailable. YOUR INTIMATE PARTNER MUST CONTACT MEGHAN BY MAIL OR PHONE. MEGHAN CANNOT CONTACT YOU OR YOUR INTIMATE PARTNER DIRECTLY WITHOUT YOUR PERMISSION. If your intimate partner is not interested in the study, he or she can fill out the bottom portion of the "Study Interest Indication Sheet" and return it to Meghan in the self-addressed, stamped envelope.
You may also call 1-800-260-2065 to speak with a counselor at the University of Iowa RGCS about questions or concerns. You are also free to contact Cathy Evers directly at

(319) 356-1160 and/or Anne Leserman directly at (319) 353-4307 with any questions or concerns. All information gathered from participants in this study is kept private and confidential within guidelines set by federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies). Meghan will not share who does and does not participate in this study with the staff at the Iowa RGCS, Division of Medical Genetics, or persons associated with the UI HD Registry. She would also be happy to discuss with you and/or your intimate partner the other measures that will be taken to keep any information shared during interviews private and confidential. Thank you for your consideration.

STUDY INTEREST INDICATION SHEET

INSTRUCTIONS: The information below should be filled out by persons who are either interested OR not interested finding out more information about the research project on “Uncertainty Among Intimate Partners.” *For those interested, fill out the top portion* of the sheet. After receiving this form, Meghan McGonigal-Kenney will contact you by phone to provide more information and answer any questions you might have about the study. *For those not interested, fill out the bottom portion* of the sheet. Please mail the sheet to Meghan at (PI home address removed). A self-addressed stamped envelope has been included for your convenience.

YES I AM INTERESTED

Name____

My intimate partner’s
or spouse’s name____

Address____

City, State, Zip Code____

Phone Number
where you can best be reached (include area code)______________________________

Time of Day
when you can best be reached____

NO I AM NOT INTERESTED

Name____

My intimate partner’s
or spouse’s name____

SCREENING LOG

1) Are you the intimate partner of someone who has tested positive for the HD gene mutation?

2) Has your intimate partner been diagnosed with HD by a doctor or other medical professional?

3) Can you identify with the experience of uncertainty, not knowing, and/or feeling unsure related to having an intimate partner who has tested positive for the HD gene mutation but who has not yet been diagnosed?

4) Are you willing and able to talk about your experiences of uncertainty, not knowing, and/or feeling unsure?

5) Are you 18 years of age or older?

6) Dates/times contact was attempted

7) Date/time successfully made contact

8) Are you interested in 1) more information 2) more time to consider 3) study participation?

9) What is your contact information (name, mailing address, and phone number)?

INFORMED CONSENT

INFORMED CONSENT DOCUMENT

Project Title: The Lived Experience of Living With Uncertainty Among Intimate Partners of Persons Who Have Tested Positive for Huntington Disease

Principal Investigator: Meghan McGonigal-Kenney, MSN, RN

Research Team Contact: Meghan McGonigal-Kenney, (319) 354-3104
Catherine Evers, (319) 356-1160
Anne Leserman (319) 353-4307
Howard Butcher, (319) 335-7039

This consent form describes the research study to help you decide if you want to participate. This form provides important information about what you will be asked to do during the study, about the risks and benefits of the study, and about your rights as a research subject.

- If you have any questions about or do not understand something in this form, you should ask the research team for more information.
- You should discuss your participation with anyone you choose such as family or friends.
- Do not agree to participate in this study unless the research team has answered your questions and you decide that you want to be part of this study.

WHAT IS THE PURPOSE OF THIS STUDY?

This is a research study. We are inviting you to participate in this research study because you are an intimate partner of someone who has tested positive for the Huntington disease (HD) gene mutation and have experienced what it is like to feel uncertain or unsure because of your situation.

The purpose of this research study is to understand what your experiences with feeling uncertain or unsure are like. The knowledge learned from this project may help researchers and health care providers to know how to provide better health care to intimate partners of persons who are likely to develop HD.

HOW MANY PEOPLE WILL PARTICIPATE?

Approximately 20 people will take part in this study conducted by an investigator at the University of Iowa.

HOW LONG WILL I BE IN THIS STUDY?

If you agree to take part in this study, your involvement will last for:

- Approximately 6-8 months
- The study involves more than one visit or contact
    - Three interviews will occur
    - Each interview will last approximately 1 hour in length
- The researcher will contact you by phone about 1 month after the interviews have ended, to check on your well-being

WHAT WILL HAPPEN DURING THIS STUDY?

You will be asked to participate in 3 interviews and make either an oral or written recording. The purpose of the interviews and recording is to understand how you experience uncertainty.

- ***Interview #1*** You and the researcher will meet in person for the first interview. The researcher will ask you questions about yourself and times you felt uncertain related to your situation of having an intimate partner who has tested positive for the HD gene mutation but who has not yet been diagnosed. The researcher will also ask you to respond to a questionnaire.
    - Sometimes people prefer to express their thoughts and feelings in written or artistic form. If this applies to you, the researcher will ask you to bring these to the interview, and you and the researcher will talk about these expressions.
    - At the end of the first interview, you will have the option of creating an oral or written recording of your experiences with uncertainty. If you choose to make an oral recording, the researcher will provide an audio recording device to you for you to speak into.
- ***Interview #2*** You and the researcher will meet in person for the second interview. You and the researcher will talk about initial findings from the first interview. You will have the opportunity to clarify and/or expand upon the things talked about in the first interview.
    - You may bring written or artistic expressions to discuss during the interview.
    - You will return the audio-recording device, if applicable
    - The researcher will bring her own written or artistic forms of uncertainty and ask what they mean to you.
- ***Interview #3*** You and the researcher will talk over the phone for the third interview, unless it is possible to meet in person. You and the researcher will talk about your oral or written recording. You will have the opportunity to clarify and/or expand upon the things you and the researcher talked about in prior interviews, or other insights on what it is like to feel uncertain that you may have to date.
- All interviews will be done at a time, day, and location that is convenient for you.
    - Together, you and the researcher will choose a location that is private and quiet.
        - This may be in your home or a building with a private room available for public use.
- You are free to skip any questions during the interviews or on the questionnaire

that you would prefer not to answer.

- The researcher will make a follow-up phone call to you about 1 month after the third interview. The purpose of this call is to check on your well-being and see if you have questions. No information for the study will be collected. The researcher will call you once and leave a message on your answering machine if you are not available. The researcher will leave her phone number should you choose to contact her.

Audio Recording/Video Recording/Photographs

One aspect of this study involves making audio recordings of what you say. Audio recordings are being made so that the researcher can transfer what is said during the interviews into written form. The purpose of this is to carefully examine and analyze your descriptions of uncertainty so that the researcher can better understand your experiences. Only the researcher will have access to the audio recordings. The recordings will be destroyed when the study is completed.

The researcher will also take photographs of any written or artistic forms of uncertainty that you choose to bring to the interview(s). The purpose of this is to keep a record of the object(s) so that the researcher can view the object while carefully examining and analyzing your descriptions of it. Any identifying parts of the object will be removed before taking the photo.

WHAT ARE THE RISKS OF THIS STUDY?

You may experience one or more of the risks indicated below from being in this study. In addition to these, there may be other unknown risks, or risks that we did not anticipate, associated with being in this study.

There are emotional or psychological risks. You may feel embarrassment or pressure that there are right or wrong answers to the questions. You may feel distressed, uncomfortable, and/or upset when asked to think about and describe your experiences in detail.

WHAT ARE THE BENEFITS OF THIS STUDY?

We don’t know if you will benefit from being in this study. However, we hope that, in the future, other people might benefit from this study because knowledge gained may help provide increased understanding of what it is like for you to experience uncertainty and may help nurses and other health care professionals better care for intimate partners of persons who are likely to develop HD.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You may have costs for being in this research study. If you and the researcher choose to meet for the interviews at a location other than your home, there may be travel and/or parking costs.

WILL I BE PAID FOR PARTICIPATING?

You will be paid for being in this research study. You will receive a $45.00 gift card from either Target or Wal-Mart, depending on what you prefer. You will receive the gift card either in person or through the mail after the third interview, depending on whether the interview is done in-person or over the phone. There will be pro-rating for early withdrawal from the study (if you stop participating before the second or third interview). Should you withdraw after the first interview, you will receive a $15.00 gift card. Should you withdraw after the second interview, you will receive a $30.00 gift card. You may need to provide your address if a card will be mailed to you.

WHO IS FUNDING THIS STUDY?

The University and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

WHAT ABOUT CONFIDENTIALITY?

We will keep your participation in this research study confidential to the extent permitted by law. However, it is possible that other people such as those indicated below may become aware of your participation in this study and may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

- federal government regulatory agencies,
- auditing departments of the University of Iowa, and
- the University of Iowa Institutional Review Board (a committee that reviews and approves research studies)

To help protect your confidentiality, we will assign you a code number. This will be used in place of your name. The code number will be used to identify the audio recordings. When the researcher makes a transcript of what was said during the interviews, only codes or pseudonyms will be used in place of names of people or towns. The researcher will cover eyes and names of persons or locations, if present, in any digital photos of object(s) you bring to the interview(s). Field notes and journal entries made by the researcher will not contain actual names or other identifying information about you.

The master list containing your name and assigned code, transcripts, digital photos, and the researcher's field notes and journal entries will be kept on the researcher's personal computer, under the researcher's control, in password-protected files. The master list will be stored alone and separate from all other documents. Whenever the researcher transports materials from the study from one place to another, they will be transported in the researcher's briefcase and stored in a locked filing system at the researcher's home address. Audio recordings will be stored separately from consent forms and contact information to reduce the likelihood of linking your name with your voice recording.

All materials listed above will be permanently destroyed by the researcher when the study is finished. The researcher will 1) not share which persons choose to participate or not participate in this study and 2) not share data in a way that is personally identifiable with staff at the University of Iowa Regional Genetic Consultation Service so that the research study will not affect any member of your family's care. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

IS BEING IN THIS STUDY VOLUNTARY?

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

Can Someone Else End my Participation in this Study?

Under certain circumstances, the researcher might decide to end your participation in this research study earlier than planned. This might happen if you are consistently unable to attend interviews which have been arranged or if the researcher has difficulty contacting you.

WHAT IF I HAVE QUESTIONS?

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Meghan McGonigal-Kenney, (PI phone number removed). If you experience a research-related injury, please contact: Meghan McGonigal-Kenney, (PI phone number removed) or Howard Butcher, (319) 335-7039. If you have questions, concerns, or complaints about your rights as a research subject or about research related injury, please contact the Human Subjects Office, 340 College of Medicine Administration Building, The University of Iowa, Iowa City, Iowa, 52242, (319) 335-6564, or e-mail irb@uiowa.edu. General information about being a research subject can be found by clicking "Info for Public" on the Human Subjects Office web site, http://research.uiowa.edu/hso. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

This Informed Consent Document is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by signing this Informed Consent Document. Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subject's Name (printed):

____

Do not sign this form if today's date is on or after EXPIRATION DATE: 09/17/11.

____
(Signature of Subject) (Date)

Statement of Person Who Obtained Consent

I have discussed the above points with the subject or, where appropriate, with the subject's legally authorized representative. It is my opinion that the subject understands the risks, benefits, and procedures involved with participation in this research study.

____
(Signature of Person who Obtained Consent) (Date)

DEMOGRAPHIC QUESTIONNAIRE

Participant ID #____

Instructions: Please answer the following questions below. You may choose not to answer any question(s) you do not want to answer.

1. What is your gender? (circle one)
    - Male
    - Female
2. What is your age?__________years
3. What is your marital status? (circle one)
    - Married
    - Unmarried
4. How long have you been in your current relationship? (fill in blank and circle one)__________(months/years)
5. What is the highest level of education you have completed? (circle one)
    - Grade School
    - High School
    - Associate's Degree
    - Bachelor's Degree
    - Master's Degree
    - Doctoral Degree
    - Other (please describe):____________________
6. What is your race? (circle one)
    - Asian or Pacific Islander
    - Hispanic
    - African American
    - American Indian or Alaskan Native
    - Caucasian

    Other (please specify):____________________
7. How many children do you have from your current relationship?
__________child(ren)
8. How long before your partner had the predictive DNA test for HD did you know that he/she was at risk for having HD? (fill in blank and circle one)
__________(days/weeks/months/years)
9. How long has it been since he/she got the result from the predictive DNA test for HD? (fill in blank and circle one)
__________(days/weeks/months/years)

INTERVIEW SCHEDULES

Interview Guide 1

The interview is unstructured and conversational in tone. Not all questions listed may be raised during interview. While there are three interview guides total, there will be a need for fluidity between the three guides if necessary, due to the descriptive and interpretive nature of inquiry. Therefore, question(s) listed here may be used for interview 2 and/or 3, for example, although they may not be explicitly listed on Interview Guide 2 or 3. The interviewer will exercise discretion in determining the direction, flow, and use of questions/probes. Participant may bring to interview object(s) reflective of his/her experience of uncertainty.

An audio-recording device may be issued to each participant at the close of the interview. The interview will conclude when participants feel they no longer have information to share. The interviewer will thank them for sharing their stories and insights.

Opening Question(s):

- Tell me what it has been like for you since your partner/wife/husband received his/her positive test result for Huntington disease.
- How has your life changed since knowing this information about your partner/wife/husband?

Questions on uncertainty:

- Think of a time when you felt uncertain or unsure. It could be a time when you were unsure, in doubt, or when you just didn't know. Go back to that time. Can you describe that situation?
- What about now, in your situation of being an intimate partner of someone who has tested positive for the HD gene mutation, can you describe the types of things you feel uncertain about?
- How is this experience of feeing uncertain like or unlike your experiences of uncertainty that you had before you learned of the test result?
- Can you describe an image, metaphor, or symbol of someone who feels uncertain?
- How do you express or show that you feel uncertain?
- Would you act any differently if you were feeling uncertain? Why or why not? Can you say more?
- Could I tell just by looking at you if you were feeling uncertain? Why or why not? Can you say more?
- Do your connections with others change when you feel uncertain? If so, how do they change?
- What happens to your sense of time when you feel uncertain?
- If you feel like your life feels different when you feel uncertain, can you tell me a story about that?

Questions tailored to elicit descriptions of literature, personal diaries, logs, journals, and/or art, depending on whether participant and/or interviewer chooses to bring one or more of these items:

- As you think about this item and what it is like to feel uncertain, can you tell me

what meaning the item has for you?
- How is the item like or unlike your own experience with uncertainty?
- What feelings does this item evoke for you?

Probes:
- How have you made sense of your situation, of being a partner of someone who has tested positive for the HD gene mutation?
- Have you found a new purpose or gained a new perspective on life?
- How has your outlook on life changed?
- Is there a positive side to being in your situation? A negative side? Does feeling uncertain or unsure contribute to either of those? If so, can you describe how?
- Are there other experiences or emotions you find to be a part of or related to uncertainty?
- (if applicable, based on response to previous question) Explore the role those experiences or emotions play in participant's experience of being a partner of someone who has tested positive for HD
- Is feeling uncertain or unsure desirable for you? Is it undesirable for you? Can you tell me more about that?
- What kinds of things do you turn to or use during times you feel uncertain?
- If you had a friend who was in the same situation as you, how would you help that friend with his or her own feelings of uncertainty?
- If you knew then what you know now about what it's like to live with uncertainty, would you have done anything differently if you could do it over?

Question to allow participant to add additional comments or ask questions:
- Have I forgotten to ask you anything that you wanted to tell me?

Interview Guide 2

The interview is unstructured and conversational in tone. Not all questions listed may be raised during interview. While there are three interview guides total, there will be a need for fluidity between the three guides if necessary, due to the descriptive and interpretive nature of inquiry. The interviewer will exercise discretion in determining the direction, flow, and use of questions listed below. Participant and/or interviewer may bring to interview object(s) reflective of his/her experience of uncertainty.

The interview will largely focus on reflecting upon each participant's anecdotal narrative and respective themes. Each participant will have a copy of his/her narrative to view as the interviewer is able to view it. Audio-recording device will be returned to PI/interviewer if participant used it to create oral narrative. The interview will conclude when participants feel they no longer have information to share. The interviewer will thank them for sharing their stories and insights.

Opening questions:
- As you read your anecdotal narrative, what thoughts come to mind?
- As you look over the themes I have come up with so far, what thoughts come to mind?

Questions for reflection and interpretation:

- How does the content in the narrative fit or not fit with your experience of feeling uncertain or unsure related to your situation of being an intimate partner of someone who's tested positive for the HD gene mutation?
- As we examine the theme (insert thematic heading name), is this really reflective of what the experience of uncertainty is like? In other words, how does this theme fit or not fit with your experience of feeling uncertain or unsure? How is this so or not so? (proceed to reflect upon the remaining themes asking this question for each theme)
- Do you have any suggestions for how to better capture how your experience uncertainty?

Questions tailored to elicit descriptions of literature, personal diaries, logs, journals, and/or art, depending on whether participant and/or interviewer chooses to bring one or more of these items:

- As you think about this item and what it is like to feel uncertain, can you tell me what meaning the item has for you?
- How is the item like or unlike your own experience with uncertainty?
- What feelings does this item evoke for you?

Probes:

- How have you made sense of your situation, of being a partner of someone who has tested positive for the HD gene mutation?
- Have you found a new purpose or gained a new perspective on life?
- How has your outlook on life changed?
- Is there a positive side to being in your situation? A negative side? Does feeling uncertain or unsure contribute to either of those? If so, can you describe how?
- Are there other experiences or emotions you find to be a part of or related to uncertainty?
- (if applicable, based on response to previous question) Explore the role those experiences or emotions play in participant's experience of being a partner of someone who has tested positive for HD
- Is feeling uncertain or unsure desirable for you? Is it undesirable for you? Can you tell me more about that?
- What kinds of things do you turn to or use during times you feel uncertain?
- If you had a friend who was in the same situation as you, how would you help that friend with his or her own feelings of uncertainty?
- If you knew then what you know now about what it's like to live with uncertainty, would you have done anything differently if you could do it over?

Question to allow participant to add additional comments or ask questions:

- Have I forgotten to ask you anything that you wanted to tell me?

Interview Guide 3

The interview is unstructured and conversational in tone. Not all questions listed may be raised during interview. While there are three interview guides total, there will be a need for fluidity between the three guides if necessary, due to the descriptive and interpretive nature of inquiry. The interviewer will exercise discretion in determining the direction, flow, and use of questions listed below. Participant and/or interviewer may bring to interview object(s) reflective of his/her experience of uncertainty.

The interview will largely focus on clarifying and/or reflecting further upon any information shared in the prior interview(s), if necessary. The interview will conclude when participants feel they no longer have information to share. The interviewer will thank them for sharing their stories and insights.

Questions about protocol and other insights to date:

- Based on what you shared with me in the last interview(s), and/or based on what I learned after listening to or reading your protocol (from audio-recording or written document), my understanding of what uncertainty means is (insert content specific to participant's description).
- In what ways does this ring true for you?
- In what ways does it not ring true for you?
- Can you give me any additional examples that help me to further understand how you experience uncertainty?

INSTRUCTIONS FOR CREATING A PERSONAL PROTOCOL

Creating your personal story: Guide for making oral or written home recordings

Please audio record or write about, depending on your preference, a direct account of a personal experience of *feeling uncertain or unsure related to having an intimate partner who has tested positive for the Huntington disease gene mutation* as you lived through it.

Focus on a specific event or incident surrounding uncertainty. Be as descriptive of the actual experience that you can be. This means avoiding the use of causal explanations, generalizations, and abstract interpretations. Choose an event that “stands out” for its vividness, as if one could experience it again for the first time.

Talk or write about what happened to make you feel uncertain, what the feeling was like, how it resolved, and any other insights that you have. Include feelings, moods, and emotions experienced. Include bodily sensations, such as sounds, smells, sights, and so on.

Talk or write as much as you’d like, as often as you’d like.

Thank you for your participation. Please contact me with any questions.

Meghan McGonigal-Kenney
(PI phone number removed)

APPENDIX C: ANECDOTAL NARRATIVES

ANECDOTAL NARRATIVE: KAREN

I feel joyful and blessed to be in relation with my intimate partner. It is a real treasure. When he first told me he was positive for the Huntington disease gene mutation, I wasn't concerned or frightened. We became involved in seeking information, attending conferences, facilitating an HD support group, and participating in research. We are not in the throes of HD, but we are dedicated to helping others who are. There was a time when I was concerned, however, about some changes in his memory. My antennas went up. I didn't know the cause of these changes, I just knew they were frequent, significant, and not normal. He was not himself. I felt a strong need to act, so I talked to him about the changes I noticed, but he froze, acting as though I had put a bomb in his lap. The fear, stress, and denial in his voice stunned me. I backed off. Things between us were tense for awhile, but I came away with a better understanding of his fear. I felt I was in closer touch with his feelings. A couple of people outside of our relationship provided some reassurance to me. One person didn't see any changes at all in him, and the other gave some alternative explanations for his changes in behavior that had nothing to do with HD. I tend to agree with the latter, that his changes were likely due to a stressful situation at work. After all, this explanation made more sense to me, given the things I know about his personality and character and how he handles stress. The concerning changes disappeared a month or so later. My fears, concerns, and tensions also dissipated. Now, I live with greater awareness, alertness, and watchfulness. My concerns get triggered again when there's an issue with his memory. It doesn't take a hold of me though. In fact, none of this do I sit and chew on. HD isn't a problem for us, and it likely will not be. Research reports say that if a person has reached older age and HD symptoms haven't appeared, chances are they won't. He is older. I can have hope, and this hope makes it more comfortable living with the knowledge that HD could develop. But I do feel more certain that he won't develop HD than I do uncertain about whether he will. Feeling certain about this puts me in a place where, when possible HD-related changes do arise, I'm less likely to worry or have a strong reaction. I don't freeze and say "oh, this is HD," but rather, I stay open to other possibilities as reasons for the changes. Being with him and knowing about HD has changed me. I have a heightened awareness of personal blessings, of others' struggles, and of death. Lately, at night when we snuggle up for bed, I think about what it would be like to lose (intimate partner's name). I would feel empty ~~and tortured~~. To lose him would be to lose a relationship unlike any other I've ever had. My fear of losing him is deeply-rooted, and it doesn't really come to the surface and intrude my everyday thoughts. How does it manifest then? I think it manifests as anger. Sometimes my expectations for how he should be are narrow, unfair, and unrealistic. When they are unmet, I feel my need for control and perfection escalate. I become more irritable, yell, and cannot roll with the punches as usual. I might be more *sharp* ~~short~~-tongued, less considerate of others, impatient, and stressed. I become more hyper-vigilant in an attempt at gaining control. I don't know if these things would be apparent to anyone else. Just my partner, perhaps. If I could vent to someone, besides him, it might help me to process it, to look at all things possible. I'd like someone to listen more than talk, to be a gentle presence and offer support.

ANECDOTAL NARRATIVE: GEORGE

My partner and I met about 10 years ago. We both had kids from prior relationships, and we have one from our relationship. A few years ago, I was diagnosed with a rare autoimmune disease. Then she found out she was positive for the HD gene mutation. We didn't even know it was in her family until her dad got diagnosed. The day we found out her results from the predictive test was a traumatic, scary event for me. Before the nurses told us, I still didn't know, and I still had hope. It was a letdown to find out she did have it. What is it? What will happen? What about the kids and their futures? Where will she end up? What will she be able to do? Unable to do? Why does it have to happen? Why her? She’s so smart, so personable. I know it has nothing to do with her, it’s genetic. It’s still hurtful though. It’s hard to not know, especially when it comes to the symptoms. Will they happen next week or in a few years? I’ve seen her dad get worse, so I know what to expect. But I also know it’s different in different people; it helps to know that, to remember that, when I see something that could be an HD-related symptom. I can still have hope. I don’t have to think “this is it.” If I did, I’d be down and depressed. I do feel confused though. She is in the middle of the HD spectrum. She’s already tested positive, but she’s not like her dad. *It's like playing a waiting game*. Along with my own illness, it’s crazy trying to figure out my thoughts along with hers. It’s a back-and-forth, mixed up situation with a lot of ups and downs. We are definitely a unique couple. It’s not normal to be young and afflicted with two, rare disorders. It’s weird how we went from not knowing anything to finding out life-altering stuff. We turned to God, and God responded. I experienced several moving moments and knew God had touched me. Now, I can’t wallow in the what-if’s or wonder anymore “what next?” In fact, I don’t need to wonder. I know what the outcomes are. I am a Christian now, and I accept what God has given me. God’s plans for us are infallible and unchangeable. What happens is what happens. I still think about my tomorrows, about our tomorrows. But my approach is more intentional, less carefree. What I do today has an impact on tomorrow. If I can better myself by watching what I eat or tending to the symptoms of my own illness, maybe I can prolong my life. If I can do something to better someone else, maybe I can make the world a nicer place. Life isn’t dark anymore. I used to think as though life would end tomorrow, but I let go of the doom and gloom. Our diagnoses are no longer death sentences. When God lays something in my lap, I see it as a test. Everything happens for a reason; knowing that changes my approach, not only with myself but also my family. I have fewer angry outbursts with my children. I look to books on parenting to give me direction and help me make sense of the difficulties we face as a family. I realize we are not alone. I realize it’s best to take things day-by-day. Uncertainty is still a way of life, but it’s not traumatic anymore. It all has meaning and purpose. If I know that tomorrow could be worse than today, I would rather not know. If I know tomorrow is going to a whole lot better, I would rather know. Based on what we’ve come to believe as Christians, my partner and I know the next life is better than this one. And I can rest in that certainty.

ANECDOTAL NARRATIVE: MADISON

My partner and I have been married for 10 years. Since then, he’s tested positive for the HD gene mutation. We were not on the same page with our perspectives related to his motivation for testing as well as how he’s been since finding out the result. For me, when something happens, I’ll deal with it. I’ll try not to think or worry about it. He talks about death and what will happen in the future way more frequently. It was most difficult in our household for about 2 years after he got the result. Our ~~step~~ son moved in with us around that time too. My partner changed into a different person. His personality, his temper, his use of profanity changed so drastically it made me wonder “Who are you?” I didn’t know him anymore. He became very hard to live with; he complained, was negative, whined, and just went crazy. It’s so hard with HD, because it’s an unknown somewhere out there; I don’t even know if or when it will happen. So I choose to not live in that. There’s just nothing anyone can do right now. So him living in that space and me not living there created a tension-filled home with not as much peace and happiness as I would have liked. We became two separate people living under one roof and were not meeting the needs of the other during that time. We weren’t feeling very loving towards each other, and I just couldn’t relate to him. I wouldn’t divorce him, but I did ask myself “Oh my gosh, what have I done?” Things are better now, but I’m not sure what I would’ve done if he would’ve moped around forever. In fact, that’s one of my biggest questions: What would I do with him if he did? How do I handle him? When something happens, I ask myself “what am I supposed to do with this? How can I live like this?” We got into an argument once and I left for a walk to cool down. I returned, knowing I had to not stand down when things seemed hardest. I was crying, upset, frustrated, scared, and annoyed. I had to get those emotions out of the way and make a choice to work things out. After all, I want to be the best version of me God wants. There is purpose to each thing in life. My purpose is to find the sunshine, the joy, and the good in situations and bring that to others. I refuse to allow my whole life to go downhill because of what's happened to my partner. After all, there's just not a whole lot we can do. I hold onto it loosely in my head, realizing it's something that can't be controlled. I don't know the outcome, so I just let it go. When he's not himself or is difficult to deal with, I do start wondering: if something happened tomorrow, how would my life be different? What would it look like if I'm 50 and he dies? What if he takes his own life? I can't really spend time there though. Sure, I think about my future, but it's about things like vacation, my ~~step~~ son's school activities, financial security, and moving into a different home. If and when he dies, we both hope it's from something other than HD. Right now, I'm not sure how I handle knowing *(italicize "knowing" to emphasize)* he's tested positive and he will get it at some point if he lives long enough. It's like being diagnosed but not. With cancer or Alzheimer's, you see it right away. You know what to do. It's not like that with HD, and that's one of the hardest things. So I take God's lead, and I lean on my friends who are like family for support. They don't remind us of HD all of the time, but they do acknowledge it. It's been difficult dealing with our families, since I wonder if they even care or understand. In the end, I keep a strong faith, take things one day at a time, try to understand, and maintain optimism that ~~things won't get bad again~~ *challenges will occur, life moves forward, and growth is inevitable*. While our love has changed, we complement each other. Whatever happens, I believe I have the capacity to deal with it.

ANECDOTAL NARRATIVE: KARL

My partner and I met about three years ago and are engaged to be married. When she told me she was positive for the HD gene mutation, I didn't know what HD was, so I didn't think much about it. *(Karl indicated he would insert a story here, about coming home from work and feeling overwhelmed with different feelings and wondering. This event happened a few days after she told him about HD. He said the story, or his "personal battle with grappling with the uncertainty" would make his narrative a bit more "negative" in tone. He tells the story and ends with saying that he was able to turn a corner or come out of it)* I didn't talk much about it with others, except my dad and brother. When my mom was ill with cancer, I didn't want to talk about things then either. Talking about it meant I was acknowledging it, and I didn't want it intruding too much into my thoughts. Now, I am doing things differently. I want to tackle things head-on when it comes to my partner and HD. My choice to commit to her on a deeper level meant I could not hide from it. I talked with my closest friends about it to get it off my chest and to let them know I might need their support and love in different ways at some point in my future. I participate in research studies. Even though I know about and am involved with HD now, it is hard to grasp the thought of any future changes because they are beyond control. In general, HD is always in the back of my mind, but it can creep forward when I'm feeling particularly melancholy. There's a bit of doubt, a tiny voice that says to me: "Things could be bad, they might be tough. Are you sure about being able to handle this?" I know I'll do a good job as a friend, a husband, a supporter, a caregiver, but I don't know how much strength I'll need or what will be asked of me during those trying times. I feel weak, but I don't even know what to feel weak about yet. I feel scared, but I don't know what to be afraid of. When will it happen? That is the whole mystery. I know HD has varying degrees of severity in different people; how will my partner be? How will she be with me? My mind gets stuck in a state of worry, working towards a solution to these questions even though I know there are no answers.

If I could just solve it, it wouldn’t bother me again. The only thing I know is that it will happen down the road. It is hard to be in this place of knowing it will happen but not knowing when. I would want to know when, if I could. I can get lost in my thoughts, in the worry. I feel angry and sad. Why did this happen to her? To me? To us? Why can’t something be done? Things start to seem futile, I feel helpless. Time slows, my face might look more serious to those around me. My partner and closest friends would know when I’m feeling stuck, but not those who don’t know me as well. They might just think I’m a quiet person. I’m not too aware of my surroundings, nor do I care; it wouldn’t matter if I was sitting on a comfortable couch or a hard rock. Nothing feels good when my mind has taken over. I can come out of it though, and I do so with a certain knowing. I know I will never be able to fix the problem of having no answers. I know I can accept that getting stuck, getting down, will happen once in awhile. I can move in and out of it relatively easy. I see both sides of the coin; it’s fine to feel these things while also feeling like I have things to look forward to. Talking with my buddies, playing games with friends, anticipating our upcoming honeymoon, exercising, and simply seeing her walk through the door at the end of the day are all things that help those feelings and thoughts to melt away. I try to keep HD in my mind, maintain some level of worry so I am prepared when something happens. I can’t bury it but I can’t let it come to the forefront either. It will be serious, severe, and taxing on our relations with each other and with the world. I find comfort in knowing I have good tools at my disposal. Even though it is hard to know about HD and not know how it will shape our futures, I have chosen love above all else.

ANECDOTAL NARRATIVE: RYAN

My partner and I have been dating about 6 years, and we are about to celebrate the 1-year anniversary of our marriage. He knew about his positive gene status before we dated, so I was able to weigh the pros and cons and dive into the relationship with eyes wide open. I don’t want to ever deny what is there but I also don’t dwell on it. I know HD will rear its ugly head someday eventually. Sometimes the word “Huntington’s” can penetrate and seep into my brain. I break down and cry. It feels impossible to see or imagine what he might be like with full-on symptoms. He’s so smart, one of the most together people you could meet. I can’t imagine losing him. But no matter how much I love him, HD will affect my life negatively. Nobody wants to deal with that, especially so early on in life. Most people don’t know of the disease until it really attacks. They can fantasize about being old and having to think about and deal with it then. But for me, in my 20s, it’s a reality now. We talked about me going on with my life, because this will all happen so early. I’ll always take care of him, but my life would have to go on. It seems unreal, weird. Others have the luxury of having a disease attack and the person dies. This is different; it goes on for years. He’s going to have strong personality changes. Our friends can’t wrap their heads around this kind of a situation, knowing the relationship will end but not knowing where or when. They get to fantasize about their relationship lasting through old age. We are at an extreme disadvantage because we can’t live completely in denial like they do. What will I do? How will our friends be? Will we lose our connections with them? What will people think of me if I start dating again? It’s like the domino effect, like a tree effect: There’s the HD, but then what direction will this take? What direction will that take? You don’t know. Sometimes he shakes at night, after he’s fallen asleep. I know it’s a symptom of HD, but stressed-out people can do that too. Maybe it’s aging and maturing. He has obsessive issues too. It’s hard distinguishing what could be a symptom and what is just his personality. Sadness is borne out of this not knowing. My eyes become focused and angled down. Time slows. I listen intently. I turn inward, analyzing what’s going on in my own head. I don’t talk; I don’t want to let something slip out about being upset. I don’t want it weighing me down or consuming me. You can’t have the best life possible when you’re talking about it all the time. So, I’m continuing on, grasping for every little bit of him that I can get. Even if he fades away, he's already impacted my life enough that any child we have someday would be a product of the two of us. Knowing about HD has had a positive impact on our life. We try to live life fully and see things in the most positive way possible. Because we don't know when this will affect him, we do things and go places now, while we are young and able. It's intensified the desire and incentive to not live in pre-life but to live in the present moment. There's so much good that is happening right now in my life. But we always feel the weight of the reality of the disease. There is a clock ticking away, and the alarm will go off. I can see an ending where a lot of people can't. It's in the back of our heads, an unspoken, silent motivator to live life while we can live it before the disease hits. It's a luxury and a curse. In the end, everybody will have to deal with death and disease. Let's live for this moment.

ANECDOTAL NARRATIVE: BRIAN

My wife and I have been married for over 25 years and have 2 children. Her father had HD, and I watched him move through the stages. His capabilities changed due to the decline in cognitive and motor skills. I know she will go through these changes too, and in some ways, she already has. I wonder about some child-like behaviors, some tendencies towards irresponsibility. What are the changes from? It could be stress, or it could be HD. Is this part of the dementia? If I see her being forgetful, it could simply be a natural change due to aging, or again, it could be HD. When I don't know the reason and can't connect it with something, it's angering, irritating, and frustrating. But if it becomes a pattern and a cause becomes more apparent, then it feels easier to move on. I can come to a certain, but never fully certain, acceptance. Ok, it's real, and it's something I understand. Now we can talk and I can try to help her out. But it's difficult to know when to be concerned, when to help or intervene, and how much. Right now, it feels like we are on a plateau. There are occasional drops, and then you go along again on the plateau until the next one. I am fearful about what the drops in her impairments could lead to. When will she go to that deeper level? I watch and monitor more closely, becoming more guarded, focused, tentative, and aware. I am intent on finding a solution. This places me in a different role, almost more of a parental one. Is this my role now? I'm not sure whether she's able to recognize her impairments, and she has a difficulty accepting my concerns about them. This pushes one of my buttons and I feel ignored. This adds tension and strain to our relationship. It's not just her disease. It's ours. I feel like I'm on the edge of moving into being a caregiver. Questions and thoughts are in my mind, and then I question whether I should even be having them. I didn't have to do this before. Now, the possibility for something going wrong is there. I am afraid of what her decline could lead to. But I don't feel immobilized or paralyzed. As we deal with the things life brings to us, we must walk tight ropes to get to the other side to find solutions. I am the one, not her, that walks the tight rope now. The decisions are up to me. When I do not have the answers, I remain inquisitive, digging and turning rocks in order to find them. This is the solution to feeling uncertain. I adjust my thought process about what I had hoped for in our retirement. I wanted to save now and enjoy retirement later. But she probably will not be able to do so. I feel disappointed about having to change my thought process at times. None of what I'm going through do I try to hide; someone who knew me would probably know something was going on. Uncertainty is like a rocky mountain or an outcropping protruding out of life's soft, green pastures. You have to be like a rock climber, thinking ahead before your next move and asking "Is this the right action that culminates into finding a solution? What are the possibilities?" Feeling uncertain is the thing you need to climb to find a solution. We're handed all kinds of different things after getting involved with somebody. She brought several things into our marriage, into our family. I wish some of those things didn't exist, but the others that do are cherished gifts. You just take them all and move forward.

ANECDOTAL NARRATIVE: JOE

My wife and I have been together for over 30 years, ever since a high school wrestling tournament where we met. We have 4 children together. I see some changes happening in her, and it's very tough for me to deal with. She gets angry and it comes out at inappropriate times, like during our recent mission trip to Europe. It can get embarrassing. She does things that are unpredictable. She's fine, then all of a sudden, she's not. It's hard for me to understand. Our whole living situation is so not normal. Her life doesn't really revolve around us. We don't talk much. She won't discuss things with me before making decisions like she used to. I have no reason why she does certain things. I don't know how to deal with her when those situations come up. If there's a situation between my wife and someone else, I tend to side with the other person. It's easier to get mad at her and not make other people mad because I may need them in the future. I try to understand it, how she is. Maybe she's not doing these things on purpose. Maybe it's the HD. I know she is a loving, caring person on the inside, but on the outer edges always lives that anger, and I have no idea why. My kids don't relate. They don't understand what it's like to be a caregiver. Others don't get it either. On the outside, she looks normal. But on the inside, there's a lot of stuff going on that people can't see. I live with her every day. I can see it. She isolates herself. She is sick. It's like she died when she got the results of the HD test. Others can't relate to that. They can't relate to her or treat her with compassion. Sometimes they treat her with contempt, as if she has leprosy. She feels unloved. I feel angry and sad. I'm not sure how to deal with those feelings. Usually I hold the anger in, under the surface, but down deep inside it feels like a vicious animal tearing up a helpless animal, like a bear clawing and swiping at flesh non-stop. Sometimes when my anger comes out, it might be noticeable. I might become more quiet, withdrawn, or raise my voice. Sometimes I just want to walk away from it. Not my marriage, but having to deal with it. I can't deal with it. And I know that this is only a precursor of what is to come. It will escalate and get worse. If she gets as bad as her uncle was, I wonder if I'd be able to handle that situation. His wife and the rest of the family were so supportive and strong. But in the end, they couldn't handle it. If they couldn't do it, how will I? I can't deal with my own emotions and somebody else's that, down the road, will be out of control. I can't do it now. How will I do it then? I want to and have to learn to deal with it, but nobody helps me, and nobody helps her. We're dealing with this on our own, day-by-day. When I think of my wife down the line, I don't consider my future to be a bright and happy one. I know that we'll be unable to have a normal retirement. Should I retire so we can spend some time together before she gets really bad? What are we going to have together? We don't know what's going to happen. There are no answers. There is no resolution. I feel like a guy floating in space. Nobody's there. There's nothingness all around. It's dark, isolated, and cold. I feel lost, lonely, and I can't breathe. There's no sense in finding enjoyment whatsoever. I don't have relationships outside of our own. It would be devastating to lose it. I'm just going with the flow now. If she's happy, then I'll be happy too.

ANECDOTAL NARRATIVE: ELLEN

My husband and I met in college, nearly 30 years ago. We knew then he was at-risk for HD. I knew it was always a possibility I would be a caretaker someday for someone who would be difficult to care for, much like I was for my mother when I was a young girl. Because he was at-risk, we decided not to have children of our own and adopt a little girl. Then he wanted to get tested. I couldn't even imagine knowing; it was too soon after we adopted. He was tested but didn't tell me until months later. It was a betrayal, and I was mad. It felt like he took something from me. We could always be hopeful before, but he took that away. I wanted to adopt again but couldn't bring myself to do it after that. It's had such a huge impact on us, on me. I've been waiting for the other shoe to drop all the time, thinking I know this is going to happen, I just don't know when. I'd see him twitch or be clumsy and begin to think, begin to worry. I knew I could get through it if it was, indeed, the start of the disease. I knew it doesn’t happen all at once. Despite knowing this, I had automatic reactions filled with panic, depression, dread, and despair. Life would speed up somehow, taking me out of the present and right to the really bad part, thinking “this is it.” I wondered about work, childcare, and the kind of caretaker I would be. Pictures would come to mind about all kinds of strange things that happened with his relatives. I didn’t talk with him about this. I isolated myself from others, hid what was going on. We kept it a secret from most people. Those who do know don’t understand what it means to predict something in such a clear-cut way. There’s so many unknowns but there’s enough known that it gives the unknowns a direction. I know everyone will die. But knowing that it will be miserable for him, miserable for me…it’s not a good thing. I felt worried, sad, anxious, and stressed constantly. It changed my every day life, living. I felt like I’ve been stuck grieving. You can cry, you can bargain, but you can’t do the whole process or you’d be disconnected from that person. I could always tell myself intellectually something else was going on, but then I’d have a gut feeling that no, he’s getting sick. The worry is never-ending. You can’t be sure about when and how the disease starts, because it’s insidious, progressive, and slow. When do you know for sure that they actually have it? I’ve been in a constant state of anticipation. His CAG repeats indicated he’d get sick around age 50. As he got closer to that age, I felt more stressed, yelled, became more controlling. I felt awful, like why am I so worried when I’m not the one getting it? I should be doing everything to take the stress off of him. I should and will take care of him, even if it upsets me. With my cancer, it was easier to know the diagnosis than to wait for it. Not knowing is helplessness. Knowing means there are no choices, you can really do something. Now, we are in the midst of getting a divorce. I wonder if he really is getting the HD or having a mid-life crisis. He’s making poor decisions, seems depressed, and his grooming is declining. I don’t trust him about anything anymore. Or, it could be me and my neurosis. After all, I don’t feel like I’ve ever been able to have a positive attitude. I don’t know. I fear that I will have to be a caretaker for him at some point, and that feels shitty. I don’t want to. I am trying to see more possibilities, for my future. Mindful meditations have kept me from ruminating about the past and worrying about the future. The love I experience for my daughter keeps me in the present moment. It’s like the opposite of worrying.

ANECDOTAL NARRATIVE: ANGIE

My husband and I have been together over 5 years. Our relationship early on was based on fun, and we didn’t have many thoughts of our future. Then we got pregnant. We knew his mom had HD, but my husband hadn’t tested yet. It felt scary to think we hadn’t really thought about it, how to handle it. We got married after our son was born, and then my husband was tested. We wanted another child. We considered in vitro, but decided that since we’d taken a risk with our first that we would take a risk with this one, too. We maintain a lot of hope for a treatment or cure. And, people die every day from horrible things. We just know we have a higher risk of that happening. Sometimes I wonder about his legs twitching at night, thinking “oh my gosh, is this an early sign?” It’s scary. I don’t know why it’s happening. I search for answers. I feel like we’re not ready for that scenario. But who’s to say it’s even HD; it’s normal for everyone to twitch when falling asleep. I would be lying if I said there wasn’t days that I thought it would just be easier if I wasn’t with him, because it’s scary, very scary and sad to think “oh my god, am I going to end up alone?” When you pick your spouse, you think you’re going to take a journey together. I wonder how I can prepare for what may inevitably be coming down the road. And I remember how his mom was, what if he ends up in a situation like that? Am I going to have to take care of him alone? Am I going to be able to take care of him? What will he feel, what will he know or not know at the end? Are we going to build a life together and one day it’s going to abruptly be just me? Then here I am, with memories together, with kids, then what happens if the kids get sick? Then I’ll really be alone because my whole family is ill and gone. Then what happens? I wonder what I would’ve done if I was more responsible and confident in myself when we first started dating. Would I still have chosen him? I don't know. There's no clear answers to anything, no right or wrong, no set of rules. But I continue to search for answers, be pro-active, and take steps to prepare. Knowledge is power. We plan and create a vision of our future filled with big goals, like a trip to Europe or building our dream home. But I'll have a little thought, in the back of my mind, like "will it really happen?" I feel a bizarre mix of feelings: sadness, fear, and excitement. I include HD in my vision for the future, but it's not the main spoken thing I see for myself. In other words, it's there, so I try to deal with it, but I try not to let it eat away at me and the other things I see for my future. But, at the same time, I don't want to build my life and then all of a sudden it's just me. Alone. Journaling about my feelings and acknowledging HD helps me to let go, release it from being the focus. I don't have to harbor it or mull it over and over in my head. I don't act differently when feeling unsure, no one would probably know, I'd keep it to myself. The questions I have in the back of my head, about our future, especially…I don't really bring those up to him. The ones about twitching, wondering "is this it?" seem more intense right now. I do ask him about these, but with caution; I fear he will end up thinking about HD all day long. After all, is this really the worst thing in the world? Things are good now. We know there's something negative that could be a very real part of our future. But I remind myself it's not the only thing that's going to be for me. I think of the quote I painted on our bedroom wall: "enjoy this moment for this moment is your life." Things might happen in the future, but right now is awesome.

ANECDOTAL NARRATIVE: LAURA

My husband and I have been together for over 15 years. We've known for about 4 years that he is gene-positive for HD. I am glad he tested, because I don't have the turmoil of not knowing whether he is or isn't. But my turmoil arises when I see changes in him. He gets road rage, he swears, he yells, and once, during a temper outburst, punched a hole in the wall. It is all so out of character for him. It's hard to know why he is this way at times. Knowing what we know makes me watch, makes me think, is this it? Is this the HD? Maybe I think this just because I know he's gene positive. I wonder, are these signs? Are these symptoms? Is this the start? Are we going down this path? Maybe he's just exhausted. Maybe it's the effects of aging. We have a son together whom I worry and wonder about as well. I want to differentiate the reason for his behaviors too. He has autism. Are his behaviors due to that? Or juvenile HD? Or attention deficit? My mind starts going and my imagination runs wild when I lay in bed at night, thinking of the future. What will it hold? We bought some land together, and I thought we'd spend our retirement there watching the beautiful trees and growing a garden, growing old together. Now I think, will he have the motor skills to do that? I think about the changes happening and wonder how much time do we have left until he starts having problems? I guess you never know, with someone you love, how much time you have. But the difference with others is they don't know if their spouse is going to change. I do know, and it is terrifying to think of him slipping away from me. I think about losing the person I know, the kind and gentle man I fell in love with *(this part resonated strongly with Laura)*. I know change is what life is all about. But I'm afraid of the change, just afraid. To think of him changing as a person fills me with dread and terror. I feel like he's going to slip away and I won't know him anymore. You can't know what's going to happen in life, but I know that these things are going to happen. I don't know to what extent, how, and when things will unfold. It's like a ticking bomb, but I don't know when it will go off. My husband has this positive thing that is going to erupt in him sometime. He is the one that will experience that. And I know I'm going to be along for it when it happens. What is our course going to be? What will happen to his rational mind? I am frightened that he will be unable to use his guns in a responsible way. Will he commit suicide? Will he turn abusive towards us? My son has issues too, with no concept of things he does. Things feel so dysfunctional now, I wonder what will happen to our family structure in the future? How would I deal with things, what would I do? I don’t have answers yet. I try to think it out, what the worst case scenarios might be, even though part of me doesn’t want to think about it at all. I want to be able to plan, to prepare myself. The knowing, the thinking, and the worrying can be both powerful and disturbing. It can be productive and anxiety-provoking. Sometimes I feel panicked. I try to envision the future and can’t. Time gets distorted. I don’t have good energy. I put isolating walls up between myself and those around me. Things are happening that other people might not even know are going on. If they ask questions, I give them evasive responses. I can’t and don’t share this with others. It’s just one big secret I must keep hidden. I wonder if I had someone to talk to if I wouldn’t sit here and stew about it. I don’t want to give up hope on anything though. I should be more positive. Life is a gift, my husband a treasure. We should enjoy it every day we have.

REFERENCES

Adamson, C. (1997). Existential and clinical uncertainty in the medical encounter: An idiographic account of an illness trajectory defined by Inflammatory Bowel Disease and Avascular Necrosis. *Sociology of Health & Illness, 19*(2), 133-159.

American Academy of Pediatrics Committee on Bioethics. (2001). Ethical Issues With Genetic Testing in Pediatrics. *Pediatrics, 107*(6), 1451-1455.

American Society of Human Genetics. (1998). Professional disclosure of familial genetic information. The American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure. *American Journal of Human Genetics, 62*(2), 474-483.

American Society of Human Genetics Board of Directors, & American College of Medical Genetics Board of Directors. (1995). Points to consider: Ethical, legal, and psychosocial implications of genetic testing in children and adolescents. *American Journal of Human Genetics, 57*(5), 1233-1241.

Ammer, C. (1997). *The American heritage dictionary of idioms*. Boston: Houghton Mifflin Co.

Anderson, K. E., & Marshall, F. J. (2005). Behavioral symptoms associated with Huntington's disease. *Advances in Neurology, 96*, 197-208.

Apostolo, J. L., Viveiros, C. S., Nunes, H. I., & Domingues, H. R. (2007). Illness uncertainty and treatment motivation in type 2 diabetes patients. *Revista Latino-Americana de Engermagem, 15*(4), 575-582.

Aubeeluck, A. (2005). Caring for the carers: Quality of life in Huntington's disease. *British Journal of Nursing, 14*(8), 452-454.

Babrow, A. S., Kasch, C. R., & Ford, L. A. (1998). The many meanings of uncertainty in illness: Toward a systematic accounting. *Health Communication, 10*(1), 1-23.

Baier, M. (1995). Uncertainty of illness for persons with schizophrenia. *Issues in Mental Health Nursing, 16*(3), 201-212.

Barnhart, R. K. (Ed.). (1995). *The Barnhart concise dictionary of etymology*. New York: Harper Collins Publishers.

Batchelor, S. (1990). *The faith to doubt: Glimpses of Buddhist uncertainty*. Berkeley, CA: Parallax Press.

Baxter, L. R., Jr., Mazziotta, J. C., Pahl, J. J., Grafton, S. T., St. George-Hyslop, P., Haines, J. L., . . . Phelps, M. E. (1992). Psychiatric, genetic, and positron emission tomographic evaluation of persons at risk for Huntington's disease. *Archives of General Psychiatry, 49*(2), 148-154.

Beck, C. T. (1991). How students perceive faculty caring: A phenomenological study. *Nurse Educator, 16*, 18-22.

Beck, C. T. (1994). Phenomenology: Its use in nursing research. *International Journal of Nursing Studies, 31*(6), 499-510.

Beglinger, L. J., O'Rourke, J. J. F., Wang, C., Langbehn, D. R., Duff, K., Paulsen, J. S., & Huntington Study Group Investigators. (2010). Earliest functional declines in Huntington disease. *Psychiatry Research, 178*, 414-418.

Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice*. Menlo Park, CA: Addison-Wesley.

Benner, P. (1985). Quality of life: A phenomenal perspective on explanation, prediction, and understanding in nursing science. *Advances in Nursing Science, 8*, 1-14.

Benner, P. E., & Wrubel, J. (1989). *The primacy of caring : Stress and coping in health and illness*. Menlo Park, Calif.: Addison-Wesley Pub. Co.

Bergum, V. (1991). Being a phenomenological researcher. In J. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 55-71). Newbury Park: Sage.

Berrios, G. E., Wagle, A. C., Markova, I. S., Wagle, S. A., Ho, L. W., Rubinsztein, D. C., . . . Hodges, J. R. (2001). Psychiatric symptoms and CAG repeats in neurologically asymptomatic Huntington's disease gene carriers. *Psychiatry Research, 102*(3), 217-225.

Beskow, L. M., Burke, W., Merz, J. F., Barr, P. A., Terry, S., Penchaszadeh, V. B., . . . Khoury, M. J. (2001). Health law and ethics: Informed consent for population-based research involving genetics. *JAMA: Journal of the American Medical Association, 286*(18), 2315-2321.

Binedell, J., Soldan, J., & Harper, P. S. (1998). Predictive testing for Huntington's disease: I. Predictors of uptake in South Wales. *Clinical Genetics, 54*(477-488).

Bird, T. D. (2010, December 23). Early-onset familial Alzheimer disease Retrieved March 30, 2010, from http://www.genetests.org

Bishop, A. H., & Scudder, J. R. J. (1991). *Nursing: The practice of caring*. New York: National League for Nursing Press.

Bloch, M., Adam, S., Wiggins, S., Huggins, M., & Hayden, M. R. (1992). Predictive testing for Huntington disease in Canada: The experience of those receiving an increased risk. *American Journal of Medical Genetics, 42*(499-507).

Bloch, M., Fahy, M., Fox, S., & Hayden, M. (1989). Predictive testing for Huntington disease: II. Demographic lifestyle patterns, attitudes, and psychosocial assessments of the first fifty-one test candidates. *American Journal of Medical Genetics, 32*(217-224).

Bombard, Y., Penziner, E., Decolongon, J., Klimek, M. L. N., Creighton, S., Suchowersky, O., . . . Hayden, M. R. (2007). Managing genetic discrimination: Strategies used by individuals found to have the Huntington disease mutation. *Clinical Genetics, 71*, 220-231.

Boss, P. (1999). *Ambiguous loss : Learning to live with unresolved grief.* Cambridge, Mass.: Harvard University Press.

Bourne, C., Clayton, C., Murch, A., & Grant, J. (2006). Cognitive impairment and behavioural difficulties in patients with Huntington's disease. *Nursing Standard, 20*(35), 41-44.

Brackis-Cott, E., Mellins, C. A., & Block, M. (2003). Current life concerns of early adolescents and their mothers: Influence of maternal HIV. *Journal of Early Adolescence, 23*(1), 51-77.

Brandt, J., Quaid, K. A., & Folstein, S. E. (1989). Presymptomatic DNA testing for Huntington's disease. *The Journal of Neuropsychiatry and Clinical Neurosciences, 1*(2), 195-197.

Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. A., & Haas, S. M. (1999). 'In an important way, I did die': Uncertainty and revival in persons living with HIV or AIDS. *AIDS Care, 11*(2), 201-219.

Brashers, D. E., Neidig, J. L., & Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication, 16*, 305-331.

Brashers, D. E., Neidig, J. L., Russell, J. A., Cardillo, L. W., Haas, S. M., Dobbs, L. K., . . . Nemeth, S. (2003). The medical, personal, and social causes of uncertainty in HIV illness. *Issues in Mental Health Nursing, 24*, 497-522.

Brenner, G. (2003). *Webster's new world American idioms handbook*. Indianapolis: Wiley Publishing, Inc.

Briggs, J., & Peat, F. D. (1989). *Turbulent mirror: An illustrated guide to chaos theory and the science of wholeness*. New York: Harper & Row Publishers.

Briggs, J., & Peat, F. D. (1999). *Seven life lessons of chaos: Timeless wisdom from the science of change*. New York: HarperCollins Publisher, Inc.

Brinkman, R. R., Mezei, M. M., Theilmann, J., Almqvist, E., & Hayden, M. R. (1997). The likelihood of being affected with Huntington disease by a particular age, for a specific CAG size. *American Journal of Human Genetics, 60*, 1202-1210.

Broadstock, M., Michie, S., & Marteau, T. (2000). Psychological consequences of predictive genetic testing: A systematic review. *European Journal of Human Genetics, 8*, 731-738.

Brouwer-DudokdeWit, A. C., Savenije, A., Zoeteweij, M. W., Maat-Kievit, A., & Tibben, A. (2002). A hereditary disorder in the family and the family life cycle: Huntington disease as a paradigm. *Family Process, 41*(4), 677-692.

Brown, M. A., & Powell-Cope, G. M. (1991). AIDS family caregiving: Transitions through uncertainty. *Nursing Research, 40*(6), 338-345.

Bugental, J. F. T. (1965). *The search for authenticity: An existential-humanistic approach to psychotherapy*. New York: Holt, Rinehart & Winston.

Bugental, J. F. T., & Kleiner, R. I. (1993). Existential Psychotherapies. In G. Stricker & J. R. Gold (Eds.), *Comprehensive handbook of psychotherapy integration* (pp. 101-112). New York: Plenum Press.

Bugermeister, J. (2003). Teacher was refused job because relatives have Huntington's disease. *BMJ, 327*(7419), 827.

Buhr, K., & Dugas, M. J. (2002). The intolerance of uncertainty scale: Psychometric properties of the English version. *Behavior Reserach and Therapy, 40*(8), 931-945.

Bunkers, S. S. (2007). The experience of feeling unsure for women at end-of-life. *Nursing Science Quarterly, 20*(1), 56-63.

Bunkers, S. S. (2010). A focus on human fluorishing. *Nursing Science Quarterly, 23*(4), 290-295.

Burke, W. (2002). Genetic testing. *New England Journal of Medicine, 347*(23), 1867-1875.

Burns, N. (1989). Standards for qualitative research. *Nursing Science Quarterly, 2*(1), 44-52.

Butcher, H. K., & McGonigal-Kenney, M. L. (2010). Living in the doldrums: The lived experience of dispiritedness in later life. *Research in Gerontological Nursing, 3*(3), 148-161.

Campodonico, J. R., Codori, A. M., & Brandt, J. (1996). Neuropsychological stability over two years in asymptomatic carriers of the Huntington's disease mutation. *Journal of Neurology, Neurosurgery, and Psychiatry, 61*(6), 621-624.

Carleton, R. N., Norton, M. A. P. J., & Asmundson, G. J. G. (2007). Fearing the unknown: A short version of the intolerance of uncertainty scale. *Journal of Anxiety Disorders, 21*, 105-117.

Carson, J. R. (1986). Closing the gap between research and practice: Conversation as a mode of doing research. *Phenomenology and Pedagogy, 4*(2), 73-85.

Chantrell, G. (Ed.). (2002). *The Oxford dictionary of word histories*. New York: Oxford University Press.

Chapman, E. (2002). Ethical dilemmas in testing for late onset conditions: Reactions to testing and perceived impact on other family members. *Journal of Genetic Counseling, 11*(5), 351-367.

Chodron, P. (2002). *Comfortable with uncertainty*. Boston, MA: Shambhala Publications, Inc.

Clarke, J., & Wheeler, S. (1992). A view of the phenomenon of caring in nursing practice. *Journal of Advanced Nursing, 17*, 1283-1290.

Clayton, E. W. (2003). Genomic medicine: Ethical, legal, and social implications of genomic medicine. *New England Journal of Medicine, 349*(6), 562-569.

Codori, A. M., & Brandt, J. (1994). Psychological costs and benefits of predictive testing for huntington's disease. *American Journal of Medical Genetics, 54*, 174-184.

Codori, A. M., Slavney, P. R., Young, C., Miglioretti, D. L., & Brandt, J. (1997). Predictors of psychological adjustment to genetic testing for Huntington's disease. *Health Psychology, 16*(1), 36-50.

Cohen, M. H. (1993). The unknown and the unknowable: Managing sustained uncertainty. *Western Journal of Nursing Research, 15*(1), 76-96.

Cohen, M. H. (1995a). The stages of the prediagnostic period in chronic, life-threatening childhood illness: A process analysis. *Research in Nursing & Health, 18*, 39-48.

Cohen, M. H. (1995b). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. *Qualitative Health Research, 5*(1), 63-77.

Cohen, M. Z., & Omery, A. (1994). Schools of phenomenology: Implications for research. In J. M. Morse (Ed.), *Critical Issues in Qualitative Research Methods* (pp. 136-156). California: Sage Publications.

Corbin, J. M., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass Publishers.

Cummings, J. L. (1995). Behavioral and psychiatric symptoms associated with Huntington's disease. *Advances in Neurology, 65*, 179-186.

Davis, J., Krasnewich, D., & Puck, J. M. (2000). Genetic testing and screening in pediatric populations. *Nursing Clinics of North America: Clinical Genetics, 35*(3), 643-650.

Dawson, S., Kristjanson, L. J., Toye, C. M., & Flett, P. (2004). Living with Huntington's disease: Need for supportive care. *Nursing & Health Sciences, 6*(2), 123-133.

de Witt, L., & Ploeg, J. (2006). Critical appraisal of rigour in interpretive phenomenological nursing research. *Journal of Advanced Nursing, 55*, 215-229.

Decruyenaere, M., Evers-Kiebooms, G., Boogaerts, A., Cassiman, J. J., Cloostermans, T., Demyttenaere, K., . . . Van Den Berghe, H. (1996). Prediction of psychological functioning one year after the predictive test for Huntington's disease and impact of the test result on reproductive decision making. *Journal of Medical Genetics, 33*(737-743).

Decruyenaere, M., Evers-Kiebooms, G., Boogaerts, A., Demyttenaere, K., Dom, R., & Fryns, J. (2005). Partners of mutation-carriers for Huntington's disease: Forgotten persons? *European Journal of Human Genetics, 13*, 1077-1085.

Decruyenaere, M., Evers-Kiebooms, G., Cloostermans, T., Boogaerts, A., Demyttenaere, K., Dom, R., & Fryns, J. P. (2004). Predictive testing for Huntington's disease: relationship with partners after testing. *Clinical Genetics, 65*(24-31).

Donovan-Kicken, E., & Bute, J. J. (2008). Uncertainty of social network members in the case of communication-debilitating illness or injury. *Qualitative Health Research, 18*(1), 5-18.

Downing, N. R., Williams, J. K., & Paulsen, J. S. (2010). Couples' attributions for work function changes in prodromal Huntington disease. *Journal of Genetic Counseling, 19*, 343-352.

Duff, K., Paulsen, J. S., Beglinger, L. J., Langbehn, D. R., Wang, C., Stout, J. C., . . . Predict-HD Investigators of the Huntington Study Group. (2010). "Frontal" behaviors before the diagnosis of Huntington's disease and their relationship to markers of disease progression: Evidence of early lack of awareness. *The Journal of Neuropsychiatry and Clinical Neurosciences, 22*, 196-207.

Duncan, R. E., Gillam, L., Savulescu, J., Williamson, R., Rogers, J. G., & Delatycki, M. B. (2008). "Youre one of us now:" Young people describe their expereinces of predictive genetic testing for huntington disease (HD) and familial adenomatous polyposis (FAP). *American Journal of Medical Genetic Part C, 148C*, 47-55.

Eimer, B., & Torem, M. S. (2002). *Coping with uncertainty: 10 simple solutions*. Oakland, CA: New Harbinger Publications, Inc.

Epstein, C. J. (2004). Genetic testing: Hope or hype? *Genetics in Medicine, 6*(4), 165-172.

Evers-Keibooms, G., & Decruyenaere, M. (1998). Predictive testing for Huntington's disease: A challenge for persons at risk and for professionals. *Patient Education and Counseling, 35*, 15-26.

Evers-Keibooms, G., Swerts, A., Cassiman, J. J., & Van Den Berghe, H. (1989). The motivation of at-risk individuals and their partners in deciding for or against predictive testing for Huntington's disease. *Clinical Genetics, 35*, 29-40.

Evers-Keibooms, G., Swerts, A., & Van Den Berghe, H. (1990). Partners of Huntington patients: Implications of the disease and opinions about predictive testing and prenatal diagnosis. *Genetic Counseling, 39*(1), 151-159.

Evers-Kiebooms, G., Welkenhuysen, M., Claes, E., Decruyenaere, M., & Denayer, L. (2000). The psychological complexity of predictive testing for late onset neurogenetic diseases and hereditary cancers: Implications for multidisciplinary counselling and for genetic education. *Social Science & Medicine, 51*(6), 831-841.

Falk, K., Swedberg, K., Gaston-Johansson, F., & Ekman, I. (2007). Fatigue is a prevalent and severe symptom associated with uncertainty and sense of coherence in patients with chronic heart failure. *European Journal of Cardiovascular Nursing, 6*, 99-104.

Folstein, S. E. (1989). *Huntington's disease: A disorder of families*. Baltimore: The John Hopkins University Press.

Folstein, S. E., Abbott, M. H., Chase, G. A., Jensen, B. A., & Folstein, M. F. (1983). The association of affective disorder with Huntington's disease in a case series and in families. *Psychological Medicine, 13*(3), 537-542.

Forrest, D. (1989). The experience of caring. *Journal of Advanced Nursing, 14*, 815-823.

Frankl, V. E. (2006). *Man's search for meaning* (I. Lasch, Trans.). Boston: Beacon Press.

Fromm, E. (1947). *Man for himself: An inquiry into the psychology of ethics*. New York: Rinehart & Company, Inc.

Geller, L. N., Alper, J. S., Billings, P. R., Barash, C. I., Beckwith, J., & Natowicz, M. R. (1996). Individual, family, and societal dimensions of genetic discrimination: A case study analysis. *Science and Engineering Ethics, 2*(1), 71-88.

Giorgi, A. (1970). The meaning of science in psychology. In A. Giorgi (Ed.), *Psychology as a human science: A phenomenologically based approach* (pp. 5-56). New York: Harper & Row.

Gleick, J. (1987). *Chaos: Making a new science*. New York: Penguin Books.

Gordon, K. (2003). The impermanence of being: Toward a psychology of uncertainty. *Journal of Humanistic Psychology, 43*(2), 96-117.

Gove, P. B., & Merriam-Webster Editorial Staff (Eds.). (1993). *Webster's third new international dictionary of the English language unabridged*. Springfield, Massachusetts: Merriam-Webster Inc.

Greene, B. (1999). *The elegant universe: Superstrings, hidden dimensions, and the quest for the ultimate theory*. New York: Vintage Books, A Division of Random House, Inc.

Gubrium, J. F. (1995). Taking stock. *Qualitative Health Research, 5*(3), 267-269.

Guirgescu, C., Penckofer, S., Maurer, M. C., & Bryant, F. B. (2006). Impact of uncertainty, social support, and prenatal coping on the psychological well-being of high-risk pregnant women. *Nursing Research, 55*, 356-365.

Gusella, J. F., Wexler, N. S., Conneally, P. M., Naylor, S. L., Anderson, M. A., Tanzi, R. E., . . . Martin, J. B. (1983). A polymorphic DNA marker genetically linked to Huntington's disease. *Nature, 306*(17), 234-238.

Hahn-Barma, V., Deweer, B., Durr, A., Dode, C., Feingold, J., Pillon, B., . . . Dubois, B. (1998). Are cognitive changes the first symptoms of Huntington's disease? A study of gene carriers. *Journal of Neurolology, Neurosurgery, and Psychiatry, 64*(2), 172-177.

Hamilton, J. M., Salmon, D. P., Corey-Bloom, J., Gamst, A., Paulsen, J. S., Jerkins, S., . . . Peavy, G. (2003). Behavioural abnormalities contribute to functional decline in Huntington's disease. *Journal of Neurology, Neurosurgery, and Psychiatry, 74*(1), 120-122.

Hans, M. B., & Koeppen, A. H. (1980). Huntington's chorea: Its impact on the spouse. *The Journal of Nervous and Mental Disease, 168*(4), 209-214.

Harper, P. (1996). *Huntington's disease: Major problems in neurology* (2nd ed.). London: WB Saunders.

Harper, P. S., & Jones, L. (2002). Huntington's Disease: Genetic and molecular studies. In G. Bates, P. Harper & L. Jones (Eds.), *Huntington's Disease* (pp. 113-158). New York: Oxford University Press.

Hayden, M. R. (1980). Social perspectives in Huntington's Chorea. *South African Medical Journal, 58*, 201-203.

Hayden, M. R. (1981). *Huntington's chorea*. New York: Springer-Verlag.

Hayes, P. A. (1997). *A Heideggerian hermeneutical analysis of the lived experience of nursing faculty teaching in a caring curriculum in the southeast United States.* PhD doctoral dissertation, Georgia State University.

Hayne, Y. M. (2003). Experiencing psychiatric diagnosis: Client perspectives on being named mentally ill. *Journal of Psychiatry, 10*, 722-729.

HDSA Center of Excellence at Hennepin County Medical Center. (n.d.). Facts about Huntington's disease Retrieved April 30, 2008, from www.hcmc.org/depts/hd/facts.htm

Heidegger, M. (1962). *Being and time* (J. Macquarrie & E. Robinson, Trans.). New York: Harper & Row.

Hilton, B. A. (1988). The phenomenon of uncertainty in women with breast cancer. *Issues in Mental Health Nursing, 9*, 217-238.

Hilton, B. A. (1992). Perceptions of uncertainty: Its relevance to life-threatening and chronic illness. *Critical Care Nurse, 12*(2), 70-73.

Hilton, B. A. (1994). The Uncertainty Stress Scale: Its development and psychometric properties. *Canadian Journal of Nursing Research, 26*(3), 15-30.

Ho, A. K., Sahakian, B. J., Brown, R. G., Barker, R. A., Hodges, J. R., Ane, M. N., . . . Consortium, N.-H. (2003). Profile of cognitive progression in early Huntington's disease. *Neurology, 61*(12), 1702-1706.

Hoffman, N. (1999). Understanding the neuropsychiatric symptoms of Huntington's disease. *Journal of Neuroscience Nursing, 31*(5), 309-313.

Huggins, M., Bloch, M., Wiggins, S., Adam, S., Suchowersky, O., Trew, M., . . . et al. (1992). Predictive testing for Huntington disease in Canada: Adverse effects and unexpected results in those receiving a decreased risk. *American Journal of Medical Genetics, 42*(4), 508-515.

Huntington's Disease Society of America. (2011). Clinical Trials Retrieved March 31, 2011, from http://www.hdsa.org/research/clinical-trials.html

International Huntington Association and the World Federation of Neurology Research Group on Huntington's Chorea. (1994). Guidelines for the molecular genetics predictive test in Huntington's disease. *Journal of Medical Genetics, 31*(7), 555-559.

Jeffers, S. (2003). *Embracing uncertainty: Breakthrough methods for achieving peace of mind when facing the unknown*. New York: St. Martin's Griffin.

Jorde, L. B., Carey, J. C., Bamshad, M. J., & White, R. L. (2006). *Medical Genetics* (3rd ed.). St. Louis: Mosby.

Kalman, M. (2007). *The principles of uncertainty*. New York: The Penguin Press.

Kaplan, M., & Kaplan, E. (2006). *Chances are: Adventures in probability*. New York: Viking: The Penguin Group.

Kaptein, A. A., Scharloo, M., Helder, D. I., Snoei, L., Van Kempen, G. M. J., Weinman, J., . . . Roos, R. A. (2007). Quality of life in couples living with Huntington's disease: The role of patients' and partners' illness perceptions. *Quality of Life Research, 16*, 793-801.

Kenen, R. H., & Schmidt, R. M. (1978). Stigmatization of carrier status: Social implications of heterozygote genetic screening programs. *American Journal of Public Health, 68*(11), 1116-1120.

Kent, A. (2004). Huntington's disease. *Nursing Standard, 18*(32), 45-51.

Kessler, S. (1993). Forgotten person in the Huntington disease family. *American Journal of Medical Genetics, 48*, 145-150.

Kiecolt-Glaser, J. K., McGuire, L., Robles, T. F., & Glaser, R. (2002). Psychoneuroimmunology: Psychological influences on immune function and health. *Journal of Consulting and Clinical Psychology, 70*(3), 537-547.

Kierkegaard, S. (1954). *Fear and trembling, and the sickness unto death* (W. Lowrie, Trans.). Garden City, NY: Doubleday.

Kierkegaard, S. (1957). *The concept of dread*. Princeton, NJ: Princeton University Press.

Kirkwood, S. C., Su, J. L., Conneally, M., & Foroud, T. (2001). Progression of symptoms in the early and middle stages of Huntington's disease. *Archives of Neurology, 58*(2), 273-278.

Kleinman, A. (2006). *What really matters: Living a moral life amidst uncertainty and danger*. New York: Oxford University Press, Inc.

Kremer, B., Goldberg, P., Andrew, S. E., Theilmann, J., Telenius, H., Zeisler, J., . . . Hayden, M. R. (1994). A worldwide study of the Huntington's disease mutation: The sensitivity and specificity of measuring CAG repeats. *The New England Journal of Medicine, 330*(20), 1401-1406.

Kuzel, A. J. (1999). Sampling in qualitative inquiry. In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research* (2nd ed., pp. 33-45). Thousand Oaks, Calif.: Sage Publications.

Langbehn, D. R., Brinkman, R. R., Falush, D., Paulsen, J. S., & Hayden, M. R. (2004). A new model for prediction of the age of onset and penetrance for Huntington's disease based on CAG length. *Clinical Genetics, 65*, 267-277.

Lapham, E. V., Kozma, C., & Weiss, J. O. (1996). Genetic discrimination: Perspectives of consumers. *Science, 274*(5287), 621-624.

Lawrence, N., & O'Connor, D. (1967). The primary phenomenon: Human existence. In N. Lawrence & D. O'Connor (Eds.), *Readings in existential phenomenology* (pp. 1-11). Englewood Cliffs, NJ: Prentice-Hall, Inc.

Lawson, K., Wiggins, S., Green, T., Adam, S., Bloch, M., Hayden, M., & Testing, T. C. C. S. o. P. (1996). Adverse psychological events occurring in the first year after predictive testing for Huntington's disease. *Journal of Medical Genetics, 33*(856-862).

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Pub. Co.

Leal-Pock, C. (1998). If he's the one who's sick, why do I feel like dying? In C. Leal-Pock (Ed.), *Faces of Huntington's* (pp. 22-26). Belleville, Ontario: Essence Publishing.

Lemaire, G. S. (2004). More than just menstrual cramps: Symptoms and uncertainty among women with endometriosis. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 33*(71-79).

Lemiere, J., Decruyenaere, M., Evers-Keibooms, G., Vandenbussche, E., & Dom, R. (2004). Cognitive changes in patients with Huntington's disease (HD) and asymptomatic carrers of the HD mutation--a longitudinal follow-up study. *Journal of Neurology, 251*(8), 935-942.

Lilani, A. (2005). Ethical issues and policy analysis for genetic testing: Huntington's disease as a paradigm for diseases with a late onset. *Human Reproduction and Genetic Ethics, 11*(2), 28-34.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, Calif.: Sage Publications.

Lindberg, C. A. (2004). *The Oxford American writer's thesaurus*. New York: Oxford University Press.

Little Brown and Company. (1996). *Bartlett's Roget's thesaurus* (1st ed.). Boston: Little Brown.

Lynch-Sauer, J. (1985). Using a phenomenological research method to study nursing phenomenon. In M. M. Leininger (Ed.), *Qualitative Research Methods in Nursing* (pp. 93-107). Orlando, FL: Grune & Stratton.

Macy, J., Gomes, M. E., & Kremer, J. (2000). The wisdom of uncertainty: Living with the Shambhala prophecy. *ReVision, 23*(2), 19-23.

Maputle, M. S. (2006). Becoming a mother: Teenage mothers' experiences of first pregnancy. *Curationis, 29*(2), 87-95.

Mast, M. E. (1995). Adult uncertainty in illness: A critical review of research. Including commentary by Mishel MH. *Scholarly Inquiry for Nursing Practice: An International Journal, 9*(1), 3-24.

Mattson, B., & Almqvist, E. W. (1991). Attitudes towards predictive testing in Huntington's disease: A deep interview study in Sweden. *Family Practice, 8*, 23-27.

May, R. (1961). The emergence of existential psychology. In R. May (Ed.), *Existential psychology* (pp. 11-51). New York: Random House.

May, R. (1983). *The discovery of being*. New York: Norton.

McCormick, K. M. (2002). A concept analysis of uncertainty in illness. *Journal of Nursing Scholarship, 34*(2), 127-131.

McGonigal-Kenney, M. L., Williams, J. K., Schutte, D. L., Hamilton, R., Rehak, D., Sparbel, K., & Jarmon, L. (2005). *Evidence of ambiguous loss experienced by families with Huntington disease*. Paper presented at the Poster presentation at Midwest Nursing Research Society 29th Annual Research Conference, Cincinnati, OH.

McNulty, K., Livneh, H., & Wilson, L. M. (2004). Perceived uncertainty, spiritual well-being, and psychosocial adaptation in individuals with multiple sclerosis. *Rehabilitation Psychology, 49*(2), 91-99.

Meiser, B., & Dunn, S. (2000). Psychological impact of genetic testing for Huntington's disease: An update of the literature. *Journal of Neurology, Neurosurgery, and Psychiatry, 69*(5), 574-578.

Merleau-Ponty, M. (1964). *The primacy of perception, and other essays on phenomenological psychology, the philosophy of art, history, and politics*. Evanston, IL: Northwestern University Press.

Merleau-Ponty, M. (1974). *Phenomenology of perception* (C. Smith, Trans.). New York: Humanities Press.

Merriam-Webster Inc. (2006). *Merriam-Webster's collegiate dictionary* (11th ed ed.). Springfield, Mass: Merriam-Webster, Inc.

Mindham, R. H. S., Steele, C., Folstein, M. F., & Lucas, J. (1985). A comparison of the frequency of major affective disorder in Huntington's disease and Alzheimer's disease. *Journal of Neurology, Neurosurgery, and Psychiatry, 48*(11), 1172-1174.

Mishel, M. H. (1981). The measurement of uncertainty in illness. *Nursing Research, 30*(5), 258-263.

Mishel, M. H. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship, 20*(4), 225-232.

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship, 22*(4), 256-262.

Mishel, M. H. (1993). Living with chronic illness: Living with uncertainty. In S. G. Funk, E. M. Tornquist, M. T. Champagne & R. A. Wiese (Eds.), *Key Aspects of Caring for the Chronically Ill: Hospital and Home* (pp. 46-58). New York: Springer Publishing Company.

Mishel, M. H. (1997). Uncertainty in acute illness. In J. J. Fitzpatrick & J. Norbeck (Eds.), *Annual review of nursing research : Volume 15, 1997*. New York: Springer.

Mishel, M. H. (1999). Uncertainty in chronic illness. In J. J. Fitzpatrick & J. Norbeck (Eds.), *Annual review of nursing research : Volume 17, 1999*. New York: Springer.

Mitchell, G. J., & Cody, W. K. (1992). Nursing knowledge and human science: Ontological and epistemological considerations. *Nursing Science Quarterly, 5*, 54-61.

Mitchell, G. J., & Cody, W. K. (1993). The role of theory in qualitative research. *Nursing Science Quarterly, 6*(4), 170-178.

Morris, W. (Ed.). (1971). *The American heritage dictionary of the English language.* New York: American Heritage Publishing Co., Inc.

Morrow, M. R. (2010). Feeling unsure: A universal lived experience. *Nursing Science Quarterly, 23*(4), 315-325.

Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research, 5*(2), 147-149.

Morse, J. M., & Penrod, J. (1999). Linking concepts of enduring uncertainty, suffering, and hope. *Image: Journal of Nursing Scholarship, 31*(2), 145-150.

Munhall, P. L., & Oiler, C. J. (Eds.). (1986). *Nursing research: A qualitative perspective.* Norwalk, CT: Appleton-Century-Crofts.

Nelson, J. P. (1996). Struggling to gain meaning: Living with the uncertainty of breast cancer. *Advances in Nursing Science, 18*(3), 59-76.

Neville, K. L. (2003). Uncertainty in illness: An integrative review. *Orthopaedic Nursing, 22*(3), 206-214.

Newman, M. (1986). *Health as expanding consciousness*. St. Louis: Mosby.

Newman, M. (1990). Newman's theory of health as praxis. *Nursing Science Quarterly, 3*(37-41).

Nichols, P. R. (2001). *Alzheimer's disease caregivers: Personal conflict and depression.* The George Washington U., US.

Nopoulos, P. C., Aylward, E. H., Ross, C. A., Mills, J. A., Langbehn, D. R., Johnson, H. J., . . . PREDICT-HD Investigators and Coordinators of the Huntington Study Group. (2011). Smaller intracranial volume in prodromal Huntington's disease: evidence for abnormal neurodevelopment. *Brain, 134*, 137-142.

Northouse, L., Templin, T., & Mood, D. (2001). Couples' adjustment to breast disease during the first year following diagnosis. *Journal of Behavioral Medicine, 24*(2), 115-136.

Northouse, L. L., Mood, D., Kershaw, T., Schafenacker, A., Mellon, S., Walker, J., . . . Decker, V. (2002). Quality of life of women with recurrent breast cancer and their family members. *Journal of Clinical Oncology, 20*(19), 4050-4064.

Northouse, L. L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science & Medicine, 50*, 271-284.

Northouse, L. L., Mood, D. W., Montie, J. E., Sandler, H. M., Forman, J. D., Hussain, M., . . . Kershaw, T. (2007). Living with prostate cancer: Patients' and spouses' psychosocial status and quality of life. *Journal of Clinical Oncology, 25*, 4171-4177.

Oiler, C. (1982). The phenomenological approach in nursing research. *Nursing Research, 31*(3), 178-181.

Omery, A. (1983). Phenomenology: A method for nursing research. *Advances in Nursing Science, 5*(2), 49-63.

OMIM. (2011). Huntington disease. Retrieved March 21, 2011 www.ncbi.nlm.nih.gov/omim

Onions, C. T. (Ed.). (1966). *The Oxford dictionary of English etymology*. London: Oxford University Press.

Osborne, J. P., Munson, P., & Burman, D. (1982). Huntington's chorea: Report of 3 cases and review of the literature. *Archives of Disease in Childhood, 57*, 99-103.

The Oxford English Dictionary. (1989) (2nd ed.). Oxford: Clarendon Press.

Parse, R. R. (1987). *Nursing science: Major paradigms, theories, and critiques*. Philadelphia: Saunders.

Parse, R. R. (1998). *The human becoming school of thought: A perspective for nurses and other health professionals.* Thousand Oaks, CA: Sage.

Parse, R. R. (2001). *Qualitative inquiry : The path of sciencing*. Sudbury, MA: Jones and Bartlett Publishers.

Parse, R. R., Coyne, A. B., & Smith, M. J. (1985). *Nursing research: Qualitative methods*. Bowie, MD: Brady Communications Company.

Paterson, J. G., & Zderad, L. T. (1988). *Humanistic nursing*. New York: National League for Nursing.

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, Calif.: Sage Publications.

Paulsen, J. S. (2010). Early detection of Huntington's disease. *Future Neurology, 5*, 85-104.

Paulsen, J. S., & Conybeare, R. A. (2005). Cognitive changes in Huntington's disease. *Advanced Neurology, 96*, 209-225.

Paulsen, J. S., Hayden, M., Stout, J. C., Langbehn, D. R., Aylward, E., Ross, C. A., . . . Predict-HD Investigators of the Huntington Study Group. (2006). Preparing for preventive clinical trials: The PREDICT-HD study. *Archives of Neurology, 63*, 883-890.

Paulsen, J. S., Hoth, K. F., Nehl, C., & Stierman, L. (2005). Critical periods of suicide risk in Huntington's disease. *The American Journal of Psychiatry, 162*(4), 725-731.

Paulsen, J. S., Langbehn, D. R., Stout, J. C., Aylward, E., Ross, C. A., Nance, M., . . . Predict-HD Investigators and Coordinators of the Huntington Study Group. (2008). Detection of Huntington's disease decades before diagnosis: The Predict-HD study. *Journal of Neurology, Neurosurgery, and Psychiatry, 79*(8), 874-880.

Paulsen, J. S., Nehl, C., Hoth, K. F., Kanz, J. E., Benjamin, M., Conybeare, R., . . . The Huntington Study Group. (2005). Depression and stages of Huntington's disease. *The Journal of Neuropsychiatry and Clinical Neurosciences, 17*(4), 496-502.

Paulsen, J. S., Zhao, H., Stout, J. C., Brinkman, R. R., Guttman, M., Ross, C. A., . . . The Huntington Study Group. (2001). Clinical markers of early disease in persons near onset of Huntington's disease. *Neurology, 57*(4), 658-662.

Pelletier-Hibbert, M., & Sohi, P. (2001). Sources of uncertainty and coping strategies used by family members of individuals living with end stage renal disease. Including commentary by Brunier G with author response. *Nephrology Nursing Journal, 28*(4), 411-419.

Penrod, J. (2001a). The advancement of the concept of uncertainty using phenomenological methods (Doctoral dissertation). ProQuest Dissertations & Theses (PQDT) http://search.proquest.com/docview/251422142?accountid=14663

Penrod, J. (2001b). Refinement of the concept of uncertainty. *Journal of Advanced Nursing, 34*(2), 238-245.

Penrod, J. (2007). Living with uncertainty: Concept advancement. *Journal of Advanced Nursing, 57*, 658-667.

Penrod, J., & Hupcey, J. E. (2005). Concept advancement: Extending science through concept-driven research. *Research and Theory for Nursing Practice: An International Journal, 19*(3), 231-241.

Phillips, J. (2000). *God is at eye level: Photography as a healing art.* Wheaton, IL: Theosophical Publishing House.

Polkinghorne, D. (1983). *Methodology for the human sciences: Systems of inquiry.* Albany: State University of New York Press.

Porter, E. J. (1994). "Reducing my risks": A phenomenon of older widows' lived experience. *Advances in Nursing Science, 17*(2), 54-65.

QSR NUD*IST NVivo. (1999) [Computer software]. Victoria, Australia: Qualitative Solutions and Research Pty. Ltd.

Quaid, K. A., & Wesson, M. K. (1995). Exploration of the effects of predictive testing for Huntington disease on intimate relationships. *American Journal of Medical Genetics, 57*(1), 46-51.

Quarrell, O. (2002). *Huntington's disease: The facts* (2nd ed.). New York, NY: Oxford University Press.

Ray, M. (1985). A philosophical method to study nursing phenomena. In M. M. Leininger (Ed.), *Qualitative research methods in nursing* (pp. 81-92). Orlando, Fla.: Grune & Stratton.

Ray, M. (1994). The richness of phenomenology: Philosophic, theoretic, and methodologic concerns. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 117-135). Thousand Oaks: Sage Publications.

Reich, J. W., Johnson, L. M., Zautra, A. J., & Davis, M. C. (2006). Uncertainty of illness relationships with mental health and coping processes in fibromyalgia patients. *Journal of Behavioral Medicine, 29*, 307-316.

Reich, J. W., Olmsted, M. E., & van Puymbroeck, C. M. (2006). Illness uncertainty, partner caregiver burden and support, and relationship satisfaction in fibromylagia and osteoarthritis patients. *Arthritis & Rheumatism, 55*, 86-93.

Richards, F. (2004). Couples' experiences of predictive testing and living with the risk or reality of Huntington disease: A qualitative study. *American Journal of Medical Genetics, 126A*, 170-182.

Richards, F., & Williams, K. (2004). Impact on couple relationships of predictive testing for Huntington Disease: A longitudinal study. *American Journal of Medical Genetics, 126A*, 161-169.

Riemen, D. (1986). Noncaring and caring in the clinical setting: Patients' descriptions. *Topics in Clinical Nursing, 8*, 30-36.

Riemen, D. J. (1986). The essential structure of a caring interaction: Doing phenomenology. In P. L. Munhall & C. J. Oiler (Eds.), *Nursing research: A qualitative perspective* (pp. pp. 85-108). Norwalk, CT: Appleton-Century-Crofts.

Ring, H. A., & Serra-Mestres, J. (2002). Neuropsychiatry of the basal ganglia. *Journal of Neurology, Neurosurgery, and Psychiatry, 72*(1), 12-21.

Rolland, J. S., & Williams, J. K. (2005). Toward a biopsychosocial model for 21st-century genetics. *Family Process, 44*(1), 3-24.

Rose, J. F. (1990). Psychologic health of women: A phenomenologic study of women's inner strength. *Advances in Nursing Science, 12*(2), 56-70.

Rosenblatt, A., Brinkman, R. R., Liang, K. Y., Almqvist, E. W., Margolis, R. L., Huang, C. Y., . . . Ross, C. A. (2001). Familial influence on age of onset among siblings with Huntington disease. *American Journal of Medical Genetics, 8*, 399-403.

Rosenblatt, A., & Ranen, N. G. (1999). *A physician's guide to the management of Huntington's disease* (2nd ed.). New York: Huntington's Disease Society of America.

Saab, P. G., McCalla, J. R., Christensen, A. J., Johnson, S. B., Stepanski, E., Coons, H. L., . . . Melamed, B. (2004). Technological and medical advances: Implications for health psychology. *Health Psychology, 23*(2), 142-146.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*, 27-37.

Santacroce, S. J., & Lee, Y. L. (2006). Uncertainty, posttraumatic stress, and health behavior in young adult childhood cancer survivors. *Nursing Research, 55*, 259-266.

Sartre, J. (1956). *Being and Nothingness* (H. E. Barnes, Trans.). New York: Washington Square Press.

Seidman-Carlson, R., & Wells, D. L. (1998). The ability to comprehend affective communication in individuals with Huntington's disease. *Journal of Gerontological Nursing, 24*(12), 16-23.

Snell, R. G., MacMillan, J. C., Cheadle, J. P., Fenton, I., Lazarou, L. P., Davies, P., . . . Shaw, D. J. (1993). Relationship between trinucleotide repeat expansion and phenotypic variation in Huntington's disease. *Nature Genetics, 4*, 393-397.

Sobel, S., & Cowan, C. B. (2003). Ambiguous loss and disenfranchised grief: The impact of DNA predictive testing on the family as a system. *Family Process, 42*(1), 47-57.

Sobel, S., & Cowan, D. B. (2000a). Impact of genetic testing for Huntington Disease on the family system. *American Journal of Medical Genetics, 90*, 49-59.

Sobel, S., & Cowan, D. B. (2000b). The process of family reconstruction after DNA testing for Huntington disease. *Journal of Genetic Counseling, 9*(3), 237-251.

Sowell, R., Bramlett, M., Gueldner, S., Gritzmacher, D., & Martin, G. (1991). The lived experience of survival and bereavement following the death of a lover from AIDS. *Image, 23*, 89-94.

Spears, R. A. (2005). *McGraw-Hill's dictionary of American idioms and phrasal verbs*. New York: McGraw-Hill.

Spears, R. A. (Ed.). (2000). *NTC's American idioms dictionary: The most practical reference for the everyday expressions of contemporary American English* (3rd ed.). Chicago: NTC Publishing Group.

Sutherland, F. (Ed.). (1997). *Random House Webster's College Thesaurus*. New York: Random House.

Taylor, C. A., & Myers, R. H. (1997). Long-term impact of Huntington disease linkage testing. *American Journal of Medical Genetics, 70*, 365-370.

Taylor-Walton, C. (1989). *Life is hard: A phenomenological study of homeless women diagnosed as chronically mentally ill.* PhD doctoral dissertation, Texas Woman's University.

Teel, C. S., & Carson, P. (2003). Family experiences in the journey through dementia diagnosis and care. *Journal of Family Nursing, 9*(1), 38-58.

The Huntington's Disease Collaborative Research Group. (1993). A novel gene containing a trinucleotide repeat that is expanded and unstable on Huntington's disease chromosomes *Cell, 72*(6), 971-983.

Tibben, A. (2007). Predictive testing for Huntington's disease. *Brain Research Bulletin, 72*, 165-171.

Tibben, A., Duivenvoorden, H. J., Niermeijer, M. F., Vegter-van der Vlis, M., Roos, R. A., & Verhage, F. (1994). Psychological effects of presymptomatic DNA testing for Huntington's disease in the Dutch program. *Psychosomatic Medicine, 56*(6), 526-532.

Tibben, A., Duivenvoorden, H. J., Vegter-van der Vlis, M., Niermeijer, M. F., Frets, P. G., van de Kamp, J. J. P., . . . Verhage, F. (1993). Presymptomatic DNA testing for Huntington disease: Identifying the need for psychological intervention. *American Journal of Medical Genetics, 48*(3), 137-144.

Tibben, A., Frets, P. G., van de Kamp, J. J. P., Niermeijer, M. F., Vegter-van der Vlis, M., Roos, R. A., . . . Verhage, F. (1993). Presymptomatic DNA-testing for Huntington disease: Pretest attitudes and expectations of applicants and their partners in the Dutch program. *American Journal of Medical Genetics, 48*, 10-16.

Tibben, A., Frets, P. G., van de Kamp, J. J. P., Niermeijer, M. F., Vegter-van der Vlis, M., Roos, R. A. C., . . . Verhage, F. (1993). On attitudes and appreciation 6 months after predictive DNA testing for Huntington disease in the Dutch program. *American Journal of Medical Genetics, 48*(2), 103-111.

Tibben, A., Frets, P. G., van de Kamp, J. J. P., Niermeijer, M. F., Vegtervan der Vlis, M., Roos, R. A., . . . Verhage, F. (1993). On attitudes and appreciation 6 months after predictive DNA testing for Huntington disease in the Dutch program. *American Journal of Medical Genetics, 48*, 103-111.

Tibben, A., Timman, R., Bannink, E. C., & Duivenvoorden, H. J. (1997). Three-year follow-up after presymptomatic testing for Huntington's disease in tested individuals and partners. *Health Psychology, 16*(1), 20-35.

Tibben, A., Vegter-van der Vlis, M., Skraastad, M. I., Frets, P. G., van de Kamp, J. J. P., Niermeijer, M. F., . . . Verhage, F. (1992). DNA testing for Huntington's disease in the Netherlands: A retrospective study on psychosocial effects. *American Journal of Medical Genetics, 44*(1), 94-99.

Timman, R., Claus, H., Slingerland, H., van der Schalk, M., Demeulenaere, S., Roos, R. A. C., & Tibben, A. (2005). Nature and development of Huntington disease in a nursing home population: The behavior Observation Scale Huntington (BOSH). *Cognitive Behavioral Neurology, 18*, 215-222.

Timman, R., Maat-Kievit, A., Roos, R., & Tibben, A. (2004). Adverse effects of predictive testing for Huntington disease underestimated: Long-term effects 7-10 years after the test. *Health Psychology, 23*(2), 189-197.

Tost, H., Wendt, C. S., Schmitt, A., Heinz, A., & Braus, D. F. (2004). Huntington's disease: Phenomenological diversity of a neuropsychiatric condition that challenges traditional concepts in neurology and psychiatry. *The American Journal of Psychiatry, 161*(1), 28-34.

Trice, L. (1990). Meaningful life experience to the elderly. *Image, 22*, 248-251.

Turner, J. A. (1999). *The experience of multiple AIDS-related loss in persons with HIV disease: a Heideggarian hermeneutic analysis (immune deficiency).* PhD doctoral dissertation, Georgia State University

Tyler, A., Harper, P. S., Davies, K., & Newcome, R. G. (1983). Family break-down and stress in Huntington's Chorea. *Journal of Biosocial Science, 15*, 127-138.

Ullah, M., & Wolkenhauer, O. (2010). Stochastic approaches in systems biology. *Wiley Interdisciplinary Reviews: Systems Biology and Medicine, 2*, 385-397.

Vamos, M., Hambridge, J., Edwards, M., & Conaghan, J. (2007). The impact of Huntington's disease on family life. *Psychosomatics, 48*(5), 400-404.

van Kaam, A. (1959). Phenomenological analysis: Exemplified by a study of the experience of being really understood. *Individual Psychology, 15*, 66-72.

van Manen, M. (1984). Practicing phenomenological writing. *Phenomenology and Pedagogy, 2*(1), 36-69.

van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, N.Y.: State University of New York Press.

van Manen, M. (1997). From meaning to method. *Qualitative Health Research, 7*(3), 345-369.

van Swieten, J. C., Rosso, S. M., & Heutnik, P. (2010, October 26). MAPT-Related disorders Retrieved March 30, 2010, from http://www.genetests.org

Walker, F. O. (2007). Huntington's disease. *Seminars in Neurology, 27*(2), 143-150.

Wallace, M. (2005). Finding more meaning: The antecedents of uncertainty revisited. *Journal of Clinical Nursing, 14*, 863-868.

Walters, A. J. (1995). The phenomenological movement: Implications for nursing research. *Journal of Advanced Nursing, 22*, 791-799.

Walton, J., & Madjar, I. (1999). Phenomenology and nursing. In I. Madjar & J. Walton (Eds.), *Nursing and the experience of illness: Phenomenology in practice* (pp. 1-16). London: Routledge.

Wang, C., Gonzalez, R., & Merajver, S. D. (2004). Assessment of genetic testing and related counseling services: current research and future directions. *Social Science & Medicine, 58*, 1427-1442.

Warby, S. C., Graham, R. K., & Hayden, M. R. (2010). Huntington disease. Retrieved from http://www.genetests.org

Wasmuth, J. J., Hewitt, J., Smith, B., Allard, D., Haines, J. L., Skarecky, D., . . . Hayden, M. R. (1988). A highly polymorphic locus very tightly linked to the Huntington's disease gene. *Nature, 332*(21), 734-736.

Watson, J. (1985). *Nursing: Human science and human care*. Norwalk, CT: Appleton-Century-Crofts.

Welch, H. G., & Burke, W. (1998). Uncertainties in genetic testing for chronic disease. *JAMA, 280*(17), 1525-1527.

Wiener, C. L., & Dodd, M. J. (1993). Coping amid uncertainty: An illness trajectory perspective. *Scholarly Inquiry for Nursing Practice: An International Journal, 7*, 17-31.

Wiggins, S., Whyte, P., Huggins, M., Adam, S., Theilmann, J., Bloch, M., . . . Hayden, M. R. (1992). The psychological consequences of predictive testing for Huntington's disease. Canadian Collaborative Study of Predictive Testing. *New England Journal of Medicine, 327*(20), 1401-1405.

Williams, J. K., Erwin, C., Juhl, A., Mills, J., Brossman, B., Paulsen, J. S., & I-RESPOND-HD Investigators of the Huntington Study Group. (2010). Personal factors associated with reported benefits of Huntington disease family history or genetic testing. *Genetic Testing and Molecular Biomarkers, 14*(5), 629-636.

Williams, J. K., Hamilton, R., Nehl, C., McGonigal-Kenney, M., Schutte, D. L., Sparbel, K., . . . Paulsen, J. (2007). "No one else sees the difference:" Family members' perceptions of changes in persons with preclinical Huntington disease. *American Journal of Medical Genetics Part B (Neuropsychiatric Genetics), 144B*, 636-641.

Williams, J. K., Hamilton, R., Sparbel, K., Schutte, D. L., McGonigal-Kenney, M. L., Rehak, D., . . . Jarmon, L. (2005). What happens when HD caregivers seek help. *Poster presentation at Midwest Nursing Research Society 29th Annual Research Conference*.

Williams, J. K., Paulsen, J. S., Schutte, D. L., & Tripp-Reimer, T. (2001). Family Health After Predictive HD Testing: National Institutes of Health, National Institute of Nursing Research.

Williams, J. K., & Schutte, D. L. (2000). Genetic testing and mental health: The model of Huntington disease. *Online Journal of Issues in Nursing, 5*(3), 19.

Williams, J. K., Schutte, D. L., Evers, C., & Holkup, P. A. (2000). Redefinition: Coping with normal results from predictive gene testing for neurodegenerative disorders. *Research in Nursing & Health, 23*(4), 260-269.

Williams, J. K., Schutte, D. L., Holkup, P. A., Evers, C., & Muilenburg, A. (2000). Psychosocial impact of predictive testing for Huntington disease on support persons. *American Journal of Medical Genetics, 96*(3), 353-359.

Williams, J. K., Skirton, H., Paulsen, J. S., Tripp-Reimer, T., Jarmon, L., McGonigal-Kenney, M., . . . Honeyford, J. (2009). The emotional experiences of family carers in Huntington disease. *Journal of Advanced Nursing, 65*(4), 789-798.

Witjes-Ane, M. N. W., Zwinderman, A. H., Tibben, A., van Ommen, G. J. B., & Roos, R. A. C. (2002). Behavioural complaints in participants who underwent predictive testing for Huntington's disease. *Journal of Medical Genetics, 39*(11), 857-862.

Wolfe, L. (2008). Finding a heart. *O: The Oprah Magazine, 9,* 149-156.

Yalom, I. D. (1980). *Existential psychotherapy*. New York: Basic Books.