HOW PEOPLE WITH MITOCHONDRIAL DISORDERS
CONSTRUCT KNOWLEDGE WITHIN THE
HEALTH CARE RELATIONSHIP:
A NARRATIVE INQUIRY

by

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June 2003

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ABSTRACT

Mitochondrial disease is an inborn error of metabolism that has a wide variety of manifestations. Because it is difficult to diagnose, people may live with the disorder without medical answers for many years. During this time, they struggle to have their personal knowledge about their bodies accepted and validated in the health care system. Once the disorder is diagnosed, there is no cure and few effective treatments.

Narrative inquiry, a qualitative research method, was employed to explore how adults with mitochondrial disease construct knowledge about their disorder and how they use it within the health care relationship. Thirteen people were interviewed. The content, structure, interpersonal factors, and context of their narratives were analysed to interpret overall meaning. One main narrative, “you can’t sit back and be the patient”, and two sub-narratives, “there was no magic out there” and “now I’m the educator” emerged from participants’ stories. Many narratives were composed of a combination of the two sub-narratives. Some individuals only told “there was no magic out there” stories.

“You can’t sit back and be the patient” represents the awareness that mitochondrial disease is not widely known or understood by health care professionals or the general public. Individuals realized that the traditional concept of ‘patient’ did not apply to mitochondrial disease and that it therefore required reconceptualization. The shared sub-narratives embodied their reactions to this realization. “There was no magic out there” is the classic chaos story, replete with complications and void of action. These stories were told by individuals who were overwhelmed by their circumstances. “Now I’m the educator” is the classic story of quest. These individuals created negotiated knowledge
from their formal, experiential, and bodily knowledge to manage uncertainty and self-advocate in the health care system.

The findings had several implications for changes in practice including patient education, health care professional education, and model of care. Overall, the findings indicate that what is needed is a paradigm shift in what counts as knowledge, reducing feelings of frustration, vulnerability, and uncertainty within the health care relationship and improving the quality of life for individuals with mitochondrial disease.
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DEDICATION

This thesis is dedicated to my husband Chris, whose unwavering support over the past three years has made it possible for me to complete this master’s degree. For always knowing just what I needed to make life a little easier and for believing in me, thank you. Your generosity of spirit and selflessness are a constant source of inspiration and I am lucky beyond measure to have you in my life.

From the bottom of my heart,

Thank you Chris.
ACKNOWLEDGEMENTS

I wish to acknowledge the many people without whose guidance and support this project would not have become a reality.

Thank you to my Mom for not only smoothing my transition from ‘new mother’ back to ‘student’, but for always being interested in and supportive of my work.

Thank you to my committee: Kjell, for tirelessly coaching me to reduce the ‘jungle of data’ into meaningful parts so that the findings could emerge; Dan, for challenging my concepts of learning and knowledge; and Barbara, for enriching my understanding of chronic illness and for helping me turn my chaos story into one of quest. Thank you all for your guidance, generosity in time, patience, and encouragement.

Thank you to Sandra Sirrs, the medical director of the Adult Metabolic Diseases Clinic, for your constant support, facilitation, and encouragement of this endeavour and for always being an exemplary mentor.

Above all, thank you to the participants of this study, who, by sharing your stories so willingly with me, opened a window between your world and ours.

My heartfelt gratitude to each and every one of you.
This thesis will tell the story of a “long lost” citizen of a foreign country, brought up in a place void of their native tongue or culture. The few words they have learned from the media and from schooling by no means make them fluent in the language. Strange things begin to happen to them that make them question where they belong. In their quest to find their rightful home, they are doubted and discounted. Furthermore, attempts to get a visa to the country of their birth are futile; the country officials do not recognize their reasons for wanting to emigrate as valid. Finally, someone admits them into the country and grants them citizenship. Now that they live in the country, they struggle to learn the language so that they can make sense of the customs and the meaning of living in this new country. The visa is helpful in their dealings with some of the more suspicious officials and other citizens, however, it still is not obvious to all why and how they got into the country in the first place. Doubt prevails. The person finds him or herself in the tiresome position of having to tell their story again and again. Sometimes officials are sympathetic and understanding and sometimes they are not. Sometimes the person’s reasons for getting into the country are obvious and sometimes they are not. Subsequently, the person feels vulnerable. They continue to try to better their knowledge of the language and to get more information, but this proves to be a monumental challenge. They are very tired after a very long journey and feel brow-beaten from being doubted so much along the way.
CHAPTER ONE: INTRODUCTION

This thesis is a narrative inquiry into how people with mitochondrial disease construct knowledge about their disorder and how they use this knowledge within the health care relationship. This chapter will provide background to the problem, the purpose for this research study, and assumptions made. I will conclude with an outline of the following chapters.

Background to the problem

There are approximately 1300 different inborn errors of metabolism, including mitochondrial disorders. Mitochondria are tiny cucumber-shaped structures that exist in all cells of the body except red blood cells and, depending on the energy requirements of the cell type they are serving, can number up to 1000 (Thorburn & Dahl, 2001). For instance, muscle cells have a higher proportion of mitochondria than hair cells. Mitochondria are widely believed to have been independent creatures that were adopted into our cells millions of years ago. Today, mitochondria are thought to be the indispensable batteries of the body, supplying the body cells with energy. The energy production of mitochondria can be compared to an industrial town full of power plants. When the mitochondria do not function properly, it is comparable to half the power plants being shut down. People with mitochondrial disease therefore run on ‘low power’ most of the time and fatigue very quickly.

Mitochondrial disease can affect “any disease, any organ, any age” (Christodoulou, 1999) and has been estimated to affect 1 in approximately 8500 North Americans (Chinnery & Turnbull, 2001, p. 99). Mitochondria have their own DNA and therefore their own genetic code. After fertilization, the mitochondrial DNA contained in sperm is
actively eliminated (DiMauro & Schon, 2001). Therefore, both mitochondrial DNA and most mitochondrial DNA-related diseases are inherited from the mother (Thorburn & Dahl, 2001). Mitochondrial dysfunction can also be acquired after birth, caused by environmental toxins, including pharmaceuticals, or due to the aging process (Dahl & Thorburn, 2001).

The manifestations of the disorders are diverse (Cohen & Gold, 2001). “Although the underlying characteristics of all of them is lack of adequate energy to meet cellular needs, they vary considerably from disease to disease and from case to case in their effects on different organ systems, age at onset, and rate of progression, even within families whose members have identical genetic mutations” (Cohen & Gold, 2001, p. 626). Many problems such as migraine headaches, Parkinson’s, Alzheimer’s, diabetes, and autism are now believed to be linked to mitochondrial dysfunction (Dahl & Thorburn, 2001; Travis, 1995).

In general, people diagnosed in adulthood initially seek medical attention because of pain, muscle fatigue, and cramping (Cohen & Gold, 2001). Other manifestations include droopy eyelids or “ptosis”, hearing loss, cardiac disease, depression, and diabetes (see Table 1 for a complete list of problems that are associated with mitochondrial disease). Illness, general anaesthetic, and stress tax the already limited energy reserves of people with mitochondrial disease.

The disorders are generally difficult to diagnose and often mimic other conditions like multiple sclerosis, chronic fatigue syndrome, and fibromyalgia (Cohen & Gold, 2001). A person may live with the disorder and without medical answers for many years before a diagnosis is made.
<table>
<thead>
<tr>
<th>Organ System</th>
<th>Possible Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Muscles</td>
<td>Hypotonia (low muscle tone), weakness, cramping, muscle pain, ptosis, ophthalmoplegia (decreased power to the muscles that move the eyeballs, making eyeballs immobile)</td>
</tr>
<tr>
<td>Brain</td>
<td>Developmental delay, mental retardation, autism, dementia, seizures, neuropsychiatric disturbances, atypical cerebral palsy, atypical migraines, stroke and stroke-like events</td>
</tr>
<tr>
<td>Nerves</td>
<td>Nerve pain and weakness (which may be intermittent), fainting, absent or excessive sweating, aberrant temperature regulation, neuropathic gastrointestinal problems</td>
</tr>
<tr>
<td>Kidneys</td>
<td>Loss of protein, magnesium, phosphorus, calcium and other electrolytes through kidneys as a result of Fanconi syndrome</td>
</tr>
<tr>
<td>Heart</td>
<td>Heart blocks, cardiomyopathy (muscle wasting in the heart)</td>
</tr>
<tr>
<td>Liver</td>
<td>Hypoglycemia (low blood sugar), nonalcoholic liver failure, problems with gluconeogenesis (biosynthesis of sugar in the body)</td>
</tr>
<tr>
<td>Eyes</td>
<td>Optic neuropathy and retinitis pigmentosa</td>
</tr>
<tr>
<td>Ears</td>
<td>Hearing loss, sensitivity to the drug class aminoglycosides</td>
</tr>
<tr>
<td>Pancreas</td>
<td>diabetes</td>
</tr>
<tr>
<td>systemic</td>
<td>Failure to gain weight, short stature, fatigue, respiratory problems including intermittent air hunger</td>
</tr>
</tbody>
</table>
Patients may be dismissed as hypochondriacs, complainers, or as having psychiatric problems. Once the disorder is diagnosed, there is no cure and very few available treatments.

Many people have been referred to the Adult Metabolic Diseases Clinic (AMDC), Vancouver, British Columbia as the ‘last stop’ on their arduous journey to determine the cause of their symptoms. Many have been struggling to be diagnosed for an average of ten years. Once the disease is diagnosed, uncertainty still abounds. The prognosis and disease course are unknown. It has been my experience as a metabolic nurse educator, that although people are happy to have a name for the symptoms they have been experiencing, they are frustrated that nothing can be done and that there are no real answers beyond diagnosis. They often describe social withdrawal as a result of not being able to effectively explain their disorder and the variability of its symptoms to others. On a daily basis, therefore, people with mitochondrial disease struggle to find ways to manage their chronic illness, enhance their quality of life, and to make themselves understood.

Because awareness of this disease is a relatively new phenomenon to the medical community, research interests have focused on causes, effects, and treatments (e.g. Chinnery & Turnbull, 2001; Cohen & Gold, 2001; DiMauro & Hirano, 1998; DiMauro & Schon, 1998; Koga, Ishibashi, Ueki, Yatsuga, Fukiyama, Akita, & Atsuishi, 2002; Munnich & Rustin, 2001; Shanske & DiMauro, 1997). The experience of living with mitochondrial disease has not been explored and is therefore not well-understood by health professionals. In her book, Negotiating health care: The social context of chronic illness, Thorne (1993) demonstrated that people with chronic illness, like mitochondrial
disease, have a very different experience than those with acute illness. To get what they need from the health care system, they often actively educate themselves to build a body of knowledge about their disorder.

Unlike more common chronic illnesses such as diabetes, HIV/AIDS, multiple sclerosis, and cystic fibrosis, mitochondrial diseases have not gained national recognition and therefore educational supports and resources are not plentiful. As a result, there is very little easily accessible information available to this group and subsequently, they depend on their lived experience, information they gather from the Internet, patient conferences, and chat groups to construct their knowledge, as opposed to more traditional ways of learning about a disorder such as the workshops offered to people with diabetes (Rickheim, Weaver, Flader, & Kendall, 2002).

People with mitochondrial disease are susceptible to the same maladies and ailments commonly found in the rest of the population, such as diabetes, heart disease, and arthritis. These general health concerns (i.e. those other than the problems related to the metabolic disorder) are best addressed by the family physician. It has been our experience, however, that people feel more comfortable accessing the AMDC for these common ailments instead, because they generally mistrust the judgements of their family physicians. This presents a problem on three accounts. Firstly, our waiting list is long and our patient population is exploding, leaving little time to address issues not directly related to the mitochondrial dysfunction. Secondly, we are not as accessible to the person as their family physician. Thirdly, unlike the family physicians, the ‘general practitioners’, we are not specialists in general ailments. One might surmise that because of the rare nature of this disorder, the family physician does not know as much about the
disorder as the patient does. Thus, the patient is often in the position to educate the doctor. The potential for risk in this reverse transmission of knowledge is that the person may misrepresent the disorder as the cause of a number of actual unrelated conditions such as diabetes and heart disease. For instance, they may tell the physician, that the diabetes caused by their mitochondrial dysfunction differs from the kind of diabetes found in the general population\(^1\). This may lead the physician to believe that the patient is not as susceptible to the dangers of high blood sugars and thus not act accordingly to help the patient maintain their blood sugars within the safe range. Because the patients often do know more than their doctors about their disorders, the family physician may accept the conclusions of the patient instead of pursuing the diagnosis of ‘normal things’. What could potentially result then, is harm to the patient.

By beginning to uncover how people with mitochondrial disorders learn about their disorder and how they use the knowledge as a tool within the health care relationship, practitioners can begin to understand their experience. This may in turn lead to an understanding of how lay and professional knowledge effectively overlap and inform each other and how we as health care providers can best help people with mitochondrial disorders to build a body of knowledge that is credible and that will ensure safe care.

Thorne (1993) found that many people with chronic illnesses expected recognition and acceptance of their experiential knowledge as legitimate and valuable within the health care relationship. This acknowledgement has been shown to lead to “reciprocal trust in health care relationships”, potentially resulting in better health outcomes (Thorne & Robinson, 1988). Learning constitutes a process of constructing knowledge within a

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\(^1\) What is important to note is that many diseases, such as diabetes, may result from a number of causes, but have the same treatment.
web of power, language, and social interactions. Thorne (1993) describes this “social context of chronic illness”, as shaping patients’ experiences in significant ways. How, then, do individuals with mitochondrial disorders build personal knowledge about their disease? From their perspective, how does their knowledge and that of health care professionals differ in terms of validity and legitimacy? And ultimately, where do they meet to provide the best health care for this population?

**Statement of purpose**

Mitochondrial disorders represent a relatively new area of interest, having really only come to the forefront in the past ten to twelve years. A literature review has revealed that the only publications on mitochondrial disorders are focused on pathology and treatment. I could not locate any research specific to this patient population in the psychosocial realm; no qualitative research appears to have been done in this area. Interest for this study was generated by ongoing issues involving patient knowledge and the tensions created within the health care relationships at the AMDC. The purpose of this study is threefold.

**Helping People build a Knowledge Base that is Credible**

People with mitochondrial disease are often assumed to be very well-informed about their disorders and are in fact expected to be the ones educating their family physicians and community health care providers about the disease. However, no studies have been conducted to confirm this assumption or to determine how people construct knowledge about the disorder. Like mitochondrial disease, cystic fibrosis is a chronic illness with a genetic cause. “In a study of adult patients with cystic fibrosis, approximately three of four patients rated themselves as well-informed about the genetics, physical
complications, prognosis, and treatment of cystic fibrosis. However, no attempt was made to audit patient knowledge” (Nolan, Desmond, Herlich, & Hardy, 1986, p.229).

We need practical tools, based on research, that help clinicians to learn from patients and help patients learn from medical experts. Asking patients how they understand their illness and how much they want to be involved in decisions regarding treatment can be a foundation for doctors seeking an informed, collaborative model of care (Kravitz & Melnikow, 2001, p. 585).

Therefore, to prevent patients from potentially making harmful self-care decisions and to preclude their community care providers from doing the same, it is very important to begin to understand how it is that they construct their knowledge about their disorder. This understanding may lead to the development of a program to help them critically appraise the knowledge they find on their own about their disorder and how to best use that knowledge. One patient in Thorne’s (1993) study was quoted as saying, “you almost need somebody to educate people as to how to work with the medical system” (p. 211). The person, therefore, not only needs to have knowledge of the disorder, but also knowledge of effective approaches to communicating with health care professionals.

Improving the Health Care Relationship

There is a great need for research on how knowledge weaves the fabric of the health care relationship and how patients and health care professionals can work together to make that fabric as strong as possible. The current body of literature calls for “research that explores the intricacies of developing partnerships between professional and experiential knowledge” (Reutter & Ford, 1997, p. 143).

This study has the potential to shift professionals’ views of, and attitudes towards, people with mitochondrial disorders and what counts as knowledge. “If services are to be shaped by patients’ views, methodologically sound ways of obtaining their views and
encouraging people to come forward and present them are needed" (Richards, 1999, p. 277). The findings from this study can begin to redirect the management of patients with mitochondrial disease, based on their input and “inner perspective” (Playle & Keeley, 1998, p. 309).

**Hearing the Patients’ Voices**

In the Canadian health care system, patients have traditionally been marginalized by the dominant culture of the medical model. The dominant culture predicates one way of seeing and doing things, which directs and shapes certain practices and attitudes as ideals to which everyone should aspire (Holmes & Warelow, 2000). “People who have an illness must tell their story in medical terms and limit it to specific areas if they want to be heard. People are stripped of their experience, their story, when seen as bodies, symptoms, and diseases” (Clayton, Rogers, & Stuifbergen, 1999, p. 513).

It is important to give people the opportunity to share their stories in unstructured ways. In a large quantitative study to assess health promotion and quality of life of patients with multiple sclerosis (MS), twenty five per cent of the respondents wrote narrative comments in the margins and on the blank pages of the questionnaire (Clayton et al., 1999). These ‘answers to unasked questions’ indicated to the researchers that the participants in this study were taking the opportunity to tell them things that were important to understanding their experience. This illustrates the value in asking people to tell their stories *their* way without the confines of structured questions that may exclude valuable insights to the experience of what life is like for them with the chronic illness with which they are living.
People with mitochondrial diseases are marginalized both by virtue of having a chronic illness and by having a chronic illness that is not nationally recognized. Because this qualitative research study focuses on their stories within the social context of health care, it has the “liberatory potential” (Marshall & Rossman, 1999, p. 198) to “‘give voice’ to otherwise silenced groups and individuals” (Coffey & Atkinson, 1996, p. 78). Every story needs a listener. People with mitochondrial disorders have a story to tell that can enrich our understanding, which in turn could improve the quality of the health care relationship.

The research question

The question posed to address the three purposes of this study was: How do people with mitochondrial disorders construct and negotiate knowledge about their disease? The following are sub-questions that underlie the umbrella question:

a. How do people make use of formal knowledge in building their own understanding of mitochondrial disease?

b. How do people make use of their own experience in building their understanding of mitochondrial disease?

c. How do people perceive their experiential knowledge in relation to the knowledge health care professionals have about mitochondrial disease?

Clandinin and Connelly (2000) argue that ‘research question’ misrepresents the work of narrative inquirers. “Problems carry with them qualities of clear definability and the expectation of solutions, but narrative inquiry carries more of a sense of search”. They instead suggest responding to the question, “What is the narrative inquiry about?” (p. 124).
Assumptions

For the purposes of this study, it was assumed that certain people with mitochondrial disease specifically set out to build knowledge about their disorder and that they wish to use their knowledge to negotiate their health care. I did not assume that all adults with mitochondrial disorders desired an active role in their care.

Outline of following chapters

The chapters that follow serve to expand the reader's understanding of the role that knowledge plays in shaping the experience of adults with mitochondrial disease. In Chapter two, the results of the literature reviewed will be presented, including the types and role of knowledge in chronic illness and in health care interactions, models of the health care relationship, and what is needed to better serve the chronically ill population. The methodological approach and its relationship to the purpose and direction of this inquiry will be discussed in Chapter three. Study findings will be presented in Chapter four according to the main storyline and two sub-narratives. The findings and their relationship to the relevant research as well as implications for practice will be discussed in Chapter five.
CHAPTER TWO: LITERATURE REVIEW

This chapter is an overview of the literature search and the implications for and relevance to this study. I will begin the chapter with a description of the resources accessed for the literature review. I will then define chronic illness and distinguish it from acute illness in the context of uncertainty. The three types of knowledge described in the literature will then be presented as will the role of knowledge in the health care relationship. Models of the health care relationship will be explored. I will conclude the chapter with a summary of the literature review.

**Resources accessed for literature review**

Literature searches were conducted in the areas of chronic illness in general, patient/lay knowledge, the role of knowledge in chronic illness, coping with chronic illness, change in management of chronic illness, the health care relationship, medical decision making, and narrative inquiry. Information for the literature search was retrieved from the computerized databases CINAHL, MedLine, Academic Search Elite, and PsychLit. References from articles obtained led me to new areas not previously entertained, such as the experience of patients who present physical symptoms in the absence of pathology. I noted names of authors that were recurrent throughout the review and performed an author search to see what original works had been published in their areas of expertise. Throughout the literature search, I attempted to keep the information focused on the research topic.

**Chronic illness defined**

In acute illness situations, once a diagnosis is made, a trajectory is established for symptom treatment and control (Mishel, 1999, p. 275). Unlike acute illness, chronic
illness is unpredictable. It generally has a gradual onset, can be attributed to many causes, is of indefinite duration, may have an uncertain diagnosis, and often no available cure (see Table 2) (Lorig, 1993; Thorne, 1993).

Uncertainty is a key concept in chronic illness. In the context of chronic illness, it is defined as resulting from “unpredictable and inconsistent symptom onset, continual questions about recurrence or exacerbation, and unknown future due to living with debilitating conditions” (Mishel, 1999, p. 269). Hilton (1992) reminds us that not all uncertainty relates to the unpredictability of one’s future. It also pertains to “not feeling safe, being in doubt, being undecided, and not being able to rely on someone/something” (p. 72). Uncertainty in acute illness centres on diagnosis, treatment options, and recovery. In chronic illness however, it is more indefinite. In addition, although health care professionals have been shown to play a significant role in decreasing uncertainty for acutely ill individuals, there is less evidence for what role practitioners assume in helping the chronically ill to manage uncertainty (Mishel, 1999, p. 279).

Cohen’s model of the “Assumptive World” is composed of “a relatively stable cognitive world of accumulated knowledge, values, beliefs, and expectations and an action world of predictable events, routines, behaviours, and social relationships” (p. 80 italics hers). She asserts that when something happens in life that challenges the certainty of the “Assumptive World”, transformation is necessary. This concept is supported by others in the literature. Mishel (1999) posits that uncertainty from illness extends into multiple areas of the person’s life “dismantling the meaning given to everyday events” (p. 272) and discusses the gradual transition a person makes to reorganize their life and their view of reality.
Table 2

**Contrasts between acute and chronic disease**³ (Lorig, 1993, p. 13)

<table>
<thead>
<tr>
<th></th>
<th>Acute disease</th>
<th>Chronic disease</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Beginning</strong></td>
<td>Usually rapid</td>
<td>Usually gradual</td>
</tr>
<tr>
<td><strong>Cause</strong></td>
<td>Usually one</td>
<td>Many</td>
</tr>
<tr>
<td><strong>Duration</strong></td>
<td>Short</td>
<td>Indefinite</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>Commonly accurate</td>
<td>Often uncertain, especially early</td>
</tr>
<tr>
<td><strong>Diagnostic tests</strong></td>
<td>Often definitive</td>
<td>Often have limited value</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td>Cure common</td>
<td>Cure rare</td>
</tr>
<tr>
<td><strong>Role of professional</strong></td>
<td>Select and conduct therapy</td>
<td>Can act as teacher and partner of patient</td>
</tr>
<tr>
<td><strong>Role of patient</strong></td>
<td>Follow orders</td>
<td>Can function as a partner to health professionals; responsible for daily management</td>
</tr>
</tbody>
</table>

³ It is important to note that these distinctions between acute and chronic illness are generalizations. It is possible, for example, that the role of the professional may be the same in chronic and acute illness. In addition, certain chronic illnesses such as diabetes are easily diagnosed and have a certain and expected course.
Mishel and Murdagh (as cited in Hilton, 1992) studied the process that family members undergo in response to uncertainty in heart transplantation. They reported that "redesigning the dream" was a necessary response to ongoing unpredictability (p. 71).

In order to undergo transformation, Cohen (1993) describes strategies for the management of uncertainty including "(manipulation) of the known, the unknown, and the unknowable" (p. 85). She comments that people decide what strategies to employ based on their assessment of whether the information will empower or overwhelm them (p. 85). Hilton (1992) maintains that for some, uncertainty can be allayed through knowledge or clarification, but that it is necessary for practitioners to determine when people do not want their uncertainty decreased. She argues that for some individuals, "their state of uncertainty is less anxiety-provoking that a state of certainty and that they prefer to keep it that way" (p. 72).

Chronic illness is therefore defined by the uncertainty that it inevitably generates. The literature indicates that acquiring knowledge may or may not reduce uncertainty. Through this inquiry, I hope to demonstrate how, why, and when knowledge is constructed by people in response to mitochondrial disease.

**Types of Knowledge described in the health care literature**

Knowledge weaves the pattern of the health care relationship. Who owns it, how knowledge is defined, and who is listened to, all play a vital role in shaping the way that health care professionals and patients interact in chronic illness care and management. Three broad groups of knowledge are described in the health care literature: bodily, lay, and biomedical.
Bodily knowledge, or “body listening” is defined as an “awareness of and attention to understanding and interpretation of one’s body (Price, 1993, p. 37). In a study exploring how healthy and chronically ill adults understand their experiences, “participants described the characteristics of body listening as continuous, internal, varying in awareness from a precognition or vague attention to full cognitive consciousness, and critical to the process of choosing and/or attending to specific self-management activities” (Price, 1993, p. 37). This type of knowledge was learned as a response to a diagnosis; “a new understanding of one’s body had to be constructed” (Price, 1993, p. 38). Mishel (1999) discusses bodily knowledge in the context of managing uncertainty. Familiarizing oneself with symptom triggers and signs of oncoming attacks are key to self-management (p. 282). However, Smeltzer (1994), Weitz (1989), and Hilton (1988) (cited in Mishel, 1999) found that because symptoms of chronic illness are often erratic, uncertainty arises from the inability to distinguish symptoms of the illness from other bodily changes (p. 274).

The concept of bodily knowledge is supported by the distinction between illness and disease. Disease is defined in the literature as “abnormalities in the function and/or structure of body organs and systems” (Eisenberg, 1991, p.9); illness, on the other hand, is defined as “a sufferer’s subjective experience of such pathology” (Banks & Prior, 2001, p. 11). This delineation between disease and illness is based on a division between professional and lay knowledge. “Bodily knowledge” is unique in that only the patient has access to it. This concept is discussed in the literature in several different ways. Salmon (2000) found that patients use their knowledge as a source of authority. Their “direct sensory experience of their symptoms” or bodily knowledge, is more reliable to
them than the indirect, fallible medical tests that doctors have to rely upon (p. 108). A study by Peters, Stanley, Rose, and Salmon (1998) of patients with medically unexplainable symptoms, found that “most patients emphasized their inevitably superior knowledge of their problems…(that) only the patient could feel a symptom; i.e., use a faculty which was both infallible and unavailable to the doctors” (p. 562, italics theirs). In a study of everyday self-care decision making in chronic illness, Paterson, Russell, and Thorne (2001) found that “many people …have learned highly attuned and individualized approaches in managing their illness through considerable experimentation and testing for variations in body response” (p. 336).

The terms experiential or lay knowledge have been used to “denote ideas that are culturally or personally based rather than directly attributable to medical understanding” (Peters et al., 1998, p. 559, italics added). Practical knowledge is embedded in the patient’s experience of managing the illness, described as “knowing how” versus theoretical knowledge of “knowing what” (Price, 1993, p. 50). Where “professionals generally concern themselves with disease processes, …laypeople [sic] focus on the personal experience of illness” (Brown, 1992, p. 267). Lay knowledge is closely linked to the concept of bodily knowledge. Kingfisher and Millard (1998) explored the topic of lactose intolerance in pregnant and lactating women to examine the “clashes of power, authority, and knowledge in clinical interactions and interpretations of laywomen [sic]” (p. 447). These women had the experiential knowledge of how milk affected their bodies and made attempts to share this knowledge with the nurses and nutritionists in the study. In a study on self-care decision making in chronic illness, Paterson, Thorne, and Russell (2001) concluded that “people with chronic illness come to rely heavily upon the
knowledge and skill base founded upon personal experience with the disease within the context of their unique lives rather than standardized knowledge alone” (p. 17). In my experience as a metabolic nurse educator, many people with mitochondrial disease share their descriptions of how they perceive the disease to be affecting their bodies. They relate that this experiential knowledge of their bodily symptoms is often dismissed by the medical community.

How is lay knowledge constructed? In a study of public understanding of genetics, lay knowledge was found to be a complex, interdependent combination of technical knowledge, cultural knowledge, institutional knowledge (e.g. knowledge of funding practices, pharmaceutical companies, etc.), and methodological knowledge (i.e. knowledge about the methods of science), embedded in social context (Kerr, Cunningham-Burley, & Amos, 1998, p. 43). This package of information is therefore completely tailored to the needs of the individual affected by the illness.

This same process was described in the study on the health beliefs around milk. It was found that some pregnant and lactating women created their own synthesis of information of bodily and clinical knowledge that formed their lay beliefs and directed their health care decisions. This synthesis of knowledge, however, was found to be detrimental to their health on occasion (Kingfisher & Millard, 1998, p. 448). As mentioned earlier, it has been our experience that some people with mitochondrial disease seem to diagnose their own symptoms as uniformly being related to the disease itself. Like the individuals in Kingfisher and Millard’s study, these people are sometimes at risk because of these beliefs. The women were drawing on their own knowledge base about milk, created from social context, cultural beliefs, and bodily experience. The data
from this study indicated that clients “may not divulge important information that could change medical advice” if their health beliefs and decision-making were not adequately explored in the clinical interview (p. 459). This finding has specific relevance to the clinical interactions with people with mitochondrial disease.

Kerr, Cunningham-Burley, & Amos (1998) described lay knowledge as resulting from people’s “zones of relevance” that determine their uptake of information (p. 43). Lay knowledge is therefore said to be constructed out of a need for relevant information and constitutes a synthesis of information from a wide variety of sources.

To learn about their disorder, people with chronic illnesses have been shown to utilize a variety of sources such as books, journals, the World Wide Web, patient conferences, and Internet chat groups. This serves to enhance their “ability to communicate on a level more compatible with that of the professional” (Thorne & Robinson, 1988, p. 786). In this process of becoming ‘well informed’, patients describe “a sort of constant comparative analytic process by which they interpret each new piece of formal knowledge in the light of what they know from their own experience” (Thorne, 1993, p. 189).

Marton & Ramsden (1988) describe this process of critical thinking as promoting conceptual change learning. By “highlighting the inconsistencies within and the consequences of learners’ conceptions, and by creating situations where learners centre attention on relevant aspects”, they posit that learners are able to restructure the way they think about a phenomenon (Marton & Ramsden, 1988, p. 277). Practitioners can guide conceptual change learning, thereby promoting critical thinking.
Lay knowledge is often invisible and not able to be proven (Thorne, 1993). Biomedical knowledge, on the other hand, is generally quantifiable, objective, and visible and therefore often seen as “the truth”. Biomedical knowledge (also referred to as formal, professional, and authoritative knowledge in the literature) concerns itself with the disease process, the indisputable truths about medical science. However, it is argued that “many aspects of medical knowledge are not always based on science, but are rooted in myth and professional self-belief” (Playle & Keeley, 1998, p. 305). Bradley (1995) states that the definition of knowledge is confounded by beliefs. She concludes that “health professionals may share a set of beliefs not all of which have been tested and verified, ...(but) are inclined to refer to these beliefs as knowledge rather than beliefs” (p. 99). Is this not suggesting, then, that health care professionals incorporate their own health beliefs (i.e. lay or experiential knowledge) into their practices? How then, is this much different than the knowledge of people educating themselves about their own chronic illnesses? According to the literature, it is different on two accounts. Firstly, the knowledge of health care professionals is seen as legitimate, or credible on the basis of how it is obtained. “Specialized training, research and technical literature, conferences, etc.” (Salmon, 2000, p.108) are concrete sources that grant legitimacy to the knowledge learned from them. Secondly, “it is accepted as inherently credible because of the status of the producers of that knowledge” (Playle & Keeley, 1998, p.305). “The power of authoritative knowledge is not that it is correct but that it counts” (Jordan as cited in Kingfisher & Millard, 1998, p.450).
The role of knowledge in the health care relationship

The manner by which people tailor their lay and bodily knowledge to the medical setting is described in the literature. The process serves to make the knowledge more legitimate and therefore presumably more likely to be accepted by health care professionals. How patients make use of biomedical ideas to understand and describe their symptoms has been described in the literature on patients with chronic fatigue syndrome, and medically unexplained symptoms (Banks & Prior, 2001; Hyden & Sachs, 1998; Peters, Stanley, Rose & Salmon, 1998; Salmon 2000). "To express one’s suffering in terms of illness means that it must fit into and fulfill certain criteria and preconceptions about disease and its treatment...this means that to have suffering recognized as a disease and to obtain relief, patients must transform their suffering in a way that enables them to seek help and be accepted as patients for medical care" (Hyden & Sachs, 1998, p. 176). The goal of this transformation is for patients to have their pain and suffering “confirmed in terms of a medical diagnosis and consequently to receive treatment that can heal or alleviate their suffering” (Hyden & Sachs, 1998, p. 190).

Loewe, Schwartzman, Freeman, Quinn & Zuckerman (1998) studied the illness narratives of physicians interacting with patients with diabetes mellitus and distinguished between how the two parties told their stories. The authors described the medical consultation as an exchange of narratives (p. 1268). Peters et al. (1998) assert that “lay and medical beliefs are not separate systems” (p. 559). In their study of patients who presented physical symptoms that could not be explained medically, they found that these patients incorporated medical beliefs into their description of their symptoms so as to access physical treatment.
People with chronic illnesses are described in the literature as “learning as much as possible about how medical science view(s) their particular disease condition” (Thorne, 1993, p. 189). Becoming well-informed enables some individuals to better manage their health care. Corbin and Strauss (1988) define self-management knowledge and skills as the work necessitated by chronic illness. Braden (1990) describes a learned self-help response to the chronic illness experience and states that “the essence of the response is learned...diagnosis of a chronic illness represents entry into a new learning condition with severity of the illness serving as a stimulus for the learning process” (p. 24).

However, Cohen (1993) reports that information-seeking behavior may become “problematic when it conflicts with the ideology of the health care provider. Physicians, nurses, and others each have their own concept of how much and what type of information is appropriate for (patients) to have and when it should be given” (p. 87).

On the other hand, not all individuals with chronic illnesses cope by gathering information and using it to negotiate their health care. Cohen (1993) suggests that people who fear that knowledge may overwhelm them employ strategies to limit the amount of information they receive. Their decisions regarding knowledge accumulation may be based on appraisals of how much the information will reduce uncertainty (p. 88). There are two types of patients described in the literature with respect to information-seeking: monitors and blunters. “Blunters distract themselves from the adversity and do not seek information; monitors prefer to have high levels of information about threats” (Braden, 1990, p. 27). In a study on the information needs of people with multiple sclerosis, monitors were found to be more interested in gathering information earlier in the disease
process and blun ters seemed to desire more information after having coped with the
disease for a number of years (Baker, 1998).

An area described in the literature that culminates bodily, lay/experiential, and
biomedical knowledge is self-care decision-making. As discussed, in the AMDC, many
of our well-informed patients with mitochondrial disease seem to 'self-diagnose', often to
their detriment. For example, a patient who attributes a bout of explosive diarrhoea to
her mitochondrial disorder and hence decides there is nothing that can be done about this
symptom, puts her self at risk for bowel perforation from the parasitic bowel infection,
completely unrelated to her disorder, that caused the diarrhoea. These patients can have
concurrent acute illnesses (such as bowel infections), as well as concurrent chronic
illnesses (such as diabetes). “People do not neatly distinguish the everyday decisions they
make about their disease and its treatment from the affective, social and physical context
of their lives” (Paterson, Russell, & Thorne, 2001, p.337). Knowledge constructed by the
patient is the key determinant in self-care decision making and when they will consult
with a health care professional, and to what degree they will decide to take their advice
(Playle & Keeley, 1998).

Although the literature describes how the three types of knowledge are employed in
the health care relationship, no one speaks directly to just how people amalgamate their
knowledge for use in the health care relationship. The literature review therefore led me
to coin the term, negotiated knowledge; a fourth type of knowledge employed in the
health care relationship that is a fusion of bodily, biomedical, and experiential
knowledge.
Models of the health care relationship

The relationship between doctors and patients with disorders such as chronic fatigue syndrome (CFS) is discussed in the literature as unique because these disorders have physical symptoms in the absence of pathology. Although mitochondrial disease does have actual pathological findings on muscle biopsy and blood work, the symptoms are often subjective, invisible, and widely varied. Because these patients have often undergone years of exhaustive testing that has not resulted in any answers, they have learned the same coping skills described in the literature used by patients with symptoms in the absence of pathology, such as CFS. As a result, the health care relationship and its concurrent issues in mitochondrial disease is often very similar to that in CFS. The common thread is that both are “disorders under construction” (Banks & Prior, 2001, p. 14). This idea is intriguing. As mentioned in the introduction, mitochondrial diseases are a relatively new phenomenon to the medical community. “As with much that is new in science and technology…(it is) subject to a large degree of ‘interpretive flexibility’…not just flexibility in how people account for the disorder, and how it ought to be managed, but also what it ‘is’”(p. 14). This leads to what the author calls “micropolitical struggles” within the health care relationship.

Several models of the health care relationship have been studied and critiqued for their value in chronic illness care and management. Roter & Hall (as cited in Salmon, 2000) identified three types of doctor-patient interactions: paternalism, mutuality, and consumerism. Salmon (2000) presents these models as: doctor as expert, doctor as partner, and doctor as service-provider.

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4 It is important to note that, although the term ‘doctor’ is used, the dynamic applies to all health care professionals interacting with people with chronic illnesses.
Each of these models will be examined with respect to the role that knowledge plays within them, and, as previously discussed, the ownership issues around each type of knowledge.

**Doctor as expert (paternalism)**

Knowledge is seen as purely biomedical and the doctor is viewed as owning all knowledge related to the disorder. “According to this view of an inexpert patient consulting an expert professional the role of each is defined clearly: the doctor must gather the necessary information, decide on an appropriate response, and tell the patient what to do; the patient should comply” (Salmon, 2000, p. 106). All knowledge and accordingly, all power, is held by the doctor or health care professional and the patient’s bodily and experiential knowledge is entirely excluded.

The judgement made regarding lack of competence allows the professional to exert influence and legitimately override the wishes of the patient in their ‘best interests’... in order to demonstrate ‘insight’ and competence, the patient has no choice but to concur with the professional view... the professional may presume that insight has been achieved...(and) that a collaborative and trusting relationship has been developed with the patients. In turn, such patients are seen as ‘good’ patients (Playle & Keeley, 1998, p. 308).

**Doctor as partner (mutuality)**

“Doctor and patient are seen as partners with different areas of expertise” (Salmon, 2000, p. 106). Each party has their own reality, shaped by their unique social context. Knowledge of both patient and health care professional are seen as having equal weight and negotiation between the two parties is fundamental. Thorne (1999) endorses “the rejection of expert knowledge and acceptance of partnership as a valued ideal” in health care relationships (p. 19). Paterson (2001), however, argues that while many claim to espouse this approach in health care, it is often a “myth of empowerment”. In her study
of self-care decision making in diabetes, she found that “despite their intention to foster particular decision making, practitioners frequently discount the experiential knowledge of diabetes over time” (p. 574).

**Doctor as service-provider (consumerism)**

“Consumerism is typically seen as emphasizing the power and authority of the patient over that of the doctor, particularly in relation to decision-making (Salmon, 2000, p. 107). In this model, the patient is very much ‘in the driver’s seat’. They have choices about who to select as their health care provider and are taking the control of their health care. The patient owns all the power in the relationship, but the doctor is still the one holding most or all of the knowledge. If the patient’s bodily and experiential knowledge are not being heard and acknowledged, they regain power and control by ‘shopping around’ for another health care provider who will listen and consider their knowledge and input (Thorne, 1993).

These three models serve to provide insight into the mechanics of the health care relationship. However, it is worth noting that relationships are changeable and dependent on a number of factors. Perhaps, for instance, a person may have a paternalistic relationship with their new and unfamiliar metabolic physician, a consumer relationship with their family physician of thirty years, and a mutuality relationship with their metabolic nurse who they find friendly and approachable. In addition, these relationships may change over time. In a study on the interpersonal relationships between persons living with HIV/AIDS and their primary health care providers, Carr (2001) found that “trust is a state of mutuality that is dynamic, volatile, capable of rupture, and may be
negotiated and renegotiated at various times during the process of creating and maintaining the relationship (p. 41). In a study of a large group of patients and families with chronic illness, Thorne and Robinson (1988) found that both trust and confidence were integral to the success of the health care relationship. Perhaps they are also the common denominators in determining the quality of the relationship. Thorne and Robinson proposed the Guarded Alliance Model to describe health care relationships in chronic illness (see figure 1). The four relationships that compose this model mirror Roter and Hall’s models of paternalism (hero worship), consumerism (consumerism), and partnership (team playing). However, the fourth relationship, that of resignation, is unique to the Guarded Alliance Model. The authors suggest that when experience over time cause trust and confidence in the health care relationship to diminish, resignation results. This model will be further explored in Chapter five in the context of the study findings.

**Summary of literature review: Need for change in management of chronic illness**

Several important themes relevant to this study emerged from this literature review. First of all, I had initially expected to find descriptions of only two knowledge types: the ‘formal’ knowledge of health care professionals and ‘lay’ knowledge of patients. It was interesting to find that there are three very distinct types of knowledge described in the literature that are all accessed and blended in different ways by patients and health care professionals alike. This explains the gaps noticed in the clinical setting where knowledge does not fit into ‘neat little boxes’.
Figure 1. The guarded alliance model (Thorne & Robinson, 1988, p. 298; diagram from Thorne, 1993, p. 107)
Secondly, it is evident from the literature that **power** plays a large role in determining what and how we come to know about certain things and not others. What does this mean for patient care? Kilgore (2001), refers to Foucault’s concept of “power-knowledge…that which is ‘known’ in a particular field”. Depending on how knowledge is used, it may oppress or liberate (p. 59). Power-knowledge in health care is the scientific, research-based knowledge in medical libraries, online databases, patient lab results, and medical charts. Health care professionals easily access this information. Patients, on the other hand, are marginalized by their limited access to this information. If this power-knowledge is not shared with patients, it could be oppressive.

In the “hierarchy of credibility, patients are clearly at the bottom” (Playle & Keeley, 1998, p. 307). The knowledge of health care professionals, even if it is peppered with experiential knowledge and personal health beliefs, is valued over the knowledge of the patient. This “eclipsing” of the patient’s knowledge serves to reinforce the power relationship (Kingfisher & Millard, 1998). The way that clinics are run and medical interviews are conducted undermines the patient’s experiential knowledge. Kingfisher and Millard (1998) found that the ‘routinization’ of the medical interview typically used in clinic settings (i.e. use of yes/no questioning), “leaves little opportunity for clients to tell their renditions of their experiences and concerns, possibly resulting in delegitimization, obfuscation, or eclipsing of potentially serious problems, such as a pregnant woman’s lactose intolerance or an infant’s feeding troubles” (p. 455). They assert that this routine questioning in clinic visits serves to reproduce the power base of health care professional and reinforces the professionals’ decisions over those of the patient.
This brings us to the third theme elucidated by the literature review. Throughout the literature, there is a resounding echo for a new approach to the health care professional-patient relationship in chronic illness (Carr, 2001; Playle & Keeley, 1998; Reutter & Ford, 1997; Salmon, 2000; Thorne, 1993). From the perspective of the participants in Thorne’s study, “successful relationships that include trust or confidence are possible only when the norms of typical health care professional behaviour” are adapted (Thorne, 1993, p. 125, italics added).

Reutter and Ford (1997) assert that the “melding of professional and client knowledge is foundational to health promotion strategies and is predicated on a collaborative relationship in which each person’s viewpoint is perceived as valuable and worthwhile” (p. 148). In their study of public health nursing education they found that “in building on the client’s experiential knowledge, nurses connect with the client’s experience, convey acceptance of where the client is at, and communicate respect for what the client brings to the situation” (p. 149). Watson (1999) has proposed a model for postmodern nursing and medicine that embodies this paradigm shift. The transpersonal caring-healing model “integrates all ways of knowing” (p. 102) and is therefore aligned with the purposes of this study. By adopting an inclusive model for relationships at the AMDC, both the knowledge of the health care professionals and the patients can be recognized as valid and worthy.

Therefore, a paradigm shift away from the biomedical model and “a need to see patients as individuals who construct and give meaning to their encounters with professionals” is necessary (Britten, as cited in Playle & Keeley, 1998, p. 309). This paradigm shift involves recognition on the part of health care professionals, of other
ways, particularly patients’ ways, of knowing. Encouraging, “thoughtful challenges of all
claims, especially those that create dualisms within our thinking and divisions within our
practice” (Thorne, 1999, p. 19) will undoubtedly plant the seeds necessary for a paradigm
shift to occur.

This study’s “emphasis on ways of knowing makes sense because knowledge is often
what is debated in struggles to win ownership” (Brown, 1992, p. 268). By describing the
intricacies of knowledge construction in mitochondrial disease, we as health care
professionals may begin to understand the experience of people with mitochondrial
disorders and provide a better way to work together.
CHAPTER THREE: METHODS

In chapter two, it became apparent that there was a need for research specific to adults with mitochondrial disease and to the role of knowledge in their chronic illness experience. In this chapter I will describe narrative inquiry and my reasons for choosing it to explore this phenomenon. I will describe the setting and recruitment strategies, introduce the storytellers, and discuss the methods of data collection and analysis. Finally, I will explore the ethical considerations, issues of rigor, and limitations of this study, concluding the chapter with a summary.

Description of and Rationale for Research approach

Narrative inquiry was the research method chosen to explore how adults with mitochondrial disease construct knowledge and how they use this knowledge in the health care relationship. The focus of research in mitochondrial disease to date has been concentrated in the quantitative realm. Mattingly and Garro (2000) argue that there is a need to “reorient medical practices in society....to distinguish disease, as phenomena seen from the practitioner’s perspective (from the outside), from illness, as phenomena seen from the perspective of the sufferer” (p. 9). Narrative inquiry offers this emic, or insider perspective.

A research method is chosen based on the nature of the problem, how much is known about the subject, possible restrictions of the characteristics of the participants and the setting itself, and the characteristics of the researcher (Morse & Field, 1995, p.12). The nature of this phenomenon is best suited to an inductive qualitative research method because it strives to understand experience. To my knowledge, the concept is not reported
in the literature. The participants and setting were easily accessible and posed no restrictions. In fact, I had noted that people were eager to tell stories at their clinic visits and wished that I had more of an opportunity to hear these stories. Narrative inquiry provided a vehicle for them to be heard and for the information to be shared with the health care professionals who play a part in shaping their experience. In addition, because I was known to most of the participants, I had a pre-existing rapport and was not faced with the challenge of “gaining, building, and maintaining trust with the participants” (Morse & Field, 1995, p.70). Lastly, as an inexperienced researcher, I was intrigued by narrative inquiry as a research methodology and wanted to apply it.

So, what exactly is a narrative inquiry? Simply stated, it is “stories lived and told” (Clandinin & Connelly, 2000, p. 20). Through a joint effort whereby narrators recount stories of their life events, and researchers interpret the structure and content of these stories, meaning is connected to experience. In this way, stories offer a powerful means of gaining insight into “what one has not personally experienced” (Mattingly & Garro, 2000, p.1).

**Description of the setting**

The Adult Metabolic Diseases Clinic at Vancouver General Hospital is the first free-standing clinic for adults with metabolic disease in North America. It was opened in April 1999 to serve the entire province of British Columbia. The patient population has more than doubled in the three years of its existence and adults with mitochondrial disorders represent the largest group of new referrals.

The clinic is located in an office building away from the main hospital grounds. The clinic space has recently been expanded. At the time the interviews were conducted, it had two examination rooms, one multipurpose room with a large table for meetings and a
full kitchen, and four offices across the back of the clinic for the nurse educator, physician, dieticians, social worker, and psychologist. The small waiting area for patients was located in the hall inside the clinic where there was a bookcase and bulletin boards for pamphlets and educational materials.

Adults with mitochondrial disorders are seen in clinic two to four times per year and close contact is maintained either by telephone or email in between appointments. A typical appointment lasts up to three hours. The person meets with the entire team including nurse educator, physician, social worker, and dietician as appropriate. With the exception of those who have neurological symptoms, the metabolic physician follows all patients. The clinic neurologist follows those with neurological concerns such as ataxia (trouble walking).

**Recruitment strategies**

A poster advertising the study (Appendix A) was displayed in the waiting room and examination rooms of the Adult Metabolic Diseases Clinic. For the purposes of this study, participants needed to be eighteen years of age or over and have a confirmed mitochondrial disorder. Because data was collected from interviews, participants also needed to be able to clearly communicate using spoken English and to have no impairment that would make it difficult for them to participate in the interview. In May 2002, all twenty-two people with mitochondrial disease who met this eligibility criteria were mailed an information letter (Appendix B) describing the study and inviting their participation. Contact information was provided in the event that they had questions about the study or wished to participate. One person had moved and the letter was sent back. Of the remaining twenty-one, ten people contacted me to participate in the study.
I also posted the information letter for the study on ‘adult mitos’, a listserv for adults with mitochondrial disorders and recruited three more participants. Two others volunteered, but one lived in the Netherlands and did not speak English well, and the other was profoundly deaf and lived in Ontario. Both were sent a questionnaire to complete and one participant sent her story along with the questionnaire. Because these people were not interviewed face-to-face or over the phone, this data was not included. Overall, then, it was easy to get participants for this study.

When people unknown to me indicated an interest in participating, I determined their suitability through a telephone conversation. Three participants were chosen in this manner. It was interesting that some people called within the first twenty-four hours, and others took up to several weeks to respond. One woman called months after the letters had been sent, offering to participate, but the data already had been collected.

The storytellers

An attempt was made to represent both genders, as well as a variety of ages, employment statuses, and levels of education by inviting the participation of all people with mitochondrial disease that met the inclusion criteria. The majority of the patients at the AMDC diagnosed with mitochondrial disease are women.

Demographic information was collected from the participants at the beginning of the interview. The demographic variables of the thirteen participants are presented in Table 3. Despite several attempts to represent both genders, the study population consisted of twelve women and one man, ranging from twenty-six to sixty-nine years of age. Ten of the participants were Canadian and three were American. One participant was deaf, but fully able to communicate using spoken English. To ensure clear
communication, she read my questions and clarifying statements from a computer screen placed between us. Three of the participants had no post-secondary education. Five had started college or university, but had not finished. Four had a college or university education and one had completed graduate school. At the time of the study, eight of the participants were on disability benefits, two were retired, and three were in the workforce. Time since diagnosis ranged from one month to fifteen years, with the average time being four years, eight months. The ten Canadian participants were followed by a multidisciplinary team (i.e. physician, nurse, dietician, social worker) as part of their regular treatment, and a specialist followed the three American participants. In conclusion, other than gender, all demographic variables were well-represented in the study population.

Data collection

Data was collected from seven telephone interviews and six person-to-person semi-structured interviews, all conducted in a private room at the AMDC. Interviews were held at a time convenient for the participant. After basic demographics were recorded, participants were asked questions around central themes designed to elicit stories of how they generate and access knowledge about their disorder and how they see their knowledge in comparison to that of health care professionals (Appendix C). Specifically, the participants were asked to share their stories of how they learned about mitochondrial disorders (as this often precedes diagnosis), their diagnosis experience, their stories of how they used knowledge in health care interactions, and what their vision of the ‘ideal health care professional’ was.
Table 3
Demographics of study participants

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Females (12), Male (1)</td>
</tr>
<tr>
<td>Age</td>
<td>Median: 54 years /range: 26-69 years</td>
</tr>
<tr>
<td>Education level</td>
<td>no post secondary education (3), completed university/college education (4), started university/college education but did not finish (5), completed graduate school (1)</td>
</tr>
<tr>
<td>Occupation</td>
<td>on disability (8), retired (2), in workforce (3)</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>Mean: 4 years 8 months/ range: 1 month-15 years</td>
</tr>
<tr>
<td>Support group affiliation</td>
<td>No (9), yes (4) –listservs</td>
</tr>
<tr>
<td>Nationality</td>
<td>Canadian (10), American (3)</td>
</tr>
<tr>
<td>Mitochondrial management</td>
<td>multidisciplinary team (10), specialist only (3)</td>
</tr>
</tbody>
</table>
Before data collection began, I interviewed two patients with disorders other than mitochondrial disease to ‘fine tune’ the questions and my interviewing technique. I also asked two friends with chronic illnesses to review the questions prior to the formal data collection and made changes based on my experience with both ‘practice runs’ and their feedback. This proved to be a good exercise in transitioning from my role as nurse educator to researcher. Morse and Field (1995) describe the reflecting and summarizing techniques that nurses use in practice as a “common pitfall of interviewing” (p. 101). They caution that use of these techniques early in the interview will inhibit it. I found I needed to focus intently on providing silence and space for the person to contemplate their answers or to reflect back on their responses without ‘jumping in’ to fill the silence with a solution or reassuring comment. For example, I had to practise “acknowledging with ‘hmmm’” rather than responding and leaving the participant with the feeling that I was hurrying them along (p. 102).

Furthermore, I realized the wording of some questions was awkward and confusing and made changes according to the feedback of the two participants and my friends. For example, in the original set of questions, I had asked, “What knowledge do you think people with mitochondrial disorders need?”. People remarked that this question was ambiguous and therefore it was omitted. Also, the question “how do you tell health care professionals about your disorder?” was adapted to “how do you use your knowledge in your interactions with health care professionals?”, based on their feedback. I found that the wording of the questions made a difference to the comfort level of the participants, either inviting them to share their stories or intimidating them by making it seem like a ‘test’. This was evident by a comment made by both participants in the
practice runs, “I hope I’m answering these questions all right”. For the actual interviews, I was a lot less directive in asking my questions and essentially allowed the participant to set the pace of the interview.

The interviews were conducted between the end of May and the beginning of July 2002, at the AMDC, either in person, or over the phone. I did not have any ‘no shows’. By the time I had interviewed the thirteen participants, I had a sense of the storylines and felt I had reached the point of data saturation. Although I could have interviewed more participants, I decided to close the study at this point, in order to analyze the data and present the findings in a timely fashion.

People were eager to volunteer their time and share their stories with me. I had initially expected to have them focus entirely on their learning about mitochondrial disease. I found that it was important for the participants to be able to tell their story their way, without too much direction from me. Most people needed to share their symptoms and their diagnosis experience before attending to details of how they learned about the disorder. In almost all cases, I did ask the questions I had prepared, but many were answered independently by the participants, through their stories. All participants had trouble answering the question of what an ideal health care professional was to them, but were able to express qualities with clarification of what I was asking. Some participants needed quite a bit of direction to stay on the topic of what role knowledge played in their journey and not to become too focused on recounting their symptoms or their children’s symptoms and stories related to these experiences. I had expected each interview to be between sixty and ninety minutes long. All interviews were at least ninety minutes in duration. Although this seems like an exhausting length of time for people, this was very
much at their choosing. At the onset of each interview, I encouraged people to tell me when they were fatigued and would like to stop. The challenge for me was often concluding the interview, as people really seemed to enjoy the opportunity to share their story and to talk.

During each interview, silence was employed as much as possible to encourage full expression of the story. Participants were encouraged to format their stories in whatever way made best sense to them. I "(paid) attention to 'narrative inconsistencies', which signalled points of confusion, uncertainty, or conflicting emotions in the narrator" (Poirier & Ayres, 1997) and used probes such as "tell me more about that" to ask the narrator to further explore these inconsistencies. Tracking, or jotting down notes for further exploration during the interview, was used to "minimize the interviewer’s interference with the natural flow of subjects’ conversations" (Sandelowski, Davis, & Harris, 1989, p. 81). For each interview, I had a copy of the questions with space after each one for field notes. During the interview or immediately afterwards, I would jot down any of the participant’s words or phrases that stood out from the interview (e.g. "there was no magic out there"). At the conclusion, I would note on this same sheet how I felt the interview went, immediate impressions, non-verbal behaviour and the affect of the person, both to remind me of the interview details later on and to provide the setting for their story.

In the case of interviews conducted over the telephone, notes were made as I listened during the interview, in case the tape recorder failed in any way (Chapple, 1999). Although the affect and non-verbal behaviour of the participant was not available over the telephone, field notes were still completed at the end of the interview to record
immediate impressions and words or phrases that stood out. As the interviews were conducted, I maintained a journal to record which stories seemed most relevant to my study. I also noted practical matters such as what worked and what did not work in each interview. Examples of this were ways I found that effectively kept people on topic and ways that functioned to signal the end of the interview. The doodle pad idea, originally thought to provide an alternative medium for people to express themselves, was abandoned early in the person-to-person interviews as it seemed to intimidate people. Upon seeing it at the table, several participants asked if they had to draw as part of the interview!

Each interview was tape-recorded and then transcribed verbatim “with strict notations of such features as pauses, repetitions, false starts and asides” (Sandelowski, 1991, p. 163). Exact transcription is very important in narrative analysis as the structure of language is key to revealing the narrator’s meaning. Interviews were conducted until the point in time where data adequacy or saturation was reached and no new storylines were emerging.

I had expected to find it difficult to interview the ten people who volunteered from our clinic population because of our pre-existing relationship. This proved not to be an issue. All except one participant acknowledged that I was wearing a ‘different’ hat on this occasion. The one exception was a participant who wanted to show me her pills and have her vital signs and weight done in the middle of the interview, but was happy to wait until the end when asked if we could finish the interview first.

I had also expected the data from the person-to-person interviews to be of higher quality than that of the telephone interviews. This was definitely not the case. A few
people interviewed in person at the clinic came prior to their appointment. Their thoughts may have been preoccupied with questions they wanted answered at the appointment or with health concerns. The clinic setting may also have been more intimidating for participants. Because they did not have to leave their home, people interviewed over the telephone may have been more relaxed, rested, and comfortable in their own surroundings. Consequently, they may have been able to share their stories more freely.

**Equipment**

Because many people found it difficult to get to the clinic because of geographical distance or physical challenges such as fatigue, taping the telephone interview using the speakerphone in the office was indispensable. The speakerphone was on loan from the hospital. The voice quality on the tapes was excellent with the tape recorder positioned right next to the telephone.

**Data management**

All interviews were transcribed verbatim using a word processor within a day of being conducted so that the non-verbal communication such as shrugs and nods were fresh in my mind. Each interview took approximately five hours to transcribe. I had initially planned to hire a transcriptionist, but decided against it as I found that listening to the interviews while transcribing them brought me even closer to the data. I could hear the unspoken in the patient’s stories and could make notes as I proceeded. Kvale (1996) cautions against “becoming lost in a jungle of transcripts” and suggests returning to the original story told by the participant and foreseeing the final story to be conveyed to the audience (p. 184). As I transcribed each interview, I spent time thinking of it within the context of the final outcome.
Data analysis

According to the tenets of narrative inquiry, data analysis was not guided by a theoretical framework. Clandinin & Connelly (2000) argue that narrative researchers begin instead with experience with the objective to explore the experience in its entirety, outside of the confines of theory.

What is essential to narrative inquiry is the interpretation of meaning. Narrators interpret the telling of their stories when they decide what events and details to include and researchers interpret the stories themselves. However, Poirier and Ayres (1997) suggest that the interpretation of narratives is "contested ground"; that no story can entirely be told and no interpreter can be completely "omniscient" (p. 552). What I hope to have captured in the process of analysis is the narrators' evaluations of their stories and the significance and meaning of it to them.

Clandinin and Connelly (2000) refer to "field texts" (i.e. the transcripts) and "research texts" (i.e. the finished product of the inquiry) and describe the process of analysis as bridging the gap between the two entities (p. 130). The data analysis spiral (Cressler, 1998) guided the overall process of data management and analysis to aid in the process of transforming field text to research text (see Figure 2). This model was appealing because it embodied the idea of constantly revisiting and re-examining the data throughout the analysis phase and provided a means for reducing the data into manageable pieces. After each interview was transcribed, I read it to get a sense of how the person had told their story, making notes in the margins of words they had repeated or emphasized, and metaphors they had used. I then re-read the interview to get a sense of what the person was telling me and to consider this in relation to the other interviews.
**Figure 2.** The Data Analysis Spiral. “To analyze qualitative data, the researcher engages in the process of moving in analytic circles rather than using a fixed linear approach. One enters with data of text...and exits with an account or narrative. In between, the researcher touches on several facets of analysis and circles around and around.” (Cressler, 1998, p. 142).
I then highlighted passages in yellow that were salient to the topic of inquiry. When all data had been collected, I revisited the transcripts as a whole, highlighting pertinent quotes in green. I created a mind map to organize my thoughts around categories. The emerging categories were then transferred onto four by six-inch index cards. On the back of each card, I referred to pertinent quotes by interview and line number. Once all the categories were represented on cards, I laid them out on the floor and transcribed the layout onto paper, summarizing the emergent themes. Themes are described as “significant concepts that link the interviews together” (Morse & Field, 1995, p. 139).

Mishler’s (1986) framework was used to “position the field texts within a three-dimensional narrative inquiry space” (Clandinin & Connelly, 2000, p. 131). Mishler emphasizes the temporal, social, and meaning structures of narratives (Kvale, 1996). According to Mishler, the three dimensions of language to consider are its structural, thematic, and interpersonal features. This framework provided an opportunity to examine the narratives from all angles (Riessman, 1993).

The first window into interpretation is structure of the story itself. In narratives, language is not transparent (Riessman, 1993). The way the narrator tells the story and the language he or she uses is essential to understanding the overall meaning. Labov’s analytic framework, referred to as “paradigmatic” by Riessman (1993), classifies narratives into six categories: Abstract, Orientation, Complicating Action, Evaluation, Result, and Coda (Riessman, 1993, p. 18). The narrative is summarized, the setting and characters are introduced, the problem is presented, the actions are evaluated, there is an outcome, and the narrator returns to the present (Mishler, 1986; Riessman, 1993).

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5 Creating a mind map involves writing down a central idea and organizing related thoughts, which branch out from the centre.
According to Labov, “narrators say in evaluation clauses (the soul of the narrative) how they want to be understood and what the point is” (Riessman, 1993, p. 20). These six categories represent the “fully formed narrative”; many narratives may not be arranged according to this order or contain all elements. Another aspect of structure to attend to is that stories often conform to classic plots including romance, comedy, tragedy, or satire (White as cited in Riessman, 1993; Kvale, 1996). In addition, “overreading” or attending to choice of words and their expression, such as elongated vowels (e.g. aaaaab—solutely dreadful), emphasis (e.g. I told him I didn’t understand), word repetition, emotional tone, silences, pauses, and contradictions further reflect meaning through structure.

The second window into interpretation is content. Content, according to Mishler (1986), is “expressed through themes and their relations to each other” (p. 87). To attend to the expression of recurrent themes in this study, each interview was carefully read, and ideas and concepts that came to mind were noted. To represent and visualize the data, I reflected on the interviews as a whole, identifying the overarching themes of: “the struggle to be believed”, “vulnerability”, “no answers—uncertainty”, “lack of information”, “the struggle to explain it to others”, and “mistrust in the health care system”. From these overarching themes, I determined the main storyline and the two sub-narratives. This is in keeping with Kvale (1996), who suggests that during analysis, a researcher alternates between being a “narrative finder” and a “narrative creator” who shapes the many events into coherent stories to be shared with an audience (p. 201).

The third window into interpretation is interpersonal factors. This represents the relationship between the storyteller and the researcher; specifically, the “interviewer’s participation in a story’s production” (Mishler, 1986, p. 96). Paterson (1994) refers to
this as reactivity and proposes a framework to actively reflect on the impact of the researcher’s role on the research. Riessman (1993) maintains that “meaning is interactionally accomplished” (p. 20) and that “role relationships between speakers...allows for the expression of social and personal relations through talk” (p. 21).

Finally, this three-dimensional viewpoint of the narratives is considered in the context of the story’s creation and rendering. Stories are told in unique contexts, never to be repeated. The time in which the story was interpreted and told, the circumstances surrounding its telling, the people involved, even the socio-political climate, all shape its inimitability. Furthermore, we can only understand these stories in context of how and by whom they were interpreted. Narratives do not therefore, “provide direct access to other times, places, or cultures” (Personal Narratives Group as cited in Riessman, 1993, p. 22). However, the Personal Narratives Group argues that “…it is precisely because of their subjectivity—their rootedness in time, place, and personal experience, in their perspective-ridden character—that we value them” (p. 5).

**Ethical Considerations**

Each potential participant was given an information letter detailing their involvement in this study and provided with names and telephone numbers of my supervisor and university research services department. Interested participants were asked to sign an informed consent, alerting them to the fact that interviews would be recorded and to potential positive or negative consequences their involvement in the study may have for them. They were made aware that they had the option to withdraw at any time without any impact on their care. Confidentiality was ensured to the degree that the patient did not disclose intention to harm themselves or another. Approval from the
ethical review boards of Vancouver Hospital and the University of British Columbia was obtained.

People generally enjoy sharing their stories and the opportunity to have “an hour of sympathetic listening” (Marshall & Rossman, 1999). However, in asking them to share their experience, I was making a pre-reflective experience into a reflective experience which had the potential of bringing issues into the participant’s awareness (Marton & Booth, 1997, p. 130). Because the interview was like a conversation, the patients shared information with me not related to the research. If any of the participants identified concerns of a physical, emotional, or spiritual nature, I was prepared to refer them to the appropriate clinic or community resources. There were a few instances in the interviews where the participant raised issues of clinical concern. Because of the dual nature of my role as interviewer and nurse educator, I was able to follow up on these issues post-interview, with the permission of the participant. An example of this was one person who had commented that her disorder had been diagnosed secondarily to her child’s. She wanted more ‘proof’ of her own mitochondrial disease. A muscle biopsy was arranged post-interview at the patient’s request to confirm diagnosis.

The participants were very open with me and therefore my initial concern for the data, that the patients may ‘hold back’ on stories they may perceive as potentially jeopardizing their care at the clinic, was not an issue. I was always mindful of this potential and reassured patients of the confidentiality of the information disclosed and their ability to withdraw at any point in the study.

The importance of anonymity could not be overstated, as this group of patients is very well known to the staff at the AMDC. Before the study began, I described the
procedure with my colleagues and informed them of my obligation to keep information obtained for the purposes of this study confidential. The final document will be circulated for them to read, with participants’ numbers (e.g. P3) removed from all quotations so that identities cannot be reconstructed.

The taped interviews and transcripts were labelled with codes and kept in my office at the AMDC in a locked drawer to which only I had access. In narrative inquiry, “the importance of examining exact words within their context competes with the need for anonymity” (Poirier & Ayres, 1997, p. 557). Although verbatim quotes are included in the research account to contextualize the findings, all identifying information has been removed in transcription to protect the privacy of the participants. Only aggregate demographic information has been reported in the findings and any identifiers that would allow reconstruction of the informants’ identities has been eliminated (Morse & Field, 1995). Because twelve of the thirteen participants were female, the pronoun ‘she’ is used throughout, so as not to reveal the identity of the one male participant. Once the thesis is handed in to the library, the taped interviews will be destroyed by taping over them to erase the conversations. The transcripts will be kept for a period of ten years for possible secondary analysis.

Issues of Rigor

In Chapter one, the purposes of this study were outlined. One purpose was to ‘hear the voice of adults with mitochondrial disease’. Riessman (1993) very provocatively argues that we cannot ‘give voice’; rather we “create and recreate voices over and over again during the research process” (p. 16), representing reality through the interpretation of experience. Stories are told by people who choose what events to
include, how to share the story, and what meaning they wish to convey. They are therefore not exact replicas of the original experience, nor are they meant to be. However, this limits how we as researchers can represent reality. Being mindful of the limits of representation helps us to “be more conscious, reflective, and cautious about the claims we make” (p. 16).

In qualitative research, the goal is not statistical validity and reliability of the findings as it would be in a quantitative study; rather, the goal is trustworthiness. Riessman (1993) posits that “‘trustworthiness’ not ‘truth’ is a key semantic difference: the latter assumes an objective reality, whereas the former moves the process into the social world” (p. 65). Lincoln and Guba (as cited in Morse & Field, 1995) propose four aspects of trustworthiness applicable to both qualitative and quantitative studies: truth value, applicability, consistency, and neutrality.

**Truth value** recognizes that there are multiple realities. In this study, I focused on reporting the views of the participants and topic of inquiry as clearly as possible. This was achieved by carefully attending to the structure, content, context, and interpersonal factors of the narratives in order to represent their collective reality as accurately as possible.

**Applicability** is used to determine whether the findings are relevant to other settings or contexts or within other groups (Morse & Field, 1995, p. 143). Although the findings of this study may contribute to the overall understanding of the role that knowledge plays in the experience of adults with mitochondrial disease, they are only meant to represent the stories of those individuals who participated in this study and are therefore not intended to be applicable to other settings.
Consistency refers to the ability of the study’s findings to be replicated in another context or with the same subjects. Like applicability, this was not the intent of this study. The findings are meant to be unique to this particular group of adults with mitochondrial disease.

Neutrality is defined as “freedom from bias” and has objectivity as its goal (Morse & Field, 1995, p. 144). It is not possible to remain purely objective in this type of study. The storylines and sub-narratives presented in this study are based on my thoughtful interpretation of the structure, content, interpersonal factors, and context of the participants’ narratives, with constant acknowledgement of the personal nature of my work. Reflexivity means “the writer is conscious of his or her biases, values, and experiences that are brought to the qualitative research study” (Cressler, 1998, p. 248). Memos and field notes were recorded that documented my “decisions, choices, and insights” (Morse & Field, 1995, p. 144). For example, I recorded my perceptions of the participants’ collective meaning as I conducted the interviews, struggles and challenges I faced along the way, and thoughts related to implications for practice. Reflexivity is further defined as “the ability to critically examine and use previous experience to influence further action” (Von Wright as cited in Paterson, 1994, p. 309). As I carried out data collection and analysis, these notes helped me to be grounded in what I was thinking and how this was influencing my interpretation of the data. More importantly, the notes brought into my awareness areas of potential bias that may have threatened the credibility of the study.

Riessman (1993) proposes four ways of aiming for trustworthiness that are specific to narrative work. Persuasiveness is the degree to which the interpretation is
convincing. The storylines in this study were illustrated through the exact words and excerpts from the participants themselves. In this way, the reader can establish a sense of the stories, draw their own conclusions about how persuasive the study is, and how well the storylines capture the essence of the narratives.

**Correspondence** is the extent to which the participants feel the outcome of the study represents their views and stories. By taking the results back to those who participated in the study, the researcher is able to determine if they are ‘on the right track’ in their interpretation. In August and September 2002, I held two meetings and invited all the participants of this study to attend. I presented preliminary findings in the form of themes and discussed the emerging storyline of “you can’t sit back and be the patient” with the participants. Although only one-third of the participants were able to attend, the positive response and reinforcement that I was accurately representing their stories was overwhelming. One participant said, “I read myself in this”.

**Coherence** represents the levels at which individual narratives are interpreted. Agar and Hobbs (as cited in Riessman, 1993, p. 67) propose three kinds of coherence: global, local, and themal. The ultimate goal of attention to coherence is to demonstrate that interpretation is a systematic endeavour. **Global coherence** is defined as the overall goals the narrator aims for through the telling of their story. For the participants of this study, global coherence may have been to improve the understanding and appreciation of their struggles and challenges from health care providers. **Local coherence** is the effect the narrator tries to create through the telling of their story, demonstrated by word choice and repetition, emphasis, contrasts, and the like. **Themal coherence** focuses on the content of the narrative and its recurrent themes. Riessman (1993) suggests that for
coherence to be as “thick” as possible, it needs to relate to all three levels (p. 67). In this study, global, local, and themal coherence were attended to through Mishler’s framework, which provided thorough analysis of the interview data.

The final validation criteria proposed by Riessman, is pragmatic use, the “extent to which a particular study becomes the basis for others’ work” (p. 68). It is my intent to disseminate the findings of this study through journal articles and poster presentations. Perhaps the attention of other nurse researchers working with adults with mitochondrial disease will be attracted to furthering the understanding of this phenomenon.

Limitations

Two limitations were anticipated in the research. It was predicted that the logistics of people getting to the clinic in Vancouver for an in-person interview might be a problem. This was indeed a limitation but was easily overcome by the use of the telephone for interviewing. Obtaining an adequate number of participants was the second concern; however, people readily volunteered for the study.

Demographic variables impede the ability of the findings to be generalized to the other populations of adults with mitochondrial disorders. First of all, because twelve of the thirteen people interviewed were female, the results are limited to the female viewpoint. One can postulate several reasons why almost all who volunteered to participate were female. Women are known to use talking as a means of coming to terms with their illness (O’Neill & Morrow, 2001). This may explain why women are well-represented on the listserv and why they showed greater interest in participating in this study. In addition, perhaps women pursue diagnosis more aggressively; perhaps they know their bodies better or are more ‘in tune’ with what is normal for them and therefore,
what is not normal. Of the twenty-two people I approached from our clinic population, seven were men. One volunteered to participate, one’s invitation to participate was returned to me as he had moved, and one called me and said he did not need to participate because, “I already knew all about him”. From the listserv, one male responded, but was not interviewed because he lives in the Netherlands and does not speak English well. Also, the long distance charges would have been beyond the budget of this study. It was interesting to note the different experience described by the one male I did interview for this study. It was difficult to discern if the differences in his responses were related to his gender or whether they reflected his stage in life and the visibility of his disorder.

Secondly, the majority of the participants involved in this study are followed by a multidisciplinary team. Thus, the findings of the study may not accurately portray the experiences of those followed solely by a specialist.

Thirdly, the results do not apply to those diagnosed in early childhood or for those with very visible symptoms. The findings are specific to those diagnosed as adults and for whom symptoms are largely invisible.

The fourth difference in demographics is the subset of participants identified as a result of their child or grandchild being diagnosed. Their diagnosis experience and the time leading up to diagnosis is therefore different than those who actively pursued help based on their symptoms. These people also differ in that, as parent or grandparent, their focus and that of the health care professional is on the child. One participant commented that she did not realize that all the information she received about her child’s disorder also applied to her until she and her child began coming to the adult clinic. Those diagnosed secondarily then, represent a special subset of adults with mitochondrial
disorders. They have unique issues and the findings of this study may not entirely reflect their experience.

Summary

Narrative inquiry was the method chosen and utilized in this study to open the doorway to understanding knowledge construction of adults with mitochondrial disease. This chapter outlined the methods employed to conduct this narrative inquiry. Data were collected using semi-structured interviews conducted both in person and over the telephone. The interviews were transcribed and analysed according to Mishler’s framework and Labov’s structural categories. Techniques to ensure trustworthiness, maximizing this study’s contribution to the field, were discussed. The limitations were outlined and the ethical considerations presented. Narrative inquiry proved to be an effective and unique method to deepen the understanding of this phenomenon.
CHAPTER 4: ANALYSIS AND FINDINGS

The purpose of this chapter is to explore the role that knowledge plays in the relationship between people with mitochondrial disorders and their health care providers. In this chapter, I will offer the findings of this inquiry, revealed by stories shared in interviews with adults affected by mitochondrial disorders. The chapter begins with an overview of the general features of the interviews for this inquiry. The findings will then be presented according to Mishler’s (1986) framework. Interpersonal factors, structure, and content of the narratives will be explored to present the overall meaning of the narratives. The main narrative of “you can’t sit back and be the patient” and the two sub-narratives, “there was no magic out there” and “now I’m the educator,” will be presented, illustrated by the participants’ quotes.

Overall Features of the Interviews

Each of the participants freely offered their stories. Some narratives were told quietly and with contemplation; others were told with emphatic passion. In general, the interviews were composed of stories about ‘swimming upstream’ with a disorder that is largely unfamiliar to health care professionals and to the general public. Motifs of struggle, uncertainty, vulnerability, and frustration were ubiquitous. All participants gave detailed accounts of their diagnosis experience. The telling of this story was integral to providing context for the role knowledge played in their journey. Participants agreed that like other stories of significant life events, such as childbirth, the telling of these narratives helped them in coming to terms with their experience (Riessman, 1993). Overall, the narratives provided a window on the world of people with mitochondrial
disease, including an increased understanding of their past, present, and future experience with the disorder.

**Interpersonal Factors**

"Stories are not material to be analysed; they are relationships to be entered" (Frank, 1998, p. 200).

Interviews differ from stories told in other contexts, such as naturally occurring conversations, in that interviews are artificial situations. Naturally occurring conversations are unplanned, unprompted, and unstructured. Interviews, on the other hand, are directed by a research question; the interviewer is looking for stories that will be enlightening to the research. As a result, stories told in interviews are subject to interpretation and influenced by the research context. It is therefore of paramount importance to consider the impact of context on the participants' accounts. The relationship of the interviewer and participant and their joint discourse, the setting of the research, and ultimately what meaning the researcher attributes to the narratives, all influence the outcome of the inquiry.

Semi-structured interview questions were used to guide this inquiry. Merton, Fiske, and Kendall (as cited in Mishler, 1986) maintain that the focused interview "is designed to study variation in perceptions and responses of individuals who have been exposed to the same event or been involved in the same situation" (p. 99). In order to derive "attributes and prior experience of the interviewees which endow the situation with ... distinctive meanings" (p. 99), it was necessary to focus on what role knowledge played in their journey. If I had not reflected on this, my understanding of the phenomenon under study would have been limited. It can be argued that different types
of interview and question formats produce different types of stories (Mishler, 1986, p. 96). Had I just opened with, “Tell me about how you have learned about mitochondrial disease”, the responses would have been very different. Despite having a set of questions to guide the inquiry, it was not my intention to use them as anything more than a guide. I was not militant about asking each question in sequential order, nor asking them precisely as written in the original guide. My questions took on more of a conversational tone:

Um…and then I imagine that there were a lot of specialists and things involved after that. What did you do with the new knowledge and understanding of the disorder itself, it sounds like you got (son’s name) resources…how 'bout for yourself?

Mishler (1986) notes that “an interviewer’s questions, assessments, silences, and responses enter into a story’s production” (p. 96). Because of my pre-existing relationship as nurse educator with the ten Canadian participants, I had to change the usual way I interacted with them, specifically by employing more silence and not offering advice as I would have in a clinic visit. In fact, I had to warn people of this ahead of time so that they did not misinterpret my silence as disinterest.

Because of our pre-existing relationship and the comfort level between us, I think it may have been easier for the Canadian participants to share their stories with me. In addition, I was familiar with their context and characters (i.e., family members and health care professionals) in their stories. Even for the three American participants who I had never met, there was an easy, comfortable, conversational tone to all the interviews.

Most participants told their own stories and relied on me to focus them back on the role that knowledge played in the experience. None of the participants seemed to be ‘holding back’ as I had anticipated they would, for fear of negatively impacting on their
care. In fact, many were eager to share their stories with me in the hopes that positive changes would result.

I’m hoping that, um, that’s my hope and prayer, that…. it’ll all, that the education’ll get out there and so the support, things like what you’re doing now, that increases my level of hope! (P11)

Others reflected on and evaluated their experiences as a result of rendering their story, coming up with solutions along the way.

I’ve found that some doctors, you can tell right away when they don’t know what you’re talking about cause I say, “well I, I think this is being caused by my mitochondria… disease… disorder”. And they’ll just kinda look at me and they’ll nod their head and that’s it! You know, they don’t want to admit they don’t know what’s going on. You know, and that just made me think, from now on, when that happens I’ll say, “do you know what that is?” (laughing) (P9)

Bell (as cited in Mishler, 1986) argues that “both parties are aware of their respective dual roles and that they attend to them in specific ways and manage shifts and transitions between them” (p. 102). For example, the respondent gives an ‘answer’ to the interviewer’s question and then shifts back to the ‘story’ that as a narrator she is telling to a listener (p. 102). According to Bell, the researcher is “an interviewer as well as listener-to-a-story” and the participant is “a subject in (the) investigation as well as a narrator” (p. 102). Implicit in this relationship is the joint construction of meaning (Mishler, 1986). Meaning is revealed and shaped in the narrator’s stories by the researcher’s questions and vice versa. An example of this from this inquiry is as follows:

Interviewer: Right, and how did you find him?
P8: Oh, I found him absolutely wonderful.

The meaning I was trying to convey was location (i.e., where did you find him?) and the participant interpreted my meaning as quality.
Setting also impacts on the research context. The interviews were held both on the telephone and in person at the clinic. Some interviews preceded people’s regular clinic appointments. These individuals may have been somewhat preoccupied with what was to follow in the clinic visit, or concerned with finishing on time, catching a ferry, etcetera. However, I was able to attend to their body language and this may have enriched the understanding of the narratives’ meaning. Those individuals interviewed over the telephone may have been happy to be in their own comfortable surroundings and may have been less reluctant to share stories because of the anonymity the telephone affords. No matter how and where the interviews were held, participants seemed to be open and forthcoming with their narratives.

**Structure of the Narratives**

“Narratives have rather specific, distinct structures with formal and identifiable properties” (Coffey & Atkinson, 1996, p. 57). Examples of these properties are “how (narrators) give the events they recount shape; how they make a point; how they ‘package’ the narrated events and their reactions to them, and how they articulate their narratives with the ...audiences that hear them” (Coffey & Atkinson, 1996, p. 58).

Attending to these structural details is an essential preliminary step in narrative analysis. The content of the stories (i.e., *what* was said) is enriched by the consideration of *how* people convey meaning through the language they choose to express their stories.

Structure of the narratives will be explored in the following section by considering the organization of the narratives, comparing classical narrative typologies, and by attending to features of speech.
Narrative Organization

I will use the framework detailed by Labov (cited in Coffey & Atkinson, 1996) to describe the organization of the participants' narratives. According to Coffey and Atkinson, Labov and Mishler offer similar frameworks for unpacking narrative structure and revealing meaning in stories. However, Mishler's framework uses the word 'resolution', implying that problematic situations have been resolved, settled, or 'fixed'. Labov's structural units of Abstract, Orientation, Complication, Evaluation, Result, and Coda are better suited to the narratives shared in this study because participants' stories had more elements of 'evaluation' and 'result' versus 'resolution'. The "Abstract" serves as a snapshot of the story to follow. The "Orientation" encompasses setting, characters, context; elements to create a picture in the mind of the listener. The "Complication" is the climax of the story; the problem or the dilemma. The "Evaluation" is the narrator's perception and action, or lack thereof, toward the complication. "Result" is the outcome of the evaluation; what happened in the end. Finally, the "Coda" signals the end of the story.

Labov (cited in Coffey & Atkinson, 1996) asserts that not all stories contain an "Abstract" and "Coda", and that the elements of structure are not always sequential. In addition, he suggests that "there may be multiple occurrences (of narrative elements) embedded and recurring within a single narrative" (Coffey & Atkinson, 1996, p. 58). This was generally the case in the stories shared in this study. Each interview was one long narrative with several episodes clustered around stories of the pre-diagnosis, diagnosis, and post-diagnosis phases of their journey with the disease. However, the episodic nature of the participants' narratives may have been elicited by my questions about specific periods of their experience with the disease.
Narrators generally began the interview with “Orientation”, omitting the “Abstract”. The “Orientation” was composed of detailed accounts of how they came to be diagnosed and generally included dates and descriptions of tests done and symptoms experienced. It often incorporated the impact of the disease on ‘normal life’, including work and self-image.

So ... when I couldn’t keep it under control and I didn’t have the physical energy any more, that was very hard to accept. But what was harder to accept than that, was when other people wouldn’t see anything going on, in me, and so, um, that was hard, ‘cause my work ethic is very strong. And the fact that I had to go on disability...2 years ago, was quite difficult. (P11).

The diagnosis stories of affected children or grandchildren were intertwined in the “Orientation”. This participant was describing what information she had received at the time of diagnosis.

Printed material, but it was meant for a doctor, or, more. And even our family physician had no idea, what it meant. The only thing we got out of it was the fact that (son’s name) shouldn’t live past his 1st birthday. And, I think that’s still in a file, somewhere at home. Other than that, we’ve got nothing. Because there basically was nothing for patients. (P8)

The majority of each participant’s narrative focused on “Complications” and Evaluations”. This participant’s response to whether this learning experience mirrors those in her past is illustrative of this:

Um, not really. I, this has been quite a new experience for me. And every time I wanted an answer, it took me a while to get on to the Internet, because my upbringing was the library. So, that was arduous, and not very informative, and every time I’d go to the library, I’d get frustrated. So this was really quite... a new experience for me. The only other time I’d really used this process was when I was in college and working on my thesis? And I never really applied that process to everyday living, so this was very new to me. Normally in the past, I’ve.....been able to easily access, I’ve either been given the information? I’ve been... able to go, and get a book, and get the information. Um, I’ve never had to investigate anything like this before. [Complication]
And that’s why the learning curve was so long, and I feel like I wasted 4 or 5 years, in terms of not being able to, not being given the tools, I don’t mind doing the work but at least..... at the beginning, had I been given the tools, to investigate the disease, the learning curve would have been a lot faster (P10) [Evaluation].

Most narrators did not include “Results” at the end of their narratives, nor end with a “Coda”; rather, I would conclude the interview and then participants generally wanted to chat about other things, indicating to me that they had more stories to tell than the time and interview questions allowed.

Standard Narrative Types

Another way to analyse structure is to listen to the type of story being told. The narratives in this study are collectively representative of the “chronicles of life events” story (Coffey & Atkinson, 1996, p. 68). This standard narrative type encompasses descriptions of “how it all came to be”.

Frank (1998) proposes three basic and recognizable narrative types told specifically by people with “deep illness”. These are the stories of restitution, chaos, and quest (p. 200). The restitution story “tells of getting sick, suffering, being treated, and through treatment being restored to health” (p. 200). This, according to Frank, is the story “preferred” in our culture. On the contrary, the hallmark of the chaos story is that it is exhausting for its listeners. Through emotion and disconnected segments of unfinished stories, it depicts the struggle and turmoil of the narrator. Frank eloquently describes the chaos story as being one of “how thin the ice is that we skate upon, and how cold and deep is the water we can suddenly sink into” (p. 202). He argues that the chaos story cannot really be told; that the narrator is too entrenched in living it to be able to render it to another.
The quest story is one of “an unflinching view of the reality of illness” (p. 204).

Narrators share what they have salvaged in their lives and what they have learned along the way.

The sub-narratives identified in this research and described within this chapter epitomized some of these classic stories. The participants’ sub-narrative of “there was no magic out there” exemplifies the classic chaos story.

...the dominant style of chaos stories is a series of incomplete sentences. Actions end with a shrug, not an object of the verb...The world of the chaos story is devoid of effective action...Events take place in a perpetual present tense punctuated by “and then” constructions: “and then” the physical problem, “and then” the family problem,...and then how each of these makes the others all the more unresolvable. (Frank, 1998, p. 202)

In addition to the distinctive “and then” structure, chaos stories in these narratives were often marked by an exclamatory tone.

...and I thought, ‘oh good, I’ll finally get this over with!’ Doctor comes in Wednesday morning and I’d done the blood work, I’d been fasting and he said, ‘oh there’s nothing wrong! You can go home! We need the bed!’ (P8)

Overall, the narrators’ trains of thought were disjointed and it was clear they were attempting to share all of what they had experienced and thought with the listener.

OK...when I went on disability, um....it was called chronic fatigue syndrome, a year and a half ago. It didn’t really seem like chronic fatigue syndrome. I had a lot of neurological things going on that didn’t fit chronic fatigue syndrome. Um...but, I was on disability and....I have, 3 children at home, that are...(ages of children). But, um, my --year old was in the hospital constantly when he was little, and, uh, would still would like, pass out, when he... didn’t eat or something, even though he’s obviously in really good physical shape because (type of job), but then my -- year old has been in the hospital 38 times now. And my -- year old, 16 times. In fact my -- year old was born up at (hospital’s name). When he, um, was a month old, he, was in the hospital for close to a month...with respiratory and bowel problems and things. They just, they had all those problems, that they would seem OK in between! And so, it was this constant thing where, getting acute treatment and then, um, they would seem OK in between. But then (name of child), my -- year old...had actually got measles from his measles vaccine and decompensated a lot after that. So he was always
weaker and had more problems. Um...he started having autonomic dysfunction where he used to sweat all the time then he stopped sweating and his heart rate was going all wild, so 2 years ago, um a doctor said, in (city name) said he had dysautonomia. Well, when I started researching about that, I would come across mitochondrial a lot as, you know, a symptom of autonomic dysfunction. At the same time, I was also trying to lose weight, because I’d put on weight since I’d gotten sick and was on the Atkins diet? And was on the Atkins listserv. And I was talking about how hard it was to stick to the diet, when my, son was sick, (name) my -- year old was sick a year ago with a lot of migraines, vomiting and in the hospital a lot. And a woman emailed me and said, “um, I think that you have mitochondrial disease”. And I said, “oh, I’ve heard of that, that’s isn’t, you know, that’s when people, like blind— kids, are blind and deaf and everything and that’s not us”. And she said, “no sign on to the UMDF and do some research about it”. And so, um, I signed on, and saw the information and it seemed really bleak and I wasn’t willing to accept that, and, so I just said, it’s just coincidence that (name of child) has these bad migraines and it has all these other problems. So, um, but she kept emailing me, and after a couple of weeks, I finally signed on to the mito listserv on the Internet. And I started seeing a lot of similarities (P11).

The way this participant begins with “OK” is like a gasp of air before going underwater.

The sub-narrative of “now I’m the educator” is the classic quest story. There is no restitution; no ending or answers, but many actions detailing how the narrator goes about trying to reclaim control of her life by accumulating knowledge and learning to negotiate with health care professionals.

OK, well it was (Dr’s name) I really felt did the most to-to, um….bring me to the point where I felt I could move on and do some investigation personally, um...roused my curiosity in it, made it, made it feel real? Um, made me feel like I wasn’t ....um psychosomatic. Um...he gave me information, sat down with me with a blackboard, drew graphs, explained about organelles and the genetics of it, and uh, I think I had about a 3 hour appointment with him and I left feeling he really has explained things to me, my husband was involved too, I did leave feeling.....believed. Prior to that point in time, I had a lot of feelings that I wasn’t believed....and, uh, a lot of feelings that I was possibly psychosomatic and yet I believed in myself that there were things going on and yet people were telling me that, that uh it was....possibly all in my mind, uh, some of the stuff. Either you have...fibro-fibromyositis OR you have menopausal symptoms, ah...maybe you can have both but I think you’re...crying wolf a little bit. And that didn’t feel...real good (laughs). (P4)
Features of Speech

Features of speech are the ways that people use language to convey meaning. Looking at the words used and how they are used can contribute to the overall understanding of the narratives; specifically, how they are used to describe the role knowledge plays in their experience with the disorder. The meaning of speech features in narratives can only be viewed by interviewers as possible clues that might suggest directions for the interview, unless the participant directly clarifies the meaning. For example, many participants ended sentences with an upward inflection, such as in this quote: "Because it’s not...they can’t see it?" (P7). It was not immediately apparent if this was a typical speech pattern or an indication that they were looking for reassurance that the listener understood what they were saying.

There were several commonalities among linguistic presentation within the narratives of this study. Interviews took on emotional tones. Some were very upbeat and positive; some were depressed; some were angry and frustrated; some were passionate; others dispassionate. Many people laughed throughout. Two participants had a few weepy episodes. Some stories were punctuated by sighs, indicating frustration and defeat. For example, “With children, with friends, you go to the doctor...within reasonable guidelines, you get helped! (sigh) I don’t.” (P1). Some people were very dramatic in their renditions of stories. For example, when asked what it is like to explain this disorder to others, this participant said, “Dreadful, aaaaab—solutely dreadful.” (P1). Many narrators would begin an episode of their story with a summary of the emotions it raised. For instance, one participant, began her response to my question of what her
experience of the disorder was before she had a name for it with, “Well, it was really frustrating” (P12).

Emphasis was used by all participants to invoke the emotional tone to the meaning they were trying to convey, as in the following excerpt:

...nobody gave me anything, or even steered me in a way as to where I could get an, and increased understanding or even support and I was just so disgusted, at that time, at the whole medical profession. (P10)

Emphasis occurred by stressing certain words, by drawing them out, and also through repetition: “you know, I wasn’t even sure I’d remember what he had to say and um... and he just totally dismissed that... totally dismissed it” (P6), or, “‘Oh you have to live with it’, blah, blah, struggle, struggle, struggle every day of my life...” (P5).

Many narrators ended sentences with words to ensure that I understood what they were saying such as “right?”, “you know?”. Others trailed off in their responses, not having anything else to add, ending with words like “yeah”, “so”, and “I don’t know”. For example: “so I sort of well, OK! It was...”.

Participants tended to refer to their disorder as “mitochondrial”, “mito”, “mitochondria”, and “mitochondrial disease” in sharing quest stories, whereas they were more likely to use “this disease”, and “the disease” in chaos stories. One participant used the word “it” to refer to her diagnosis throughout her narrative.

Overall, participants referred to themselves in the first person, and sometimes recreated parts of the conversations they had with others in their story: “I’m going, OK, that shoots that theory out the window! (P8)”. Some people waited and contemplated the answers to the interview questions; others spoke immediately or finished the sentences for me. For example:
Interviewer: So, it sounds like you’re not getting heard. Like you’ve got this diagnosis, and this is the reason for a lot of things and people are sort of...
P8: dismissing it. Yeah, which is part of, yeah, in some ways....

I provided as much silence and encouraging body language (in face-to-face interviews) such as sitting forward, as possible for narrators who hesitated in their answers.

Some people were very matter of fact and succinct in answering the questions. These people usually wanted to tell their story in chronological order, giving exact dates. For example, “that was ’96 by this point in time” (P10). These stories sounded more like a factual medical history. Coffey & Atkinson (1996) argue, “narratives...produced in the interview are not necessarily unique to that context. Many will have been rehearsed...Many stories are worked up and are recounted on repeated occasions” (p. 78).

Often, narrators began the interview in this prepared manner, looking to the questions to guide their responses. One participant asked for the questions ahead of time so that she could prepare for the interview. As I did not want her to feel like it was an examination, I explained to her that there were no ‘right answers’ and that I wanted to hear her stories and perspectives rather than prescribing questions. Two other participants commented that they had wanted to write out their story before coming to see me.

...when I was thinking of coming to see you, I thought, “should I write...” um cause I’m good at writing apparently, is what they tell me, “should I write my story, or not” and just come and sort of ad lib it to you. And I thought, no, I don’t think I will write it. Because when you write it, you edit it .... (P5)

Others directed the interview with spontaneous stories and did not rely on the questions for direction. They would offer a stream of dialogue with multiple stories and then return to ‘fill in the gaps’. These participants’ responses took up an entire page or more in the transcripts. Despite their style, all interviews were full of pauses, ‘ums’, and ‘uhs’.
When I asked people for clarification, they would either answer ‘yes’ or ‘no’, tell a story to deepen my understanding, or repeat what I had asked in an affirmative manner.

Interviewer: So printed material?
P8: printed material, but it was meant for a doctor, or, more. Others used nodding to indicate ‘yes’ or ‘no’. This was recorded in the transcripts.

Many people described a sort of ‘scripted abstract’ they offered to health care professionals to explain their disorder and how it affects them.

Um…. (sigh) I guess the, you know, the short version I usually give, is basically, you know, “I have a mitochondrial disorder and my cells are producing energy at a, at a much lower rate than normal and as a result, I have, um, a lot of stiffness in my muscles, I also have a lot of joint pain” (P13)

Despite my reassurance that their stories would be anonymous, some people had persistent concerns about confidentiality as evidenced by comments such as, “I shouldn’t say that on tape” (P2), “I hope none of you guys are hearing this!” (P9). They were assured of the confidentiality agreement between us and the offer of stopping the interview at any time was frequently reinforced.

**Content of the Narratives**

Thematic analysis was used to reduce the data into meaningful parts that would reveal the storylines. All participants told the story of how they were diagnosed with mitochondrial disease, and their experience prior to, and after diagnosis. This story had several episodes. Some episodes had a beginning, middle, and an end; other stories ‘in progress’ merely had a beginning and middle. Woven throughout the stories were the motifs of frustration, vulnerability, uncertainty, and struggle. These themes provided coherence to the narratives as a whole.

The analysis revealed one main narrative and two sub-narratives represented in the interviews. Sub-narratives should not be seen as ‘splintering off’ from the main
narrative, rather, as incorporated into and co-existing with it. The storylines will be introduced below, supported by the voices of the storytellers.

**You can’t sit back and be the patient**

The main storyline is: *I have known something was wrong with my health all my life. At some point, I tried to get answers for my symptoms. My symptoms were minimized or misdiagnosed. I began to doubt myself and the health care system. When I was finally diagnosed, I was relieved that I did have something ‘real’. I soon realized, however, that there were no real treatments, cures, or answers beyond the diagnosis. Furthermore, I realized that many health care professionals were not familiar with mitochondrial disease. I decided that I had to become the expert on my disorder.* The soul of this narrative is reflected in the sentiment: “you can’t sit back and be the patient” (P11).

This storyline began with a description of experiences leading up to diagnosis. Many people told stories of knowing something had been wrong all their lives: “It was always there. I was always sick (P1)”. This bodily knowledge was something they lived with until the symptoms interfered too much with their activities of daily living, or were identified by a health care professional.

“You can’t sit back and be the patient” was depicted in the participants’ stories of bringing their symptoms to doctor after doctor, trying to get an answer about why the symptoms existed. Woven throughout the narrative is the struggle to translate bodily knowledge into something that would be heard, accepted, and validated by the medical profession. The degree to which the individual’s bodily knowledge was credited by the medical system appeared to largely depend on whether or not the health care provider knew about mitochondrial disease. Two participants described the serendipity of having a
physician who had recently learned about mitochondrial disease and therefore entertained it as a differential diagnosis.

That was his first thought, and he was proved right, and he said, because he had just come from Stanford, and he had worked there with that disease, and he was really surprised, he said, “I, I you don’t see this very often so it’s really weird that I get you”... (P9)

Diagnoses that were considered prior to mitochondrial disease included diabetic neuropathy, multiple sclerosis, myasthenia gravis, fibromyalgia, psychiatric disorders (such as depression, stress-conversion), arthritis, menopause, hypochondriasis, and chronic fatigue syndrome. “You can’t sit back and be the patient” was somewhat less of an issue for those with observable physical manifestations such as cardiac problems, droopy eyelids, difficulties walking, or hearing loss. These manifestations were associated with “black and white” (P3) objective data that health care practitioners could measure and diagnose. However, even if these symptoms were being addressed and diagnosed in isolation, many participants expressed frustration that no one was seeing the big picture to “tie it all together” (P11) and pinpoint mitochondrial dysfunction as the common denominator.

I was seeing all these different specialists. But because the mito isn’t a known umbrella, I wasn’t seeing like a ‘mitochondrialist’ that would have tie—or anybody! To tie it all in together! (P11)

The struggle to be believed and to find answers prior to diagnosis therefore seemed to result from the lack of intersection between the knowledge of the person about their body and the biomedical knowledge of the health care professional.

Because the symptoms of mitochondrial disease were often not recognized by health care professionals or were attributed to psychiatric causes, many participants experienced self-doubt: “… without the name it’s just, is it in your mind, or is it really
happening?” (P3). The frustration they experienced during this pre-diagnosis period was deepened by not having bodily symptoms taken seriously enough for a physician to pursue diagnosis.

...one doctor patted me on the shoulder and said, ‘oh, we get lots of women in your age bracket with these problems’ And you know, this isn’t menopause! (P7)

In their stories of the pre-diagnosis period, people used words like “silly” (P4), and “bumping around in the dark” (P9) to describe the impact of having ‘no magic answers’ for what they were experiencing. As this participant stated, “I really didn’t have a very good explanation for people, ‘Well I don’t feel well and I’m having lots of trouble walking’” (P6). Without the name, participants had no formal knowledge to explain their bodily knowledge in a way that would be accepted by others.

I had a lot of feelings that I wasn’t believed...a lot of feelings that I was possibly psychosomatic and yet I believed in myself that there were things going on and yet people were telling me that...it was...possibly all in my mind. (P4)

“You can’t sit back and be the patient” was manifested as a response to the lack of medical explanations for their symptoms. Some participants began to search for their own answers. This person, initially diagnosed with arthritis stated that: “(my) symptoms didn’t fit into the category ...upon researching that, I kept saying, “no way, it’s not...that’s not my problem” (P7). Others’ search for answers led to a suspicion of mitochondrial disorder when they learned about the symptoms or disorder from peers. For example, one participant was actively researching her symptoms on the Internet and became suspicious that she had mitochondrial disease.

...when I started researching about that, I would come across mitochondrial a lot...I finally signed on to the mito listserv on the Internet. And I started seeing a lot of similarities...(P11)
The storyline continued with participants’ descriptions of when they first heard
the words ‘mitochondrial disease’. Some heard the words as their diagnosis, coming to
them as the formal outcome of a series of tests.

...they came to me at the end of all these tests and they presented to me that what
I have is mitochondrial disease. And I said, ‘I, I’ve never heard of that.” And,
“what is it. How do you spell it”. Was the first question I asked. There was
some confusion, even, on how to spell it, among this team of medical
practitioners. And um, so the doctor, the specialist said, “well I’ll leave” a young
woman, an intern “to explain it to you”. And then the 6 or 7 of them trouped off,
leaving me with this intern, who, wrote it for me on a piece of paper, and that’s all
the information I got. (P10)

Others overheard ‘mitochondrial disease’ discussed with medical students, residents, or
technicians as being a possible cause of their symptoms.

There was a student there, he was like a neurology fellow, I think he was called?
And, who was travelling around with that particular doctor for that particular
week or month or whether, and, and um, the neurologist...was trying to, give him
enough information to try to get him to come up with it? ...And um, and he
didn’t, he couldn’t produce it, even though the doctor, the doctor there gave him
several hints. But I didn’t follow all that or really get all the things that he had to
say although he talked, to the fellow you know, about there being, you know, lack
of energy in the cells, but, but the young man didn’t pick it up, so then the, more
seasoned neurologist, sort of explained it in a few sentences to him and to us. (P6)

Still others were told by specialists that mitochondrial disease was a possible diagnosis,
prompting people to investigate the disorder on their own.

...he got me thinking about, you know well, I’ve got to find out then, what
mitochondrial disease is then....I went on the Internet. And I, every day, I would
spend time searching. (P6)

A subset of participants first heard the words when their child or grandchild was
diagnosed. Because of this finding, they and other family members were investigated for
mitochondrial disease. These participants’ stories were unique in that they were very
much intertwined with the stories of the affected children.
...I had more...strength to try to find answers for (child), than myself, 'cause you're fighting for your child, right? (P3)

Most people therefore just heard the words, with little or no explanation of what the words meant.

Without a diagnosis, participants perceived that other doubted the reality of their symptoms. Upon diagnosis, this feeling was temporarily alleviated.

It was like you gave me a Christmas present (pause). It was like, “Thank God there’s a name for it”. And even though they can’t do anything to cure it, at least there’s people out there, working towards a cure, like in muscular dystrophy, and MS and whatever, and that it’s acknowledged, that it’s a disease, and I’m not walking around pretending I have...something. (P5)

Narrators universally used the word “relieved” at receiving a diagnosis and having something recognized as ‘real’. Having a name for their bodily knowledge gave vague symptoms credibility, made “a whole bunch of stuff click” (P12), and left people feeling “connected with something” (P2).

...wow, there is a reason...I was glad...that...somebody’s actually putting a name to, to all this nonsense and...you know, it is kind of nice to know, there is something to explain all these problems that I’ve had all my life. (P7)

Having the “knowledge inside” (P3), as one participant phrased it, also helped to dispel feelings of self-doubt regarding the reality of their symptoms and helped family and friends to be more understanding. Participants described being hopeful at this point, that their struggles were over now that they had a diagnosis. However, realization dawned that diagnosis was simply a milestone in their journey and not the destination. Several participants described their disbelief that the diagnosis was correct, either because they had never heard of it, or because they wondered if their symptoms were in fact bona fide.

...sometimes still, doubts cross my mind and I’m not able to do things and I feel like, maybe I’m just lazy, you know?...I wish I actually had the...proof...rather than just the words. (P3)
Others looked for second opinions, hoping it was a misdiagnosis and that they instead had something treatable.

I keep saying, "maybe I don't have this, maybe it's something else" but nobody else has any explanation whatsoever. (P1)

In addition to their own struggles with believing the reality of the diagnosis, people told stories of how health care professionals did not always accept it as valid. Even if the diagnosis was accepted, professionals were not always familiar with it. Narrators described a 'shifting of gears' from assuming that everyone was familiar with mitochondrial disease to assuming they were not.

Generally, I don't run into anybody that knows what I'm talking about. And I sort of make that assumption. That, um... you know, they're not going to have any idea. (P6)

Mistrust in family physicians, emergency departments, and specialists grew with the realization of the lack of awareness and knowledge of mitochondrial disease.

And I called the doctor 'cause I was afraid to go to the emergency room because they are, they don't know what's wrong with you, if you have anything uncommon. Even though they're wonderful if you break your leg or, you have a heart attack or, something like that. (P12)

As it became evident that the disorder was not widely known and because symptoms were so varied and individual, people described feeling vulnerable in the health care system.

...I had to have...surgery, I was, uh, seen by uh, a surgeon...and when I wanted to make sure that I had...he didn't believe me that I had mitochondrial disease....And uh, so...I was really afraid! Because I need to have the special anesthesia done but I didn't feel confident that my situation was being taken seriously. (P4)

Faith in health care professionals diminished even more when individuals received conflicting advice.
...physiotherapists...say that when my muscles get that sore, I should use a wheelchair. Well, my family physician tells me no! I shouldn’t. So who do you believe? (P8)

Because participants had limited choices of where to access health care, frustration and vulnerability deepened. It was not a case, as with other diseases, of changing health care professionals in response to dissatisfaction. In addition, many participants perceived that, because mitochondrial disease is uncommon, health care professionals did not want to spend their time learning more about it. Regarding a booklet given to her at her clinic, this participant commented

...I’m sure nobody...even looks at it. They’re not going to run into another patient with, mitochondrial disease, so why bother... (P8)

Several participants commented that they avoided their family physicians for general health care because they perceived they were not knowledgeable about the disorder.

...some people...just don’t want to know...even my family physician, “it’s out of my league! I don’t know anything about it!” you know, um, “What do you want me to do!” I’m going, but I’m coming to you for advice! (P8)

They concurred that this poses a “big problem” because the person depends on the knowledge of the health care professional for diagnosis and continuing care. Others told stories of avoiding health care professionals because they were afraid that they would be harmed, rather than helped, due to health care professionals’ lack of knowledge.

And, my experiences in the past with exercises that, the people I’ve worked with, the trainers, have not understood my limitations and have, allowed me to, to push myself to the point of exhaustion. And so I, now, I’m worried about working with somebody who doesn’t have any understanding about the limitations. That’s really gotten in the way of, exercising. (P10)

Mistrust in the health care system, therefore, resulted from a general lack of awareness of mitochondrial disease. When health care professionals admitted that the disorder was new to them, participants believed that the practitioners would rather turn to them to
make the decision rather than to research it themselves. Because the patient did not have the background or easy access to medical knowledge, this intensified their feelings of vulnerability.

Mitochondrial disorders are not well known and accepted in the general population, as are diseases such as cancer or diabetes. In the words of one participant, mitochondrial disease is an “obscure, bizarre, never-heard-of disease” (P10). The narrative of “you can’t sit back and be the patient” was illustrated by participants’ stories of their challenges in explaining the disorder and how it affected them as individuals. The difficulties in explaining mitochondrial disease to others centred around the symptoms themselves, the knowledge level of the affected person, and the knowledge level of the person being educated. To explain it to others, several participants described comparing it to more common diseases that people would recognize and accept.

...there aren’t that many people familiar with mitochondrial disease, but there are a lot of people know someone who’s got diabetes. And I say, ‘well it’s similar to that—you can’t metabolize sugar properly and it affects every cell in your body and it gives you a lot of extra health problems’. And I, I kind of draw comparisons to mitochondrial disease, which is also a metabolism problem. (P12)

Not only was the disease itself difficult to explain, so were its individual manifestations. One of the reasons why people were challenged in explaining symptoms their to friends, family, and health care professionals was because of the variability of the symptoms:

...it’s like a moving line, that’s one day you can do more, so what’s your problem, why can’t you do it tomorrow? And you don’t know yourself where the line is! (P3)

The invisibility of mitochondrial symptoms also made the disorder difficult to explain to others. In the words of one participant, “an energy deficit is not something that is easily understood” (P4). It is not something people can see “on the outside” (P11) in most
instances. It is “…not like a broken arm, it’s obvious, it’s clear, you know, the restrictions are there and they’re relevant” (P3). One participant shared that every time she parked in a handicapped spot in a parking lot, she felt guilty, as though people were looking at her and thinking there was nothing wrong. The severity of the disorder was also described as challenging to explain to others.

I’ll say, I’m really tired, and I have to nap every day…they’ll say, well, everybody needs a nap once in a while…people just don’t, see the severity of it. (P6)

Explanations to others were further complicated by the fact that people themselves often did not have a solid understanding of mitochondrial disease.

… to explain it to the extent that, they would understand and, like I say, I have to understand before I can start explaining it. (P7)

This point was illustrated by a participant’s story about her family’s doubt that the disorder really existed. It took an outside source to prove to them that she was not fabricating the diagnosis.

…and as soon as they heard the interview with the doctor and saw the word ‘mitochondria’ in articles, it validated it. (P10)

Because many of the participants struggled with fatigue and being believed, the onus to explain the disorder and its symptoms over and over again to friends, family and health care professionals was draining, adding to the difficulty to explain it to others.

…the thought of going out there to explain it to somebody…feels like a big job…where do you start…how much are they going to understand… (P3)

Another participant stated that, when asked about her disorder, it was

…always a balance between just smiling and shrugging it off and then, giving education or, or even getting defensive sometimes about it. (P11)
In summary, “you just can’t sit back and be the patient”, was evident from the fact that people with mitochondrial disease could not expect that others would automatically know about the disorder and absolve them of the task of repeatedly explaining it. What ensued from “you can’t sit back and be the patient” was the realization that it was up to them to become ‘the expert’. Their individual response to this realization was revealed in the following two sub-narratives, “there was no magic out there” and, “now I’m the educator”.

The Sub-Narratives

Two sub-narratives are woven into the main storyline. In general, the stories all had elements of each sub-narrative, although one was always more prominent, giving an overall tone of ‘chaos’ or ‘quest’ to the narrative. “Now I’m the educator” stories were often laced with “there was no magic out there” stories. However, interviews existed where only one sub-narrative was represented. The chaos story of “there was no magic out there” was more likely to be the sole sub-narrative in an interview.

There was no magic out there

So….to me it was almost like….being the first person to ever have a disease. And they tell you, this is what you’ve got, and they don’t tell you what it is. You know, or what’s going to happen to you. I still don’t know what’s going to happen to me. They don’t know what’s going to happen to me! But at least, I know they don’t know (P9).

The sub-narrative of “there was no magic out there” is: I became frustrated with the fact that no one had any answers for me, or seemed to know what I had. I was overwhelmed with the task of educating myself and besides, the ending was always the same. I decided to accept the fact that there was no magic out there. This is the classic
chaos story, sated with unanswered questions, unremitting symptoms, disability and pain, lack of understanding from medical professionals and from family and friends, frustration at the inability to work and to fulfill family obligations, and social isolation (Frank, 1998, p. 202). The listener recognizes this story when they feel “sucked into a whirlpool and only want to get away” (Frank, 1998, p. 202).

The interviews with a prominent chaos sub-narrative were replete with detailed accounts of participants’ medical history. It was difficult to lead these people back to the topic of inquiry and impossible to elicit any information about their educational experiences until they had shared these stories at least in part. In this sub-narrative, there was the absence of power and elements of being victimized by health care professionals. These stories were told emphatically and passionately, conveying frustration and feelings of vulnerability. Often, the story itself was composed of mini-stories all rolled into one long dialogue, or sometimes, diatribe. Whether it was told by someone who chose to self-educate or not, the final outcome of the story was a hands up, frustrated, “there was no magic out there” response.

Right, everything I knew up until that point was not correct. Even though the information I got was from one of the little booklets she helped write! Which is about the only thing I have on mitochondrial diseases. But even that booklet, you take it into... the nurses’ station or whatever, and I’m sure nobody receives it, or even looks at it. Because, they’re not going to run into another patient with, mitochondrial disease, so why bother. You know, you hear nurses talking in the hallway, “oh yeah, so and so has such and such. Well what a hypochondriac she is!” and you think, “and you’re a professional? Like, excuse me!” You know, and, then you have nurses who say, “well can you talk to so and so about your interstitial cystitis because she’s really having a hard time” So I sit down and I talk and I say, “well what do you eat”. And, first thing they, “oh, I have about 5 bananas a day” and I say, “you know what, you cut your pain down to nothing if you give up those bananas!” And...then the nurse confides in me, “we think she’s addicted to painkillers, ‘cause she drinks tons of coffee, eats tons of bananas and then crawls in here for a shot of demerol”. And I’m going, “yeah, there’s nothing I can do!” (P8)
“There was no magic out there” sub-narratives were told by people too overwhelmed by barriers, physical suffering, or life in general, to search for answers and information.

Yeah, you just basically go into survival mode. And, you.....when you’re trying to assimilate all this information, the last thing you want to worry about is whether or not there’s going to be a meal on the table for your 5 year old, um....how are you going to pay for that medication....when’s that ambulance bill coming in... (P8)

Others who shared this sub-narrative were those not interested in investing in a task that was not likely to reveal new insights. For example, one participant whose mobility was obviously affected discussed how the realization that “there was no magic out there” was liberating. She decided not to pursue her search for information and answers and instead focus on other activities to improve quality of life.

...ultimately, what it meant for me was, there wasn’t a need to keep looking for a cure, because at the moment, there wasn’t one. There wasn’t anything I could do about most of the symptoms and in a lot of ways, that was a relief. Because, um, the stress of having to, deal with, um, you know, trying to find solutions, um, it, it often, I find, more...... I guess the need to be aware of your symptoms so they can be treated, um, often makes the symptoms worse. And, um, knowing that the symptoms couldn’t be treated, and, there really wasn’t much that could be done, um, at least nothing that was going to be effective, meant that I could allow myself not to pay as much attention to it (P13)

Some participants said they did not want to learn more about the disorder, fearing the realization of what may be in store for their future.

“There was no magic out there” stories were replete with barriers standing in the way of acquiring knowledge and increased understanding about the disorder. These barriers included the scarcity of resources....

...the research I would have...done in the past would be something like, looking into a course, and taking a course, but there’s no course on this... (P3)
...and physical limitations such as poor eyesight, fatigue, and muscle aches. In addition, just the perception that they would not be able to understand the information prevented people from conducting their own research.

And we were really not on the Internet at that time, and it never occurred to me to go to a hospital library and, try to research it, because my perception was, the documents would be beyond my understanding. (P10)

Information and support groups accessible to people with mitochondrial disease are chiefly on-line, excluding those who are not ‘computer literate’ or who do not own a computer.

...other people seem to jump from website to website and have no trouble and I always have trouble...I’d be more interested in going to a library....I’m better in that respect than, than on the Internet. But I don’t know, what’s available where. (P7)

Ultimately, many participants who told “there was no magic out there” stories found the information retrieved in their search disappointing. The information was described as being “too technical to understand” (P7) and not specific to them. There was a paucity of clear and credible information relevant to their particular presentation of the disorder and this was described as frustrating.

...I occasionally look around for, for information and, again, I haven’t found, anywhere that has information that seems relevant...and is credible. There’s certainly a lot of um...I guess a lot of ‘witchcraft and ‘snake oil’ out there! (P13)

In the words of one participant, “...there’s information, but the ending is always the same” (P1).

Many participants who told “there was no magic out there” stories were skeptical of peers as a useful resource for learning. One participant avoided listservs and chat lines based on her belief that
...when I see the drip come, I have to ask, ‘Well, what’s in there?’ And yet, if I’m asked, ‘well, what should we, what should we be using?’ I’m not a doctor! And I’m not real sure of what, how to answer that question. So, there’s still not enough information out from doctors to patients in order to be able to self-advocate, effectively. And be believed. (P4)

The mothers in this study who were diagnosed with mitochondrial disease as a result of having their child diagnosed described the frustration of knowing something was wrong with their children but having their knowledge dismissed repeatedly.

And, well even getting (child’s name) diagnosed to start with. I kept taking this child in and they kept telling me, “oh you’re a, you’re a new mom...All babies cry! All babies kind of have lapses in breathing.” And finally he, he was started taking what looked like seizures. And, “oh no, you’re imagining them”..... Then, within 5, 10 minutes of us being on the ward, he went into what the nurses called respiratory failure. Cause I was catching him in the time between when you stop breathing and your heart stops. And I was told that I was imagining this. But you know, when all the bells and whistles go off, you know it’s not your imagination anymore! (laughs) (P8)

One woman, whose children were also diagnosed with mitochondrial disease, was accused of pathological motivations for her interest in her child’s symptoms.

I was actually accused of Munchausen’s syndrome with my kids, which has been closed as unfounded, totally unfounded, but, um, it was a pretty horrendous, year... And the primary thing was that I was, had a lot of information. (P11)

Using formal knowledge to self-advocate therefore was not always a simple task. People with mitochondrial disease, who would generally prefer to ‘sit back and be the patient’, were forced to self-advocate out of feelings of vulnerability. Others realized that knowledge was not always the ‘magic’ solution to protect themselves and make others understand the nuances of their disorder.

On the other end of the spectrum, there were a few participants who did not feel that they had any knowledge to impart to health care professionals. These people shared stories of using knowledge as a tool in the health care relationship, but did not recognize
...they’re not, they’re not an expert in it. They’re just a receiver of this whole thing and I don’t believe that their information could be any better than what I’ve got. (P1)

Others echoed this sentiment, doubting the credibility of the information passed around on listservs.

It’s...generally information based on, you know, either anecdotal evidence...that this or that concoction of vitamins is having a dramatic effect on them, or, you know or their family doctor put them on this prescription or that prescription and it’s dealing with this symptom or that symptom. Um, but without any...any clear link, or enough data to really back it up. (P13)

These were individuals who expressed a preference in learning only from scientific resources, such as journal articles and health care professionals who were experts in the field, the closest they could get to ‘magic’ answers.

Interviewer: So what you’re saying is that there’s the expert knowledge. When it comes from the universities or from the clinic, or some formal place is a lot more reassuring to you than people’s experiential knowledge. Would you agree with that?

P1: Yeah, that’s exactly it! So I don’t see the...I don’t know...I’m a non-believer. Let’s put it at that...

Other participants had tried learning from peers but were discouraged by negative experiences in this regard. One participant described a time when she had spoken to another person with mitochondrial disease.

....she was so adamant that everything I had learned up to that point was wrong. And...felt like I was constantly being put down and stuff, like I didn’t know anything, at all! (P8)

After this experience, this participant was reluctant to pursue other opportunities to learn with peers. A few people commented that they did not want to participate in listservs or chat groups because they found them depressing.
I tried the Internet support group... and I found it more depressing than supportive. I found that a lot of the chat was focused on...frustration at doctors, frustration at...conflicting advice, uh, frustration on lim—physical limitations. (P10)

These participants therefore concluded that peers had no “magic answers” either.

Sadly, several participants also commented on how they felt that health care professionals had the ‘magic answers’ and were withholding this information from them.

...there wasn’t as much information as, I perceived there might be and that somebody was withholding it from me? That it was in medical journals that, I couldn’t understand, and, didn’t have access to. Which I’ve subsequently have learned is incorrect. I’m...I thought I didn’t have access to that information. (P10)

“There was no magic out there” stories often casted health care professionals in a negative light; as those not to be trusted. This characterization seemed to be borne out of feelings of frustration and vulnerability based on bad past experiences. In response to “you can’t sit back and be the patient”, people described their struggle to impart knowledge about mitochondrial disease to health care professionals, in particular, physicians. Participants shared instances when they had discussed their needs with health care providers prior to procedures and the information was disregarded.

I went to have a colonoscopy last year. And I had told the doctor, the specialist who was doing it that, uh, that I didn’t want to have Ringer’s lactate used and he said, “well, we don’t use it”. So, I went into the hospital and they started up a drip and within 30 seconds, I could feel my heart rate start to climb and I said, “what’s in this?” And she said, “uh...Ringer’s lactate” and I said, “I can’t have that”....And so then I had to go in, and I had already given, the people in the daycare, the, the card that I’ve gotten from the, the, from here and the information about anesthesia and all the rest of it, because it does talk about Ringer’s lactate in that. So, uh, and, still, they used Ringer’s lactate as a source of drip. (P4)

This participant continued by describing her predicament of having to self-advocate without the knowledge to answer questions from health care professionals who were unfamiliar with the disorder.
...when I see the drip come, I have to ask, ‘Well, what’s in there?’ And yet, if I’m asked, ‘well, what should we, what should we be using?’ I’m not a doctor! And I’m not real sure of what, how to answer that question. So, there’s still not enough information out from doctors to patients in order to be able to self-advocate, effectively. And be believed. (P4)

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Using formal knowledge to self-advocate therefore was not always a simple task. People with mitochondrial disease, who would generally prefer to ‘sit back and be the patient’, were forced to self-advocate out of feelings of vulnerability. Others realized that knowledge was not always the ‘magic’ solution to protect themselves and make others understand the nuances of their disorder.

On the other end of the spectrum, there were a few participants who did not feel that they had any knowledge to impart to health care professionals. These people shared stories of using knowledge as a tool in the health care relationship, but did not recognize
it as such. They maintained that they had no formal knowledge to share. These participants often described relegating bodily or experiential knowledge to their care provider. They told stories of offering bodily knowledge and then depending on the health care professional to determine the cause, not seeing it as their ‘job’ to educate.

I’m not the kind of person who goes in to a doctor and says, ‘I want this and this and this done’ like a lot of people would go in to see a doctor. Like I would go and see a doctor and say, ‘this is what I’m feeling’, then wait for them to do the test, ‘cause that’s what I think their job is. (P5)

This often resulted from discomfort in communicating experiential or bodily knowledge to physicians.

I always have a problem speaking to doctors because I, I think...I try and over-explain my symptoms, to try to make them understand...And...then they may think I’m...you know, um...over-blowing a situation or whatever. (P5)

Variations therefore existed in the ways people described using bodily and experiential knowledge: those who shared it with health care professionals to try to get the answers they needed; those who discounted it or did not think that it was worth sharing; and those who used it to come to their own conclusions about symptom management.

...I don’t seem to get the severe attacks anymore but I think that’s because I’ve learned how to behave, you know, and what to do and what not to do? I don’t overdo it now like I used to. I still get twinges but when I do, then I deal with it right away, instead of just...ignoring it and carrying on, until I’m crippled. (P7)

Regardless of the type of knowledge they were imparting, the participants rarely described educating health care professionals as an entirely comfortable role. It elicited anxiety and feelings of vulnerability. Because their resources or motivation for finding information were limited, they did not feel confident in being looked upon as the ‘expert’.

In addition, they struggled with the way they imparted bodily, experiential, and formal
knowledge to health care professionals, keeping in mind they did not want to alienate themselves, and wanting the information to be taken seriously.

Ultimately, these stories would end with the lament that they were given so little information at the time of diagnosis. Participants collectively stressed how much better the quality of their learning and their experience would have been if someone had spent time with them at the beginning, giving them information.

But it’s not like television. It’s not like a show or a movie where you go in there and sit down and the doctor spends half an hour giving you, “well this is what you have and this is what your life is going to be like”... It’s just like, oh, yes, you, your biopsy came back, you’ve been diagnosed with mitochondrial disease and this is what we want to do. (P5)

One participant stated that she felt she had wasted many years of potential learning and understanding that may have improved her quality of life because of not having more information at diagnosis. In this same vein, people commented that they did not mind doing their own research, but needed direction at the beginning to get them going.

I don’t mind doing the work but a least....at the beginning, had I been given the tools to investigate the disease, the learning curve would have been a lot faster. (P10)

Another participant was frustrated that she had been forced to do the research on her own.

You know, I shouldn’t, I shouldn’t have had to go on the Internet and, and dig around on there, I mean that should have been my second resource, you know. I should have had a lot of information,...and I didn’t. (P9)

The specific type of information people wished they had been given at the time of diagnosis was the name of their particular manifestation of the disorder (if available) and what to expect in the long term, even if was just a presentation of “possibilities” (P3). All participants wanted information, no matter how broad, on what to expect in terms of prognosis and symptoms. Often this information was not provided because it is not
known, but even general information of potential outcomes would have been helpful according to this group.

I think that’s the big important thing is to know... the truth and the long-term and like, you know, having the long-term possibility explained earlier. So nobody knows for sure, I mean, you take that into consideration, but it’s possibilities. (P3)

Practical things such as potential financial and future caregiving implications, ideas of what to expect based on what may happen to their bodies and resources for education and support were suggested.

What... might we expect for our future life, because then we can make decisions, about our lifestyle, based on what my happen. What are a list of resources. Reading material, or web sites, support groups, that are available for me, to contact.... Those would be really... those would have been really helpful for me. (P10)

Because the Internet is their sole source of information, this is where participants turned for answers. Just as ‘cancer’ serves as a global term for a number of different diseases (e.g., breast cancer, melanoma, Hodgkin’s lymphoma), mitochondrial disease encompasses a number of different syndromes. When the person does not present with the symptoms of a certain syndrome (e.g. MELAS, MERFF), they are diagnosed with ‘mitochondrial disease’ in general. Participants stressed the importance of giving the person as much information about their specific disorder so that they have that knowledge when researching on the Internet. Otherwise, the information they may uncover may not pertain to them, and could be very frightening.

... Then I could go on the Internet and I’d look up things, you know, but as soon as she told me the name of it, I could eliminate all these awful ones! Mine’s not that great either, but, you know! I could eliminate all these other ones... (P9)

As well as giving relevant, individualized information when possible, the participants stressed the importance of giving as much information on symptom management and
limits. For example, a few participants suggested giving guidelines for exercising, so that they would know their limitations and would not harm themselves.

...I started going to the gym. And I go about five times a week now...But, I never know if I'm hurting myself when I'm in there, you know? ...I'd like to try new things, but I don't know if I can get—if I can do it, you know? Like I don't want to drop dead in the street or something, you know?! (laughing) (P9)

Information on symptom management gave them ‘something to work with’ and reduced the feeling of being “left in limbo” (P4).

To say there’s no cure or treatment, come back and see me in a year, had somebody said, there’s no cure or treatment, let’s focus on what we can do to improve the quality of your everyday life, I would have left the offices feeling, I had some power...You feel powerless. You really do. You feel like your power is taken away from you. And because you have so little knowledge, you don’t know where to go, and, you don’t go! (laughs). You go back in a year, and nothing’s changed. (P10)

Involving and educating family members was mentioned by a few participants as something that would enhance support and understanding.

And, the more understanding that my family has, the more support I feel I have. And that’s been really important to me. With an illness that you can’t cure or treat, support seems to be, um....um...critical (P10)

Participants wanted their family to hear the explanations first-hand.

I think one thing, that really needs to be stressed is, is, the families, the families also have to be included in this learning process. Because, ....if it’s hard for me, it’s doubly hard for them, because they don’t come to all, all my appointments and that, so they’re kind of, they’re lost, you know. So, you know, I think it’s really important that they get the family in there, you know. And we had every step along the way, we had, I had to bring my family, I didn’t ask, I just brought them. But you know, nobody asked me, “would you like, you know, would you like to bring your (children) in? or whoever?” you know? (P9)

In addition to the quality of information, participants commented on the importance of acknowledging the person’s prior knowledge and building on it to explain the disorder at the time of diagnosis. Several participants had backgrounds in science and
health care related fields and therefore had a framework in place, including familiarity with medical terminology and ability to access and read scientific information. This needed to be considered by the health care professional when educating them about their disorder.

She knew I was...acquainted with a lot of the technical literature, um, she gave me a whole bunch of reprinted papers and stuff...That was a good approach...she gave me enough reading material that I could look at on my own time, and, and you know, get more knowledgeable about it. (P12)

In this same vein, it was important to participants that they were given the appropriate level of information to take away from the appointment.

...put it more in laymen’s terms....the literature...given (to) me is very technical. And I’m, I’m reasonably good at...reading that kind of stuff, ‘cause I’ve done a lot of that, but I can’t imagine somebody who’s never had any medical background or...education I’m sure would just, read three lines and give it up. (P7)

Therefore, the importance of providing individualized answers to typical questions and giving the appropriate level of information at the time of diagnosis cannot be overstated. Although it would not provide ‘magic answers’, it may serve to decrease the feeling of being overwhelmed by where to look for information and give people some sense of control. In essence, it may serve to transform the chaos story into one of quest.

“There was no magic out there” stories ultimately left the listener with an overwhelming sense of the narrator’s powerlessness and frustration. They did not end with any sort of action or decision, but generally an evaluation of the hopelessness of the situation. They were stories of being left in limbo.

I’ve always been like that but this one is overload. I get so overloaded that I don’t know what I’m thinking even. I’m (age) now, not 16. And I can’t filter the....I can’t filter out the important things. I read and read, remember not having any medical knowledge and really, I really have no education, I, I finished, part of first year university when I was 17, so, I don’t know what I retain out of it. I may
read it, but I don’t know what I retain. And um... I couldn’t pull anything from all that research, except that it’s done. So... that’s... I don’t know what else to say. (P1)

Now I’m the educator

The sub-narrative of “now I’m the educator” is: I realized that it was up to me to educate health care professionals about my mitochondrial disease. I decided that, in order to advocate for myself in the health care system, I had to learn more about my disorder. I went about accumulating knowledge with which to negotiate my health care and educate health care professionals. I discovered that I knew more about the disorder than most health care professionals. This was both empowering and frightening to me.

Prior to diagnosis, individuals struggled to have their bodily and experiential knowledge believed. As a result, they often expressed feeling vulnerable in the health care system. As in “there was no magic out there”, this vulnerability often translated into doubt that nothing was being done or that their symptoms were not being taken seriously. People commented that they felt that the physician had given up on them if their problem was not easily diagnosed.

...a lot of medical people, if they don’t get it the first time, they just write you off. I mean, it’s like the business model in medicine.... if you don’t get, like, immediate success, or, if the tried and true remedies don’t work,... it’s not financially advantageous to continue with a patient. (P12)

Contrary to “there was no magic out there” stories however, “now I’m the educator” stories portrayed participants as taking action in response to this mistrust. Some participants were motivated to accumulate formal knowledge about the disorder and their individual symptoms in order to self-advocate.

(long pause). It took a while to come out of the downtrodden feeling that I had after that experience in this hospital. Um... I really felt that my self worth took a trouncing. I knew that because I looked well, it was hard for people to believe. And I wasn’t real sure about how to go about self-advocacy. I didn’t have the
Internet...um...my dictionary didn’t have anything other than the word, mitochondrion! (laughs) in it, there was, none of the medical books that I could get my hands on had very much information about it. So, my source of finding out information was...low. I knew nobody else with...the disorder. So I felt really isolated, felt really lonely, um....I felt misunderstood. Um, what little I did know, the only one thing that, that the doctor who yelled at me told me was that, that if I had a mitochondrial disorder that having a general anesthesia would be a problem, but he didn’t tell me what the problem would be, he didn’t give me any information. When I asked him about support groups, he said he didn’t think that a support group was a good idea for anybody. So, so, uh, I just got a lot of negative information that I had to overcome. And it, it took quite a while to get over the, the I’ll call it depression. It was situational rather than...a chemical problem, it was a situational problem. And once I, once I got on to the Internet, it took me a while to get the courage to get on to the Internet, I’d heard a lot of bad things about it and it took a while before I got the courage to do that. Once I did, wow, one of the first things I did was type in mitochondrial disorder and, the world opened up. And from there, I joined listservs and uh, learned more about how to used the Internet, and uh...went from there. (P4)

No matter how well the participants felt they knew the disorder and how it affected them, “now I’m the educator” stories described how this was a completely new type of learning experience. First and foremost, people who wanted to learn more about mitochondrial disease had no obvious resources to turn to, as would someone with a mainstream disease like cancer. One woman stated that she’d “never had to investigate anything like this before” (P10). To research things in the past, people described going to the library and getting a book, taking a course, getting pamphlets from their doctor’s office—all fruitless in this instance. One participant had other health concerns as well as the mitochondrial disease and described how her learning experiences differed.

Because there’s so much information, that you can get. You can just walk into your doctor’s office and get this information, you know. So, and I find that, a lot of people, like, like the colitis and the um....osteoporosis, those are things that, almost everybody knows someone that has something like that, or has it. So, most of my information came from the doctor’s offices. (P9)

In the days before the Internet, the library was generally the first place participants turned to accumulate more information about their disorder.
...the most helpful thing for me was the Internet, but when I first learned about this, I didn't have my computer yet. So I went to the library. And I was looking through all the, the books, the Mayo Clinic and things like that, and there wasn't very much on it, at all. (P9)

I....did as much...research as I could in terms of, you know, trying to find research in the library and that turned up pretty much nothing, um, you know, generic text book explanations of mitochondria! (P13)

Even once the Internet was available, several participants commented that they still preferred to do research using reference books at the library. However, this strategy often resulted in frustration, because the library did not have any useful information on mitochondrial disease.

Because the library was not a good resource in the days before the Internet was widely available, there were virtually no resources available to people who wished to self-educate. They therefore had to depend entirely upon the health care professionals to educate them.

I just couldn't do the research that I would love to do, and so, I relied on the doctors and nurses... (P3)

With the advent of the Internet, people continued to learn from health care professionals but used the knowledge more to guide their own self-directed learning.

Therefore, as in "there was no magic out there" stories, participants faced many barriers in their search for answers. The sub-narratives differed with respect to the degree of persistence to find information despite these obstacles. "Now I'm the educator" stories revealed three tools that had been helpful in people's search for more formal knowledge about their disorder. The first was being given the 'words' by allied health care professionals such as physiotherapists and massage therapists to express their bodily knowledge in medical terms.
And she was very good about being able to give me, scientific words...to explain, what I was feeling. Um...you know I couldn’t always express what it was. You know, I would say, “my leg hurts!”. Well, that is way too vague for what people need to make a diagnosis. But she, really could help me pinpoint what exactly was the matter. And um, and that, I think, helped, everybody else...to be able to have her knowledge and her knowledge of how my muscles in particular were working. (P6)

Having ‘scientific words’ helped these people to convey their symptoms to the health care professional in a language that would be heard and accepted. The second tool was giving them enough knowledge to know what questions to ask or where to look.

...it also gave me a list of um, investigators, who were studying the disease, so, I can, find their work fairly quickly on PubMed and read abstracts and stuff. (P12)

Finding health care professionals that were willing to guide them towards where to find information or current research was identified as critical to their access of formal knowledge. The third tool, which participants identified as helping to validate their disorder to others (i.e. health care professionals, family, friends) as something ‘real’ was printed material such as pamphlets, journal articles, and lists of websites from the doctor or from the clinic. Printed material helped family and friends to understand what the person was experiencing without them having to explain themselves. This participant referred to the introductory information package and yellow emergency wallet card provided to people newly diagnosed with mitochondrial disease at the AMDC.

I came home with the folder and the yellow card which I said was a, a very good thing for me to...to, ah, have. I didn’t have to explain myself. I didn’t have to. (P1)

Another participant described the value of having the United Mitochondrial Disorders Foundation (UMDF) newsletter to share with her family.

And...um......I know that it’s...really been comforting to my Mom and Dad, particularly my Mom, to, be able to read the UMDF newsletter. Just to see that this is con-crete! I mean, everything they hear is just from me, you know from
what I’ve learned and somehow seeing it in print and seeing that other people are dealing with this, is some kind of reassurance. I’m not sure exactly what it is, but you’re not in it alone, I guess. (P6)

“Now I’m the educator” narrators turned to the Internet at some point in their quest for more information, if it was available at the time of their diagnosis, and later on in their journey if it was not. People described using search engines to research mitochondrial disease and joining listservs and chat groups online.

...there’s a national clearing house of rare disorders, I’m not sure exactly what it’s called—they have a fair number of things and eventually I got to where I really used the um...muscular dystrophy association website, but not early on. Early on, I um...you know, I’d just put in ‘mitochondria’ and see what came up! (laughing) And um...you know, I read people’s studies and research. (P6)

Some participants who were not confident in their computer skills elicited help from family members who looked up sites on the Internet for them.

I had help. I have a son that’s a...a genius with the computer. So, he looked up sites for me. I found a few on my own. (P1)

Another participant who preferred using the public library to learn asked her son to do the research for her.

I actually...didn’t do any research, hoping that my son would tell me which sites to go to, ‘cause he’s very good on computers! And I sent him all the websites and all that and I was hoping he’d do all the research... (P7)

The self-educators unanimously agreed that the Internet was the most helpful resource in their search for more information. One participant described her experience of being ‘on line’ to research her disorder.

Once I got on the Internet...one of the first things I did was type in mitochondrial disorder and, the world opened up. (P4)

Many “now I’m the educator” stories described positive learning experiences with peers on listservs and Internet-based chat groups.
I have to tell ya, that's where I’ve learned so, so much is from those group of people...there’s some people that, in those groups, who are, who have excellent science background and...are very knowledgeable, and...amongst the group, you can get a lot of information!...it really helped me to find...other journal articles and other places to look...so you’re always, you know, getting information, scientific information, plus anecdotal information, from people. (P6)

In addition, people named these groups as the place where they received support from others facing the same challenges.

And uh, I learned later that a lot of people have that and they describe it and, “wow it sounds just like me and”...bowel trouble and having to eat small meals and having trouble swallowing and...you know, it doesn’t um...it doesn’t make you better but, learning that other people are living with it, and they’ve lived with it for a long time- and they’re finding ways to cope with it, uh, it really helps a lot. (P12)

The listservs for these people, then, offered a means to increase formal knowledge about the disorder as well as experiential knowledge to improve their quality of life.

The majority of “now I’m the educator” stories centred on how people used knowledge in their interactions with health care professionals. Some described ‘testing the waters’ and waiting to see if the health care professional showed an interest in the disorder before offering to educate.

...I don’t offer to educate them, but if they show an interest and they ask me questions, then I always say, ‘well hey, I’ve got, there’s a web site I could pull some information off if you want’ you know, and when, as soon as I say that, they want it....So usually, I’ll just approach it that way. If I see they’re interested and ask me a few questions, that’s what it takes for me to say...if they don’t show an interest, they don’t ask a question, I don’t say anything. (P9)

Others were more assertive in educating their care providers. Participants described taking information to clinic appointments...

I print off the journal articles or the abstracts, um, from PubMed and I’ll actually take those to them, to an appointment, to review later....Or I, or I picked up extra stuff at the mito conference and, uh, ....I underlined and highlighted the, the parts that talk about, about many,...mitochondrial patients being, misdiagnosed with
chronic fatigue syndrome. And um, so I will just give that to them to peruse at their own time. And I found that’s a little bit better approach to take... (P11)

... linking mitochondrial dysfunction to the health care professional’s particular specialty....

I tell them that I have mitochondrial disease—they look at me, uh, with a blank look which is a pretty good indicator either that they never heard of it, or, they don’t know anything about it, so then I go on to explain that it’s a genetic disease, that affects my, energy function. And I explain to them the type of mitochondrial disease I have—that it’s (name of particular disease), and the...the ways that that affects me now and could potentially affect me in the future? and...um....they....I guess what ever the particular concern I’m seeing them about at the time, I try to link my conversation to their specialty, or, or the particular concern I’m there to see them about. For example, when I go into to, to see an eye specialist, for an eye exam, uh, because I have (condition) I explain to them how it affects my eyesight. Um, they never—rarely—ask me any questions about the disease, so I don’t, um, experience a high level of curiosity from them? I do experience though, a relatively high level of acceptance of what I tell them. (P10)

...or using knowledge to raise awareness about mitochondrial disorders.

And he said, “well last time you were here, you were having a lot of muscle weakness” and I said, “yes, and I have a name for that now. I have a diagnosis.” And he looked at me and he said, “You do?” and I said, “yeah, I have mitochondrial disease and the exact one is...” and I told him about (name of disorder) and...um....(laughing) he, you know he said, “well it must be so, nobody’d learn a name like that”, and I gave him the whole name, “nobody would learn a name like that if it weren’t so” (P6).

In “now I’m the educator” stories, nurses and allied health care professionals were generally characterized as expressing interest in learning about the disorder.

...whenever I go in the hospital, or for procedures, the people I find the most interested and the, as soon as I say, “I have mitochondrial disorder”...It’s the technicians, it’s the nurses, you know? ...they want to know about this! (P9)

Others also described physicians who were inquisitive, thereby inviting the person to explain the disorder to them.

I get there, and the radiologist...you know, says, “why are you having this study?” And you know, it actually was just before, it was before I had my diagnosis. And I said, “well they think I have a mitochondrial disease”...So...
gave him a two sentence definition and said, “you know what sometimes happens is it affects the muscles in the esophagus and that’s what we’re looking for today”. (P6)

Many participants who described these positive experiences had pre-existing relationships with their physicians. Regarding her family doctor, this participant remarked that

So we know each other in a lot of ways, you know, socially and professionally and so, um… he does, he trusts me and, I trust him! (P6)

When she wanted to try a new drug for her symptoms that she had learned about from her own research, her family doctor trusted her judgement.

...now my local doctor will do anything for my symptoms, and um, you know, he’d do anything! But he doesn’t always know. And um, so, he is totally open... When I went on the Carnitor, he was nervous. He was very nervous. He said “(participant’s name) did you read about this?!” and he had given me his book that talked about drugs while I was there and he’d gone off to do something and he came back then later on he called me and he said, “did you read all this? Did you read about all these side effects? Are you sure you want to do this?” (laughing) And I said, “yep, I’m gonna do it! (P6)

Others had physicians who were willing to listen and learn from them in more of a partnership approach.

I’ve occasionally had doctors where they’ve come in and said, ‘now tell me what we’re going to do with you now! (laughing) Because I would have researched whatever medications or whatever and said, ‘yes I’m going to take this’ or ‘no I’m not’. So I’ve certainly been involved in my own health care. (P7)

However, this seemed to be the exception versus the rule. Most “now I’m the educator” stories did not describe positive experiences with educating physicians. Several participants related occasions where they perceived doctors as being “intimidated (P10, P11)” by their use of knowledge in the interaction. This participant was relating a time when she got into an altercation with a physician because he discounted her knowledge.
...he seemed to be threatened? By the fact that I thought I knew what I was talking about? And...that I was, um, telling him what I thought needed to be done, rather than him telling me what he thought we should do....I said I really didn’t feel that we could work together...that he was....um, challenging me, on a disease that he knew absolutely nothing about, and um, that I was the one living with it, and had researched it...(P10)

No matter how, why, or with whom knowledge was used, “now I’m the educator” stories generally revolved around self-advocacy. For instance, having formal knowledge often took the form of a ‘protective shield’ in the health care arena.

So, knowing, and gathering the information, and having those facts and having, the names of....um, leading specialists that have said, yes this is a differential diagnosis, that a lot of them are misdiagnosed with this, that, having those, having the information, at your finger tips so to speak, so that if it does become an issue that, you can protect your family....is very important. (P11)

Similarly, other narrators told stories of putting the health care professional ‘to the test’ with respect to their knowledge about mitochondrial disease. This participant described using her knowledge as “a screening device” to determine who could be trusted to help her.

I’ve kind of got a filter on to figure out as to when people are bluffing and they don’t know, you know, you’re telling them something that’s absolutely new to them...just mentioning it, unless the person is able to come up with something that sounds like they’re on top of it, you can pretty much discount the fact that they’re going to be able to help you until, they, are educated better. (P12)

Several participants described watching for the “blank look” (P 9, 10, 12) to gauge how familiar health care professionals were with mitochondrial disease.

I’ve found that some doctors, you can tell right away when they don’t know what you’re talking about cause I say, ‘well I, I think this is being caused by my mitochondria...disease...disorder’. And they’ll just kinda look at me and they’ll nod their head and that’s it! You know, they don’t want to admit they don’t know what’s going on. (P9)
On the other extreme, some participants told stories of times that health care professionals would turn to them for direction, looking on them to be the ‘expert’ on their disorder. This was described as both flattering and frightening to the patient.

I felt very vulnerable with that kind of situation because it put pressure on me to know what I needed when I didn’t know what I needed. I could educate myself…but the education I could get, was limited to what I could get from other patients, and…I thought, that DID make me feel vulnerable and YET, it was empowering in a way as well. (P4)

What is evident from the “now I’m the educator” sub-narrative is the significance of the relationship between the person with mitochondrial disease and their care provider on learning and ultimately on the quality of the overall experience. The health care professional has the power to ‘make or break’ the experience for the individual with mitochondrial disease. Intersecting back into the main story line of “you can’t sit back and be the patient”, “now I’m the educator” stories not only depicted narrators’ shifting perception of what ‘being a patient’ entailed, but also what an ‘effective health care professional’ was to them. In order to accomplish this shift, they needed to determine their own criteria for deciding whether the health care professional would be an effective partner in the journey with their disease.

Five qualities of the ideal health care professional emerged from participants’ stories. In sharing these qualities, nearly all participants used the word “willing” or “willingness”. The five qualities described below all fall under this umbrella of ‘willingness’: to be accessible, honest, knowledgeable, persistent, and to advocate on the patient’s behalf. Challenges specific to the primary health care relationship will be discussed under the qualities of ‘persistent’ and ‘knowledgeable’.
First of all, participants valued health care professionals whom they could reach by telephone or email to ask questions between appointments. **Accessibility** extended into the relationship itself. The value of feeling comfortable enough within the health care relationship to be able to ask questions at office visits was mentioned, as was a health care professional who took the time to explain things. For a few participants, accessibility also took the form of having the health care professional be willing to make notes during clinic visits for them to take home. This was particularly important to people with hearing loss and for people who needed to absorb the information after they have left the appointment.

and...also, because I’m deaf and I miss a lot and some of the doctors I’ve found, are very reluctant to write things on paper, and I don’t know why that is. I don’t know if they’re afraid that I’m going to run out with it and sue them, or something, I don’t know. (Dr’s name) was very bad for that. Um, I could ask him 2, 3 times if he’d write that down, ‘cause I didn’t, couldn’t read his lips, you know and it’d take me 3 times before he’d start writing it down. And...so, I’d miss a lot, so how could I, go home, and tell my kids, this is what happened, you know? (P9)

Secondly, participants emphasized the importance of **honesty** and respected health care professionals who admitted their lack of familiarity with mitochondrial disease.

I really appreciate it when a, a physician will say, “I don’t know, but I’ll look it up”...for something like mitochondrial disease, there’s still an awful lot up in the air, the most top-notch researchers don’t understand it, and there shouldn’t be any stigma whatsoever, for a physician, say in family practice, or you know, in a, some kind of a specialty... to admit that they don’t know all the details about mitochondrial disease and how to treat it properly. (P12)

Several participants commented on being able to see through dishonesty or a façade of knowing. It was damaging to the relationship when the health care professional was perceived to be ‘bluffing’. 
Third, participants stated the importance of health care professionals keeping **up-to-date in their own knowledge** of mitochondrial disease. Several participants said they trusted new medical graduates more than those ready to retire for two reasons: one, because their knowledge was more current and two, because they were more receptive to learning from the patient.

I believe that older doctors should get a lot more...should go back to school...and learn. ‘Cause it seems to be, the younger doctors, younger specialists, that know about the diseases. Not the older neurologists, or the older cardiologists, or whatever. (P5)

Furthermore, participants expressed a desire for health care professionals to be willing to learn about the disorder *from them* when they were unfamiliar with the disorder.

I’d also like to have um...and this is a big wish, ‘cause I’m not sure it’s realistic at this point in time, the doctor to say, when you say you have a mitochondrial disorder to say, “A, a what?!” (laughing) And discover that I know more than the doctor does. And asking me the reality of the situation. And when that happens, then a willingness to say, how does it affect you? (P4)

A specific issue identified by study participants was the perceived lack of knowledge their primary care physicians had about mitochondrial disease. The experiences described by participants varied in terms of how the physicians dealt with this gap in their knowledge. Some practitioners admitted to not being familiar with the disease, but gave no indication that they wanted to learn more. One person quoted her family physician as saying, “well it’s a rare disease. I don’t have a patient that has that”. She went on to comment that she said, “...felt like saying, ‘well study up on it! You’re the doctor!” (P5), a statement made through clenched teeth, emphasizing her frustration with her family physician. This sentiment was echoed by another participant.

...even my family physician, “it’s out of my league! I don’t know anything about it!” you know, um, “What do you want me to do!” I’m going, but I’m coming to you for advice! (P8)
This left people not only with the feeling that they were unimportant, but also that they had no where to turn for help with respect to primary health concerns. It also led to mistrust of the family physician as a diagnostician, as illustrated by this participant: “No, um, the current family doctor I have, I, I don’t honestly believe he could diagnose much! (laughs) When he has diagnosed, he’s diagnosed wrong!” (P13). Since general practitioners are the experts on more common ailments, it is of great concern when the patient loses trust in their diagnostic abilities.

Most participants stated that they felt (and some had physicians who even stated this) that they knew more about the disorder than the family doctor. Some described instances where primary physicians had turned to them for advice and found this to be simultaneously empowering and frightening. In the eyes of the participants, therefore, the honesty of the health care professional in admitting their lack of knowledge about the disorder did not absolve them from taking responsibility to learn more about it themselves.

there should be no shame about not knowing, but of course, if they accept a patient that’s got that, then they do have a certain burden to increase their knowledge, or obligation. (P12)

The fourth quality identified by study participants was the importance of persistence. This took three forms. The first was being committed to finding solutions for the person, even if it meant referring them to someone else.

I have no problem with a doctor they don’t know, or the nurse telling me they don’t know, or the physiotherapist telling me they don’t know. “But, I’m willing to help you find somebody who does know, that will help you”. (P10)
If the physician was not immediately able to determine a cause for the symptoms, a readiness to pursue diagnosis and refer the person on to another health care professional were essential. One person described this as “paving the way” (P6).

Secondly, participants voiced frustration at health care professionals who ascribed all their symptoms to the mitochondrial dysfunction...

since the diagnosis, I really haven’t had much to do with the family doctor, because, ....they either, um.....want to treat...all of my symptoms... or, they attribute anything and everything, including the common cold, to being part of my mitochondrial disorder. (P13)

... and wanted practitioners to be persistent in ruling out other ailments versus ‘scapegoating’ the disorder.

The only ones I tell is here because my own family doctor, I, I never say nothing to him. ‘cause I said, “oh, I’m so tired half of the time”; “well, that has to come with your, with what you have”, so you know, big deal, you know, that’s the end of that, right? (P2)

Many people perceived that the diagnosis of mitochondrial disease provided an easy excuse for the family physician not to persist in determining the cause of their symptoms.

Several people described the challenge of having their family physician follow up on recommendations made for their primary care by the metabolic clinic. The patient was aware that these recommendations were made, but when the family physician did not mention them, it put the person in an awkward and vulnerable position, and one in which they did not feel they were receiving good, holistic care. Therefore, people also saw room for improvement in the persistence of the family physician in follow-up.

Finally, persistence in maintaining dialogue between specialists was emphasized as important by several participants. Many commented that it was incorrectly assumed that they knew why they were being referred to certain practitioners. They needed to be
asked if they knew why they had been referred, so that they could understand the process.

The psychological damage of not keeping the patient informed was illustrated by one individual’s belief that people with mitochondrial disease are used as ‘guinea pigs’, being passed from specialist to specialist for medical learning and undergoing unnecessary tests and procedures for study purposes.

You know, someone who’s finding the relevant information that isn’t um, isn’t looking for a guinea pig. Um, and, I mean I had, I really, I found, particularly with (Dr’s name), um that he was always looking for a guinea pig for his new therapy, or his next therapy. You know, and it was, it was sort of one of those things that, you know, I don’t want to be a guinea pig. Don’t order tests for me unless, you actually expect to see something on them. (P13)

The final quality participants expressed was the desire for metabolic clinic staff to advocate for them, either silently by sending information from the clinic to give validity to what they were trying to convey to other health care professionals, or verbally, by calling and intervening when needs were not being met by family physicians, allied health professionals, or specialists. One participant said that her affiliation with the AMDC gave her credibility, that specialists would “listen differently” (P10) to her now that she was being followed by a metabolic specialist. People extolled the virtues of having something to ‘back them up’ in the medical system, such as the yellow wallet card currently provided to the clients of the Adult Metabolic Diseases Clinic.

The best thing you did for me was hand me that yellow card...Because I handed it to my dentist, without saying anything. He read it, he didn’t ask me, he called the dental surgeon, and told him...(P1)

It was suggested that the information on this card be augmented to include suggestions with rationales of what to avoid such as specific anaesthetics, over the counter medications, and intravenous solutions. This information would bridge the gap between the knowledge of the metabolic specialists and that of the specialists in the community,
absolving the responsibility of the patients to ‘be the educator’ and leaving them feeling less vulnerable in the system.

In summary, the common denominator of these five qualities was a team approach where health care professionals and patients mutually respect what the other has to offer in terms of knowledge. Because there are no ‘magic answers’ to the disorder and therefore no ‘quick fixes’, the need to work together and to learn from each other is of utmost importance to the quality of life of these individuals; in essence, a willingness on the part of health care professionals to accept the “now I’m the educator” story.

Well I think if they put themselves in the position—if they were dealing with a, a client who had cancer, or, um, any other disease that they see on a fairly frequent basis, where there’s a lot more knowledge and treatment out—if they used the same attitude, even though there is no cure and treatment. They wouldn’t tell a patient that they had cancer, then say, “there’s nothing I can do for you. Come back and see me in a year”. They wouldn’t do that. Why do they do that with us. Why, if they could just put us, in the same perspective, “there’s no cure, there’s no treatment, I can’t send you for chemotherapy, I can’t send you to an oncologist, but there are other places that I can send you”. If they just looked at it that way. They don’t have to know a lot about the disease. They have to take the same approach as they do, with a person with cancer. All these, tools and resources and options, you know, you have all these options, you have cancer with all these options. Those options exist for us, even though they’re not focused on curing it. There are options for us, to give us power over our life. I would say that. And they don’t have to go back to school, learn anything, they just have to switch their attitude. (P10)

**Summary of the Findings**

The impetus for this study was to gain insight into how adults with mitochondrial dysfunction constructed and negotiated knowledge about their disorder. The three part research question asked how people made use of formal and experiential knowledge in building an understanding of the disorder and how they perceived this knowledge in relation to that of health care professionals.
Examples of how people make use of formal knowledge, the first part of the research question, were richly described in the “now I’m the educator” sub-narrative. Participants universally expressed that this learning experience was completely new; that is, different from any other learning experiences they had had in the past. As detailed in the findings, people described accessing a variety of resources, including health care professionals, peers, libraries, and the Internet, in an attempt to learn more about this disease. They discovered that their source of finding information independently was limited to the Internet. Participants described several barriers that prevented them from learning more about the disorder, including inaccessibility of information, the quality and the level of the information itself, physical impediments, and lack of computer skills.

The second part of this question was how people make use of experiential knowledge in building their understanding of this disorder. Many people had backgrounds in science and health-related fields that facilitated their access to and understanding of formal knowledge.

And um, so then, kind of trained myself in Internet research, and then was hired for a job, but most of what I did was Internet research. So, I would like, put in key words, you know, like dysautonomia or autonomic dysfunction and just some of the other, signs and symptoms, and sites would come up, and I would also go to PubMed and do, research that way. (P11)

When asked to describe what led her to believe that she had something different than she was diagnosed with, this participant said

I guess my own research and um, I’ve got ...a little bit of medical background knowledge because of the job I did...And...have an understanding of medical terminology. (P7)

Many of the participants described using their bodily and experiential knowledge to set limits, conserve energy, determine when something was wrong and seek help, and
to modify their lifestyle. Those who valued learning from peers discovered ideas for coping with symptoms, as well as support and validation for their bodily and experiential knowledge. This part of the question, therefore, can be expanded to how people make use of the experiential knowledge of others. The answers to the questions demonstrated that they built knowledge over time based on their own experience, that of their peers and that of health care professionals.

The third part of the question, how people perceive their experiential knowledge in relation to that of health care professionals, was clarified by the findings of this inquiry. At the AMDC, we had believed that people who used their knowledge in health care interactions led their care providers to believe that all symptoms they were experiencing were somehow related to mitochondrial dysfunction. Although it was certainly the case that they had more experiential knowledge than their health care providers and in many instances, more formal knowledge, their perception was not that they were the experts, but quite the opposite. Participants' "there was no magic" stories instead revealed that being looked upon as the 'expert' left them feeling vulnerable and frustrated. They acknowledged that their sources of information were limited to peers and the Internet and hence, did not feel confident in making the ultimate decisions or conclusions about their physical condition. They wanted their health care providers to have the answers and the knowledge about mitochondrial disease. It appeared that people used their knowledge in health care interactions only out of a need to protect themselves and advocate on their own behalf, in response to the realization that "you can't sit back and be the patient". Using their knowledge in these interactions was always done with
some trepidation. People repeatedly expressed not wanting to alienate themselves from those who were there to help them.

The narrative and sub-narratives identified in this inquiry therefore more than adequately respond to the research question as well as offer new insights. In addition, they provide the platform for a number of changes that have the significant potential to improve the quality of life for individuals with mitochondrial disease. The findings and their implications for practice will be discussed in the following chapter.
CHAPTER 5: DISCUSSION AND IMPLICATIONS FOR PRACTICE

This chapter will begin with a summary of the research study. I will then discuss the research findings as they compare and contrast with the relevant literature and present the implications for practice. Unexpected findings will be explored, as will the strengths and limitations of narrative inquiry in addressing the research question. The chapter will conclude with ideas for future research generated by this study and some closing comments.

Summary of the Narrative Inquiry

The purpose of this study was to begin to understand how adults with mitochondrial disease construct knowledge and the role that this knowledge plays in the health care relationship. The findings that emerged from the analysis of the interview data support the benefit of narratives in illuminating this phenomenon. It was through their stories that the participants were able to share the depth and scope of the impact of knowledge on their illness experience.

One main narrative and two sub-narratives emerged from the collective interviews. The main storyline, “you can’t sit back and be the patient” depicted participants’ realization that mitochondrial disease is not easily diagnosed, explained, or recognized by lay people or health care professionals alike, and hence, the role of ‘patient’ does not fit the traditional concept. This awareness led people to conclude that if they wanted to advocate for themselves in the health care system, they needed to become the expert on their disorder.

This storyline had two sub-narratives, the first being “there was no magic out there”. This was the classic chaos story, void of action and direction, and full of
complications and challenges. In this story, narrators were frustrated by the fact that there were no answers and became overwhelmed with the task of educating and advocating for themselves. They decided to accept that this disease was different and that they could not do anything to change their circumstances. The second sub-narrative was “now I’m the educator”. Narrators of this classic quest story decided that, in order to advocate for themselves, they needed to accumulate knowledge. Their stories highlighted the challenges of using their knowledge as a tool in the health care relationship.

Discussion

Defining a disorder and how it should be managed involves what Banks and Prior (2001) describe as “micropolitical struggles” within the health care relationship. The following discussion will centre on the micropolitical struggles around knowledge in the relationship between health care provider and adult with mitochondrial disease. This discussion will pertain to what constitutes knowledge, how people use knowledge, and what form it takes in the health care relationship in light of the study findings and the literature reviewed. Specifically, attention will be paid to how ‘having to be the expert’ plays out in the context of the health care relationship and the development of negotiated knowledge as a response to “you can’t sit back and be the patient”.

What constitutes knowledge?

At a mitochondrial conference I attended last spring, a patient told me, “What’s worse than not being believed is being belittled.” Likewise, the participants’ stories included elements of not only being doubted, but being left with the feeling that their knowledge about themselves, their bodies and experience, was being judged for validity.
To make sense of the phenomenon of questioning the patient’s knowledge, we can turn to the work of French intellectual, Michel Foucault. This work can deepen the understanding of how knowledge is defined. “Foucault’s central thesis was that modern societies control and discipline the individuals in those societies by enabling powerful groups of ‘experts’, by virtue of their claim to ownership of knowledge, to define what is the standard or the norm” (Cheek & Rudge, 1994, p. 587). Foucault proposes that ‘normalization’ is achieved through a surveillance process whereby individuals are scrutinized to “push to the tails anything idiosyncratic, peculiar, and unfamiliar” (Roth, 1992, p. 688). Mitochondrial disease is an “obscure, bizarre, never-heard-of disease (P10)”. It therefore fits Foucault’s description of all that is “pushed to the tails” in the process of ‘normalization’.

In addition to being marginalized because it is not within the realm of ‘known’ and ‘normal’ diseases, mitochondrial disease is often not seen as ‘real’ by health care professionals, friends, and family members. Because symptoms are ambiguous, they can easily be doubted. People with mitochondrial disease are seen as abnormal, or, “the Other” in Foucault’s words, because they do not fit into neat, little diagnostic boxes (Selden, 2000, p. 236).

Our society sees scientific knowledge as being the ‘truth’, because it is objective and quantifiable. Also, as Bradley (1995) described, the knowledge of health care professionals is seen as more valid based on how it is obtained and who produces it. Because physicians are generally given more status in society than patients, their knowledge is revered over that of the patient. However, aside from bodily knowledge, no knowledge is exclusively “owned” by one particular group. The model in Figure 3
depict how knowledge constructed about chronic illness can be viewed on a continuum from bodily knowledge to biomedical knowledge, with a great deal of overlap in between (see Figure 3). I had expected people’s stories to reveal a belief that they had a richer and deeper understanding of mitochondrial disorders than the health care professional, by virtue of having some access to all types of knowledge. This was not the case. The participants perceived that practitioners did not see their knowledge as equal in the health care relationship. In fact, many participants described instances where their experiential knowledge was seen as lesser knowledge by the medical system. This suggests that both the professional and some people with mitochondrial disease see formal knowledge as the sole property of the health care provider. Therefore, while the biomedical perspective serves some purposes in the health care relationship, it often excludes other equally important and valid types of knowledge in the experience of mitochondrial disease. In addition, the ability of patients to impart their knowledge and to be heard is inhibited by the biomedical discourse. Their bodily and experiential knowledge is often silenced and invalidated within the health care relationship.

...One can say that a discourse defines what can be said and what is true. It is by limiting who can speak, and how, and what can be said, that discourse is inextricably linked to power...It is this two-way interrelationship between knowledge and power that Foucault tries to convey in his term ‘knowledge/power’ (Gordon, 2000, p. 219).

This concept was introduced in Chapter two as power-knowledge. In response to “you can’t sit back and be the patient”, many participants chose to use formal knowledge as a tool in the health care relationship. This however, was complicated by the micropolitical struggles over who has claims to this knowledge. I will now turn to how people with mitochondrial disease make use of knowledge within this milieu of knowledge/power.
Figure 3. The continuum of ownership of knowledge within the health care relationship

Only the patient has access to, and therefore ownership of, bodily knowledge. Both the HCP and patient have access to experiential knowledge, but the patient depends on and owns more experiential knowledge than the HCP. Both the patient and HCP may have biomedical knowledge, but the HCP is assumed to have more biomedical knowledge than the patient. It is known that patients gain experiential knowledge from living with the disease over time, but what is interesting is that the HCP also learns a great deal from the experience of working with the patient over time. This becomes an integral part of their ‘biomedical knowledge’. This exchange of knowledge is indicated by the two-way arrows between experiential and biomedical knowledge.

\(^6\) HCP=HEALTH CARE PROVIDER (denotes physicians, nurses, dieticians, social workers, psychologists); bold text implies who is more likely to 'own' the particular type of knowledge
How do people with mitochondrial disease make use of knowledge?

The Funk & Wagnalls Standard College dictionary (Avis, 1982) defines knowledge as "a result or product of knowing; information or understanding acquired through experience" (p.749), and learning as "the act of acquiring knowledge or skill" (p. 770). Although the dictionary definition includes reference to experiential knowledge, this is not generally accepted as what we refer to as ‘knowledge’ in our society. What this inquiry revealed is that all participants ‘learned’—that is, they increased their knowledge about the disorder, whether it was through formal or informal means. Application of that knowledge held different meanings for different people based on their individual response to “you can’t sit back and be the patient”; some accessed formal knowledge and others relied on their own experience.

Everyone uses knowledge in relationships. The question is therefore not who uses it as much as what type of knowledge is used. The participants of this study differed in how they used formal knowledge in the health care relationship. In fact, four different responses to “you can’t sit back and be the patient” were noted in their narratives with respect to the accumulation of formal knowledge.

The first group responded to the realization that they were not typical patients for whom there was a wealth of information, by becoming actively involved in researching their symptoms and the disorder. Their motto was, “I’ve tried to learn. You know, if you’re going to have a chronic illness, you might as well know what it is!” (P6). These individuals were highly motivated, confident in their ability to learn, and in their own knowledge, usually had post-secondary education, and often had interest, work
experience, or schooling in science or health-related areas. These people primarily shared “now I’m the educator” stories.

The second group responded to “you can’t sit back and be the patient” by reluctantly self-educating because they perceived this as a necessity. These individuals expressed that self-education should be a secondary, not a primary way of learning about mitochondrial disease. They combined “there was no magic out there” and “now I’m the educator” stories.

The third group had a ‘spirit is willing but the flesh is weak’ response. These individuals indicated they would have liked the information, but did not have the energy, inclination, computer skills, or the perception that they would understand, to do the work themselves. This group of individuals primarily shared “there was no magic out there” stories.

The fourth group responded to “you can’t sit back and be the patient” by saying, ‘Oh well’. These individuals claimed not to be interested in accumulating formal knowledge about their disorder. This group also shared “there was no magic out there” stories.

Baker’s (1998) description of how people with multiple sclerosis differed with respect to information-seeking is relevant to this discussion. Baker identified two types of people in her study: ‘monitors’, who initially coped with their illness by gathering information, and ‘blunters’, who preferred not to have too much information at the onset of their diagnosis. Baker concluded that monitors were found to be more interested in gathering information earlier in the disease process and blunters seemed to desire more information after having coped with the disease for a number of years. However, the findings of this study indicated that, for people with mitochondrial disease, information-
seeking seemed to be a stable trait over time. Perhaps this disparate finding is related to
the disease populations studied. Baker had interviewed people with multiple sclerosis, a
disease for which information is more plentiful and for which there are more treatments.
Also, ‘information’ implies formal knowledge. The terms ‘monitors’ and ‘blunters’ are
therefore limited by their applicability to only one aspect of knowledge construction in
chronic disease.

Cohen’s (1993) claims that people with chronic illness use knowledge differently to
manage uncertainty also pertain to this discussion. Her assertions that some people
would “prefer to live with uncertainty rather than risk knowing what they fear they will
not be able to accept” (p. 84) are supported by the findings of this inquiry. Perhaps as
Hilton (1992) suggests, uncertainty for these individuals is “less anxiety-provoking than a
state of certainty” (p. 72).

This inquiry’s finding that people make use of other types of knowledge to manage
their disorder is also consistent with the literature. In keeping with Price’s (1993) concept
of “body listening”, people described using bodily and experiential knowledge to read
their symptoms and make adjustments in their activities, lifestyles, or regimes. However,
because people with mitochondrial disease often viewed their bodily and experiential
knowledge as less valuable than formal knowledge (or did not recognize it as
knowledge), they may not have volunteered critical information about their bodies or
their experiences because they did not want it discounted. This information may have
been key to aiding in diagnosis or to alleviating symptoms. A study by Peters et al.
(1998) revealed that “embarrassment and social withdrawal” (p. 563) resulted from
perceived denial of symptoms by doctors. Based on negative past experiences of being
doubted, people became fearful of sharing certain information with physicians. This finding was also supported by Kingfisher and Millard’s study on health beliefs around milk (1998). Many of their participants did “not divulge important information that could change medical advice” if their health beliefs and decision-making were not adequately explored in the clinical interview (p. 459).

Finally, this study’s finding that people’s mistrust of the health care system grew out of the realization that practitioners were generally not knowledgeable about mitochondrial disease is supported by the literature. Becker et al. (cited in Mishel, 1999) reported that people with asthma were hesitant to access emergency medical care during a breathing crisis for fear of inadequate treatment, based on the belief that the health care professionals were not as knowledgeable about their disorder as they were and that harm would result (p. 279).

*Now I’m the educator: What ‘being an expert’ entails*

The goal of this research project was to establish a sense of how people with mitochondrial disease construct and negotiate knowledge about their disease. Three different types of knowledge were revealed in the literature review. It was proposed that there was a fourth type of knowledge at play; that of negotiated knowledge. This type of knowledge was thought to be composed of the patient’s knowledge of their bodies and the practical knowledge gained from living with the disorder, combined with formal knowledge they had built over time to get the health care they needed.

In order to succeed in the struggle to be believed, people with mitochondrial disease described needing to learn what “the important stuff” (Mattingly & Garro, 2000) was and how to present it in a convincing and credible way. One way they went about this was to
negotiate knowledge, by creating a neat little package of bodily and experiential knowledge, peppered with biomedical knowledge.

It was apparent from the research findings that people had to learn to use their experiential and bodily knowledge in a way that gave them credibility with the health care professional, but also in a way that enabled them to communicate, “This is the relationship I want with you”, whether it be passive or active. They negotiated, both in terms of how they wanted the health care professional to interact with them and their expertise, and in how much the health care professional needed to be educated. Except for those who became overwhelmed, people learned that they had to know something about the disorder in order to self-advocate. As discussed in Chapter two, Hilton (1992) defined uncertainty as “not being able to rely or count on someone or something” (p. 71). “You can’t sit back and be the patient” therefore resulted from the realization that people themselves could not rely on health care professionals to have all the answers; they had to be the expert to some degree. However, the findings indicated that ‘being the expert’ is particularly challenging in mitochondrial disease. For instance, participants made comments about not wanting to alienate themselves by using knowledge in the health care relationship, especially when the options for professionals who specialize in mitochondrial disease are extremely limited. Use of negotiated knowledge is therefore an active response to “you can’t sit back and be the patient”, but one not void of challenges.

“Now I’m the educator” stories highlighted these challenges. Thorne & Robinson (1988) found that people learn about their disorders to be able to “communicate on a level more compatible with that of the professional” (p. 786). Furthermore, Loiselle and Dubois (2003) comment that, “it is now commonplace for patients to come to a typical
health interview equipped with printouts, self-report assessment tools and information
fact sheets about their condition” (p. 22). This indicates that patients are almost expected
to be experts on their health conditions. However, even the most resourceful person with
mitochondrial disease is not going to have the expanse of information available to people
with more common diseases like arthritis, diabetes, and cancer. This poses a problem
when the health care professional looks to them to be ‘the expert’ about the disorder;
their capacity to ‘be the expert’ is limited by the availability of the information.

The notion of ‘patient as expert’ is well-documented by Salmon and by Peters et al. in
the literature. In a series of studies of patients with medically unexplained symptoms,
Salmon (2000) reported that people preferred explanations for their symptoms that
“emerged from (their) rather than the doctor’s authority” (p. 112). Furthermore,
Marchant-Haycox and Salmon (1997) and Salmon and May (1995) (as cited in Peters et
al., 1998) propose that “patients are thought to present and explain bodily experiences in
ways that engage but also constrain doctors’ responses so as to access physical treatment”
(p. 559).

This finding may pertain to concerns of the iatrogenic risks posed by family
physicians’ accepting patient’s diagnoses of otherwise common ailments; however, the
motivation seems to be different for the presentation of these ‘diagnoses’ in the first
place. Because people with mitochondrial disease perceive that their general
practitioners are not familiar with the disorder or because the physician actually turns to
them to be the expert, they often make conclusions and engage in self-care decision
making, only to make erroneous decisions based on lack of medical knowledge. Because
the general practitioner sees the patient as the expert on their disorder, they may acquiesce to their ‘diagnosis’ of the symptoms or problem.

Salmon (2000) describes how patients use their self-knowledge as a source of authority in the medical relationship. He reports, “from the patients’ perspective, it is the patients who have the greater authority and expertise” (p. 108). In addition, Salmon describes the competition between people’s belief in the “infallibility of their direct sensory experience of their symptoms” over the “fallible result of medical tests” (p. 108). Peters et al. (1998) supports the perceived fallibility of doctors from patients’ points of view and extends this to state that doctors “are relegated to an inexpert and essentially technical role” (p. 564). These findings indicate that the participants of these studies were highly confident in their role as ‘expert’; see their knowledge as more complete than that of the physician; and see the physician as ‘inexpert’.

Contrary to the literature, the stories shared by the people in this study did not indicate that they believed in the existence of their symptoms when faced with doubt in the medical system. In fact, many people expressed self-doubt. Although the participants of this inquiry realized that they could not “sit back and be the patient”, having to be the expert was not described as either elective or comfortable. On the whole, those who viewed themselves as ‘the experts’ did so not necessarily because they had an innate desire to, or because they espoused the belief that their knowledge was superior to that of the physician, but in response to uncertainty. Many actually described relief when they determined that a health care professional knew about the disease, thereby absolving them of having to be the expert. Therefore, this inquiry indicates that ‘patient as expert’ as represented in the literature appears to be a different phenomenon than ‘patient as
expert' in mitochondrial disease. As a response to “you can’t sit back and be the patient”, this concept entails self-advocacy, rather than the authoritative expertise described in the literature.

Self-advocacy in “now I’m the educator” stories was accomplished through the use of negotiated knowledge. This concept is supported by the literature. Hydén and Sachs (1998) describe the need for patients to transform their suffering to “fulfill certain criteria and preconceptions about disease” (p. 176) in order to have it recognized as a disease and to receive treatment. Cohen (1993), Hilton (1992), and Mishel (1999) all indicated that knowledge was employed by certain individuals to manage uncertainty in their transformation between life before and after the diagnosis of a chronic illness.

However, as discussed in Chapter two, not all people with chronic illnesses manage uncertainty by gathering information and using it to negotiate their health care. This was evident in this inquiry. For negotiated knowledge to be constructed, certain conditions needed to be in place. One can only speculate, but perhaps the first condition was the degree of motivation of the individual. Many factors affected this variable including the self-confidence the person had in their own ability to learn (which may be related to level of formal education and job experience), and the quality of the health care relationship (the person’s trust in their health care professional seemed to be inversely proportional to their motivation to learn for those who chose to self-educate). The second condition was the number of barriers standing in the person’s way of accumulating formal knowledge. These included physical impediments, lack of computer access or skills, and lack of tools and direction from health care professionals.
The best conditions for formally learning about mitochondrial disease were when motivation was high and barriers were low. This ‘climate’ was optimal for the development of negotiated knowledge. When barriers were high, frustration and vulnerability resulted, whether or not the individual was motivated to self-educate. In fact, the person may have initially been motivated to self-educate and lost their enthusiasm with the realization of the barriers standing in their way. Those whose motivation to learn was low and who had few barriers were probably the individuals in this study who were not interested in learning more about the disorder for various reasons including not wanting to know what the future may hold.

The “now I’m the educator” sub-narrative indicated that people with mitochondrial disease developed and used negotiated knowledge in the health care relationship. In their stories, participants described several ways they modified their knowledge and their presentation of it to include biomedical knowledge so that it was heard and accepted by health care professionals. In essence, they used it to bridge the gap between their experience of ‘illness’ and its daily impact on their lives, and the ‘disease’ being treated and monitored by the health care provider. People found less threatening ways to impart their knowledge such as offering to provide information to the health care professional. People also negotiated knowledge by using ‘brand name’ diseases such as multiple sclerosis, muscular dystrophy, or Parkinson’s disease, to explain the disorder to friends and family.

The findings of this study, therefore, demonstrated that negotiated knowledge by certain individuals is indeed used in health care interactions and with friends and family. The various reasons proposed in Chapter two for the development of negotiated
knowledge were supported by the findings: to be able to have their symptoms recognized by the medical system; to gather as much formal knowledge as possible about their condition; and as a self-help response to manage uncertainty.

Implications for practice

The findings of this study and the recommendations raised by the participants have significant implications for practice. The qualities of the ideal health care professional from the participants’ perspective will be discussed in the context of how they may impact on the model of care. Specific implications for the primary care relationship will be explored. Ideas for modifications to existing patient education programs and to the education of health care professionals with respect to mitochondrial disease will be offered.

Change in the Model of Care

In Chapter two, The Guarded Alliance Model was introduced. This model depicts “the types of relationships that have been observed between chronically ill people and their professional health care providers” (Thorne, 1993, p. 106). Thorne describes people as either being active or passive in their disease management. She speaks to the value of knowledge in contributing to the level of confidence individuals have about their role within the health care relationship.

In order to feel confident about their contribution to health care relationships, the patients...required a sophisticated working knowledge of their illness and its management. This knowledge generally included pathophysiological implications of disease, current research findings and programs, the meaning of diagnostic determinants, and the range of available treatment options. Confidence with regard to such a wide variety of topics usually required extensive time in the chronic illness experience, combined with a dedication to learning. In addition, it required access to resources for developing knowledge-acquisition skills in such a specialized field (Thorne, 1993, p. 116).
However, this may not be as straightforward for people with mitochondrial disease due to the dearth of resources. Also, many may derive confidence in the health care relationship because of other types of knowledge and choose not to formally self-educate in the ways described by Thorne.

According to Thorne’s (1993) model, there are four types of health care relationships among people with chronic illness: consumerism, team playing, hero worship, and resignation. She argues that resignation results when both trust in the practitioner and trust in oneself as competent are low. On first glance, one could assume that the people in this study who chose not to actively self-educate had ‘resigned’.

However, the case in mitochondrial disease is not so clear-cut. This disease is unlike others in that people cannot assume that health care professionals are going to have knowledge about it. The reactions of people with mitochondrial disease to “you can’t sit back and be the patient” are not based so much on who they are as people, or what meaning the disease has for them, but also on the fact that if they do not become the expert, it could be unsafe for them. As we saw in the discussion of how people differ in their attitudes towards accumulating formal knowledge, even the people who would prefer not to self-educate, are forced to, to some degree. The findings of this inquiry therefore extend the understanding of the guarded alliance model in the context of mitochondrial disease. ‘Resignation’ implies passivity; rather, people decide. Those who ‘resign’, choose to do so. When people do ‘give up’, they are fully aware and in control of this decision and realize the consequences, that there will not be someone to take over.

In addition to the Guarded Alliance Model, three current approaches to doctor-patient interaction were introduced in Chapter two. In the context of this study’s findings,
it is clear that the "doctor as expert" model is not appropriate in mitochondrial disease because the doctor cannot always be the expert. The "doctor as partner" model is good, but as Paterson (2001) argued, this is difficult to truly espouse without succumbing to the "myth of empowerment". The idea of health care professionals and patients as partners working side-by-side has almost become cliché, a rhetoric without substance. "Doctor as service provider" carries the risk of incurring iatrogenic harm. If the patient is encouraged to become the expert to the degree that the health care provider is looking to them for answers (rather than for input and information), this is not only unsafe, but, as revealed by this inquiry, puts the person in an awkward and unwanted position.

This study's findings therefore suggest that the existing health care communication models are ill-suited to mitochondrial disease. The type of model that is needed is a true partnership; one built on mutual respect for the knowledge each has to contribute to the overall understanding of the disorder, its manifestations, and its treatment. This partnership needs a foundation constructed by the five qualities identified by the participants of this study and presented in Chapter four. The qualities described by the participants and the stories told around them, revealed the yawning potential for improvements in the health care relationship. Their implicit recommendations can be used as a framework upon which to build a foundation of trust and mutual respect in health care relationships, both in the metabolic setting and in primary care. The stories shared by the participants of this study support the need for a new model that would ultimately act to reduce feelings of vulnerability, frustration, and uncertainty in the health care relationship.
In the new model of care, it is important for the health care professional not only elicit the details of the patient's clinical status, but also to explore their underlying health beliefs and decision-making. The literature showed that people make choices about their health care based on various factors (Kingfisher & Millard, 1998). Focussing on the core of decision-making is worth the time and effort in all settings, including primary care, to ensure that the person is making healthy decisions based on accurate assumptions and a sound knowledge base. Also with mitochondrial disease, it is an opportunity to assess the accuracy of the person's formal knowledge and to help them in their encounters outside the AMDC (i.e. in “now I’m the educator” situations).

In the primary care setting, persistence on the part of general practitioners to ascertain the cause of symptoms has potential to improve the team approach to caring for the adult with mitochondrial disease. If common complaints such as colds, flu, and rashes, and common diseases such as diabetes are being diagnosed, addressed, and managed in the primary care setting, the metabolic clinic could focus on the care and management of the mitochondrial disorder itself. In turn, the person would likely feel more trusting of their family physician and be more aware of the service and the expertise they could provide.

Being open to learning from the person with mitochondrial disease and from their lived experience is also essential to making the health care relationship work (see Figure 4 on page 129). When health care professionals see themselves as the only experts, “they in effect shut themselves off from knowledge of the needs which they are supposed to serve” (Gordon, 2000, p. 225).
A great deal of information that health care professionals have to impart to people with mitochondrial disorders about their quality of life is based on learning from the experiences of other patients they have worked with. By gathering this collective knowledge and relaying it to other patients, they become a reflection of the collective. What is implicit in this gathering of knowledge is that the health care professional is actively listening to the patient and respecting that they have knowledge to impart. Because there is not a lot to offer people with mitochondrial disease in terms of treatments, this collective knowledge is invaluable. In turn, it decreases the helpless feeling the health care professional may have when unable to make recommendations to improve quality of life for the individual. The health care professional thus becomes a 'reflective practitioner'.

...there is the recognition that one's expertise is a way of looking at something which was once constructed and may be reconstructed; and there is both readiness and competence to explore its meaning in the experience of the client. The reflective practitioner tries to discover the limits of his expertise through reflective conversation with the client (Schön, 1983, p. 296).

To my knowledge, this idea has not been discussed in the literature. Figure 4 depicts the reciprocal benefits of the health care professional sharing this collective knowledge learned from the experiential knowledge of patients with mitochondrial disease.

The discussion so far has centred on the need for health care professionals to change in order to improve the health care relationship. It is equally as important that people with mitochondrial disorders meet practitioners half way and also strive to adopt a new approach in the relationship.
Figure 4. The reciprocal benefits of experiential knowledge in health care interactions

By being open to learning from the patient’s experiential knowledge, the health care professional will have more to offer other patients in the way of collective knowledge.
They need to begin to value and to trust the knowledge contributions of each part of their health care team—physiotherapists, family physicians, and metabolic specialist, for example—as having unique areas of expertise that contribute to their overall health.

Therefore, in the new model of care, the health care professional and the person with mitochondrial disease collaborate and share information, opening the window to each other’s areas of expertise and ultimately providing comprehensive health care for this population.

**Changes to Patient Education Programs**

The findings revealed a gap in the quality and quantity of information given at the time of diagnosis. Cohen (1993) claims that for the physician, diagnosis brings closure to what has been an enigma and provides direction upon which to base subsequent actions and decisions. For the patient, however, diagnosis only serves to answer the question of what the problem is called. “It does not provide any sense of closure nor suggest how they should proceed” (p. 84).

The Lonely Planet™ guides are indispensable resources that save travellers’ time and money and enhance the quality of their trip. In many respects, people need a Lonely Planet™ guide to mitochondrial disease when they are diagnosed, to point them in the right direction for learning more about the disorder if they are so inclined or to at least acclimatize them to this new and strange ‘country’ they have just entered. In this instance, back to the travel analogy, the health care professional is like the travel agent who gives their client some information about their destination and what to expect. For many people, this is enough. They will find out more about the destination by spending time there. Others will use this information to go out and learn more about it before they
arrive at their destination. As evidenced by the two sub-narratives, the same is true for people with mitochondrial disease. These variations in need for information should be determined by the health care professional at the time of diagnosis, or in the case of allied health professionals, at the point of first contact. This would ensure that the quality of the information and guidance provided is individualized, appropriate, and provides the person with the tools they need to best manage their health.

Changes to patient education programs based on the findings of this inquiry therefore centre on the “there was no magic out there” and “now I’m the educator” sub-narratives.

There was no magic out there

In response to the findings of this study and to the suggestions made by the participants, the staff at the Adult Metabolic Diseases Clinic have worked together to improve the service we provide to adults with mitochondrial disorders, beginning at the time of diagnosis. First, to address the feeling of being left in limbo and powerlessness, the feeling of “bumping around in the dark” (P9), the education program has been tailored to give individuals with mitochondrial disease the power to improve their quality of life by making lifestyle changes.

Adults with mitochondrial disorders now meet with the clinic dietician to review Canada’s food guide and discuss the importance of nutrition in maintaining overall health and well being. For instance, staying at a healthy weight decreases stress on muscles and joints that may already be taxed by the disease and reduces fatigue related to carrying extra weight. Colds and flu and other illnesses can cause setbacks for people with mitochondrial disease. The importance of good nutrition in illness prevention is
emphasized. The benefit of drinking adequate amounts of water throughout the day to improve energy and elimination deficits is stressed.

In conjunction with a neuromuscular disorders physiotherapist, an exercise pamphlet has been created, specifically for people with mitochondrial disorders. This pamphlet is to be used in conjunction with a referral to a physiotherapist, and is designed to improve flexibility and strength, prevent loss of mobility, muscle weakness and cramping, and enhance self-esteem and mood.

Most clinic patients are already connected with our social worker, but this relationship has been formalized to ensure that the financial, caregiving, and other long-term implications of the diagnosis are addressed.

These new consultations are offered in addition to the pre-existing education program for people with mitochondrial disease, which includes a discussion of pathophysiology, treatments, and how to communicate with specialists and family physicians. As discussed in changes to the model of care, it is important to 'coach' people how to communicate with health care professionals. A handout has been prepared with tips for effective communication and things to consider such as timing for optimum results. This handout is discussed with the person in the context of considering what the health care professional has to offer to their overall health care. To keep track of whom the person has met with and what has been discussed, a flow sheet has been stapled to the inside of each chart.

Second, in response to the findings, we now make a special point to ensure people know why they have been referred to us. Third, to enhance the understanding and credibility of the disorder to family and friends, we offered an education session on
mitochondrial disease and how family and friends can help. This was very well attended and will be held on a regular basis to support those with mitochondrial disease in being understood.

Future plans include continuing to build on effective ways to communicate with health care professionals by teaching people how to tell a story that will be heard and respected. Just as there are qualities for an ideal health care professional, there are qualities for an ideal patient. One quality that may work well to peoples’ advantage is to be more succinct in their health care interactions; to present the ‘edited’ version of the story. Good and Good (in Mattingly and Garro, 2000) discuss the fact that “stories and storytelling… have a central role in medical practice” (p. 50).

Learning what “the important stuff” is and how to present it in a persuasive way is central to becoming a physician. It requires that one know enough about the patient’s condition, the disease processes, the diagnostic possibilities, and the appropriate treatments to sort through a chart and present the critical issues in a minute or two. It requires the ability to tell a good story… (p. 55)

Narratives are central to the way physicians relate information about patients in grand rounds for instance and in the way that medical students are taught. “Clinical stories (are) the fundamental units for learning and organizing medical knowledge” (p. 50). The “ability to tell a good story” (p. 54) is as important a skill for patients to learn as it is for medical doctors. Because it is human nature to want to recount a story from the beginning, this may not be an obvious way for people to be ‘heard’ in the health care relationship. As well, health care professionals are not likely to have time and patience for the chaos story which leaves them feeling as powerless as the narrator themselves. Health care professionals are socialized to ‘fix’ problems and are defeated by those that are ‘unfixable’. Coaching people on the best way to present their knowledge and
questions to practitioners could therefore significantly impact on the quality of their health care experiences.

Now I’m the educator

Future plans include working with those who wish to self-educate, to reduce their barriers to accumulating formal knowledge. Because the computer is the nucleus of information and support for people with mitochondrial disease, it is critical that we spend time assessing people’s access to, and comfort level with, using computers to do research. Using the computers located in the clinic examination rooms, we could show them how to ‘surf the web’ and provide them with a list of reliable websites. If they do not have one at home, we could help them to problem-solve around where the nearest and most accessible computer is for them, for example, at their local library. If they have physical problems that interfere with learning independently such as weak arms, we could refer them to an occupational therapist to assist in supporting their arms so that they could spend time doing research on the computer. The United Mitochondrial Diseases Foundation offers an annual conference. We could ensure that all adults with mitochondrial disease are aware of this conference and how to enroll if they are interesting in attending.

Another future plan is to develop an education program to help people critically appraise the formal knowledge they find independently. We currently have a quiz for our adult patients with phenylketonuria (PKU) called “What’s your PKU IQ?”. This optional and fun quiz is given to people to complete on their first visit to the clinic. It has been an effective way of highlighting strengths and gaps in knowledge about their condition and establishes a framework for discussions and future education sessions. Adults with
mitochondrial disease may benefit from the same type of quiz, designed not to put them to the ‘test’, but to help them develop a solid foundation of formal knowledge about the disorder. In this way, we as practitioners could guide conceptual change learning, thereby promoting critical thinking about the information they encounter in their search for answers. The ultimate goal of this would be to support the “now I’m the educator” role.

Changes to the Education of Health Care Professionals

In order to increase the support for this population, the health care professionals that work with them need to be more aware of and more educated about mitochondrial disease. To promote awareness, nursing, medical, dietary, social work, physio and occupational therapy schools could be approached about offering a clinical rotation at the AMDC. Students could experience the special needs of this population in particular and learn about the care and management of chronic illness in the outpatient setting in general.

A set of questions, based on the findings of this study, could be developed for university students in the health sciences learning about chronic illness ‘management’. To increase awareness of mitochondrial disease, we could offer classroom presentations to augment these questions.

To raise awareness in the primary care setting, it would be ideal to have an article published on the findings of this study that highlight the primary care issues and distribute it to all the family physicians caring for the adults with mitochondrial disease. In addition, we could host an information session, similar to that offered to patients and families, for primary care physicians interested in learning more about mitochondrial disease.
Strengths and Limitations of this Type of Research

Because this was the first qualitative study with this population to my knowledge, narrative inquiry was an ideal way of beginning to understand the experience of living with mitochondrial disease. Hearing the participants’ stories of their daily lives and of their experience to date with mitochondrial disease effectively illuminated the role that knowledge plays in the quality of their experience.

This type of research bears both strengths and limitations. One of the ethical issues addressed in the introduction was that, because of the conversational nature of the interviews, people might share things beyond the limits of this study. My dual role as nurse educator and interviewer proved to be a real strength in this narrative inquiry. After the interview, I was not only able to refer people to the appropriate services to address their concerns, but to act on other issues that arose in the interviews. For example, one participant said she had always been bothered by the fact that she did not have more definitive ‘proof’ of her mitochondrial dysfunction. After the interview was complete, we arranged a muscle biopsy for her. In a study of a different nature, such as a written questionnaire, this issue would not have surfaced and subsequently would have remained unaddressed.

Conducting these interviews and hearing these people’s stories has enriched my understanding of what living with and learning about mitochondrial disease is like. It has given me information and insight with which to help other affected individuals. The other team members at our clinic would also benefit from reading these interview transcripts. However, because of my promise to keep the interviews confidential, I cannot share them with my colleagues. This is a weakness of the narrative approach.
However, it is my hope that the voice of the participants will resonate throughout this thesis and will enrich readers’ awareness of the issues in the same manner as it has mine.

**Unexpected Findings**

One impetus for this research study was to determine how patients utilize their knowledge in primary health care interactions. Although these findings have already been presented, they are discussed here to underscore the disparity of this finding from what we at the metabolic clinic had believed to be true. I entered this inquiry expecting to hear stories about how the participants asserted their knowledge in their interactions with their family physicians. It was my goal to gain more understanding and then help them to build a more credible knowledge base on which to educate their primary health professionals. On the contrary, several participants conveyed their frustration at physicians, general practitioners and specialists alike, who attributed every ailment and symptom, “even the common cold” (P13) as one participant stated, to mitochondrial dysfunction. These findings are consistent with Peters et al. (1998). Patients in their study commonly viewed physicians, including general practitioners, as having “denied the reality or importance of the symptoms” (p. 562). One of their participants was quoted as saying, “they don’t understand it so they just dismiss it” (p. 562). Several participants of this study echoed this same sentiment.

The participants of this study indicated that they did not want to be the expert; that they wished their primary care physicians knew more about the disorder. What I heard from the stories therefore, was the opposite of what I expected to hear, that the participants in fact wanted the ‘ordinary’ things to be diagnosed and treated and not attributed to their mitochondrial disease. Perhaps, then, it is not the patient’s insistence,
but the lack of the physician’s persistence based on lack of familiarity with the disorder that is the root of the problem. Because the patient often has some knowledge about the disorder and certainly how it affects them, they may suggest that the symptom is caused by mitochondrial dysfunction and the busy physician accepts this explanation and does not pursue it. This is not to say that there are patients who insist to their family physicians that certain symptoms or problems are caused by mitochondrial dysfunction and therefore will not respond to the conventional treatments (e.g. diabetes in mitochondrial disease). What is notable, however, is that this did not surface in the stories told to me, despite the opportunity given to participants to share this information.

**Future Research**

To enhance understanding of how adults with mitochondrial disease construct knowledge, it would be of great interest to interview other groups such as men with mitochondrial disease diagnosed in adulthood, mothers diagnosed as a result of a child being diagnosed, or individuals with very visible symptoms (e.g. those in wheelchairs).

Loewe et al. (1998) studied the narrative construction of physicians working with people with chronic illness. It would be intriguing to interview physicians working with adults with mitochondrial disease to see where their narratives and those of the people they treat intersect. This could be accomplished by doing a secondary analysis of the data collected in this inquiry and interviewing mitochondrial specialists.

In addition, it would be very informative to specifically hear how people use knowledge in their primary care interactions. The richness of these results would be greatly enhanced by also interviewing the general practitioners themselves.
Conclusion

In conclusion, this inquiry shed light on how knowledge is constructed by this particular group of adults with mitochondrial disease. How this knowledge is used by people with mitochondrial disease, both for their own benefit and as a tool in the health care relationship, was illustrated in the stories they shared and the narratives that emerged. The implications for practice that emerged from the stories demonstrated the powerful potential for improvements in the health care of adults with mitochondrial disease when knowledge is openly shared between the person and the care provider.

Their story, yours, mine—it's what we all carry with us on this trip we take, and we owe it to each other to respect our stories and learn from them.7

7 Coles, 1989, p. 30 as cited in Clandinin & Connelly, 2000
References


Appendix A

Poster advertising the research study
Appendix B

Information letter for potential study participants
Dear __________:

I am a graduate student in the Faculty of Educational Studies at the University of British Columbia. To fulfill the requirements for my degree, I have chosen to research the stories that patients such as yourself tell about how you learn about your disorder and how you use this knowledge to get the health care you need.

Because awareness of mitochondrial disease is relatively new to the medical community, research interests have focused on scientific things like causes, effects, and treatments. The process of actually living with mitochondrial disease is not well understood by health professionals. Past research has demonstrated that people with chronic illness, like mitochondrial disease, have a very different experience than those with acute illness.

The purpose of this research project is therefore to begin to study what living with a mitochondrial disorder is like for patients and what role knowledge plays in helping them to get what they need from the health care system. The benefit of this research is to promote awareness and understanding between patients and health care professionals such as doctors and nurses.

As a person with a mitochondrial disorder, you are being invited to participate in this study to share your stories and personal experiences. If you agree to participate in this study, you will be required to come to the Adult Metabolic Diseases Clinic (AMDC), Vancouver General Hospital in the spring/summer of 2002 at a time that is convenient for you. I will ask you to tell me the story of how you were diagnosed, how you went about learning more about mitochondrial disorders, and how you have used this knowledge to get the health care you need. You will be under no obligation to answer any questions that may make you uncomfortable. The interview will take about an hour to an hour and a half. It will be tape-recorded so that I may transcribe, or record on paper, what we have talked about. You will be sent a copy of the transcript to ensure that it adequately represents what you have said in the interview.

Any information resulting from this research study will be kept strictly confidential. All documents will be identified only by a code number and kept in a locked filing cabinet at my home. You will not be identified by name or initials in any reports of the completed study. This information will only be available to myself and my research supervisor, Dr. Kjell Rubenson. This information will be destroyed at the completion of this study, unless you give me permission for it to be used in further studies.

Participation in this study is entirely voluntary. If you decide to participate, you may withdraw at any time during the study without any consequences to your continuing medical care or your relationship with any of the health care professionals at the AMDC. There will be no cost for you to participate in this study, nor will you be reimbursed to participate.
Appendix C

Interview plan and questions

The purpose of this study is to better understand people's ways of knowing about mitochondrial disorders from their stories, or narratives. The goal of the interview is to ask easy questions that will invite these stories. The resulting 'learning biography' aims to elucidate the progression through time and space that led these people to their present day understanding of their mitochondrial disorder.

I will begin the interview with an explanation of how my role may be different than the role that they usually see me in, i.e. that of their nurse. I will explain that I will need to be less responsive to their comments than usual and that if I am silent in the interview, that is why.

For face-to-face interviews, I will have a large pad of blotter paper and coloured markers available on the table between us. This will provide an alternative mode of communication for the participants, who may be thinking back a long way to recall their journey in learning about this disorder and being able to doodle while they are thinking.
Interview Framework

Not knowing

Beginning to know and understand

Beginning to enter into negotiation with others to find clarity in understanding

Negotiating with health care professionals, using knowledge

Looking back on where it is they have come from and the critical moments in the journey

Recommendations/suggestions

Bodily experience; i.e. their experience that didn’t require any language

Diagnosis; have names and labels

Progression from just naming the disorder to better understanding their experience; ‘others’ may include the Internet, librarians, and health care professionals
7. Have you had any experiences where you have learned from and with other people with mitochondrial disease? (e.g. support groups, listservs, etc.)
   -what has been helpful about this way of learning?
   -what has not been helpful?

8. What barriers, if any, have you come across in your search for answers and information?

9. How did this new knowledge/information/understanding affect you? Make you feel?

10. What did you do with your new knowledge/understanding about the disorder?

11. How do you use your knowledge in your interactions with health care professionals?

12. What were difficult things/ideas/experiences to explain to others?

13. Have there been times when your knowledge about mitochondrial disease was dismissed by others?

14. What would have been useful/helpful to you at the beginning of your search for information/answers?

15. What kinds of things can you recommend to help health professionals think about better when it comes to helping a patient learn about mitochondrial disorders?

16. What does this recommend to those of us in the health profession? For other people with mitochondrial disorders?

17. What is an ideal health care professional to you?

18. Is there anything else you would like to tell me about your learning process?
Demographic information

1. Tell me a little about yourself (age, family situation, occupation, years of post-secondary education, etc.)

2. How long have you had this disorder?

3. Have you had any other health problems in the past?

4. Do you belong to a support group for people with mitochondrial disease?