A HERMENEUTIC-PHENOMENOLOGICAL STUDY OF CONVERSION DISORDER: A PATIENT’S PERSPEPECTIVE

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Abstract

Conversion disorder (CD) is a mental illness with a long and complicated history. The disorder continues to be difficult to diagnose and treat. This paper presents the results of a hermeneutic-phenomenological inquiry into the lived experience of the disorder. It is hoped that the insights discovered can help physicians work with clients who have a somatic based illness. Written journal entries compiled during the first symptoms of the illness, a search for a diagnosis, receiving a diagnosis of conversion disorder and experiences after diagnosis were used. Themes and sub themes were identified until the “lived experience” of conversion disorder was articulated.

The findings of this study reveal that the lived experience of CD can disrupt a person such that they have a disintegration of self and world. This is a result of the break in self-concept, sense of coherence and self-efficacy. Five themes discovered using Interpretive Phenomenological Analysis (IPA). They are: 1) a break in the sense of coherence and self-concept; the subjective experience of a sudden, significant, alteration of physical capacity and wellness. This includes perceptual confusion and emotions such as fear, that arise from such a change 2) the negotiation of emotions of guilt, shame and vulnerability resulting from illness 3) the change in self-concept as a direct consequence of illness that is not biological in origin or attributed to volition 4) the need for support to navigate the significant change in self-concept, break in sense of coherence and self-efficacy 5) acceptance as the means to create a continuation of self from the past into the future.
Dedication

To my two daughters for their support and love throughout my education journey. You demonstrate everyday what it means to be kind, courageous and hopeful in the face of many challenges. You are my guiding stars. You orient me in the universe.

To Scott Mason and Family for your help when I did not know where else to turn.

There are several women who have been central to my life and my healing journey. I would like to name you all individually and state how you have made a difference in my growth. Please know that each step we walked, physical or metaphorical, was a blessing to me. Your courage, love and kindness have shaped me into the woman I am today. Thank you.

To Cedrus Monte who helped me through some of the most difficult years of my life. From you I learned how to be with, rather than deny or move away from suffering. Your wisdom, generosity, patience and care supported me so that I could become aware of what was lost or unconscious. Your love sustained me until I could integrate and become a whole person.

To Cheryll Simmons, my friend and teacher, may my life reflect your many days of care and nurturing. May I reflect some of your qualities, so that those who will never meet you, will have the privilege of experiencing the wonder of your being. I miss you every day.

To Betsy Lydle-Smith you have watched me grow up. Your friendship and love taught me how to mother myself, then my children and then others. I am me, because of you.

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CHAPTER 1  INTRODUCTION

I begin this work with an overview of conversion disorder from a medical and historical perspective. The review of the literature will situate my discussion and provide the needed background to explore this mental illness. I start with the purpose and relevance for this inquiry. I state how a patient’s view could bring insight to this complex condition as it provides a “lived” experience. I will provide a list of key terms and definitions used in the thesis. I will situate myself as the author and give a brief overview of this paper.

Purpose Statement

The purpose of this hermeneutic-phenomenological inquiry is to explore the lived experience of a diagnosis of conversion disorder. Somatoform disorders have been studied for 4000 years (Dinwiddie, 2013; Kozlowska, 2005; North, 2015). Yet, they are still difficult to diagnose and cause controversy (Daum, Hubschmid & Aybek, 2013; Dinwiddie, 2013; Demartini, et al., 2014; Stone et al., 2011). The ongoing difficulty with diagnosis and treatment has serious consequences for both doctors and patients as somatic conditions comprise a large portion of the illnesses seen by physicians (Dinwiddie, 2013; de Waal, Arnold, Eekhof & van Hemert, 2006; Kirmayer, Groleau, Looper & Dao, 2004; Isaac & Paauw, 2014; Rosendal et al., 2017). Steinbrecher, Koerber, Frieser & Hiller (2011) report, that “apart from depression and anxiety, functional syndromes and somatoform disorders are the most common mental disorders in primary care” (p. 263). In fact, in those patients seeing a General Practitioner (GP) “somatoform disorder (36%) was the most prevalent group of disorders and it seldom showed a history of remission” (Toft et al., 2005, p.1181). Thus, the cost of care for these patients is significant and ongoing, and the impact of the illness on individual lives is considerable (Barsky, Orav & Bates, 2005; Lidén, Björk-Brämberg & Svensson, 2015; Morriss & Gask, 2009;
Nicholson & Kanaan, 2009; Rosendal et al., 2017). The observations drawn from "living through" a diagnosis of conversion disorder could offer new insights. Thus, a hermeneutic-phenomenological analysis of the experience written by an individual diagnosed with the disorder could provide new information. This perspective facilitates the exploration of the meaning making process, when an individual is told that their physical ailments have no medical explanation for their somatic symptoms.

This thesis will explore: What is the lived experience of having the diagnosis of conversion disorder?

**Scholarly Context**

Somatic disorders such as conversion disorder (CD) have been described, studied and treated throughout human history (Dinwiddie, 2013; Kozlowska, 2005; Lopes de Mello, 2010; North, 2015; Scheurich, 2000; Schüpbach, 2012). “It was arguably described in pharaonic Egypt, and was a regular feature of Hellenic, Roman and medieval medicine” (Veith, 1993 as cited in Kanaan & Wessely, 2010, p. 71). Yet today, the illness is not fully understood (Daum et al., 2013; Dinwiddie, 2013; Demartini, et al., 2014; Rickards & Silver, 2014; Stone et al., 2011). The diagnosis of somatoform ailments often includes “medically unexplained symptoms” (MUS) or “medically unexplained physical symptoms” (MUPS) and at times the term CD and MUS are used interchangeably. These terms can be confusing for patients and difficult for doctors to explain (Isaac & Paauw, 2014; Morriss & Gask, 2009; Rosendal et al., 2017). To make meaning of suffering is essential to the human psyche. Illness, of any sort, can be difficult to understand, accept and integrate. However, when pain is described as “unexplained” the method we traditionally use to make sense of experience, by naming it, is greatly impeded. Firestein (2012) explains that it is common to believe that “a phenomenon named is a phenomenon known” (p.
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62). This is a conviction built on the premise that terms carry explanatory information. However, a label like medically unexplained symptoms or MUS, does little to disclose the etiology of conversion disorders. Thus, the optimum process by which a patient can be taught about their somatic disorder, accept the diagnosis and engage in treatment is not established (Kapland et al., 2013; Magaard, Schulz & Brütt, 2017; Stonnington., Barry & Fisher, 2006). The phenomena of conversion disorder require further research. Therefore, descriptions of the experience written by an individual diagnosed with the disorder could provide needed insight. It could also identify the terms that are most useful for a patient with this diagnosis.

One of the main reasons that psychosomatic disorders continue to confound the medical community is the lack of agreed upon terms used to describe and explain these conditions. Many of the terms used such as “conversion” or psychogenic” are difficult to grasp. The term, medically unexplained symptoms (MUS), can be very problematic (Daum et al., 2013; Dinwiddie, 2013; Demartini, et al., 2014; Lidén et al., 2015; Stone et al., 2011). Although “General practitioners (GP’s) prefer the term MUS because it makes no underlying assumptions about the presence of mental disorder or psycho-social problems” (Moriss & Gask, 2009, p. 179), this same term can leave patients with the impression that they are “faking” or that they must “prove” they are ill. In the case of somatic disorders, “appropriate terminology is important because the explanation of functional symptoms is an important part of treatment” (Reuber, Mitchell, Howlett, Crimlisk & Grünewald, 2005, p. 307). Further to this, Rickards & Silver (2014) found “decent therapies require good knowledge of mechanism of the illness and this is currently not the case” (p. 830). This reflects that at times, scientifically, we may be able to describe a phenomenon and still not know what it is or its cause. It also highlights that terms or explanations used by scientists or doctors, may not be useful to patients.
Historically, when physical signs of illness are not accounted for by present interpretations of a physical disease, we seek another causal agent. Miller (1999) argues that MUS, specifically, are the basis for how we conceptualize conversion disorder stating, “no concepts of hysteria, malingering, or factitious disorder would be required if this were not the case” (p. 182). In this framework, when the body is excluded as the root of the problem the mind becomes the de facto causal agent. Miller (1999) states it in this way: “if symptoms without a physical basis arise and the apparent sufferer truly experiences them as real, then the underlying cause must be psychological by default” (p. 186). However, this simply illustrates the limits of human knowledge at any given time as most medical conditions include symptoms that are not fully understood or explained (Dinwiddie, 2013; Sharpe & Carson, 2001; Scheurich, 2000; Rosendal et al., 2017).

For example, rheumatologists may diagnose unexplained muscle pain and tenderness as fibromyalgia, gastroenterologists may diagnose unexplained abdominal pain with altered bowel habit as the irritable bowel syndrome, and infectious disease specialists may diagnose unexplained chronic fatigue and myalgia as a post viral or chronic fatigue syndrome (Sharpe & Carson, 2001, p. 926).

Each of these examples demonstrates that medicine is an ever-evolving field. Over-time scientific research can show that previous formulations are false and thus, the causality and treatment of some diseases are amended. This is especially true in the case of CD. da Mota Gomes and Engelhardt (2014) argue the history of the illness “express(es) the unequal evolution of medicine itself, from beliefs and prejudices until rational essays” (p. 972).

Somatic conditions have received numerous titles to clarify their etiology (Dinwiddie, 2013; Kozlowska, 2005; North, 2015). The terms reflect historical, sociological and cultural
frames for how the illness was formulated. As well, the different names demonstrate the Western Cartesian split between body and mind, as science and medicine attempted to capture the disorder as distinctly a physical or a mental disease. This split is significant as it may explain why the disorder continues to be elusive in its presentation, diagnosis and treatment (Kozlowska, 2005; Rosendal et al., 2017). Nicholson and Kanaan, (2009) affirm that rather than providing clarity and insight, the variety of terms continues to “perpetuate the sense of mystery that often surrounds the condition” (p.164). Nicholson and Kanaan, (2009) go on to state, “symptoms of conversion disorder have been variously prefixed by the terms ‘hysterical’, ‘dissociative’, ‘functional’, ‘psychogenic’, ‘non-organic’, and ‘medically unexplained’” (p.164). Schüpbach (2012) argues that this lack of consensus impacts physician’s ability to diagnose and treat. Edwards and Bhatia, (2012) go further attesting, “the choice of term is not a trivial issue, because it directly affects case definition, diagnosis, treatment, research agenda, and explanations of illness that we give to patients” (p. 250). Thus, a clarification of the term or terms used to describe the illness could assist in diagnosis and treatment.

In each era physicians attempted to unravel the underlying cause of the suffering in their patients. Symptoms in the ill are observed, named and then qualified, in an effort to cure. In ancient times conversion disorder was known as hysteria, which comes “from the Greek word hystero meaning uterus” (Crimlisk & Ron, 1999, p. 165). The uterus was thought to “wander” throughout the body and disturb bodily systems (da Mota Gomes & Engelhardt, 2014; Crimlisk & Ron, 1999; North, 2015). The results of these womb movements were bodily based symptoms as the uterus compressed “different organs and body parts” (Schüpbach, 2012, p. 279). Gynecological rationales for body disturbances continued into the 16th century, and MUS “were referred to as “hysterical”” (Sharpe & Carson, 2001, p. 927). The origin of the uterus hypothesis
is believed to be Hippocrates (460-370 B.C.E.) (Crimlisk & Ron, 1999; North, 2015; Walsh, 2014). Hippocratic writing “refers to the womb as a common origin of disease and focuses on “hysteric” maladies, many of which were related to diagnosable medical conditions, such as pregnancy” (Walsh, 2014, p. 2). There also existed the “humor theory” which was provided by Galen (130-210 AD), a Roman physician who suggested that “the disease was caused by the humoral imbalance of blood, phlegm, yellow bile, and black bile” (da Mota Gomes & Engelhardt, 2014, p. 973). Each of these theories situated patient suffering from an organic, or physical rationale, rather than a psychological perspective. This change in nosology came later.

In the middle ages, witchcraft became the focus and “medical hysteria was thought to result from the action of demonic possession” (Scheurich, 2000, p. 462). This view held until it was challenged in the late 17th century as “increasing understanding of anatomy led to disease of the nervous system being regarded as the origin of unexplained symptoms” (Sharpe & Carson, 2001, p. 927). The nervous system hypothesis has continued through the 18th, 19th, 20th and 21st centuries. Medical science has not been able to prove an organic primary causal agent, and thus, the mind and the connected nervous system have become the focus (da Mota Gomes & Engelhardt, 2014; Crimlisk & Ron, 1999; Marsden, 1986). It is important to note that while the root cause of the disorder changed, the term to describe it, “hysteria”, steadily remained the same.

The history of scientific research and its resulting knowledge are linked to the contexts of the specific populations who were studied. Many theories linking hysteria to nervous disorders were developed in Britain in the 18th century (da Mota Gomes & Engelhardt, 2014). In 1893, Gowers (1845-1915), a prominent British neurologist, published the classic text “A Manual of The Diseases of the Nervous System” (Marsden, 1986, p. 277). However, in the 19th century,
France with its crowded Parisian hospitals, became the preeminent place to study hysterical patients. The teaching hospital, La Salpêtrière, provided a leading French neurologist, Charcot (1825-1893), the perfect setting to review and challenge the work of Briquet (1796-1881), a predecessor in the study of the disorder (da Mota Gomes & Engelhardt, 2014). Mai and Merskey (1980) report that in 1859 Briquet published his thesis on hysteria, which focused on links to the nervous system and listed symptoms such as “physical complaints about bodily functions, neurological symptoms such as amnesia, paralysis, anesthesia, pain, spasms, and convulsive fits” (as cited in North, 2015, p. 499). As with previous theories, later research showed that his work “merely emphasized the predisposition that lead to certain symptoms and are not their actual cause” (Schüpbach, 2012, p. 279). Charcot, was determined to find the links between the nervous system and the symptoms that he saw in patients, going to great lengths “to define the characteristic signs of hysteria—the presence of anesthesia, concentric limitation of the visual fields, and ovarian hyperesthesia. These he believed to be evidence of abnormal function of the nervous system, whose cause was not yet visible” (Marsden, 1986, p. 278). Charcot’s methods and theories, like many before him, were eventually discredited, which provided the opportunity for two of his students, Sigmund Freud (1859-1939) and Pierre Janet (1859-1947), to test their individual hypotheses (Shorter, 1992).

Freud and Janet’s main theoretical work was to conceptualize MUS. Each of them was resolute in their commitment to explain how the “hysterical body” could mimic the “organic body.” Freud’s theories about hysteria would come to dominate the field of psychology and it is his research on the construct that fundamentally shaped the development of psychoanalysis (Gordon, Kraitunin, Kelly & Meares, 1984). Freud worked closely with Joseph Breuer (1842-1925) and in 1894 they published the well-known text “Studies on Hysteria” (Walsh, 2014).
Freud coined the term “conversion hysteria” (Crimlisk & Ron, 1999; North, 2015), and together with Breuer introduced the concept of “conversion” (Harvey et al., 2006). Freud “claimed that conversion hysteria is the transformation of psychic conflict into somatic symptoms—such as paralysis, pain, numbness, or most famously in the case of Dora, nervous coughing” (Wilson, 2004). In fact, Freud thought that the “basis of all neuroses” (Gordon et al., 1984, p. 54), was hysteria. In contrast to Freud’s “conversion” hypothesis, Janet chose an alternative “dissociation” explanation (Kozlowska, 2005; North, 2015).

Janet’s theory focused on “disturbances of conscious awareness involving amnesia and identity confusion” (North, 2015, p. 500). It must be said that dissociation and dissociation disorders have not been readily accepted by the American Diagnostic system. Spiegel, (2010) states, “despite their neurocognitive and behavioral components, dissociative disorders have never been comfortably integrated into psychiatric nosology” (p. 261). Thus, while Freud’s ideas were upheld and markedly influenced the field of psychology, Janet’s ideas were left on the shelf to gather dust (North, 2015). This can be specifically seen in the multiple versions of the Diagnostic and Statistical Manual (DSM). Kozlowska (2005) reports, “the mind and body symptoms of hysteria were formally split in 1980 in DSM-III, when they were classified as dissociative and somatoform disorders, respectively” (p.3). The differences between these two models is important because “the Janetian perspective rejected Cartesian mind-body dualism” whereas the Freudian model “reinforced Cartesian thinking” (Kozlowska, 2005, p. 2). It is also critical to note that 1) “it is Freud’s psychodynamic conceptualization of conversion disorder that remains inextricably linked with the diagnosis in current classifications” (Harvey et al., 2006), and 2) “it appears that there is no satisfactory model to show how psychological disturbance or distress could actually be converted to or become manifest as a physical symptom which the
sufferer experiences as real” (Miller, 1999, p. 187). And while research to confirm this hypothesis continues, to date, this causal argument has not been proven (Edwards & Bhatia, 2012; Rosendal et al., 2017; Stone, Reuber & Carson, 2013).

Hysteria continues to be well known in Western society, and the term is still used to describe illness (Mason & Przybylo, 2014; North, 2015; Walsh, 2014). It has also not lost its pejorative connotation. To be diagnosed with hysteria, even if the term being used is conversion disorder, is rarely palatable for the ill. This is especially true when other terms such as hypochondria, malingering or feigning have been linked to the diagnosis. It is common for individuals who experience weakness, pain, tremors, or paralysis to believe that their symptoms are biological not psychological in origin. And these beliefs are bolstered by Western sentiments that physical illnesses are tolerable but mental illnesses are not. Fink (1992) found that “mental illnesses are in general less acceptable and often regarded as “not real,” with an implication of weakness, fault, or loss of reason in patients who have them” (as cited in Sharpe & Carson, 2001, p. 928). Thus, it is critical that the terms used to delineate what is occurring help increase understanding rather than cause further difficulty.

Recently, the word “functional” has become the term to describe the symptoms that have been known as “hysteria” or “conversion.” In the DSM V, in the section titled “Somatic Symptom and Related Disorders”, “Conversion Disorder” is listed and then in brackets the terms “Functional Neurological Symptom Disorder” are listed (American Psychiatric Association, 2013, p. 318). This change may be a result of studies that asked patients what labels they felt were most useful. Stone et al., (2002) found that “although “medically unexplained” is scientifically neutral, it had surprisingly negative connotations for patients. Conversely, although doctors may think the term “functional” is pejorative, patients did not perceive it as such” (p.
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1450). Once again, this finding highlights that terminology can be a hindrance rather than a help. It also confirms that the patients and doctors often use labels differently and that similar words may hold different meanings.

A historical review of the word “functional” can bring clarification to its definition and usage. Trimble (1982), explains that the word “function” has been around for about 400 years and that “originally, it had two uses: one physiological—that is, as the activity of an organ—and one psychological—that is, as the activity of the intellectual or emotional faculties” (p. 1768). He goes on to state that as early as the 16th century the physiological sense was applied to organs that were impacted by hysteria, as they “do suffer in their function” (Trimble, 1982, p. 1768). The same label and meaning was used when the causal agent of “hysteria” went from organs to the nervous system. Many scientists in the 17th and 18th century used “function” in its physiological sense to describe symptoms that did not change the structure of the body but the way it worked (Trimble, 1982). Charcot’s (1889) writing states that

there is without a doubt a lesion of the nervous centers but where is it situated and what is it its nature? ...Certainly it is not of the nature of a circumscribed organic lesion of a destructive nature …one of those lesions which escape our present means of anatomical investigation, and which for want of a better term, we designate dynamic or functional lesion (Trimble, 1982, p.1769).

However, Freud’s interpretation of hysteria changed how the word “functional” was used. His understanding of “hysteria” separated the body and the mind and excluded organic biological mechanisms as causal agents. Since this time “the term functional has reverted to its psychological meaning” (Trimble, 1982, p. 1769). Crimlisk and Ron (1999), report that this label “is now often used to indicate the absence of any physical cause, whereas originally it implied
the opposite” (p. 166). This change in definition and usage caused confusion and for a time made the term “functional” as meaningless as the word “hysteria” (Trimble, 1982).

Today, the term “functional” is once again being used to name and/or explain somatic conditions. Reuber et al., (2005) explain that “functional symptoms are physical complaints postulated to be associated with psychological distress, which are not primarily explained by pathophysiological or structural abnormalities” (p. 307). Schüpbach, (2012) says that “functional disorders” is the preferred term “because it does not have a pejorative connotation and emphasizes the clinical problem of impaired function” (p. 279). Stone (2013) states that “‘functional neurological symptoms’ refers to symptoms that are not explained by disease. They may also be described as psychogenic, non-organic, somatoform, dissociative or conversion symptoms” (p. 80). “Functional” in this context, means that there has been a substantial change in the way in which the body is operating, such that it is impacting an individual’s daily routines (American Psychological Association, 2013). It is hoped that this term, as it is more palatable to patients, could help them accept their condition and thus their treatment (Reuber et al., 2005).

Nevertheless, it is critical that doctors assess patients understanding of this label. When an individual receives a diagnosis of “conversion disorder” or “functional neurological symptom disorder” they are being asked to give up a physiological conception of their illness, and accept a psychological rational. It is highly likely that they will find this very difficult to do (Daum, 2013; Nicholson & Kanaan, 2009; Reuber et al., 2005; Stone et al., 2002; Rosendal et al., 2017).

“Because some symptoms cannot be observed, but are inferred from conversation, there is potential for substantial disagreement between the doctor, the patient and other health professionals around the aetiology of the illness and the nature of the distress” (Stone, 2014, p. 192). Thus, even this change in term may not elicit cooperation or acceptance from the ill person.
A deeper understanding of what is occurring for the patient and how they are making meaning of it, may clarify what terms are effective.

For 4000 years, the study of conversion disorder has occurred. Over time our understanding of this illness has changed. Each change has elicited a modification in the terms used to describe and explain the phenomena. However, currently, no unified terms, theories, diagnostic criteria or explanations exist (Henningsen, Zipfel & Herzog, 2007; Isaac & Paauw, 2014; Rosendal et al., 2017). A phenomenological inquiry could provide needed insight.

**Key Terms and Phrases**

**Consciousness and awareness**

This paper will use the definition articulated by Harvey et al., (2006). I will refer to consciousness as the “qualitative, subjective dimensions of experience” (p. 14). This includes “the two key components, arousal (conferring the ‘‘capacity’’ for consciousness) and awareness (conferring the ‘‘contents’’ of consciousness) (Butler & Zeman, 2005, p. i35).

**Conversion Disorder:**

The Harvard Medical School (2013) explains that conversion disorder is a relatively uncommon mental disorder in which a person has physical symptoms that no medical condition, physical examination or testing can explain. The person is not “faking.” The symptoms do not appear to be under the person's conscious control and they can cause significant distress. Examples of symptoms are a loss of muscle control, blindness, deafness, seizures or even apparent unconsciousness. The term “conversion” comes from the idea that psychological distress is being converted into a physical symptom. The cause is not known (conversion disorder, 2013).

The American Heritage Dictionary of Medicine (2015) defines conversion disorder as
A psychiatric disorder characterized by the presence of symptoms, such as paralysis, tremor, or visual or auditory problems, that resemble those of nervous system dysfunction but cannot be explained by a neurological disorder. Development of the disorder is often associated with psychological stress or trauma. Also called conversion reaction, functional neurological symptom disorder (conversion disorder, 2015).

The Britannica Concise Encyclopedia (2014) states that the disorder was previously known as “hysteria” and goes onto explain that conversion disorder was a neurosis marked by extreme emotional excitability and disturbances of psychic, sensory, vasomotor, and visceral functions. The earlier concept of hysteria was used frequently in the first half of the 20th century to explain a wide variety of symptoms and behaviours observed particularly in women. (The term *hysteria* derives from the Greek word for *womb*, reflecting the Greeks' belief that the condition resulted from disturbances of the uterus.) Disorders with symptoms similar to those of conversion disorder include factitious disorder, dissociative identity disorder, and personality disorder (histrionic type) (conversion disorder, 2014).

**Dissociation**

“A lack of awareness of body parts or others” (Rickards & Silver, 2014, p. 830).

The term is defined by Stone et al., (2011) as “a lack of integration between an individual’s subjective experience of neurological functioning and objective evidence concerning that functioning” (p. 373).

**Functional**

The usage will follow mainly a physiological definition indicating an altered functioning of the nervous system (Tremble, 1982). The Dorland Illustrated Medical Dictionary (2012) states that
the term denotes changes in brain function but not structure (p. 749). The DSM V states that functional refers “to abnormal central nervous system functioning” (American Psychiatric Association, 2013, p. 319).

**Identity**

This concept will follow the definition articulated by Baumeister (1999).

Identity is a definition placed on the self. Your sense of identity refers to your knowledge of who you are. Identity always answers the question, “who are you?” Self-concept, in contrast, may contain answers to other questions like “What kind of person are you?” and “How good are you?” The concept of identity rests on two notions, sameness (continuity) and difference. Identity means being the same person you were yesterday or ten years ago; it also means being different from someone else (p. 248).

**Medically Unexplained Symptoms**

Morriss and Gask (2009) explain that:

Medically unexplained symptoms (MUS) are physical symptoms that doctors cannot explain by organic pathology, and that distress or impair the functioning of the patient. MUS include distress or impairment of function that is disproportionate to the underlying physical pathology. Although MUS are not explainable by lasting organic pathology, they do have a physiological explanation which is usually reversible and temporary (p. 179).

Rosendal et al., (2017) describe MUS as the circumstances “when symptoms persist but, either by their character or their negative results of clinical investigation, cannot be attributed to disease” (p. 2).
Non-organic neurological symptoms

Described by Nicholson and Kanaan (2009), they state that “Psychiatrists use ‘organic’ to denote a neurological or physical disease process, and neurologists use non-organic as synonym for psychological disease” (p. 165).

Pathogenic

Causing or capable of causing disease. An agent is recognized as a pathogen.

Psychogenic

This term implies a purely psychological origin. Edwards, Stone & Lang (2014) affirm that the etiology is stated within the term as it means “born of the mind” (p. 850).

Salutogenesis or The Saltogenic Orientation


“The salutogenic model is sometimes referred to as the ‘sense of coherence theory’” (Eriksson, 2017, p. 95).

The Center of Salutogenesis, states:

Salutogenesis, the origin of health, is a stress resource orientated concept, which focuses on resources, maintains and improves the movement towards health. It gives the answer why people despite stressful situations and hardships stay well. It is the opposite of the pathogenic concept where the focus is on the obstacles and deficits (para. 1).

Self-Concept: Your idea(s) about Yourself

This concept will follow the definition articulated by Baumeister (1999).

The self-concept is the individual’s beliefs about himself or herself, including the person’s attributes and who and what the self is. The self-concept includes many things
that might not be part of one’s identity. For example, a person’s self-concept might include many personality attributes, such as being friendly or talkative (p. 247).

**Sense of Coherence**

The usage will follow Antonovsky’s (1979) definition:

A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one’s internal and external environments are predictable and that there is a high probability that things will work out as well as can be reasonably be expected (as cited in Mittelmark & Bauer, 2017, p. 7).

**Self-Efficacy**

The usage will follow Bandura’s (1994) concept;

Perceived self-efficacy is defined as people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. Such beliefs produce these diverse effects through four major processes. They include cognitive, motivational, affective and selection processes” (para. 1).

**Self-Esteem: How You Evaluate Yourself**

This concept will follow the definition articulated by Baumeister (1999).

An important part of the self-concept is self-esteem. A self-concept is not merely an abstract summary or notion of the self, but it is full of evaluations, that is perceptions, of the self as good, bad or mediocre. Self-esteem refers to the person’s broadest self-evaluation. Of course, people also have levels of specific self-esteem for specific domains. Someone may regard herself, for example, as an excellent tennis player, a mediocre student and a poor cook. (p. 248).
Situating the Author

I am an older, white, cisgender, woman, of European descent from a Christian, blue collar, lower middle-class background. Overall, during my forty-seven years of life, I had been in relatively good health. My doctor described me as having “a thin file” (GP. January (2013), personal communication). This indicated that I did not have a history of complaints of physical ailments. In September of 2012 I became very ill. It began with flu like symptoms that I assumed I would get over in a day or two. However, within a few weeks I had to take a leave of absence from work. By mid-October I had deteriorated to the point that I needed assistance to walk and I struggled with basic care. In December, I was bed-and wheelchair-bound. My downward spiral mystified me, my husband, my children and all my friends and family. Suddenly I was no longer Pamela; I was the mysterious illness.

In October 2012, I was seen by my GP, and then assessed in the emergency ward of the Chilliwack General Hospital. I was told that I had MUS. In November 2012, I was referred to a neurologist at Abbotsford Regional Hospital and Cancer Centre. This physician eliminated organic neurological illness as the reason for my symptoms. In January of 2013 I was seen by a psychiatrist, who suggested I was depressed. As I did not feel sad, I dismissed this diagnosis. In March of 2013 I was seen by second psychiatrist at the BC Neuropsychiatry Program at the UBC Hospital. I was told I had a psychosomatic illness. The psychiatrist, a specialist in somatic disorders, explained that I was not facing something, and until I did, I would not get better. “What?” I asked, “What am I not facing?” That he said, he could not tell me. He encouraged me to find a psychiatrist to work with, as his case load was full, and I was dismissed. At one point in the conversation the word hysteria was used. This was the first time I had heard the term as a descriptor of my condition.
The signal that I was sick with something more than a simple flu took place at work. I was standing in the hall talking to colleagues when my legs buckled and I fell to the floor. Whatever kept me upright, undid. I was like a tree suddenly hollowed, a bird in flight who abruptly had no wings. I was full of vitality one moment and the next, empty, a husk. And what did I do when this happened? Did I cry out? Did I feel concern? No. I looked up at everyone and attempted to carry on as if nothing happened. I acted as if I would keep working, only this time, from my position on the floor. There was no hesitancy in this decision, no question. I noted my location and then carried on. Conversely, my coworkers were very alarmed and immediately acted. Within moments I was driven home, helped inside and a family member was called to attend to me.

My inability to make sense of what had happened, how I was, carried on unabated. I was dismayed, bewildered, at a complete loss, but determined to change. I had always been able to overcome any sickness or difficulty I encountered. This was no different. I would be better. Only I was not. My symptoms did not improve. In fact, the more I sought help, explanation, or treatment whether traditional or homeopathic, the worse I became. Day and night my body ached unceasingly. If I attempted any movement, tipping my head forward, lifting my foot from the ground, I tremored with such ferocity that I was forced to stop. I felt exhausted no matter how long I slept. And sleep was difficult because tremors would wake me or the unceasing pain would push me to consciousness. Psychologically, I felt despair as my ability to meet my basic needs steadily decreased. Yet I kept returning to the skills that had served me well in the past. Repeatedly, I would try each out skill, as if this time I would be met with success, a return to my old self. Only this did not occur.
At home, as I tried to make sense of my symptoms, I reflected on the words of the UBC physician from the Neuropsychiatric program. He said, “face what you are keeping from yourself or you will end up back here, in my psychiatric ward” (Psychiatrist. March (2013), personal communication). These words felt like a death sentence. I believed that I had always faced everything that was difficult or traumatic in my past and present circumstances. I had no place in me to receive the information that I was repressing or denying something significant, something so substantial that my body would no longer function. The dissonance between what I was told and what I believed tore me apart. I trusted the story I had told myself about who I was. And yet here was this “me” who could not feed herself or bathe unassisted. Who was she? Where did the other “me” go?

Alone, desperate and terrified I became my own case study. I began to research the words used to describe my illness such as conversion disorder, somatoform, hysteria, or psychosomatic. It was difficult to read how my symptoms were framed and the rather poor prognosis that was given. Although I attempted to read with a sense of detachment, hearing myself described as dissociative or feigning was very difficult. In a paper discussing hysteria Scheurich (2000) writes

I would argue that an illness may be said to be hysterical insofar as it stems from the patient’s deceit, whether of self or others, about his or her own capacity to affect the course of the illness. Hysteria occurs when an individual, whether through anxiety, credulity, or learned helplessness, feigns powerlessness, often unconsciously. Hysteria occurs to the degree that an individual gives up on personhood and opts for patienthood; it is the metamorphosis of demoralization into incapacity. Hysteria consists of varying degrees of “playing dead” (p. 471).
This is a typical explanation of how a somaticized illness is described in the literature. These types of descriptions added to my plight. If I was going to heal, I needed another way to frame what was happening.

In the summer of 2013, during another Google search, I happened upon a link for a therapist in Zurich, Switzerland who specialized in psyche-soma work. I picked up the phone and called Cedrus Monte (http://www.cedrusmonte.org/). In her I found a compassionate companion who could walk with me as I reclaimed my body and my life. With her partnership, I learned how to accept my diagnosis and to receive treatment. From 2012 to the present I have written about my experience in journals. This body of information will be the qualitative data for this hermeneutic-phenomenological study. My focus will be the “lived” experience of a diagnosis of conversion disorder. This perspective facilitates the exploration of the meaning making process, when an individual is told that their physical ailments have no medical explanation for their somatic symptoms.

Structure of this Thesis

The Introduction chapter, Chapter 1 provides a brief introduction of the history of conversion disorder, the terms used to describe the illness and how these have been understood through the 4000 years of study of the construct. In Chapter I articulated my purpose statement and the relevance of my topic to the field of psychology. I provided a brief overview of the research related to my topic. I go on to define key terms and phrases used throughout the thesis and close with an argument that new methods to frame CD are needed.

The second chapter, Chapter 2, provides an overview of conversion disorder. I explain how it is defined in primary care, neurology and modern psychiatry. I review diagnostic practices, explore symptoms, review current research on treatments and discuss prognosis.
In the third chapter, Chapter 3, I discuss the method I used to write this thesis, a hermeneutic-phenomenological inquiry, and explain my reason for using this research methodology. I describe how written journal entries compiled during the first symptoms of my illness, my search for a diagnosis, my diagnosis of conversion disorder and my experiences after diagnosis will be used as data. To decipher the data, I use Interpretive Phenomenological Analysis (IPA) as “IPA draws upon the fundamental principles of phenomenology, hermeneutics, and idiography” (Pietkiewicz and Smith, 2014, p. 8). I explain how the data was compiled into units of meaning and then transformed into themes that become "the basis for the writing of the general structure of the experience" (Giorgi, 2009, p. 137). In this chapter, I also address research bias.

In the fourth chapter, Chapter 4, using IPA, I outline the five themes that were distilled from the written entries in journals compiled from 2012 to 2015. Each theme is described using a narrative lens and samples from the journals are used to verify the interpretation.

In my concluding chapter, Chapter 5, I discuss the relevance of my findings and their implications for the field of psychology. I share how I think clinical counsellors can bring the results into therapy with their clients, and outline implications for future research.
CHAPTER 2 LITERATURE REVIEW

Introduction

Conversion disorder or functional neurological disorder has been studied for many years. The term conversion disorder (CD) will be used throughout this review as it is the primary title used in the DSM V (American Psychiatric Association, 2013). The DSM V lists numerous possible diagnostic features and states that “there may be one or more symptoms of various types” (American Psychiatric Association, 2013, p. 319). These include motor symptoms: “weakness or paralysis; abnormal movements, such as tremor or dystonic movements; gait abnormalities; and abnormal limb posturing” (American Psychiatric Association, 2013, p. 319). As well, a patient may experience sensory symptoms, such as loss of hearing or sight; non-epileptic seizures; and an unresponsiveness that resembles coma (American Psychiatric Association, 2013) The cause of symptoms is still not understood (Rickards & Silver, 2014; Rosendal et al., 2017; Stone et al., 2011).

Again, CD can present in numerous ways. An individual may be unable to move a limb or have non-epileptic seizures or be unable to see. CD can be diagnosed as a single presentation or as a combination of symptoms. The diagnostic criteria or “the symptoms of conversion have been variously prefixed by the terms ‘hysterical’, ‘dissociative’, ‘functional’, ‘psychogenic’, non-organic’, and ‘medically unexplained’ (Nicholson & Kanaan, 2009, p. 164). All the prefixes are used in research studies. The DSM V (2013) also reports, “clinicians use the alternative names of “functional” (referring to abnormal central nervous system functioning) or “psychogenic” (referring to an assumed etiology) to describe the symptoms of conversion disorder (functional neurological symptom disorder)” (p. 319). Thus, to discuss CD one must be able to interchange numerous symptoms as well as numerous diagnostic labels. It is very
important to remember, “the term ‘functional neurological symptoms’ refers to symptoms that are not explained by disease” (Stone, 2013, p. 80).

Today, as in the past, numerous theories have been created and tested in the hope to explain and treat CD (Epstein, Quill & McWhinney, 1999; Frommer, 2013; Gubb, 2013; Kozlowska, 2005; North, 2015). Recent theories have postulated that the disorder could be caused by

- exaggerations of normal physiological responses to stress (tremor, paralysis, change in tone and even cognitive deficits),
- unconscious mimicking of the idea of illness to elicit nurturing behaviours in others,
- lack of awareness of body parts or self (dissociation),
- over-awareness of body parts (internal hypervigilance),
- and conscious creation of symptoms (Rickards & Silver, 2014, p. 830).

But, no single theory has been able to explain the mechanisms of the illness (Rickards & Silver, 2014; Rosendal et al., 2017; Stone et al., 2011). One reason for the difficulty is that CD does not sit comfortably in a single category, but liberally falls within the fields of both neurology (the brain) and psychiatry (the mind). The disorder challenges the Cartesian separation of mind and body; the body is what appears symptomatic, while the mind continues to be the focus of research and diagnosis. Today, there is greater willingness in the fields of science and medicine to challenge and re-conceptualize the age-old split, but the biomedical model continues to dominate (Epstein et al., 1999; Mehta, 2011; Toombs 1987; Toombs, 1988).

Within the biomedical model, phenomena that arise from the mind are termed psychogenic, whereas those that have an organic origin are described as somatogenic (Shorter, 1992). This objective delineation of subjective experience prevents conditions like CD from being fully understood. White, Rickards and Zeman (2012) argue, “the current line of
demarcation between disorders of mind and of brain is counterproductive for clinicians and patients on both sides of the line” (p. 1). For it is not unusual for disorders of the central nervous system (CNS) to have symptoms like paralysis or sensory abnormalities (such as prickly skin) alongside those that are psychological: changes in affect, behavior or cognition (Butler & Zeman, 2005). Although it might be advantageous for research or medicine to isolate particular phenomena, “the mind is indivisible from the brain” (Harbuz & Lightman, 1992, as cited in White et al., 2012, p. 1). Thus, an end to the false separation of the physical and psychological could help bring understanding to the pathophysiology of CD.

This literature review will explore the role of theory in CD and the impact of the mind-body split. It will question if a specific theory can explain a phenomenon that may be an adaptive method to address crisis, pain, trauma or difficulty. The review will first examine approaches to diagnosis and symptomology, followed by research on treatment, and finally prognosis.

Diagnosis

Western culture views disease, whether in body or mind, as a negative mark on the character; something to be swiftly addressed and banished. A result of this deeply embedded ideology is that many people who are ill do not seek medical care (Epstein et al., 1999). Yet, diagnosis can be the first step towards treatment. Without it, the sick must deny or disguise symptoms, rarely allowing any sign of weakness to be detected. “Sociologists have long pointed out, the norms and values associated with illness are such that there is an expectation that people should do what they can to improve their health and alleviate their symptoms” (Nettleton, Watt, O’Malley & Duffey, 2005, p. 207). Yet, as Maté (2003) reports, “we have seen in study after study that compulsively positive thinkers are more likely to develop disease and less likely to survive” (p. 257). The felt moral incriminations for being ill could arise from an individual, their
family, work place or community. Duff (1993) in her book, “The Alchemy of Illness” relates a common response to being sick. She states, “I ignored and minimized my developing symptoms—the fevers, tiredness, muscle aches, and general ennui—for quite some time, and so precipitated my eventual collapse” (Duff, 1993, p. 35). Consequently, seeking meaning of/or understanding about bodily based symptoms may be a last step of desperation, rather than a first choice.

The diagnosis of an individual’s CD can be a difficult process. A typical journey begins in the office of a General Practitioner (GP). Research has shown that it is in primary care that symptoms are disclosed and that patients “seek the GP’s diagnostic skills and the legitimacy that the GP can bring to their perceived physical health problem” (Morriss & Gask, 2009, p. 180). We are socially trained to trust medicine to tell us what we “have” and what the label means. After the ill person walks through the doctor’s door, literature relates two important facts: 1) these individuals are more likely, than the average client, to seek help from a GP (Epstein et al., 1999; Morriss & Gask, 2009; Haller, Cramer, Lauche & Dobos, 2015) and 2) that GP’s are under-diagnosing the disorder (Haller et al., 2015; Murray, Toussaint, Althaus & Löwe, 2016; Rosendal, Bro, Fink, Christensen & Olesen, 2003; Warren & Clauw, 2012; Reuber et al., 2005).

MUS, CD or “functional neurological disorder” is the label applied when symptoms “have minimal or no apparent basis in physical disease” (Isaac & Paauw, 2014). However, this diagnostic label can leave physicians at a loss, for their education has been built on the belief that “every illness be partially attributable to a clear-cut underlying disease” (Epstein et al., 1999). For, “the initial aim of medical investigations in all patients is to establish or confirm a diagnosis” (Reid, Wessely, Crayford & Hotopf, 2002, p. 251). To complete this task, GP’s may use every diagnostic avenue open to them, subjecting a patient to numerous tests, expensive
evaluations and at times, invasive procedures (Dinwiddie, 2013; Epstein et al., 1999; Rosendal et al., 2003; Rosendal et al., 2017). These rounds of tests use many resources, and result in heavy healthcare costs (Barsky et al., 2005; Isaac & Paauw, 2014; Lidén et al., 2015; Morriss & Gask, 2009; Nicholson & Kanaan, 2009; Rosendal et al., 2017). As well, they can harm, rather than help the patient (Howman, Walters, Rosenthal, Ajjawi & Buszewicz, 2016; Nicholson, Stone, and Kanaan, 2011; Rosendal et al., 2003; Reuber et al., 2005).

A General Practitioner’s training provides them with a wide knowledge of medicine. Their education, however, does not give them the skills required to assess, communicate and manage CD (Howman et al., 2016; Morriss & Gask, 2009; Shattock, Williamson, Caldwell, Anderson & Peters, 2013; Yon et al., 2017). This lack can then translate into sub-optimal care of patients and could be connected to the finding that CD patients fare poorly. Yon et al., (2017) explain “that teaching for both medical students and newly qualified doctors about this topic is currently very limited in the UK. This highlights an urgent need to adopt a more rigorous and systematic approach to education in this area” (p. 5). Murray et al., (2016), when referring to the education of new physicians, argue, “if we consider diagnosis as a gateway to appropriate treatment, then improving the diagnostic process should be a high priority of our field” (p. 2).

For as it stands today, many GP’s have negative attitudes towards patients with CD and label them as “demanding” “difficult” and “unreasonable” (Dinwiddie, 2013; Epstein et al., 1999; Isaac & Paauw, 2014; Kirmayer et al., 2004; Kurlansik & Maffei, 2016; Morriss & Gask, 2009; Shattock et al., 2013; Werner, Isaksen & Malterud, 2004). Rosendal, Carlsen, Rask, & Moth (2015) found “symptoms that are not related to a well-defined disease are common in primary care, and GP’s generally find it demanding to deal with symptoms when no specific diagnosis can be made” (p. 97). Thus, rather than finding comfort and care when seeking medical attention,
patients with CD can end up mistrusting those tasked to serve them (Epstein et al., 1999; Lidén et al., 2015; Werner et al., 2004; Rosendal et al., 2017, Stone, 2014).

Primary physicians are trained in the biomedical model that focuses on cause and effect. Patients with symptoms that fall outside the strict categories in medicine are problematic. CD represents such a medical quandary, for although the beginning of a diagnosis of CD usually begins with a GP, “conversion disorder is primarily defined by neurological symptoms” (Nicholson et al., 2011). Hence, the first diagnosis a patient can receive is MUS; they have symptoms that “cannot be attributed to disease” (Rosendal et al., 2017, p.2). This designation allows a primary physician to move the patient to the next stage of care, a referral to neurology. The purpose of a neurological exam is to verify the GP’s finding of MUS, by ruling out any organic disease in the “brain.” If the neurologist affirms there is no organic illness, it is not unusual for a patient to ask, “Well, what do I have?” Typically, the diagnosis is then explained as “psychological’, or in the “mind.” This frame reflects the historical search for a brain “lesion” which, unfound, has left the “diagnosis” of the “cause” of CD to the field of psychology to discover.

The biomedical model continues to be as troublesome today as it was in the past. The split of “brain” and “mind” or body/mind split has been shown to be artificial (Gordon & Edwards, 2005; Maté, 2003; Mehta, 2011; Reuber et al., 2005; Vitetta, Anton, Cortizo & Sali, 2005; White et al., 2012). White et al., (2012) state that “the requirement that conditions should be classified under either mental or physical chapters causes particular difficulty in the context of the functional somatic syndromes or somatoform disorders, in which physical symptoms are often assumed to have a psychological explanation” (p. 2). This is a problem because research has been unable to find a psychological answer to CD. deWaal et al., (2006) affirms this finding
and argue “indeed, it is not very clear that unexplained physical symptoms are caused by psychological factors” (p. 474). And in fact, “psychological stressors are not always identifiable and may not be relevant even when present” (Nicholson et al., 2011, p. 6). Yet, CD is still conceptualized as an illness that falls between neurology and psychiatry, and once the patient’s symptoms have been determined “non-organic” they are framed using a psychological perspective.

The two primary sources used for diagnosing psychological disorders like CD are the Diagnostic and Statistical Manual (DSM) published by the American Psychological Association and the International Criteria for Disease (ICD) published by the World Health Organization. Both publications have gone through numerous revisions: the DSM is now in its fifth iteration and the ICD in its eleventh. Even with revisions the classification of CD and thus the methodology to diagnose the disorder, is still unsatisfactory (Daum et al., 2013; Dinwiddie, 2013; Edwards et al., 2014; Nicholson & Kanaan, 2009; North, 2015; Reuber et al., 2005; Rosendal et al., 2017; Stone et al., 2011). The signs and symptoms that lead to a CD diagnosis are not wholly agreed upon and can differ from doctor to doctor (Henningsen et al., 2007; Daum et al., 2013; Rosenthal et al., 2017). Although the DSM and the ICM expect “that the diagnosis of CD is made on clinical grounds. At present, no guidelines ensure that clinicians have the same standard across the world” (Daum et al., 2013, p. 7). Nicholson et al., (2011) in their paper “Conversion Disorder: a problematic diagnosis” found “we continue to understand and define it by criteria that are not themselves clearly understood and whose presence we cannot clearly define” (p. 5). Part of the challenge is that the terms, their usage and how they are understood, are not standard across disciplines.
The field of neurology has developed its own methods for evaluating CD symptoms. Stone (2009) attests that “the diagnosis of functional motor symptoms should always be based on positive evidence on the examination of internal inconsistency (e.g., Hoover’s sign for paralysis or a tremor that stops or entrains during contralateral cued rhythmical movement)” (as cited in Stone et al., 2013). Neurology, as opposed to psychiatry, no longer requires a psychological, or biosocial causal factor. The diagnostic criteria of “positive signs” can reliably rule out a neurological disease and thus, diagnose CD (Daum et al., 2013; Edwards & Bhatia, 2012; Nicholson et al., 2011; Rickards & Silver, 2014). Consequently, during diagnosis, neurologists focus on how the illness is presented.

Probably the commonest source of diagnostic error is when the clinician pays too much attention to the patient’s psychosocial history and not enough to the presenting symptoms. A generation and more of doctors have been taught via psychiatric diagnostic criteria that functional neurological symptoms are a form of ‘conversion disorder’ and, as such, represent the conversion of recent stress into a physical symptom. In fact, the evidence on life events is not conclusive (Stone et al., 2013, p. 105). Stone et al. (2013) go onto say that “many patients with functional symptoms are psychiatrically ‘normal’” (p.105). This change in theory is significant, but does not seem to have been adopted by all medical disciplines.

The fact that there is still confusion and controversy on this point is clearly evident in the literature. For example, Rickards & Silver (2014), writing from a neuropsychiatry perspective maintain that the one thing that all patients with CD have in common is “that they lack the features of currently accepted ‘organic’ disease, that disability has arisen as a result of a presumed problem with higher mental function, whatever that may be” (p.830). Whereas,
Rosendal et al., (2013) contend “the concept that functional somatic symptoms might simply represent somatised psychiatric illness is not tenable” (p. 4). Again, as stated earlier, Nicholson et al., (2011) argue “the diagnostic criterion for the presence of a psychological explanation of the symptoms is problematic as psychological stressors are not always identifiable and may not be relevant even when present” (p. 6). The complex, interrelating systems of mind/body are not fully understood, but “functional imaging studies are helping us to understand the neural correlates of these symptoms and that they have a biology as well as a psychology” (Stone, 2013, p. 82). Henningsen et al., (2007) affirm this argument and recommend that “practitioners in different specialties of medicine should discover the importance and the rewards of caring for patients with FSS (Functional Somatic Symptoms) in a balanced way, rather than purely biomedical or psychological approaches” (p. 952). Thus, a review of the literature suggests that 1) there is a need for improved communication between medical disciplines, and 2) “any names that presuppose a mind–body dualism (such as somatization, medically unexplained) ought to be abolished” (Fink & Rosendal, 2008, p. 182). Consequently, it is time to amend the simplistic hypothesis that if the illness is not in the “body” it must be in the “mind.”

The absence of consensus poses many problems, especially with regards to treatment and prognosis. Diagnosis is the first step towards treatment, without a “label” the ill person can be left in a “no man’s land” neither sick nor well, with the question of whether they are feigning or malingering, stated or unstated. Aronowitz (2001) attests that without a clinical based diagnosis, many patients simply become “medical orphans” (as cited in Nettleton et al., 2005, p. 205). For “every disease has a name, the name drives the choice of remedy, and the remedy restores wellness. This narrative is parallel to the medical story of diagnosis, evidence based treatment and cure” (Stone, 2013, p. 1). Along with its patients, the disorder itself has become a “medical
orphan” as no theoretical model has been able to fully explain the condition, and thus it has moved from discipline to discipline, sometimes accepted as a psychiatric disorder, others as neurological. This lack of “home” for this 4000-year-old illness is itself a phenomenon and one with grave consequences. As indicated, “patients with a somatization disorder use twice as many outpatient and inpatient resources and have double the average health care costs per year” (Isaac & Paauw, 2014). And even with all this attention and expertise, patients’ prognosis remains poor (de Schipper, Vermeulen, Eeckhout & Foncke 2014; Nicholson et al., 2011; Rickards & Silver, 2014; Rosendal et al., 2013; Reuber et al., 2005).

If CD were a rare illness, these finding would still be noteworthy, but possibly not as concerning. However, the literature suggests that patients suffering from a somatoform illness form a significant sized group (Carson et al., 2011; de Waal et al., 2006; Epstein et al., 1999; Healthcare Improvement Scotland, n.d.; Kanaan, Armstrong, Barnes & Wessely, 2009; Stone, 2009; Stone et al., 2013; Rosendal et al., 2015; Rosendal et al., 2017). Haller et al., (2015) conducted a systematic review and meta-analyses and confirmed “the point prevalence for the diagnosis of at least one somatoform disorder according to DSM or ICD was 26.2%, and 34.8% when only data from high quality studies were included” (p. 284). As well, Kanaan et al., (2009) citing the work of Carson et al., (2000) and Nimnuan at al., (2001) confirm that patients with MUS “comprise 30-60% of neurological outpatients” (p. 2889). The words “normal” or “common” are often used to describe the condition, while the actual size of the population with the illness is contested (Lidén et al., 2015). The DSM V states that the prevalence of the disorder remains “unknown” (American Psychiatric Association, 2013, p. 320). Consequently, worldwide, numerous patients arrive daily at doctors’ offices and medical clinics seeking answers.
The road to diagnosis can be long: multiple visits to a GP, a neurological assessment and potentially, a referral to psychiatry. A critical aspect of this journey is the beliefs and attitudes of physicians. The ill rely on the expertise of the medical community to appreciate their suffering. However, in the past, doctors were required to assess and exclude feigning or malingering before a patient could be diagnosed with CD (Kanaan & Wessely, 2010). This criterion is still present in DSM V as a differential diagnosis, where it is defined as factitious disorder. A finding for factitious disorder requires evidence that the individual will “derive external benefits such as money or release from responsibility” (American Psychiatric Association, 2013, p. 320). The DSM V reflects recent research that without a confession, the intentionality of specific features of CD cannot be confirmed (Reuber et al., 2005; Stone, 2013; Stone et al., 2013; Voon et al., 2010).

While faking continues to be a concern for GPs, neurologists and psychiatrists, “it remains extremely difficult to prove that someone with neurological symptoms is feigning, rather than suffering from a conversion disorder, on clinical or even experimental grounds” (Nicholson et al., 2011, p. 5). This is a relatively new change in how CD is conceptualized. The reductive biomedical model has dominated Western thinking about ill health. In this structure, theories such as Talcott Parsons (1951, 1964, 1978) and his description of the ‘sick role’ became deeply embedded. Frank (1997) explains Parson’s theory stating “the physician is expected to treat the patient without colluding in the patient’s withdrawal into sickness. The single moral expectation of the patient is to return to health, and the physician is to facilitate that return” (p. 132). Hence, it is not surprising that doctors trained in the model are focused on finding and curing disease. Nor is it difficult to see how physicians would conceptualize symptoms of “non-organic” nature as feigning or malingering.
It is understandable that symptoms that mimic but are not actual diseases, would be suspect. Yet, statistics show that diagnoses of CD or FND are trustworthy. Henningsen’s (2016) editorial, “Fear of Flying” states “diagnoses of functional somatic symptoms or syndromes can be relied upon – nowadays – to stand the test of (follow up) time in more than 99% of cases not only for functional neurological symptoms but for a broad spectrum of functional symptoms and syndromes” (p. 59). An essay written in 1873 by the physician Sir James Piaget (1814-1899) has a line that is often quoted to explain the inconsistencies noted when assessing a patient with possible CD: “She says, as all such patients do, ‘I cannot’; it looks like ‘I will not’; but it is ‘I cannot will’” (as cited in Stone, Perthen & Carson, 2012, p. 866). This formulation of diagnostic criteria is incredibly important to patients. Illness often leaves one feeling vulnerable. To then be met with disbelief, can significantly add to a sense of being alone and exposed.

Vulnerability is a key component of the patient with CD. These individuals often have been ill for some time, have sought numerous explanations for their present condition and have at times become unemployed. To contend with these circumstances, it is not unusual for the ailing to feel defensive. For as stated at the beginning of this review, Western culture blames, rather than sympathizes with the sick (Carel, 2007; Duff, 1993; Edwards et al., 2014; Frank, 1997; Gunderman, 2000; Kirmayer et al., 2004; Maté, 2003). This situation, therefore, is not ideal for a patient to be told that their symptoms mimic, but do match organic disease symptomatology. Most organic diseases have clear markers that delineate the signs of illness, how they present and their consequences. A main diagnostic marker for CD is that the symptoms imitate diseases such as epilepsy or Parkinson’s, but do not stay within their clearly defined lines. Edwards et al., (2014) state that during a neurological exam the focus is on identifying specific features principally “motor symptoms, which are experienced as involuntary but have
features that are either internally inconsistent or incongruous” (p. 851). Nicholson et al., (2011) give a fuller explanation: “CD is primarily defined by neurological symptoms such as weakness, sensory loss or blackout which, due to internal inconsistency or incongruity with known patterns of disease are not thought to be caused by a neurological disorder” (p. 1). These terms and their meanings give physicians a solid and unconfutable position that the patient is not suffering from an organic malady. However, for the ill, this description can sound as if they are being told that they are “making up” symptoms or “putting them on.”

For many patients, as their symptoms are bodily based, their original reason for seeking medical assistance is to have their physical ailment investigated. Patients seek a name for their illness, but few are prepared to be told that their “body” is not ailing because their symptoms are “inconsistent” or “incongruous” with known disease. It is at this juncture that the skills of the physician are most critically needed. CD, FND and MUS are terms used interchangeably by physicians but not widely understood or accepted by the public. These terms carry negative associations and are often used pejoratively (Edwards et al., 2014; Epstein et al., 1999; Kirmayer et al., 2004). Nevertheless, as there are no other present-day explanations, and to receive treatment an illness must be labeled, a diagnosis of CD or FND must be given. How the diagnosis is communicated can determine an individual’s trajectory.

The final diagnosis of symptoms could take place in the office of a GP, a neurologist or a psychiatrist. Where, is not as important as what is said and how it is said. Stone (2009) underscores this point, stating, “the way you say things is more important than the terminology you use” (p. 186). Epstein et al., (1999) state, “the language of medical discourse shapes both the patient’s illness experience and the physician’s response to the patient’s concerns. Patients who experience bodily symptoms often do not regard the mind as the primary “cause” of their
distress” (p. 218). Patients with bodily-based symptoms are ready to be told “how” they are sick because ailments that have an organic etiology are often seen as “beyond the person’s control and thus evoke compassion and concern” (Kirmayer et al., 2004, p. 667). Whereas, they are not prepared for a psychological diagnosis because these often ascribe personal responsibility and are tinged with blame or personal failings (Duff, 1993; Kirmayer et al., 2004; Maté, 2003). A psychiatric label can have dire social consequences for the individual, and consequently they may have little will to consider or accept it as an explanation for their circumstances. Edwards et al., (2014) explain, “it is hard to escape the strongly prevalent public attitudes that psychological difficulties are something minor or “not real” and usually signify a distinct lack of moral fiber” (p. 850). Thus, it is “only through dialogue, negotiation, and cultural exchange can clinicians find explanations that make sense to patients and their families” (Kirmayer et al., 2004, p. 670). For not only is there no cure for CD, MUS or functional neurological symptoms, but today, as in the past, treatment has many questions surrounding it.

**Management of Symptoms**

After diagnosis, the first step is acceptance of what has been found. This can take time as it is very difficult to explain to oneself or another that your physical symptoms cannot be explained medically. Thus, acceptance is a process, rather than as a one-time, global, event. Next, as there is no cure, care must be the objective for both patients and doctors. Many patients with CD have suffered for a significant length of time. A positive rapport with a physician can help facilitate a modification of their present experience. To begin this next stage, the ill need to accept that further testing or evaluations will not alleviate their suffering and may do the opposite, cause them greater harm. Trust in their doctor is fundamental for the patient to
acknowledge this truth. Stone, L. (2013) suggests that physicians who employ the following strategies can facilitate positive doctor/patient care:

1. Accept that patients are suffering: see patients as people worthy of respect
2. Remain patient-centered: provide empathetic care
3. Accept responsibility: coordinate their care and be their advocate
4. Decide how to incorporate psychological concepts and treatments into consultations early in the therapeutic relationship so that patients can make the link between physical and psychological health
5. Think in terms of harm minimization: Given that the potential for harm is always present accept the inevitable discomfort that accompanies uncertainty
6. Shift the focus from curing to healing (p. 7).

Utilizing steps such as those listed above, could help patients struggling to accept their diagnosis, to learn to live with their CD. This would be much better than a continuous journey of searching for “cause” and “cure.” It may also assist those patients with somatic symptoms who have been labeled as “hypochondriacs.” Being sick, without a known organic disease, is culturally unacceptable. Hence, the ill could be trying to comply with the typical medical framework of diagnosis, treatment, and cure. By seeking attention when they are symptomatic the “ill” may be acting as the “obedient patient”. Reid et al., (2002) argue, “the fact physicians seem unable to address their problem is one of the reasons why many patients with unexplained symptoms keep seeking medical advice” (as cited in Reuber at al., 2005 p. 311). Therefore, an open and trusting relationship with a GP could mediate the need to keep looking for answers.

It has been suggested that when psychiatrists and neurologists can work together, patients fare better (Aybek, Hubschmid, Mossinger, Berney & Vingerhoets, 2013). As well, many
authors have concluded that the management of somatic symptoms requires a multimodal approach (Aybek et al., 2013; Baslet, Dworetzky, Perez & Oser, 2015; Kurlansik & Maffei, 2016; Nielsen, Stone & Edwards, 2013; Stone, 2009; White et al., 2012). In this light Kurlansik and Maffei (2016) recommend the following:

- Scheduling regular, short-interval visits
- Establishing a collaborative, therapeutic alliance
- Acknowledging and legitimizing symptoms
- Limiting diagnostic testing
- Reassuring the patient that serious medical diseases have been ruled out
- Educating patients about coping with physical symptoms
- Setting a treatment goal of functional improvement rather than cure
- And appropriately referring patients to subspecialists and mental health professionals (p. 51).

While the above symptom management strategies could facilitate encouraging outcomes, the literature has found only one method that can improve CD. Patient-centered communication has been cited by numerous authors as the means to facilitate improved prognosis (Edwards & Bhatia, 2012; Friedman & LaFrance, 2010; Gelauff, Stone, Edwards & Carson, 2013; Lidén et al., 2015; Stone, J. 2013; Stone, L. 2013). Isaac & Paauw (2014) report “the most powerful tools available are the ability to communicate the limits of current understanding, acknowledge the difficulties faced by patients with this disorder, and reinforce the willingness and desire of clinicians to partner with patients as the focus shifts from diagnosis to symptom management” (p. 669). Stone (2013) provides several suggestions about what to say and how to say it. For example, he has found it helpful to tell patients what they do have “functional
weakness/movement disorder” and what they **do not** have “multiple sclerosis or epilepsy” (Stone, 2013, p. 82). He also has found metaphors a positive means to explain symptoms: “this is like a software problem with the brain rather than a hardware problem” (Stone, 2013, p. 83).

**Treatment models**

Treatment of CD is difficult, because the aetiology of the disorder is still unknown. Traditionally, treatment follows diagnosis. However, in the case of CD, “there are few reasons to believe that all patients falling under the rubric of ‘functional neurological symptoms’ are suffering from the same illness” (Rickards & Silver, 2014, p. 830). Thus, the care of these patients must be individual and address the symptoms they are experiencing. These can range from tremors, to non-epileptic seizures, blindness or paralysis. Each of these presentations might be helped by known treatments, but what these should be and who should deliver them is still not agreed upon. It is important to note “part of successful treatment is removal of unnecessary medications and avoidance of unnecessary tests and surgical treatments” (Edwards & Bhatia, 2012, p. 257). Therefore, a first step in treatment, as stated above, is to help the patient accept the disorder.

Treatments could include psychotherapy, physiotherapy, meditation/relaxation training and/or medication. Each of these must be placed against the individual’s needs and capabilities. Consequently, it is not surprising that Ruddy & House (2005) found “no definite treatment plan can be recommended” (as cited in Aybek et al., 2013, p. 2). However, it is highly likely that all physicians, a GP, a neurologist, and mental health professional, will be involved in the delivery of treatment. Thus, there is a need for an interdisciplinary, collaborative approach to patient care (Aybek et al., 2013; Baslet et al., 2015; White et al., 2012). It is also important to note the imperative given by Henningsen et al., (2007) that, “this necessary balance of therapeutic
approaches is in parallel with the need in research to determine empirically the relative value of interventions based on organ-oriented and experience-oriented approaches” (p. 949).

One of the most commonly cited therapies is cognitive behavior therapy (CBT) (Aybek et al., 2013; Edwards & Bhatia, 2012; Isaac & Paauw, 2014; Morriss & Gask, 2009; Reuber et al., 2005; Sharpe & Carson, 2001; Stone, 2009; Stonnington et al., 2006). The hope is that through CBT patients might modify their experience of physical symptoms and possibly change their thinking about their condition. Along with CBT, Kurlansik and Maffei (2016) and Baslet et al., (2015) found that mindfulness-based therapy could improve outcomes. As well, Baslet et al., (2015) explain that CBT and mindfulness-based therapy “overlap and are complementary rather than contradictory” (p. 63). Hypnosis has also been used with varied results (Aybek et al., 2013; Gelauff et al., 2013; Stone, 2009; Stonnington et al., 2006). However, “these techniques are only applicable to those patients who accept that psychological or behavioural interventions are valid methods of treatment for their physical symptoms” (Edwards & Bhatia, 2012, p. 257). Consequently, if patients cannot reconcile their bodily-based symptoms with a psychological treatment they are unlikely to engage with these methods.

Pharmacology has been used to treat CD. Kurlansik and Maffei (2016) report “medications used to treat somatic symptom disorder include antidepressants, antiepileptic, antipsychotics, and natural products” (p. 51). Other authors have come to the same conclusion (Gelauff et al., 2013; Isaac & Paauw, 2014; Reuber et al., 2005; Stone, 2009; Stone, 2013; Stonnington et al., 2006). However, it is important to note when considering pharmacology that “the effectiveness of many of these treatments has limited support” (Kurlansik & Maffei, 2016, p. 51). Physiotherapy is another method to improve the symptoms patients experience from CD as “a patient with mobility problems needs physical as well as psychological treatments” (Stone,
Nielsen et al., (2013) conducted a systematic review of research that studied physiotherapy as a treatment for CD. Although the number of patients in the reviewed studies was low, these authors found that physiotherapy treatment saw “improvement in 60 to 70% of patients” (Nielsen et al., 2013, p. 9). They recommend further research “to determine which therapeutic components of physiotherapy are most effective” (Nielsen et al., 2013, p. 9). This information could be very helpful, but it requires physiotherapists receiving education about CD so that they do not view these patients as “faking” or “taking up their time.” If there was one recommendation that was prevalent throughout the literature it was that “there is no ‘one-size-fits-all’ aetiological theory, so every patient has to be assessed individually, but perpetuating factors provide the best target for treatment” (Stone, J., 2013, p. 82).

**Prognosis**

Patients with CD have a poor prognosis (Aybek et al., 2013; de Schipper et al., 2014; Nicholson et al., 2011; Rickards & Silver, 2014; Rosendal et al., 2013; Reuber et al., 2005; Sharpe et al., 2011; Stone. 2013). There are many factors that could explain why patients do not improve. The greatest of these is likely that the disorder is still not understood. However, the lack of training for primary care physicians, poor doctor/patient rapport, the stigmatization that mental illness holds, and the lack of consensus about treatment all likely contribute to poor outcomes. Gelauff et al., (2013) completed a systematic review of research that revealed no “relation between better outcome and treatment” (p.5), concluding that most patients “had the same or worse symptoms at follow-up” (p. 5). To address findings like these Stone, (2009) listed the factors he felt could impact patient outcomes. For poor prognosis, these are:

- Strong beliefs in lack of reversibility of symptoms/damage
- Anger at the diagnosis of a “non-organic” disorder
- Delayed diagnosis
- Multiple other physical symptoms/somatization disorder
- Concurrent organic disease
- Personality disorder
- Older age
- Sexual abuse
- Receipt of financial benefits
- Litigation

For good prognosis, these are:

- Willingness to accept reversibility/self-help
- Young
- Recent diagnosis
- Lack of other physical symptoms
- Change in marital status (divorce/marriage) after diagnosis
- Concurrent anxiety/depression (p. 186).

Stone, (2009) also found “patients with a host of poor prognostic factors can do well and vice versa” (p. 186). Further, “many patients do not improve despite treatment, so it is important to know when to stop trying” (Stone, 2013, p. 83). Ultimately, CD is a disorder that requires further research and a clear and concise way to disseminate findings across many disciplines. A change in how the disorder is conceptualized, how it is studied and what it means could lead to definitive methods for diagnosis and treatment.
Summary

Conversion disorder, a 4000-year-old illness, affects many, but is still not well understood. The quandary that CD represents can make the journey towards diagnosis difficult. Research has shown that patient prognosis is poor and that treatments are still questionable. The only treatment, overall, to have shown success is a strong doctor/patient rapport. To improve patient care, the medical field must come to agreement on the term used to describe the condition. “Conversion” should no longer be used as there is no evidence that stress, emotions or past trauma is being “converted” into physical symptoms. Edwards & Bhatia (2012) affirm “the old dichotomy between mental and brain disorders has been increasingly been swept away by the progress of cognitive neuroscience” (p.256). In its stead, what is needed is a holistic approach that can integrate all aspects of the person; physical, social-emotional, psychological and spiritual. Hence, Chvála, Trapková & Skorunka, (2012) argue “any health condition could be understood as psychosomatic because the processes we attribute to either mind or body are actually intertwined, not separated like our disciplines” (p. 294).

To change how patients are cared for, GP’s need to receive more education about CD, for today, “GP’s receive little formal training in the assessment and management of MUS” (Morriss & Gask, 2009, p. 180). A change in understanding could improve patient care for “although complex, time taken in developing teaching around MUS has the potential to improve many consultations, resulting in better outcomes for patient and clinician as well as likely financial savings for the health care system” (Walters et al., 2016, p. 8). The call for this improvement must be heard as CD is one of the most common presentations that GP’s, neurologists and psychiatry will see. Without it, patients can linger in a no-man’s-land between specialties; numerous appointments, tests and follow up procedures that leave one feeling they are on “a
merry-go-round’ of hope and despair rather than providing any sense of a definitive progression” (Nettleton et al., 2005, p. 206).
CHAPTER 3 HERMENEUTIC-PHENOMENOLOGICAL INQUIRY

Introduction

A phenomena is any “thing” that presents itself. “Phenomenology, then, in this context, is considered to be the study of the structures of such phenomena as they appear to consciousness” (Giorgi, 2009, p.10). To make sense of our world, humans qualify and quantify phenomena. This naming and counting can give us a sense of knowledge and control, for it provides a manner to orient us in time and space. While quantifiable research is often heralded as more precise, qualitative inquires can pose different questions and thus unearth different answers. “Qualitative researchers often find quantifications simplistic and limited as this looks at a small part of a reality that cannot be isolated without losing the essence of the phenomenon” (Dahlberg & McCaig, 2010, p. 24). Conversion disorder has been studied for 4000 years. During that time, it has been largely researched using the empirical model, with its value on reduction, data sets, problem lists, observables and outcomes. However, throughout this extensive exploration, the essence of CD has remained a mystery. Therefore, another method could bring different information or a different explanation.

Empiricism, or the scientific method, has been the main method to investigate phenomena throughout the last centuries (Cozby & Rawn, 2012; Creswell, 2013; Dahlberg & McCaig, 2010; Giorgi, 2009). Quantitative research has often been synonymous with empiricism (Cozby & Rawn, 2012). Consequently, its conclusions have been held with very high regard. However, this method does not lend itself well to research that that cannot be easily quantified such as hallucinations, memory, dreams or the unconscious (Giorgi, 2009). Thus, other means must be employed if we are to investigate these matters. Phenomenological practice is not about the reduction of an object, such as the body, to its infinitesimal parts, but its goal is to discover what that body experiences. Toombs (2001) explains how this relates to medical
practice, “the phenomenologist focuses on the phenomenon of illness as it is immediately encountered or experienced (illness-as-lived)” (p. 3). Thus, it provides the means to comprehend something that does not fall under one single category, like the mind/body connection.

It must be remembered that this form of study is as devoted to understanding as any other method. “Phenomenology is not “anti-quantitative”; its position is neutral with respect to research strategies. If one asks a quantitative question, then one should use a quantitative method; if one asks a qualitative question, then one should use a qualitative method” (Giorgi, 2009, p. 5). Thus, the question, “what is it like to live through conversion disorder” requires a qualitative method to get at the answer.

**What is Phenomenology?**

Phenomenology is often referred to as a philosophy (Creswell, 2014; Daniels, 2005; Giorgi, 2009; Merriam, 2009; Toombs, 2001; Romanyszyn, 2013). It falls within the philosophical tradition because it explores “issues of intentionality, consciousness, qualia, and first-person perspective” (Smith, 2016). Daniels (2005) argues that perspectives attempting to qualify phenomena existed within philosophy before they were made into a research method (para.1). Thus, to understand what we are doing as phenomenologists, Stewart & Mickunas (1990) suggest that we start with

the meaning of the term phenomenology itself. It is derived from the two Greek words: phainomenon (an "appearance") and logos ("reason" or "word," hence a "reasoned inquiry"). Phenomenology is indeed a reasoned inquiry which discovers the inherent essences of appearances. But what is an appearance? The answer to this question leads to one of the major themes of phenomenology: an appearance is anything of which one is conscious. Anything at all which appears to consciousness is a philosophical
investigation. Moreover, an appearance is a manifestation of the essence of that of which is the appearance (p. 3).

Giorgi (2009) explains

phenomenology as a philosophy seeks to understand anything at all that can be experienced through the consciousness one has of whatever is “given”—whether it be an object, a person, or a complex state of affairs—from the perspective of the conscious person undergoing the experience. Thus, it is not interested in an objective analysis of the “given,” that is, an analysis that would exclude the experiencer, but rather in a precise analysis of how the “given” is experienced by the experiencer. The reason for this is that nothing can be known or spoken about that does not come through consciousness (p. 4).

Later, Giorgi (2009) writes, “phenomenology is interested in describing both—what is given to consciousness and how it is given” (p. 68). Consequently, the width and breadth of what can be questioned through phenomenology is broad and so, as a philosophy, it has impacted all forms of qualitative research (Merriam, 2009). However, it is also a “type of qualitative research with its own focus and methodological strategies” (Merriam, 2009, p. 27). The goal of the phenomenological inquiry is not an arrival a specific designated “effect” but to understand “what it means to be human” (van Manen, 1984, p. 38).

Phenomenology as a method, requires the researcher to examine their way of “seeing” and/or “making meaning” of the world. In other words, what form does their thinking take? Many philosophers and scientists have described the way in which phenomenology challenges typical ways of perceiving, or “thinking” (Giorgi, 2009; Romanyszyn, 2013; Smith, 2016; Stewart & Mickunas, 1990; van Manen, 1984; van Manen, 2001). Phenomenology provides “a set of methodological principles based on assumptions that provide rules for engaging in
phenomenological analysis” (Waksler, 2001, p. 67). Nevertheless, Romanyshyn (2013) citing Merleau-Ponty’s (1962) work, *The Phenomenology of Perception*, writes, “phenomenology is first a style of thinking and being, before it is a system of philosophy or we might add, a methodology” (p.88). It is beyond the scope of this chapter to describe fully what this “style of thinking” is. However, at its most basic, “it is an attitude that situates one between the two extremes of subjectivism and objectivism” (Romanyshyn, 2013, p. 88). This “attitude” encourages one to set aside “taken-for-granted presuppositions about the nature of objects or “reality” in an effort to begin with what is given in immediate experience” (Toombs, 2001, p. 1). Such a method is needed if one is to examine openly and freely a phenomenon like CD, because much is accepted about what it “is” and what it “is not.” Suspending what is “known” or “understood” can “make available alternative formulations of the defined experience” (Waksler, 2001, p. 79). An “alternative formulation” could help unlock the “what” of CD so that the diagnosis, care and treatment of patients would better meet their needs.

Phenomenology, as with many fields of study, has gone through different stages of development. Larkin and Thompson (2012) suggest “it is often understood to have two important historical phases: the transcendental, and the hermeneutic or existential (p.102). These distinctions are important as they articulate the “view” of the research and subsequently the results. Those who follow a descriptive model follow the work of Husserl.

For Husserl, phenomenology was about identifying and suspending our assumptions (‘bracketing’ off culture, context, history, etc.) in order to get at the universal essence of a given phenomenon, as it presents itself to consciousness. His phenomenology aimed to transcend our everyday assumptions (Larkin & Thompson, 2012, p. 102).
However, later writers such as Heidegger and Merleau-Ponty, argued that “we can never make Husserl’s ‘reduction’ to the abstract, because our observations are always made from somewhere” (Larkin & Thompson, 2012, p. 102). Thus, rather than trying to “transcend” an individual’s lived experience, it is instead, that lived experience which is explored.

Each person is situated in the world, and there is no possible way to completely “bracket” their daily life from their “embodied” experience (Eatough & Smith, 2017; Larkin, Watts & Clifton, 2006; Larkin & Thompson, 2012). Heidegger (1889-1976) used the term *Dasein.*

“*Dasein* means ‘there being’ (or ‘being there’), by which he implies that our very nature is to be there - always somewhere, always located and always amidst and involved with some kind of meaningful context” (Larkin et al., 2006, p. 106). *Dasein* has been interpreted as *being-in-the-world,* and this is often the “term” used when an individual’s lived experience is described (Eatough & Smith, 2017). Understanding the use of *Dasein* as the “lens” to interpret data is critical. Eatough & Smith (2017) argue “the great achievement of *Dasein* is that it replaces the individual predicated on Cartesian dualism (person/world, subject/object, mind/body and so on) with people Being-in-the-world with things and others” (p. 194). This “view,” then, provides a means to investigate CD, for the illness falls outside the Cartesian split of mind/body, and consequently needs another method to consider it. “A strong emphasis on the worldly and embodied nature of our existence suggests that phenomenological inquiry is a situated enterprise. This position is often called *hermeneutic phenomenology*” (Larkin & Thompson, 2012, p. 102).

**Study Design**

My research methodology will be a hermeneutic-phenomenological inquiry. The basis for this inquiry is written journal entries compiled during the first symptoms of my illness, my search for a diagnosis, my diagnosis of conversion disorder and my experiences after diagnosis.
Included in the journals are images and writing that provided access to the meaning of this experience. Romanyshyn (2013) states “hermeneutics refers to the act of understanding and interpreting symbolic texts of whatever source or kind” (p. 219). He then makes a statement that mirrors my motivation to write and study my lived experience of CD: “where there is ambiguity, there is need for interpretation, and interpretation is needed because there is ambiguity” (Romanyshyn, 2013, p. 219). Palmer (1969) relates how the wing-footed messenger-god Hermes is connected to this form of study, for Hermes is “associated with the function of transmuting what is beyond understanding into a form that human intelligence can grasp” (as cited in Romanyshyn, 2013, p. 219). For indeed, the experience of CD needs to be “transmuted” if we are to care for those who are suffering.

Further to this, Grondin (1994) asserted that the goal of hermeneutics “is to make meaning intelligible” (as cited in Eatough & Smith, 2017, p. 195). Although there are many explanations and philosophical stances as to how this can be accomplished, the focus in this thesis is on “how interpretation is a foundational mode of Being and that to live a life is to interpret” (Eatough & Smith, 2017, p. 195). Thus, the method used to elucidate the findings reported in Chapter 4 is Interpretive Phenomenological Analysis or IPA. IPA was chosen because it “is concerned with the detailed examination of personal lived experience” (Eatough & Smith, 2017, p. 193). Its goal is to “provide qualitative researchers with ways of thinking about and researching psychological topics which are underpinned by phenomenology and hermeneutics” (Eatough & Smith, 2017, p. 193). I am drawn to this approach as it is the best fit for my intentions; to explore the mind/body interconnectivity as opposed to the traditional Cartesian duality. Thus, this hermeneutic-phenomenological method, with its focus on Dasein or
Being-in-the-world, matches my inquiry. It is perfectly suited to examining the mind/body problem.

Where do we find consciousness and intentionality in the quantum-electromagnetic-gravitational field that, by hypothesis, orders everything in the natural world in which we humans and our minds exist? That is the mind-body problem today. In short, phenomenology by any other name lies at the heart of the contemporary mind-body problem (Smith, 2016, para. 68).

CD is essentially a mind/body problem. This thesis is a case study of this phenomenon. The use of IPA as a method, to explore this case study, could encourage the use of IPA as a valid method for future research in CD with more subjects.

There have been many previous inquiries into CD, yet to date, none of these has been able to identify the disorder’s causal mechanism or mechanisms. A hermeneutic-phenomenological inquiry approaches the “problem” from another direction, asking a different question. “The phenomenological interest is with the lived body (Leib) not the body of physiological mechanisms and chemical interactions” (Eatough & Smith, 2017, p. 195). The interest of the inquiry is the lived experience of CD. After so many years of study, it makes sense to begin with the “immediate experience of illness vs. the conceptualization of illness as a disease state, and the body-as-experienced vs. the body as the objective of scientific inquiry” (Toombs, 2001, p. 2). The hermeneutic-phenomenological method invites a review of that which is difficult to categorize or define. For phenomenology has been found “well suited to studying affective, emotional, and often intense human experiences” (Merriam, 2009, p. 26). This is especially important in an investigation of CD because as a condition, it can render an individual impotent: a body that cannot or will not cooperate and the mind, an incomprehensible mystery.
Language, at this point, can become a hindrance, rather than a help. How does a person share an experience, when every word fails to communicate the unknown, the inexplicable? How can it be transmuted? Phenomenology provides the means to enter such a journey. And IPA specifically provides the means to capture the felt sense of being-in-the-world as its goal is “to identify, describe and understand two related aspects of a respondent’s account: the key ‘objects of concern’ in the participant’s world, and the ‘experiential claims’ made by the participant” (Larkin et al., 2006, p. 111). Thus, two very critical aspects of CD can be revealed. What is it like to be diagnosed with the condition? And secondly, how does the individual experience this?

This standpoint encourages, rather than sets aside the subject’s viewpoint (Larkin et al., 2006). Although, this can suggest a relativist perspective, this caution is considered. Larkin et al., (2006) acknowledge that what is being disclosed, is only one person’s view, rather than a universal truth. Yet, the being-in-the-world account made by one person can provide insight. Larkin et al., (2006) citing Merleau-Ponty (1962) and Giorgi (1995) argue “it implies that our personal experiences have ‘a structure that spreads [or extends] across space and time that can be communicated to others through appropriate expression’” (p. 109). As CD has yet to be truly “understood,” gathering these first-person, lived experiences, could help uncover what is happening. Additionally, as CD is a 4,000-year-old illness, it would seem prudent that all avenues to collect data should be explored, rather than negated.

Diseases, disorders and illness in modern medicine, are viewed from a materialistic and mechanical perspective (Carel, 2012; Toombs, 1988; Toombs, 1990). As Leder (1984) points out, seeing the body as a machine, means that it is “susceptible to mechanical interventions; it can be divided into organ systems and parts which can be repaired, removed or technologically supplemented” (as cited in Toombs, 1988, p. 201). This way of situating the body and illness has
led to many 20th century medical innovations, yet something very important was lost when the individual was reduced to the sum of their parts. The “Cartesian” model eradicated the individual patient’s experience. The “essentially mechanistic model includes little, if anything of the patient’s experience of illness. Rather than being the central focus, the patient’s subjective experiencing is relegated to the periphery” (Toombs, 1990, p. 227). Thus, disease “represents the physician’s conceptualization of the patient’s illness as a pathoanatomical and pathophysiological fact” (Toombs, 1990, 236). The individual is reduced to disease x. However, for the ailing, the experience of sickness is much more than a chain of causal factors.

The patient experiences her illness from within, as transforming experience impacting all dimensions of life. She experiences her illness as a disruption of her previous lived experience. This includes as bodily alienation, an altered experience of space and time, frustration of bodily intentionality, social changes and challenges to self-identity and integrity (Carel, 2011, p. 11)

And thus, patient and physician may be speaking two very different languages, creating two, in some ways diametrically opposed, narratives. One focused on etiology or cause and the other on interpretation or meaning.

Phenomenology provides the means for “body as object” to communicate with and expound on “body as subject.” “Phenomenology can be used to examine the nature of the difference between patient and physician understandings, make explicit the assumptions that result in the distortion of meaning and provide a detailed account of illness as lived (Toombs, 1987 as cited in Carel, 2011, p. 11). As a descriptive method, it embraces all forms of expression including the imaginal and/or metaphorical. Western language contrasts the *imaginary* with the *real*, thus, merging together the word “imagination” with the “unreal,” or “fantasy.” However,
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Corbin (1972) states, “the word *imago* can give us the term *imaginal* in addition to the regular derivative *imaginary*. We would thus have the *imaginal* world as an intermediary between the sensible world and the intelligible world” (p. 11). This gives us a third, or middle “way” to “understand.” Corbin (1972) explains “each of these three worlds has its organ of perception: the senses, imagination, and the intellect, corresponding with the triad: body, soul and mind” (p. 5). Corbin (1972) argues

> it is the cognitive function of the Imagination that permits the establishment of a rigorous analogical knowledge, escaping the dilemma of current rationalism, which leaves only a choice between the two terms of banal dualism: either "matter" or "spirit," a dilemma that the "socialization" of consciousness resolves by substituting a choice that is no less fatal: either "history" or "myth." (p. 7).

This thesis proposes that if such a stance could be taken, then the inner workings of CD maybe illuminated.

Romanyshyn (2013) further builds on this argument and explains that “the term imaginal was coined by Henri Corbin to differentiate a region of reality that is intermediate between sense and intellect and that mediates them” and then Romanyshyn (2013) goes onto say “in Jung’s work and in the work of James Hillman, this intermediate world is the world of soul, which has its own ontological status as a domain of reality between the domains of matter and mind” (p. 81). As CD is a condition that encompasses body and mind, or falls between these, it would seem an imaginal method would offer the means to discover what is “there”. The metaphorical, provides the means to describe by also not describing. This method points at one thing, while all along saying it is actually looking at something else. Within this “method” nothing is concrete, solid or exact. Such a modality is required if one is to discover, for example, what darkness “is”.
For at times, do we not describe darkness by qualifying what is light? Romanyshyn (2013) quoting Merleau-Ponty (1962) writes

for a phenomenologist, the world that we perceive and as we perceive it is not already an object complete in itself waiting for its laws to be discovered, explained by a conscious subject who is apart from it and part of it, a subject who floats, as it were, above or beyond the world, like some disembodied spectator mind. On the contrary, phenomenology begins with our entanglement with the perceptual world, the world that makes sense as we sense it. From this starting point, the task of thinking and knowing “consists in re-learning to look at the world.” It is a work that invites one to “take up this unfinished world in an effort to complete and conceive it” (p.88).

As an individual who was diagnosed with CD, and the author of this work, I am an experiment in “seeing” what can be described from in-between places. I feel “called” to “take up this unfinished world” to explore what is “unfinished” in our understanding of the disorder and thus, to be in “service to something other and larger and different than ourselves, to some collective cultural story whose work is to be continued” (Romanyshyn, 2013, p. 95).

While phenomenological research frequently involves collaboration with several co-researchers, this thesis will demonstrate what Daniels (2005) refers to as “Individual Phenomenology”:

Researchers use their own actual and imaginary experiences and others' factual and fictional written accounts and theories to develop a thematic description of a phenomenon. This involves Introspection: a method of inner observation which involves assuming an external viewpoint toward oneself, stating the facts about oneself as others might if they could observe what the introspector observes (para.26).
Although not “typical”, this method is not unusual, for it simply “emphasizes the point that qualitative research is seeking factors of interest that may be found in only a single case rather than trying to find widespread evidence that can be generalized” (Dahlberg & McCaig, 2010, p. 114). Laverty, (2003) citing Polkinghorne, (1989), affirms this position stating in both phenomenology and hermeneutic phenomenology, data can include the researcher’s personal reflections on the topic, information gathered from research participants, and depictions of the experience from outside the context of the research project itself, including the arts, such as poetry and painting” (p. 18).

Toombs (2001) in her essay, *Reflections on Bodily Change: The Lived Experience of Disability*, describes her “experience as a person living with multiple sclerosis, an incurable, progressively disabling disease of the central nervous system” (p. 247). She argues that, “phenomenology provides a powerful means to illuminate the experience of loss of mobility” (Toombs, 2001, p. 247). The essay describes her everyday activities and how her illness frames the world in which she lives. Toombs (2001) descriptions follows Merleau-Ponty’s (1962) view, “rather than being an object for me-as-subject, my body as I live it represents my particular point of view on the world” (p. 248). Toombs (2001) argues that her phenomenological writing can provide invaluable information about the everyday world of those who live with disabilities. Such information is of enormous practical significance when devising effective therapies in the clinical setting and in determining how best to address the personal, social and emotional challenges posed by chronic disabling diseases (p. 248).

The present work follows in this tradition. I, as a person who “had” conversion disorder, will describe my experience. For I too believe that my lived account of CD could offer new information. I do this with the awareness that, as van Manen (2001) states,
the task of phenomenology is not to describe the psychological inner states, subjective experiences, motivations, feelings, understandings, plans, intentions, or purposes of particular individuals. Phenomenology cannot do that. But, nevertheless, experiential descriptions may serve as data for phenomenological reflection and as sources of meaning for understanding the structure of meanings that shape the inner lives of others (p. 469).

IPA as a method offers the means to capture “reflections” as “it can provide crucial insights into personal experiences and psychosocial processes. They may not tell us what causes $x$, or whether $y$ works – but they can help us to understand what it is *like* to live with $x$, and *how* $y$ works” (Larkin & Thompson, 2012, p. 114).

**Data Collection**

The analysis will be of a thematic nature. "Thematic analysis refers to the process of recovering structures of meanings that are embodied and dramatized in human experience represented in a text" (van Manen, 2014, p. 319). How this is done, can appear somewhat simple, although what is occurring is deeply complex. To answer the question “what is the lived experience of conversion disorder?” the researcher, reads and reflects on the words that “describe” that lived experience and then makes “sense” of these descriptions by categorizing them, and by naming “themes” that become apparent. Thus, to provide a precise account of my lived experience of CD I will employ IPA’s “units of meaning,” which Larkin and Thompson (2012) describe as clustering specific parts of the text “around ‘things that matter’ (objects of concern) and the meanings that are attached to them (experiential claims)” (p. 108). To create these, my journal entries will be read and re-read, reflected on, written about, taken apart and re-grouped, studied intensely and treated with detachment; as if I was not the subject of the
descriptors. As explained earlier by Daniels (2005), I will state “the facts about oneself as others might if they could observe what the introspector observes.” (para.26). Efforts will be made to provide an exhaustive account of the experience, so that the lived nature of the "disorder" becomes evident. It is helpful to note that the means to arrive at themes is rarely linear, but rather a more circular activity (Larkin et al., 2006; Laverty, 2003; Romanyshyn, 2013). “The knower approaches a text with some foreknowledge of it, which in turn is questioned and challenged and amplified by the text, thereby transforming the knower who returns to the text with a different understanding of it” (Romanyshyn, 2013, p. 221). And while there are “steps” to create “units of meaning” it is not strictly a step by step procedure that inevitability reveals itself, but rather a belief that what wants to be known, is as actively engaged in the process as I am as the researcher (Pietkiewicz & Smith, 2014; Romanyshyn, 2013; van Manen, 1984).

The essence of the phenomenon is what is sought. Bradshaw, Armour & Roseborough, (2007) explain that “essence stands for those characteristics without which an object would not be what it is” and then go on to say, “to determine the essence of the phenomenon (or object), the researcher employs the process of free imagination” (p. 31-32). Giorgi (2009) describes “free imagination” as “the transcendental phenomenological attitude,” one that reflects a break in our “natural attitude,” for what is required is not “the attitude that one displays in the everyday world, where most things are simply taken for granted” (p.88). Rather, what is needed is an attitude that is willing “to regard everything from the perspective of consciousness, that is, to look at all objects from the perspective of how they are experienced regardless of whether or not they actually are the way they are being experienced” (Giorgi, 2009, p. 87-88). Although difficult, this change of perspective can be achieved and utilized.
Using this “attitude” the goal of the researcher is to “determine the essence of the phenomenon” and “to describe it as accurately as possible” (Giorgi, 2009, p. 89). In IPA, “the primary interest is the person’s experience of the phenomenon and the sense they make of their experience rather than the structure of the phenomenon itself” (Eatough & Smith, 2017, p. 194). Thus, my goal is to “unpack” my descriptions of my lived experience of CD. Yet, I am aware that whatever categories I create, will be imprecise. As Merleau-Ponty (1962) attests, phenomenology, alone of all philosophies, talks about a transcendental field. This word indicates that reflection never holds, arrayed and objectified before its gaze, the whole world and the plurality of monads, and that its view is never other than partial and of limited power (p.71).

And again, Eatough & Smith (2017) state, “rather than transcend the particular, IPA aims to grasp the texture and qualities of an experience as it is lived by an experiencing subject” (p. 194). Hence, in contrast to empirical goals of affirming or falsifying a hypothesis, the phenomenological researcher “aims to open up possibilities for creating formative relations between being and acting, between who we are and how we act, between thoughtfulness and tact” (van Manen, 2007, p.13).

Although limited, what can be discovered through this attitude, this place between “subjectivism and objectivism” has value. Waksler (2001) reminds us that, “for Husserl the individual is the locus of that which can be taken as certain” (p. 68). But to ensure this statement is grasped accurately, she qualifies this by saying, “I take Husserl’s claim as a warrant to use one’s own experience as the grounding of what one takes to be knowledge but not as an invitation to solipsism” (p. 69). When I use the word experience, my usage follows the description articulated by Eatough and Smith (2017): “it means attending to aspects of
experience which matter to people and give rise to particular actions within a world that is ‘always-already to hand’ and inherently meaningful” (p. 196).

It is likely that the relating of my world will include some “unexamined tradition, guesses, suppositions, beliefs, and hopes” (Waksler, 2001, p. 69). IPA recognizes this possibility and addresses it by encouraging the researcher to start by being “wrong, presumptive, wayward, biased, creative, self-absorbed and unsystematic” (Larkin & Thompson, 2012, p. 106). Eatough and Smith (2017) citing Dahlberg (2006) explain “our prejudices should not be thought of as inherently ‘bad’, rather we can have ‘good’ prejudices which can be ‘bridled’ and revised, giving rise to more useful and creative interpretations” (p. 195-196). By starting from this point, the researcher can “own” their preconceived ideas, before delving deeper, and establishing themes. However, it must be emphasized, that what the researcher is seeking is the subject’s, individual, lived experience, not to precisely identify, in this case, what CD is.

I want to state unequivocally, that I am aware that as both the research subject and the researcher, there is the potential for bias. Unconsciously or consciously I may be trying to “prove” rather than “find” the lived experience of CD. For if I am to work between subjectivity and objectivity, I can only “arrive” at one place momentarily, before I am immediately on my way back to the other. The recognition that this potential problem exists highlights my desire to act ethically. Larkin et al., (2006) report that this understanding is one that more scientists are declaring for it is apparent that what is objective and what is subjective cannot be teased apart in any simple fashion. If the objective reality we discover is partly dependent upon processes of intellectual construction and hence upon our various modes of subjective engagement
with the world, then any analysis of our intellectual constructions must also reveal something of the objective reality (p. 110).

The blending of the objective and the subjective are clearly a challenge within this case study. However, it must also be noted that this type of pitfall is not only found in this form of research; any scientist using any method could fall prey to confirmation bias.

Alongside the need to be explicit about how the data will be analyzed, the power of the observer must be mentioned. It has been found that the observer can, simply by observing, influence what is being looked at. Goswami (1993), a quantum physicist, explains that before light can be “seen” as a wave or a particle, it is a “wavicle” not yet one or the other (as cited in Romanyshyn, 2013, p. 31). For, “the entire path of the object stays in possibility until our observation manifests it retroactively. Yes, going back in time” (Goswami, 2012, p. 102). Thus, “no thing” exists until I say it does. “There is nothing, no manifest universe, only possibilities, until we collapse it: until a sentient being appears in possibility in one of the possible branches and tangled-hierarchically observes” (Goswami, 2012, p. 102). Acknowledging this “truth” does not mean I can overcome its dictates, rather it shows that I am aware of the “messy” work I am engaged in.

van Manen (2001) describes this phenomenon using slightly different terms. Once again, he emphasizes that it is the researcher’s “style of thinking” that must be scrutinized throughout the act of “doing” phenomenology.

The phenomenological reduction consists in the attempt not only to clear away (bracket), but simultaneously to confront the traditions, assumptions, languages, evocations, and cognitions in order to understand how the existential “facilities” of everyday lived experience are actually constituted through these assumptions and affects. Only by
exploring the epistemological and ethical consequences of our perceptions, sentiments, moral imperatives, and conceptions can we strive to “free” ourselves from their perspectival effects – and yet we cannot escape them. In other words, the phenomenological reduction tries to grasp the intelligibility that lets the world “be” or come meaningfully into existence in different experiential modalities (van Manen, 2001, p. 460-461).

The emphasis here for me is that I must strive towards freeing myself, but with the acknowledgement, that in the end as a human, I am caught up in the world, as I am in the world. I am a Being who is Being-in-the-world. Or as Merleau-Ponty, “puts it ‘Man is in the world, and only in the world does he know himself’” (as cited in Eatough & Smith, 2017, p. 195). How to describe, then, is the question. Once again, the need for another “language” such as metaphor or the imaginal becomes evident. Thus, the data, that is my journals, will be sifted and sorted, and reduced to the essence of my lived experience of CD. The goal will be to keep that which is seen, felt, heard, touched and sensed as this will provide a description of CD. The IPA researcher is actively trying to create units of meaning “around ‘things that matter’ (objects of concern) and the meanings that are attached to them (experiential claims)” (Larkin & Thompson, 2012, p. 108). It is important to note that the descriptors for the “objects of concern” will often involve metaphor. Describing an experience that can encompass the affective, physical, spiritual, mental, social and cultural can be challenging. Thus, imaginal or metaphoric language arises to meet this need.

Romanyshyn (2013) uses the example of the researcher investigating dreams, by recording eye movement. He reminds us that “no measuring apparatus with goggles that record dreaming brain will ever find the meaning of a dream” for “there is more to dreaming than what
meets his eyeballs” (p. 212). To get at what is being felt, seen, heard, or sensed, the body, which
does all these acts, is described. But what are these descriptions? What do they contain? How are
they languaged? In speaking of the soul, Romanyshyn (2013) writes

the physiological measures are not the way in which the soul is reduced to and explained
by the body. Body is not the explanation of soul; it is its expression. To say the soul is
body is, then, to speak metaphorically. It is to say that it is true and not true (p. 213).

Thus, the data for this enquiry, will be made into “units of meaning” but these will be held with
openness, curiosity and ongoing reflection, until the raw data is transformed into an “essential
structure of the experience” (Giorgi, 2012, p. 6).

Participant

I am a fifty-two-year-old, white, cisgender, lower to middle class, educated woman of
European descent. I was in relatively good health prior to becoming ill in the fall of 2012.
Although I had been a sickly child (I had pneumonia, whooping cough and “poor” lungs as a
toddler), as an adult I rarely saw my GP, beyond a yearly physical. In the late ‘80’s I had two
normal pregnancies. In the early 90’s I had my only surgery, to remove an ovarian cyst. Several
food allergies were diagnosed in 2000, and I have been very careful about my diet since that
time. I began long distance running as a self-care practice in 2001 and over the years I have
completed one full marathon and several ten km and half marathons. To add to my health
routine, I took up long distance cycling in 2005. In 2010, I rode from Chilliwack to Calgary in
ten days. I would have described myself as ‘generally happy’. I liked my job, had many friends
and was active in my community. Friends and family members would regularly refer to me as
“healthy” or “fit,” both mentally and physically. Thus, my illness and collapse in 2012 was a
complete surprise. Someone, “like me”, did not get ill “like this.”
Limitations and Scope

The data used in this research reflects my lived experience. As an individual case study, it cannot be comprehensive, as it reflects only one person’s perspective. van Manen (1984) emphasizes this point, concluding that “a phenomenological description is always one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer, description” (p. 40). This work attempts to clarify, while acknowledging that understanding of the phenomena of CD continues to be difficult and problematic. It presumes that previous research has been unable to discover what conversion disorder is, although it has identified symptoms, diagnostic methods and possible treatments.

The goal of this inquiry is to recognize what has been learned, to question some of the past conclusions and to move the field of psychology one step forward on the path of understanding CD. It is understood that the generalizability of this work is limited. And in this way, it reflects other qualitative research. Dahlberg and McCaig (2010) state that “the aim of qualitative research is rarely to generalize. Instead it provides rich and detailed descriptions of the studied phenomenon and will be able to ‘tell the story’ from participants’ point of view” (p.25). IPA studies are often conducted with small or individual samples (Larkin & Thompson, 2012; Smith & Osborn, 2008). “This is not to say that IPA is opposed to more general claims for larger populations; it is just that it is committed to the painstaking analysis of cases rather than jumping to generalizations” (Smith & Osborn, 2008, p. 55-56). It is also noted, that while the conclusions of the present study maybe not be generalizable to the public, what is discovered could be used in education settings to challenge and modulate the understanding that medical students and professionals have of CD.
Initially when I began my thesis I thought that autoethnography would be the best method to share my lived experience of conversion disorder. McIlveen, (2008) reports

the defining feature of autoethnography is that it entails the scientist or practitioner performing narrative analysis pertaining to himself or herself as intimately related to a particular phenomenon. Autoethnography entails writing about oneself as a researcher-practitioner, but it is not the same as autobiography in the literary sense. It is not simply the telling of a life—not that doing such would be simple. It is a specific form of critical enquiry that is embedded in theory and practice (i.e., practice as a researcher and/or career development practitioner) (p. 3).

Thus, I felt that this method would provide a means for me to relate my experience of CD. Autoethnography, as a form of qualitative research, seeks to provide the field of psychology with unique insights that could not be discovered using other means. As a woman, and a person who had CD, I felt that my narrative could add to studies that had looked at topics like mental illness stigma, shame, vulnerability and doctor/patient rapport. However, my story would inevitably interweave the stories of others and this led to concerns about relational ethics.

All four of my grandparents are dead, one of my parents has passed, another is not well, I am divorced and I have two adult children. Ethically, as a therapist, it is my duty to act from the edict, “first do no harm.” As I considered my story and how it related to my family, I could see there were many potential pitfalls. Not the least of these is the fact that the dead can neither condone nor defend what is said about them. This is an inescapable issue when relational ethics “obligates auto-ethnographers to show their work to others implicated in or by their texts, allowing these others to respond, and/or acknowledging how these others feel about what is being written about them and allowing them to talk back to how they have been represented in
the text” (Ellis, Adams & Bochner, 2010, n. p.). Thus, a phenomenological study represented the best of both worlds. I could describe what my experience with CD was, while not implicating any others in my research.

Summary

For many years, empiricism, or quantitative research has been used to study CD. Although these enquires have produced symptom lists, diagnostic criteria and potential treatments, this modality has not been able to answer the question, what is conversion disorder? The present study posits that another method, such as phenomenology, could build on previous research by bringing new information. This method has been found to be a good match for investigating illness, health and the medical field, for “phenomenology provides concrete insights into what it is like, what it means, to experience illness and disability” (Toombs, 2001, p.12). As well, phenomenological queries “evoke a sense of wonder and questioning attentiveness about taken-for granted aspects of life” (van Manen, 2001, p. 470-471). There are several ways to conduct a phenomenological inquiry. For this thesis IPA is ideal as it synthesizes ideas from phenomenology and hermeneutics resulting in a method which is descriptive because it is concerned with how things appear and letting things speak for themselves, and interpretative because it recognizes there is no such thing as an uninterpreted phenomenon (Pietkiewicz & Smith, 2014, p. 8)

Thus, this phenomenological inquiry challenges me to suspend what I “know,” let go of my assumptions and meet the words I wrote about my lived experience with CD with an attitude of “free imagination” curiosity, openness and attentiveness. There in that space, anything is possible.
CHAPTER 4 FINDINGS

Introduction

The results of a phenomenological inquiry provide the “lived experience” of the studied phenomena. This chapter will relate the analytic themes that emerged from the writing I compiled during my diagnosis of conversion disorder. As stated earlier, due to this singular focus, the findings do not claim to be exhaustive or complete. CD is a complex phenomenon and there are multiple correlated factors involved in the diagnosis of the disorder. As well, “illness” itself is an ever-changing phenomenon. It vacillates, moment to moment and day to day. Thus, “there is no consensus on what the experience of illness is like, if it is like anything at all” (Carel, 2012, p. 3). Carel (2012) argues “the same physical disease can be experienced and understood differently by two people in different situations. Similarly, the same physical disease can be understood differently by the same person in two different times” (p. 5). Therefore, the findings described here do not propose a one-size-fits-all view of CD. Rather, they provide a lens for further deliberation and research.

My research methodology was a hermeneutic-phenomenological inquiry. I have chosen to use interpretive phenomenological analysis (IPA) to report my findings as “IPA has an interpretative (aka hermeneutic) phenomenological epistemology” (Larkin & Thompson, 2012, p. 102). I have used IPA as the lens to discover the “object of concern” and the “meaning of those experiences”. IPA is not prescriptive. A set of flexible guidelines is provided, and these can be adapted by the researcher to facilitate their research goal (Smith & Osborn, 2008). This inductive and idiographic approach aims to capture the richness and complexity of a diagnosis of CD. In particular, it draws attention to the lived experience of illness as a “disintegration of the self and world” (Toombs, 1988, 207).
When I wrote my journals, I had no conscious awareness of the use of the imaginal or the field of phenomenology. I wrote and sought out painting, sculptures, carvings and other art forms because I was trying to find a way to make sense of what was occurring. During the time of my illness I also engaged in other creative activities such as Soul Collage™, weaving, sculpting and drawing. However, as my journals are the source of data for this thesis, it was important to incorporate a couple of the images that are contained in the pages and note the numerous metaphors and “images” that are found in excerpts. It is as if I “natural” felt impelled to transmute my bodily experiences to my mind through images.

Themes

Five themes were deciphered from the data, (the content of my journals). However, these were not distinct, or separate units, rather, each wove into and formed a piece of the next. Like a very intricate, dense, woven tapestry, the themes were like threads, warp and weft, touching and overlapping. To describe one, as a singular piece, without noting how it was linked to and explained by another, would be limiting and false. Thus, in terms of the five stated themes, to articulate them as separate units would forfeit the fullness of what they express. To create a structure, I have numbered them from one to five, but any one of them could be listed as one or two or five. The themes are neither linear nor hierarchical. Rather, they are more circular and/or spiral in nature. This corresponds to Larkin and Thompson’s (2012) description of how the final analysis can appear. They state, “the final structure might be hierarchical or it may be in the form of table, or circular account” (Larkin & Thompson, 2012, p. 111)

The five analytic themes presented are: 1) a break in the sense of coherence and self-concept: the subjective experience of a sudden, significant, alteration of physical capacity and wellness. This includes perceptual confusion and emotions such as fear, that arise from such a
change; 2) the negotiation of emotions of guilt, shame and vulnerability resulting from illness; 3) a change in self-concept as a direct consequence of illness that is not biological in origin or attributed to volition; 4) the need for support to navigate the significant change in self-concept/break in sense of coherence and self-efficacy; and 5) acceptance as the means to create a continuation of self from the past into the future. The five analytic themes are written in words found in the journals as “the most effective theme labels are usually those that clearly evoke the content of the material within them, and the meanings that are attached to that content by the participants” (Larkin & Thompson, 2012, p. 111).

The analysis of the data was completed over many weeks. As both the subject and the researcher in this case study, the potential for bias was often considered during the process and especially when the themes were articulated and then interpreted. To ensure that the end results are as reliable as possible the evaluative criteria that distinguish good IPAs was used as a benchmark. These are “a sustained focus on a particular aspect of experience, rich experiential data, assessment of the thematic structure through the use of a measure of prevalence, careful elaboration of themes and of course, a detailed interpretive engagement with the material” (Eatough & Smith, 2017, p. 206). The subsequent analysis meets these criteria and provides unique insight into conversion disorder.

Two notes for the reader:

1. To differentiate between “my voice” as it exists in the journal entries (as case subject) and “my voice” used to interpret those entries (as researcher) I have primarily limited the use of pronouns “I,” “me,” “my” to journal excerpts and only used these terms outside of that context when to do so would break the flow or meaning of a passage.
2. All sentences in quotations are direct quotes from my journals. Large blocked quotes do not have quotations, but are indented.

**Theme 1: The taken-for-granted body is no longer: Profound sense of loss and confusion**

This theme interlaced several significant aspects of illness: 1) the loss of mobility and thus, independence; and 2) Fear and confusion; an inability to make sense of “who am I?” with a body so changed. CD can be expressed by numerous and varied symptoms. In this case the symptoms were as follows:

- **Internal exhaustion:** With my hand over my breastbone I would state, “In here, it is like the “light” has gone out. Like I had energy, and now there is nothing.”
- **Anxiety:** a constant sense of generalized fear. “I am afraid. I am afraid. I am afraid.”
- **A clenched, aching jaw and mouth area.**
- **Internal tremor:** a constant and unceasing feeling that I was “shaking” or “vibrating” inside.
- **External tremors:**
  1. While sitting, my legs and arms would tremble involuntarily as if I had muscle exhaustion. The leg calf and thigh muscles would bunch and ripple under the skin, as if there was a “small animal” under my skin trying to escape.
  2. If I attempted to walk, my whole body would shake and convulse, preventing me from taking more than one or two steps.
- **A constant, whole body, ache; “as if I have the flu, all the time.”**
- **Painful feet:** “constant, burning, aching, feet.” No ability to walk on any surface without wearing two or three pairs of heavy socks.
• Little to no ability to regulate my temperature. Constant and consistent complaint, “I am cold, I am cold, I just cannot get warm.”

• Hair loss and growth: Hair fell out and did not grow back from my head, arms, under arms and pubic area.

• Food intake challenges: Low appetite. When I did eat, it took me a long time to finish a meal, and digestion seemed to use up a great deal of energy. I would need to sleep after eating.

• Non-restorative sleep: I had trouble falling asleep and staying asleep. I had frequent, wakeful events throughout the night and afterwards difficulty getting back to sleep due to body aches, internal and external tremors, as well as clenched jaw and teeth grinding. When I slept for a few hours, I would wake still feeling exhausted.

• Limited ability to focus attention. My mind seemed unable to attend to any one thing for more than a few moments.

The bodily-based symptoms began in September of 2012. From November 2012 to February 2013 I was bed-and-wheelchair bound and was dependent on others for all my personal care, including being fed. In the spring of 2013 I began to have periods of mobility with the use of a walker or cane and I regained some ability to care and feed myself. While these improvements were significant, after any interactions with others or excursions from the house, I would find myself symptomatic once again; I would tremble and struggle to walk or be mobile. I would recover, but it would take several days. In 2014 until years end, my internal energy slowly increased, external tremors abated, “flu like” symptoms lessened, sleep became more restorative, but other symptoms persisted. Throughout 2015, all symptoms slowly improved. However,
painful feet, temperature regulation issues and the internal tremor persisted. In 2016, these same symptoms continued, but their severity lessened.

The theme of the “taken-for-granted” body was evident as an “essential structure of the experience” (Giorgi, 2012, p. 6). References to what it meant to be so changed were described in all years of the journals. An early excerpt reads:

I am not yet accustomed to the body I find myself inhabiting. Where once I daily took for granted movement, now how to move and how much, all of it is a mystery. What little thought I gave to the miracle of the human body. Each waking moment, I now have a different experience.

I am askance at the easy manner in which I took my breath, my movement, my abilities for granted, and ashamedly, at times more than that. I complained. I looked down and squeezed or pulled or inspected closely and found what I discovered lacking. I found it lacking beauty, or strength, or flexibility or youthfulness. I have compared, contrasted, imagined, and attempted to mirror my body with others. What I would not do today to get back a little of what I felt before, the easy strength I had before this illness. Oh, how limited is the human capacity to truly appreciate what we have!!!

Another says:

For a few days, a week almost, when I woke I believed I was getting stronger. The belief was built on my changing abilities. Just a short while ago simply sitting up was a taxing activity. Recently I found I was able to pull myself to a sitting position and then from there to standing! These modest movements, when lost, place me into the care of others every minute, of every day. If I can not support myself then others need to lift me, place me, help toilet me, wash me, and essentially care for me. No one truly appreciates what
this loss of independence costs a person, unless they too have experienced it. I cry out. I exclaim, “I am so ashamed.” I cover my face. I weep.

The descriptions of loss of mobility and independence depict a rupture in self-concept. Self-concept has been defined as an individual’s “beliefs about himself or herself, including a person’s attributes and who and what the self is” (Baumeister, 1999, p. 247). These beliefs about one’s self can include an assumption of ongoing physical wellness and competency, and are holistic in nature. However, the “taken-for-granted” body can take on a more conscious role when illness occurs. The body, which was previously thought of as the individual, the body now becomes, an object, the “thing that is sick.” The body, as stated in the above passages, is interpreted as alien, a separate and an unknown and confounding entity.

Rather than descriptions of going places or interactions with others, there are frequent passages describing how the body has changed:

Diarrhea. Had chest muscle flutters. Very shaky in my core. Hard to concentrate on anything because of the trembling…can’t read, meditate… so just watched TV. Intense exhaustion, very obvious toe dragging while walking with walker; extensive recovery needed after any activity. I refuse to use the walker or the wheel chair. Very lazy. Cannot motivate myself to walk or exercise. Woke up at 2 am from trembling…had a hard time getting back to sleep. Got up at 7am…trembled on the couch, made my green drink…got cold…used the heating pad…just wanted to eat, watch TV. Trembled in my legs and core.

And again

My walking is laboured. My legs feel like a hundred pounds, I toddle along, swishing my feet in small steps. I don’t lift my feet. The left leg, which I step out with, seems weaker
than the right, but I think it’s because I lead with that leg. The right has the advantage of
being pulled forward with the momentum of the left. Thus, the left struggles in every
step; often this causes me to cross a room diagonally rather than straight, as I don’t seem
to have the strength to correct my direction. I end up close to the doorway and then use
my hands to drag myself through. I am not using the chair or the walker, and thus not
moving much, but when I do I am trying to do it under my own will. I would be unable to
get around the house if there were not as many surfaces for me to cling to. My heart
aches when I walk, from the very first step.

Suddenly the “normal” responses from the body are totally lacking or they are of a surprising
and confounding nature. These changes are experienced as a deep source of conflict and
confusion. The body, which seemingly had been treated as it always had, is now an “other.” The
“taken-for-granted” self is now gone. The known has become the unknown. This profound
change relates a break in the sense of coherence (SOC). “The SOC is a resource that enables
people to manage tension, to reflect about their external and internal resources, to identify and
mobilize them, to promote effective coping by finding solutions, and resolve tension in a health
promoting manner” (Eriksson & Lindström, 2006, p. 376). The bodily changes are so life
altering and disorienting that the ability to identify and mobilize resources and/or find solutions
has been irrevocably altered.

Descriptions of the changed body are woven together with the problem of achieving a
valid explanation for how or why these changes could have taken place. The journals are filled
with questions like

- “did I do something?”
- “did I not do something?”
“was my self-knowledge deluded?”

“Did I not know myself at all?”

These questions are infused with doubts in self-efficacy. It is as if there is no schema for the loss of the past, predictable behaviors or to address the new and unpredictable present. Habitual, unexamined faith in the continuity of the body is now replaced with mistrust and misgivings. There are frequent statements of confusion/bewilderment, denial and shame. Such as;

- “this is not who I am, I don’t get sick.”
- “I feel betrayed by my body.”
- “I don’t want this body anymore, this is not ‘my’ body, this cannot be happening, I don’t want this to be happening.”
- “I have no energy, I ache, I am sad. I don’t know what to do. Don’t know how to be.”

The subsequent disorientation from the profound changes in independence and mobility give rise to various coping strategies. Some of these are: denial of the extent of disability, re-evaluation of past beliefs, skills and/or knowledge, and resistance to external definitions of sickness or wellness. These strategies could be a self-protective measure; a means to keep the self as in-tact as possible, until a new self-concept and/or sense of coherence could be created.

Among the writing are numerous descriptions of identity: specifically, an ability to respond. A trusted, previous capacity to overcome whatever life dealt through effort and hard work.

“I am grieving the loss of my identity. The loss of my way in life. My trust in movement, my ability to make order from chaos, my ability to make something from nothing.”

The break in self-concept, sense of coherence and self-efficacy are illustrated by the inability to fit present circumstances within the previously held frame of representation. It did not make
*sense* that past physical, intellectual, spiritual and social-emotional skills could not stop the downward spiral or moderate symptoms. Over and over the same statement is written, “I feel lost.” There are attempts to *make sense* of the changed body by writing how it feels to be so altered. The words create an image of the *experience*.

I am unsure. My body wants to run away. My mind grasps at this and that. I feel like a glass, cracked, but still being used, until the smallest of taps…and the glass is now a pile of shards on the counter, completely disintegrated. And I am looking at the pile and asking, how did that happen? Bewildered.

The struggle to make meaning, to create a coherent narrative of the loss of mobility and independence, as well as the resulting fear and confusion, was a persistent theme. Passages such as the following illustrate this:

“I had a life. It was a good life. It had a beginning, a middle, and an end. It has ended.

Now I am having this life. In this life, I walk with a cane.”

The taken-for-granted trust that the body would simply “work” was irrevocably and devastatingly broken. The sense of the world as familiar and trustworthy, was upended, as well as the certainty about the ability to be *in* the world. One result of this profound disturbance was a question of the ability to continue, or if life should end. The journals attest:

“I want to die. I want to die. I want to die.”

**Theme 2: Guilt/Shame/Vulnerability**

Prior to becoming ill, the self-concept was stable and “taken-for-granted”. Part of the self-schema appears to be a strong confidence in self-sufficiency. Journal entries, prior to the illness in the Fall of 2012, report working on average sixteen hours a day, seven days a week, with a high sense of satisfaction and accomplishment. At times sicknesses such as flu or cold are
reported, but the illnesses do not last long or have ongoing consequences. Self-esteem seems to be high. Self-esteem has been described as “the evaluative dimension of the self-concept” (Baumeister, 1999, p. 257). It appraises what occurs and judges if it is good or bad. Any information can be incorporated into the self-concept. However, negative or difficult information is not easily assimilated. An entry states:

“I was in a car crash. But my body was the car, and “it” is what crashed.”

Once again, the body has become the other and attribution for the illness is given to the body. The body is held responsible. It should not have gotten sick. Sickness is evaluated as “bad” and must be addressed. Within the previously held schema, getting sick was not too disturbing, as there was plenty of evidence of being ill and getting better. Thus, there would be no need for the self-concept and/or the sense of coherence to change. However, the present illness does not follow previously held guidelines. The present diagnosis of CD means that the symptoms are not biological in origin. Thus, the body is what seems to be ill, but it is not. Thus, the old schema does not apply, yet there is nothing new that can explain or make sense of what is occurring. Here is a passage:

my mind is crammed full of judgements, blame and fault finding. As if I could find the exact moment where I veered off course and could still correct it now, here, in the future. A desperate attempt to yet stay the execution. The boom would not have fallen. I would still have the ability to walk, to run. These thoughts are insistent. Demanding. Still clinging to a universe that can be conquered, known and controlled.

The break in self-concept, sense of coherence and self-efficacy bring about questions of self-esteem. Were the previous self-evaluations correct or faulty? The result is waves of confusion
and the strong emotional connotation that there must be a guilty party: someone/something is to blame.

Inevitably I find myself engulfed in waves of guilt/shame. My thoughts circle through my history, picking out details. I hold memories up and evaluate their content. Searching for my level of consciousness or unconsciousness. My standards are exacting. I seek proof that I was able to overcome or sustain, without surrender, specific circumstances. My goal: to assert that my efforts could not have been for naught.

The struggle to accept the old schema or develop a new one is clearly evident. To accept the diagnosis means a rejection of former interpretations of events and meaning making; the foundation of the sense of coherence has been found defective, because previous methods to respond to stressful situation are no longer effective. The acceptance of fault or the attribution of personal responsibility for the sickness, gives rise to emotions of shame and guilt.

“I am so bewildered. So, caught off guard. I cannot figure out how “this” happened. How did I get ill?” I ask myself, “Who am I if I am not this driven woman?”

These declarations are followed by feelings of shame:

I repeat out loud, and internally, “I don’t know what to do, I don’t know what to do…I don’t know what I did.” I arrive at, “why me?” again, and again, and again.”

The humility and shame are affirmed:

“the strongest feeling is humiliation.” “Emotionally I feel betrayed. I gave you…meaning my hurt self, time, love attention…”

To accept personal responsibility means a re-evaluation of the previously held self-concept, sense of coherence and trust in self-efficacy. The rupture of self-concept could be seen as the disintegration of identity. Who I was, how I was, what I was, why I was, all these ways of
making meaning are questioned, found wanting, and are completely dismantled. The sense of coherence, or the ways in which chaos was managed in the past, no longer provides any comfort or meaningful problem-solving rationales. The result, not surprisingly, is an overwhelming sense of vulnerability. The feeling is described as 

“like a burn victim, trying out her new skin. Very tender.”

And again:

“much of my body hair has fallen out or stopped growing. I am a new born. I am a supplicant. There is a vulnerability to be without a head covering.”

The dissolution of identity is a break in self-continuity and sense of coherence. The past, the knowledge and security it provided, no longer are sufficient to mediate the present circumstances. If past knowledge, skills and abilities can no longer be trusted, then the present must be interpreted with new ways of being. However, if the last attempt was a failure, how can the present methods be trusted? Will these ways be anymore successful? A description of how this is experienced is as follows;

“I have dropped into despair, lost all sense of who I am, I have said over and over again, my prayer, “I want to die, I want to die, I want to die.”

The questions about the veracity of previous self-knowledge and sense of coherence, combined with a negative self-appraisal leads to an overwhelming sense of vulnerability. The self-concept is in disintegration. The experience of this fragmentation is given voice in the words “What wants to die?” “What needs to die?”

At found this time the artist Jeanie Tomanek is discovered. The image, Fallow (Tomanek, 2013), has a very strong pull. Entries are written on why the image is so meaningful.
“Fallow” spoke to me; earth that is plowed and harrowed but left unsown for a period in order to restore its fertility. Earth left in stillness. Yet, to become resilient, to be nutrient filled, things must die, decay, plant life, animal life turned into earth once more. So, I ask myself, what needs to die? What needs to be transformed into ground? New ground, that then I may yet walk again?

It is important to note the words: ““Fallow” spoke to me.” Almost all journal entries begin with an image, many of them by Tomanek. It is through the imaginal that the self-concept seems to move into a liminal space. This space appears to acknowledge nostalgia for the irretrievable past,
but it is also cognizant that what was has gone before, has ended, and something else, a new self-schema or sense of coherence must be created.

The capacity to create an image, and then work with it, was highly personal and delicate. Under the scrutiny of authorities, such as a GP, there is the loss of both language and image. The journals reflect that assumed pressure from external authorities was internalised and created further conflict. Speaking about the doctor:

He often starts his conversations with, “So, how are you?” I never know where to start, or what to say. He asks what I think my primary gain has been in converting my emotional pain into somatic symptoms is, and what my secondary gain is. I am at a loss for words. Further passages express the need to hide or minimize physical limitations, as if there is a need to assure the GP that if the present bodily state does not form to his expressed expectations, somehow it will in the future. Yet it must be noted that much was being hidden and not being disclosed.

“it feels like I am taking out something half-baked and trying to explain what it will look when it is fully formed.”

After interactions with the GP:

“I have a deep longing to disappear. To reside in some far way refuge.”

There are also notes in the journals that indicate did the GP’s terms of “gain” and “secondary gain.” were not understood. After an appointment, there appears to be research into how the medical field understood CD.

In the larger community, a similar vulnerability and inability to language or explain, what is felt, is described. When an individual is ill, it is common for friends, family and acquaintances
to ask, “how are you?” or “Are you getting better?” A question similar to these is noted and then this passage:

I feel like such a stranger in a strange place. Alien in an alien world. Cast out. As if one day, I woke into a movie scene. The one where the landscape is unchanged but the streets are all empty. Or not empty, but everyone speaks a language I think is familiar, but I am incapable of understanding.

The excerpt conveys the disintegration of the familiar and the difficulty in integrating the new experience. The words “burned, like a burn victim” are used to describe what it is like to have physical symptoms that were not biological in origin, yet transform personhood so completely. The theme of shame, guilt and vulnerability pervades the journals.

I imagine I am a burn victim, altered, so altered. The searing of my flesh always with me, in every second, every breath. The pain, now, now, now. But my face smiles. I nod at questions asking for details. I hear myself speaking and wonder why I am talking. I say to myself, “unless you’ve been in the fire, I might as well be Charlie brown’s teacher. My words as coherent as the sounds she made.

At times, in desperation, I grab a hand, hold it, close my eyes and try and will them into my body. Saying out loud, “this, this is how it is.” Almost immediately, I see them pull away. A flurry of words and I am alone once more. As they flee I am aware they were not asking how I was. Yes, that was what they said, they asked, “how are you?” But they don’t actually want to hear. Why I keep forgetting this I have yet to discover. In this respect alone, I have short term memory loss. I find myself registering their look of distraction, their wish I would stop talking even as I attempt to answer the question. The
worst, is the looks of sympathy. An undeniable judgment I am a lost cause, their listening an act of compassion.

And again,

And while I was bewildered, every day, every fucking day I was faced with a family member or a friend wanting to know what had happened, what I “Had.” Me, the woman I was, Pamela, disappeared and all that was seen, acknowledged or questioned was my body. My shaking, inert body. Before, I did not know, there was so may faces to terror and disgust. So many forms it takes in the body or on the face. But I have become familiar, a bit of an expert, on where these emotions hide or show themselves in a look, a laugh, a turn of the head.

The term vulnerable comes from the Latin *vulnerabilis* "wounding," from Latin *vulnerare* "to wound, hurt, injure, maim," (Harper, 2017, np). To be vulnerable means to be open to wounding. The hurt may, or may not occur. However, the potential is there. To be ill is to be vulnerable. The state of sickness often leaves one less able to meet or mediate the expectations of a typical day. To be ill and to be exposed to one’s community is, at once, to be wounded and then, to expose that vulnerability, to those who may or may not add to the hurt.

An illness that is diagnosed as CD or Medically Unexplained Symptoms, can be interpreted as self-induced by the medical community, friends, family members, and workmates. Western cultural highly values youth, health and wellness. Thus, illness can be seen as a form of failure (Gunderman, 2000; Stone, 2014). An illness that does not have the privilege of being biological in origin can induce feelings of shame and vulnerability. Illness can incapacitate a person, thus causing them to be placed under the care of others. What form that care will take,
who and how it is provided is not always certain. This can leave a person feeling afraid and insecure.

**Theme 3: I am Split**

Early in the writing the words, “I am split,” occur. The theme is significant and pervasive. It reflects the experience of a break in self-concept, sense of coherence and self-efficacy. The words “I am split” indicate that what was, has changed. The “taken-for-granted” body is now no longer. The assumptive ability to address illness has ended. The belief that the medical community has the answers and can provide care has been disrupted. A new state of self-concept and sense of coherence has not yet occurred. The present moment is a liminal state; an experience of being neither in the past, nor having a vision of what continuity into the future could encompass. The entries express this experience

“All I have is sensations, feelings in my body, but no words.”

And later,

“I am of two minds… I feel as if the me that must get up, wash, eat, talk, live is a veneer…the true me is in this dark void, where there is no orientation… darkness, nothingness, in every direction. The lack of context is unbearable for long periods of time, so I slip away, and fully inhabit… well attempt to “fully” inhabit this outward me.”

There is a desire to continue to inhabit the previous self-identity narrative. If this were possible, then there would be no need to amend the self-schema or sense of coherence. Yet, arising with this desire is the realization that there is no going back. The journals describe attempts to continue to be the “Pamela” who family and friends have known. Simultaneously, they reveal that whoever that was is no longer here. An example is:

“I am grieving the loss of my identity.”
The acceptance of the new state is not stable. Thus, the theme “I am split.” There is considerable negotiation and reflection on what the past was, what it meant and what the future may hold.

“I catch myself, in the midst of some particular loud, exuberant, detailed blaming round of arguments in my mind, and I wonder who am I trying to convince. Really…who is all this story telling for?”

The journals reflect the struggle the shift in identity and sense of coherence represent:

“who is this “I”, this “me”, that I have been referring to my whole life?”

Another example

“I feel, physically as well as emotionally, as if many things are happening within and without. Seen and unseen.”

The journals contain a number of pieces of original poetry. The following one is an homage to the Hans Christian Anderson (1845) tale of the same name, and the 1948 film also entitled, Red Shoes. Both tales describe been under the sway of Red Shoes; a metaphor for being divided but feeling unable to address the condition.

**Red Shoes**

I slipped Red Shoes on my feet,

eyes aglow with hope!

Finally, the method
to move body swiftly as mind;

I never doubted its rightness.

One day I fell, collapsed.

Profound disbelief.

Stillness disorienting
as a summer fairground ride.
Awaiting equilibrium
Torture.

Every cell recalls dancing,
trust in movement undaunted.
Waking, standing,
Urgent brutal truth;
Another reality,
amputation did occur.

Denial deep as
blindness, while
glorying in achievements
blood pooled in my soles.
So indifferent to contradictions,
that it could occur.

Mornings bring back
reminders of pleading prayers,
proof of harboured doubt
answers were found
in acceleration on the dance floor.

The poem is an example of how to explain to the self and to others the profound disorientation that occurs when the continuous self is disrupted. The writing reflects that explaining how or
what or who a person is, is a daunting task. Thus, the imaginal, became a method to communicate. At times, the writing links bodily sensations and inner reflections.

“I have begun to sense that my clenched jaw, my waking feeling of “something is about to happen,” as an inkling that I about to travel “inwards”, but “in” as I have not ever known it. I wonder what “darkness”, what pain might exist there. I am without doubt the journey must be taken.”

Later, it is noted that,

“Travel must be taken. Lands yet unexplored must be found, traversed. This is not about what has been known, or is known, but about what is not known.”

The theme, “I am split,” reflects that the “familiar” is gone.

The journals contain not only the day-to-day lived experience of CD, but also many recorded night-time dreams. The theme “I am split” comes through in dreams about “marriage” and houses with many “rooms.” In one dream,


In other dreams, objects that split in two are given, or objects are presented and then

“how they come together and a part, and that they transform.”

There are several dreams of vow renewals and marriage ceremonies. In some, the case study is the one getting married, in others they are part of the wedding party. The writing indicates a belief that dreams are a method to make sense or integrate the change in self-concept and sense of coherence.
“A house, rooms, change, renovation. I am split down my torso, from my neck to pubic bone. I am with a large group of men and women, discussing: One woman says, “What you are talking about is marriage.””

The entries reveal that the nighttime dreams influenced daily life. After the “marriage dreams” there are clear efforts to integrate, rather than reject or deny the bodily. Here is an excerpt:

Past, future, past, future. And where does the present come in? I don’t know. I can only hope that by following the lead my body gives me, may reveal, what the present has to offer. What do you say body? What do you desire in this moment? What shall I do? Read? Eat? Sleep? Create? What do you want?

Alongside the dreams, there are many descriptions of feelings of anxiety, sadness, aching physically, emotionally, mentally. The physical, mental and emotional symptoms are listed again and again, as if by doing so, they could be validated and believed or accepted. In a sense, it is as if there is a desire to re-integrate what has been disintegrated.

Staying with myself, staying and staying longer, this is how I discover who I am. I have talked about my losses. Losing all the frames of who I thought I was. Deaths, all these deaths. And yet now, what it feels like is, skins, shedding skins. Shedding personas of who I thought I was. The ‘me’ that I am discovering has never left, never not been here. I just did not have eyes to see or senses to feel her.

The taken-for-granted body does not question communication between the body and mind. Typically, there is no reason to feel thirst and then say to the mind, I am thirsty. Thirst is registered and then the hand is reaching for a cup and water. The experience of “I am split” is one where automatic habits no longer exist. The body is, the mind is, but they are like warring
tribes, distrustful and constantly ready to fight. Only through the imaginal, the soul, is there a space where peace is negotiated.

The theme “I am split” is closely connected to the theme “Seeking a Guide.” There is an understanding that,

“I need a guide to help me through the inner. I have a deep sense that if I let go completely, and enter the inner alone, I could get “lost” in there.”

The loss of identity is disorienting. To try and make meaning a method is sought to regain a sense of control. Entries express needing a guide/help and concurrently the nighttime dreams are recorded. The dreams contain many symbols and images. This could be an affirmation that the unconscious was as active as the conscious mind in trying to make sense of what was occurring. The unconscious was actively trying to assist in the integration/acceptance of how the body had changed and life was altered.

**Theme 4: Seeking a Guide**

The theme of needing guidance and seeking a guide could seem somewhat obvious. A break in self-concept and sense of coherence resulted in the dissolution of identity, leading to the theme of “I am split.” It is reasonable, that if one is significantly altered physically, mentally and emotionally, that assistance would be required to move forward. Yet, how to re-kindled trust internally so that any inner wisdom could be accessed, after feeling so lost and betrayed by the self, was notably difficult. As well, the entries indicate that very few professionals discussed the concept of trust, or how trust in their knowledge and skills could provide guidance. Few in the medical field had an explicit conversation about how they could be helpful guides. In fact, it seems the opposite was experienced. The entries indicate a perception of being perpetually moved to the next expert.
The journals reflect two prominent decisions around “guidance.” One was the decision to seek a therapist. The content testifies that weekly sessions occurred with a psychoanalyst and that the work with this individual was deeply integral to the healing process. In the account, there are many excerpts like the following:

“I spoke with her today. It was soooooo good to be heard, held, and contained in her wisdom. Not alone trying to make my way. I have a teacher, a guide, a witness to my journey.”

The second decision was to record nighttime dreams and to actively contemplate their content. It is important to note that the question of what is consciousness or the unconscious is very old. There are multiple definitions of each of these phenomena. It is not possible within the limits of this thesis, to address either concept in more than a cursory way. However, it appears that becoming comfortable with these concepts was an integral part of the healing process.

Over the four years of writing, the recorded dreams had numerous themes and subthemes, and one of these was water. There were frequent references to walking beside or sailing on the ocean. Many of these seemed to indicate a desire to befriend the unconscious. In the psychoanalytical tradition, water is the most common symbol of the unconscious (Jung, 1959). The regularity of these occurrences was interpreted as the unconscious actively working to find/create acceptance and/or help to integrate the daily, lived, experience of being changed physically and emotionally. It seems that needing a guide, led to dreams being recorded. The dreams indicated that the case study was not “alone” and this allowed them to move towards acceptance. The acceptance found supported the desire to seek guidance, which led to dreams, which helped acceptance to grow: a very circular, interwoven, process.
Along with the theme of water the dream content also had many examples that were collated under the subtheme communication/learning. Some statements from these are:

- “Hazy faces, searching, know someone is there, someone trying to communicate with me”
- “I live in a house full of women, we are together because of a war, strangers who have become ‘family.’ I am to learn from them.”
- “Methods to process/understand/heal, to move forward. Two men offering methods.”
- “I have a sense that I have been trying to order, to fix…me, my life throughout the night. I also recall hearing a native elder singing, a Grandfather, then his voice, crying out, singing me into existence.”
- “I am holding a symbol, it is old, hand carved from stone. It is in two pieces that fit together very precisely. When I opened the object, I can see inside. I am being told about the image, its meaning and how and when I am to use this sacred object. I am learning the chants and prayers that I will say when I use it, when I hold it. I am learning what to do. It is only meant to be used at certain times. It is to be put away and only brought out for ceremonies. I am learning about its power. About what, when and where.”
- “12 magnets, a magician in the woods, showing me how they come together and apart, and that they transform. He changes our surroundings, I understand, I am shown their magic and what they can do. I am an initiate.”
- “I am sitting across from an Elder who is teaching me. I am being questioned. I am sitting apart from the rest of the people. My will, my willingness is being assessed.”
• “Every part of you has a lesson to learn. These words resounding in my head. A large village, I am in someone’s home. I am being assessed. I receive an edict. Listening and lesson. Listen to my lesson. I hear, “Every part of you has a lesson to learn.””

• “Somewhere in the night the words every part of you has a lesson to learn, comes through differently, as if I have heard it another way. Initially, I heard the words as a correction, now, every part has a lesson to learn, like each body part has a lesson, learning in its own time, and lesson, as in lesson to then be taught, shared, with others.”

The dream content was interpreted as “seeking guidance.” It gave rise to feelings that the situation could be remediated, even when the physical or mental condition seemed unchanged. It also suggested that guidance was being given. Part of that guidance included the need to accept that the previous selfhood and sense of coherence had ended, and that a new concept or schema of the self would need to be created.

The message received from all professionals accessed, from GP, to Naturopath, Psychiatrist, Psychoanalyst and Acupuncturist, was one of acceptance. First, there was the need to accept that the body had changed. Second, to accept that the cause was not an organic illness, nor was it due to volition. Yet, none of the experts consulted could explain how this acceptance could be found. Somehow the self-concept needed to be adapted or changed to facilitate the continuation of self into the future. “Accept”, as it is defined by its etymological root:

to take what is offered; admit and agree to (a proposal, etc.), “from Old French accepter (14c.) or directly from Latin acceptare “take or receive willingly,” frequentative of accipere "receive, get without effort," from ad "to" (see ad-)
To “take what is offered”, to “receive” or “grasp” what had happened, an active collaboration with the unconscious took place. Dreams were recorded and reflected on. Through this method a “way” to accept that the body had fallen ill and was substantially changed, took place.

**Theme 5: Acceptance**

Acceptance as a theme could be framed as in opposite to denial, or non-acceptance. The literature on CD, under the headings diagnosis and treatment, is filled with the exhortation that patients need to accept their “condition” if they are to recover. As well, the literature is quite emphatic on the point that, denial and the desire for further “tests” is a hallmark of the diagnosis and should be avoided. The theme of acceptance in the journals is likely influenced by the emphasis placed on this concept by the medical field. Many entries, throughout the time spent as a patient with CD, show a propensity to seek out information to understand the condition and to find ways to live with the condition. Statements like the passage below could be seen an attempt to follow the medical imperative to find acceptance:

“I had a life. It had a beginning, a middle, and an end. It has ended. Now I am having this life. In this life, I walk with a cane.”

However, acceptance was not something that happened once, globally. It was an act that was returned to again and again. In fact, acceptance appears to be an ongoing lived process. The journal entries imply that it was found or experienced, and then lost, over and over. Here is an example:

Who was the ‘I’ in the woman I was? I believed effort, will, desire, hard work, could take me through anything, that these could take me any where I wanted to go. Until they couldn’t. Until no amount of effort, will, hard work, prayer or acceptance could make my body come alive again. I cannot keep myself from digging for a why. Like a child
digging a hole in the sand. There must be some answer. Something here. Not just more sand.

Later,

“I trust my illness is the perfect method for me to be initiated into the next part of my life. And yet I feel such grief that my life is what it is.”

Grief, could be another term or title, for this fifth theme. For grief can be the process of accepting loss and figuring out how to move on. This excerpt illustrates powerfully the negotiation towards a new sense of identity:

The day disappears slowly. Pain. Pain. Loss. Grief. All day long I watch the snow fall outside. I try and will myself to go out and walk in it. By early afternoon I’ve given up. The day will pass. I will speak with my therapist tomorrow. She will help me be with this grief. I am weary with it. The days and days of staying with myself, while I feel the loss of the life that I thought would be mine. The dreams I thought would unfold. I am stripped bare, raw.

Slowly, over time, it seems that acceptance that life had altered, took place. Yet, initially, the acceptance appeared to be held like a bargaining chip. Acceptance was framed as a means to get physical changes, such an ability to walk, for example, after being unable to. It took many months before acceptance reflected that physical changes might be permanent, such as a need to walk with a cane or some other device for the rest of life. This is how acceptance was a lived experience.

Another example of acceptance was reflected in the decision to access support, such as physiotherapy. Going to physiotherapy meant 1) leaving the house 2) being seen in a public setting 3) being asked “what is wrong with you?” 4) explaining the diagnosis 5) mediating any
sense of vulnerability arising from perceived negative feedback about the diagnosis 6) struggling physically to comply with the physiotherapy routine 7) soothing any feelings of shame about present skills/abilities. Acceptance was involved in each of these “steps”.

Respectively, these choices were examples of *receiving* self. It was a process. It took from late 2013 to the end of 2014, before the ability to walk was fully regained. Then, over time, exercise routines were re-established. Here is writing describing what this was like;

Avoidance, resistance, aversion, this is not what helps. This only prolongs. I found myself saying, “Here it comes, here it comes, here it comes, here it is, here it is, here it is, there it goes, there it goes, there it goes.” Winter today, spring tomorrow. The moon waxing, full, waning, waxing, full, waning. The circles of life not to be avoided, but to be experienced, embraced. Every thought, every feeling, every experience, here it comes, here it is, there it goes. I ran to the top of a hill, and then stood breathing deeply, hat off, head back, letting all that has been circle through me. Me asleep, awakened suddenly by my collapse, bewilderment, grief, grief, grief, slow, slow recognition, slow embrace of what was, a voice in the wilderness—calling me out, calling me in, suffering, suffering, suffering, letting go, loosening my hands, finding myself, finding me here, finding my way home, to life, life embracing me, life here with me, life having never left me, life loving me, loving me, loving me, thanking the earth, thanking the earth, thanking the earth.

Acceptance appeared to be consolidated by the creation and then repetition of mantras. Such as,

- “Winter today, Spring tomorrow”
- “The only way out, is in,”
- “Nowhere to go, nothing to do, no one to become. Just is, just is, just is.”
Poetry, also, was written about the process. Here is an example:

**I have to take responsibility**

I have to take responsibility

for my life.

Return myself,

to myself.

Pick up the child

I left

on the road.

Ask forgiveness

while I whisper

longed for

words of love.

Patting myself

back into the body

I thought I could

Forget.

And, as well, entries illustrate the magnitude of moving through the process:

I repeat my mantra, “Nowhere to go, nothing to do, no one to become. Just is, just is, just is.” I feel my desire for the unending grief to soften, to let go, to be less full. I sit, being with myself, knowing it will be, this grief, as deep, and as long, as wide and high, as it will be. And I want to resist it. I will, I am, resisting it. This is the hardest thing I have
ever tried to do. I remind myself not to judge how I find myself. I am fine—resisting, not resisting, in pain, distracted for a moment by a TV program—however I am, is okay. Acceptance, grief, trust, these could each name this fifth theme. But also, it could be called suffering, or the acceptance of suffering. Here is the description:

Back to the beginning, back and back…or rather, full circle, round and round I go. My deepest desire is to end suffering, mine. But I am learning, slowly, slowly, that my lesson is not about ending, but getting comfortable with suffering. A paradox, getting comfortable with suffering. But this is where I am headed, this has always been my destination. I just could not see it as clearly before, whereas now, I not only see it, but feel it in my body. Yes, yes, I feel you body, your fear, your terror, run, run, you shout at me. Such an insistent urge to be anywhere, to do anything, than be with what is presently occurring. My body believes it will not survive. Or the harm, the hurt, will be so great, it could not possibly be worth the gain. And I am learning to feel, recognize, these bodily impulses. Learning to hear, see, feel their inner beginnings, the central point from which they all emanate. And I am beginning to understand that I may come ever more aware, but there is no ending, no place where I suddenly will not experience life in this way…but the feeling, the physiological experiences are in fact MEANT to be felt each and every time, because they bring me home to myself, over and over and over again. Avoiding, minimizing, attempting to short circuit the process, actually takes me out of life, not into it. So here I am back at the beginning, suffering, suffering, suffering and slowly, slowly, slowly getting comfortable with my suffering. It just is. I just am.
Once again, the images of Jeanie Tomanek are central to how acceptance is integrated. The image, Seed (Tomanek, 2010), is cited as an expression of how acceptance is a reflection that a new self-concept and sense of coherence have begun.

![Seed, 2010, oil on canvas, 24x18](image)

All rights to this image are retained by the artist, Jeanie Tomanek, and are used here with her express permission.

**Summary**

Phenomenology is a method used to describe the *lived experience.* “In other words, it aims at identifying the essential components of phenomena or experiences which make them unique or distinguishable from others” (Pietkiewicz & Smith, 2014, p. 8). In this chapter, the five themes discovered through a phenomenological inquiry were articulated. They are: 1) a break in the sense of coherence and self-concept: the subjective experience of a sudden, significant, alteration of physical capacity and wellness. This includes perceptual confusion and emotions such as fear, that arise from such a change; 2) the negotiation of emotions of guilt, shame and
vulnerability resulting from illness; 3) the change in self-concept as a direct consequence of illness that is not biological in origin or attributed to volition; 4) the need for support to navigate the significant change in self-concept, break in sense of coherence and self-efficacy; and, 5) acceptance as the means to create a continuation of self from the past into the future. It is felt that these themes “reveal something very tangible and very real” (Larkin at al., 2006, p. 110) about the experience of being diagnosed with conversion disorder. Interpretive Phenomenology Analysis (IPA) was used because

phenomenology in the Heideggerian tradition demands that the analyst develop a hermeneutic account of the person’s relatedness to the prevailing topic of interest. Typically, this requires us to identify, describe and understand two related aspects of a respondent’s account: the key ‘objects of concern’ in the participant’s world, and the ‘experiential claims’ made by the participant (Larkin at al., 2006, p. 110).

The analysis provided in this chapter aims to share how a diagnosis of CD is the “object of concern”, and the interpretation of the data is the “experiential claims” of that diagnosis. It is not meant to be comprehensive, but rather one person’s account of the experience. Larkin and Thompson (2012) state that “IPA is interpretative,” but they also remind us “the resulting structure is not explanatory and is not a model of what is ‘out there’ (although it will be a representation of your analysis and may still share some similarities with the formulatory approach common to many psychological therapeutic approaches)” (p. 112). I feel that this in-depth examination provides a unique and important addition to what is known about conversion disorder.
CHAPTER 5  IMPLICATIONS

Recap of Main Findings

Conversion Disorder is an old illness, with a long, complicated history. It is unique amongst diseases, for today, as previously noted, even the name to describe the disorder is still in dispute. Rickards and Silver (2014) attest “the language to describe functional neurological symptoms has changed, especially in the last 100 years, but the problem itself dates from antiquity” (p. 1). Over the years numerous frames have been used to conceptualize the illness and to study it. Through research, much has been discovered about symptoms and possible treatments. However, the cause is still unknown. This may be because “the mind-body connection is not one amenable to straightforward empirical investigation” (McNair & Jindal, 2010, p. 106). Yet primarily, empirical or quantitative methods have been used to determine the etiology of CD. This thesis has argued that qualitative research could provide a different conceptualization of the sickness, as qualitative methods ask different questions than quantitative methods.

Qualitative research could provide insight on how to care for CD patients, until the causal factor or factors are established. In their discussion on medically unexplained physical symptoms (MUPS), Kornelsen, Atkins, Brownell & Woollard, (2016) argue

Grounding the elusive concept of MUPS in patients’ (and physicians’) lived experiences provides a starting point for developing conceptual and treatment paradigms that bridge these experiences with an ontological paradigm (medicine) rooted in exact science and certainty. In this way, insight may be gained into larger ramifications of the realities of uncertainty in medicine (p. 1).
This is critical because CD is one of the most common disorders seen by GP’s, neurologists and psychologists (de Waal et al., 2006; Haller et al., 2015; Lidén et al., 2015; Morriss & Gask, 2009; Stone, 2013; Rickards & Silver, 2014; Reuber et al., 2005; Rosendal et al., 2003). As well, patients with CD have a poor prognosis (Aybek et al., 2013; de Schipper et al., 2014; Nicholson et al., 2011; Rickards & Silver, 2014; Rosendal et al., 2013; Reuber et al., 2005; Sharpe et al., 2011; Stone. 2013). Stonnington et al., (2006) reporting on non-epileptic seizures state “in one outcome study of 56 such patients, only half of the patients had a resolution of nonepileptic seizures a mean of 1.5 years after diagnosis, and many still exhibited depressive symptom’s suicidal ideation and suicide attempts” (p. 1515). Further to this, Gelauff et al., (2013) who conducted a systematic review of the prognosis of patients diagnosed with functional motor symptoms, found that “in a large majority of studies (20 out of 24 studies), more than one-third of patients had the same or worse symptoms at follow-up. In cases where symptoms improved, they tended to not resolve completely” (p. 5) and they concluded that “overall, prognosis appears unfavorable” (p. 7). Thus, if cure is not possible, then care becomes an imperative.

Phenomenology was chosen as the lens to study CD as it “is uniquely suited to the exploration of the experience of illness” (Carel, 2012, p. 4). As a qualitative method, it is focused on gathering the information arising from an exploration of “being-in-the-world” (Carel, 2012; Greenfield, 2011; Toombs, 1988; Toombs, 1990). This perspective is highly relevant to the patient diagnosed with CD because it is their everyday, lived experience that is impacted by the illness. A somatic illness can present with many different types of symptoms. These can range from paralysis, blindness, non-epileptic seizures and tremors to irritable bowel, overall malaise, pain, and/or muscle weakness. For the patient, these symptoms can seriously interrupt their ability to care for her self, to care for family members, to fulfill their role in their
community or go to work. Moreover, the condition can cause a break in self-concept, self-coherence and self-efficacy as most patients are unsure how to integrate an illness that is not biological in origin, yet has significant physical symptoms. While not all individuals with CD may experience a break in self-concept, self-coherence and self-efficacy, these types of descriptions are typical for those who have chronic or debilitating illnesses (Carel, 2013; Claassen-van Dessel et al., 2015; Greenfield, 2011; Stone, 2014; Toombs, 1988; Werner et al., 2004). Toombs (1988) explains

illness is experienced by the patient not so much as a specific breakdown in the mechanical functioning of the biological body, but more fundamentally as a disintegration of his “world.” This is not surprising when one recognizes that illness-as-lived is a disruption of lived body. As such, it represents a chaotic disturbance in the various and varying interactions between embodied consciousness and world, and it strikes at the very heart of the “I am.” A threat to the body necessarily incorporates a threat to my very self; a change in my body functioning represents a concurrent change in my world (my being-in-the-world). Consequently, illness results not only in a disintegration of body but in a disintegration of self and world (p. 207).

Thus, the patient diagnosed with CD can experience many multiple, interwoven and overlapping losses as they move through the diagnostic process. Where once there was certainty in personhood and world, now, there is a profound sense of vulnerability. Especially, because what conversion disorder “is” or why they “have” it is unlikely to be adequately explained by medical professionals. Schüpbach, (2012) remind us that the pathophysiology of symptoms “remains elusive” (p. 280). Therefore, the patient is left with the knowledge that their symptoms are not
organic or biological in origin, nor are they necessarily caused by their mind, yet their body does operate as it once did.

The five themes outlined in Chapter 4 reflect and affirm Toombs’ (1988) premise that the lived experience of CD is essentially a disordered self and world. Indeed, the five themes could be seen to confirm her argument that any experience of illness always involves certain features, or are eidetic. “Eidetic” characteristics are those that are essential to the thing-itself and that remain unchanged regardless of any varying empirical features” (Toombs, 1987, p. 229). This is a critical outcome of this thesis. If CD, because its cause is not yet known, means those with the diagnosis must be cared for rather than cured, then the form that care takes becomes the preeminent issue. At present CD continues to “fall” between neurology and psychology.

Friedman and LaFrance (2010) argue “patients with conversion disorders often wander for years in the borderlands of neurology and psychiatry” (p. 754). However, if this aliment could be re-conceptualized as a disorder that “mirrors” all illness trajectories, rather than an anomaly that falls outside them, a patient’s questions of “what do I have” or “why did I get it” could be answered by physicians using the frame: “what is it like to be ill?” and “how can I help?” This would mean a shift in medical practice as presently, “interview questions are often standardized and focus on dysfunction, rather than on trying to understand the overall experience of illness in its diversity” (Carel, 2012, p. 3). Yet, this shift could provide a means for patients with CD to feel received, held and understood: essential aspects of the therapeutic relationship (Rogers, 1961).

Toombs (1987) suggests that the “eidetic” or “essential” characteristic of all illness experiences are: “the perception of loss of wholeness and bodily integrity, loss of certainty and concurrent apprehension or fear, loss of control, loss of freedom to act in a variety of ways, and a
loss of the hitherto familiar world” (p. 234). Other qualitative researchers who investigated the lived experience of patients with MUS found similar or the same features reflected in their conclusions (Claassen-van Dessel et al., 2015; Kornelsen et al., 2016; Lidén et al., 2015; Nettleton et al., 2005). Claassen-van Dessel et al., (2015) when referring to medically unexplained physical symptoms (MUPS) found that “to a certain extent dealing with MUPS may be similar to dealing with chronic diseases” (p. 46). The overall message is that illness can bring about a very significant change in a person’s view of their self, the world, and their place in it. Whereas the medical world sees illness primarily as a biological event that must be identified and amended, sickness from a patient’s view, is one that influences every aspect of one’s life. “The impact is not only physical, but also psychological, social, cognitive, emotional, existential and temporal” (Carel, 2008 as cited in Carel, 2011, p. 11). For ailments can involve suffering and suffering is “experienced by persons, not merely by bodies” (Toombs, 1984, p. 230). Thus, what is needed is holistic care; care that is not centered solely on a pathogenesis model (a focus on risk factors and disease), but one that also includes salutogenesis (a focus on the origins of health and assets for health) (Mittelmark & Bauer, 2017).

**Implications for Therapists**

A visit to a GP is the first stop on the long journey towards a diagnosis for someone who may have MUS (Haller et al., 2015; Isaac & Paauw, 2014; Rosendal, Carlsen & Rask, 2016; Rosendal et al., 2017; Stone, L. 2013). Bardes, (2009) relates the following example:

A patient consults an orthopedist because of knee pain. The surgeon determines that no operation is indicated and refers her to a rheumatologist, who finds no systemic inflammatory disease and refers her to a psychiatrist, who sends her to a physical
therapist, who administers the actual treatment. Each clinician has executed his or her craft with impeccable authority and skill, but the patient has become a shuttlecock (p. 1).

This story is a very familiar one for patients with symptoms that cannot easily be explained and may fall into the category of medically unexplained, functional somatic symptoms or conversion disorder. Each of these “labels” a reflection that there is no objective criterion to decide whether a pattern of bodily complaints should be seen as a functional somatic syndrome or as indicator of a medically explained disease or as something else, and lists drawn up by different authors reflect their particular backgrounds and views (Henningsen et al., 2007, p. 946).

The “name” given to a list of symptoms is a significant issue because the choice of term “directly affects case definition, diagnosis, treatment, research agenda and explanation of illness” (Edwards & Bhatia, 2012, p. 250). Thus, the ailing person, typically feeling very vulnerable, unsure and unwell, keeps putting themselves in front of “experts” in the hopes of discovering “what” is wrong. Typically, patients engage in this process not only because they seek an understanding of their symptoms, but also because employers frequently demand proof of illness and thus require notification from a medical specialty for the “reason” an employee is not at work. Kornelsen et al., (2016) found “the variability of illness without a seeming cause made leaving work or seeking a disability pension uncertain” (p. 5). Receiving a diagnostic “label” that does not “cleanly and clearly” fall into a particular category, can leave the sick person feeling anxious and confused. The impact of this lack of clarity does not fall on patients alone, but also affects the doctors and medical professionals charged to treat them.
During the diagnostic process, it is very likely that the individual will come up against a negative view of themselves or their “symptoms” and maybe even be described as “difficult” (Aiarzaguena, Gaminde, Clemente, & Garrido, 2013; Epstein et al., 1999; Johansen & Risor, 2016; Kirmayer et al., 2004; Kurlansik & Maffei, 2016; Maatz, Wainwright, Russell, Macnaughton & Yiannakou, 2016; Stone, 2014). Jackson & Kay (2013), citing the work of a number of research articles, state “it is a dirty little secret that every provider has patients that make their “heart sink” when they see them on their schedule” (O’Dowd, 1988). Such patients have been variously called “blackholes” (Gerrad & Riddell, 1988), “difficult” (Jackson & Kroenke, 1999) “frustrating” (Lin, Katow, Von et al., 1991) “disliked” (Goodwin, Goodwin &Kellner, 1979)” (np). Jackson and Kay (2013) go on to say that physicians often respond to patients who are not easily diagnosed with “undifferentiated fear responses, vague feelings of frustration, dread, dislike, and even hate” (np). The reasons doctors struggle with CD or MUS patients and often to refer to them as “difficult,” is linked to the ambiguity around symptoms and the criterion that the disorder is not “organic in nature” (Kirmayer et al., 2004; Maatz et al., 2016; Rosendal et al., 2016; Stone, 2014; White et al., 2012). Consequently, doctors continue to be unsure what to do with patients whose symptoms fall outside of typical criteria (Howman et al., 2016; Johansen & Risor, 2016; Kornelsen et al., 2016; McNair & Jindal, 2010; Stone, 2014).

The medical professions’ struggle with CD arises primarily from the lack of clarity about why or how symptoms arise. Stone (2014) argues that “medically unexplained symptoms present a profound crisis of meaning in Western culture” (p. 193). The Western medical model is premised on the separation of the mind/body (Carel, 2012; Toombs, 1987, Toombs, 1988). And while this method has afforded many scientific discoveries, it is built on a false premise. Barsky, Peekna and Borus, (2001) affirm “all physical symptoms contain both somatic and psychological
components” (p. 266). And they go onto say, “the distinction between “organic” and “functional” symptoms (are) theoretically unsound, arbitrary, and clinically impossible to establish” (Barsky, Peekna & Borus, 2001, p. 266). Yet, the Cartesian model continues to be the lens through which is CD is viewed.

The diagnosis that CD patients receive, reflects the false dichotomy of body/mind. This conception of the illness leaves patients and doctors in “a semantic no-man’s-land” (Kirmayer et al., 2004). Consequently, it is no surprise then, that if the “experts,” especially those charged with “helping” these individuals, have difficulty with this group of patients then it is not a far leap to imagine that other groups such as friends, family members, community and employers may also subtlety or explicitly reject them. And, while many conceptual models have been created to study and understand CD, none have been able to fully explain what is occurring. This includes the recent focus on a biopsychosocial lens. Initially, it was thought that this frame would replace the search for a “lesion” in the brain and could explain “why” a person could experience symptoms like non-epileptic seizures, blindness or paralysis. However, this model, like all those before it, has come under disrepute (Butler, Evans, Greaves & Simpson, 2004; Johansen & Risor, 2016; Nicholson et al., 2011; Rickards & Silver, 2014; Stone, 2013, Stone et al., 2013).

It is important to note what is problematic with the biopsychosocial model. First, we must recall what history has shown us about the interrelationship between biology, psychology and sociology. Kanaan and Wessely, (2010) remind us that in the early 19th century hysteria was chiefly diagnosed in women of the upper class, whereas malingering was associated with the working class, primarily foreigners such as German-Americans, those of Irish or Polish descent and as well individuals of the Jewish faith. They also found there was a long history of lower-
class males, whether soldiers or prisoners being given the diagnosis of malingering (Kanaan & Wesley, 2010). Bourke (1996) attests, this became a problem during WW1 when “medical authorities were confronted by ever-increasing numbers of soldiers with functional illness— invariably males, often officers, and sometimes decorated heroes” (as cited in Kanaan & Wesley, 2010, p. 79). Thus, previously held notions of “what” this illness “was” had to be amended. However, it is Kanaan and Wesley’s (2010) conclusion that must be highlighted when we consider a biopsychosocial frame: “Any examination of the history of hysteria or malingering thus reveal a striking dichotomy: while distinguishing the conditions by clinical or psychological means can be very difficult, distinguishing the conditions by gender or class can be very easy” (p. 79). This finding must be noted and placed against Stone et al.’s, (2013) argument that the link between stressful life events and the development of somatic symptoms has not been found: “many patients with functional symptoms are psychiatrically ‘normal’, and around a third of patients with defined neurological disease have comorbid psychiatric symptoms. The upshot of this is that it is dangerous to base your diagnosis on the psychosocial history” (p. 105). Thus, it seems imperative that the field attends to the argument made by Butler et al., (2004).

The role of the clinician is therefore not necessarily to hunt for disordered pathophysiology nor, if none is found, to do an awkward dance of collusion with the patient around the notion of somatized illness, possibly attempting to get him or her to ‘reframe’ the illness, as systems theory would imply is necessary. Rather, clinicians have an important role as experts in the process of helping patients interpret and make sense of their pain as part of their legitimate experience of the world (p. 221).

And while it is likely that many or most physicians indeed want to attend to their patients suffering, the lens through which they evaluate and ultimately diagnose is one that is still seeking
a “cause”. It is this “need” that becomes very problematic for the patient with CD. For they, their body, or their history and culture end up being “blamed.”

To be ill is to be vulnerable. To be ill and to have few “acceptable” places to turn for care can make one feel extremely exposed and uncertain. Thus, a critical implication for therapists is the likelihood that the patient with a diagnosis of CD or MUS state is experiencing an extreme state of vulnerability. The ill person may have been ill for some time before seeing a GP. Their symptoms may have, as per the above example, been reviewed by a number of medical professionals. They may have been told that their symptoms are not “organic” and thus are not “real.” Nettleton et al., (2005) report “all study participants described how, at some point, they had felt that practitioners, acquaintances and even relatives might see them as either a ‘fraud’ a ‘timewaster’, a ‘hypochondriac’, a ‘malingerer’, a ‘fake’, or a ‘hysteric’” (p. 207). Therefore, it is reasonable to assume that most patients arriving at a therapist’s office with a diagnosis of CD, MUS, FND, have been on a long, typically very difficult journey, and what they require is time, compassion and understanding. Patients do not want to “convince” one more “expert” that they are suffering or that their “experience” is “real.” They certainly do not want to feel blamed. Thus, while it is important to gather information, take the patient’s history and discuss their experiences, it is vital that the counsellor remain unbiased while they consider what is occurring. I would argue, to create a therapeutic alliance, it is critical that counsellors resist the impulse to think, “somatic symptoms, I know what those mean.”

Rosendal et al., (2016) “indicate that patients with symptoms (but no diagnosis) are not taken as seriously as other patients” (p. 8). Consequently, in their attempt to get a diagnosis, many sick individuals have focused on “proof” of illness, so that they can, “legitimately” receive care (Aiarzaguena et al., 2013; Lidén et al., 2015; Nettleton et al., 2005; Stone, 2014; Werner et al.,
The “realness” of what a patient is experiencing physically seems to be a pivotal issue in the care of the ill with MUS, FSS or CD. Psychogenic is a term used to described symptoms of patients with a diagnosis of CD. Psychogenic implies a purely psychological origin. Edwards et al., (2014) affirm that the etiology is stated within the term, as it means “born of the mind” (p. 850). Kornelsen et al., (2016) report that the rationale given to patients for stopping further investigations into their illness was the “physicians saying, “it is all in your head”” (p. 5). This belief can lead to care that is focused on getting patients to disavow the lived experience of their physical symptoms. A proposal that most patients find unpalatable and very difficult to accomplish, and one that can have very negative outcomes. “When patients reject the notion that their pain is not really physical (because they experience it precisely as ‘really physical’), doctor–patient relationships can be damaged” (Butler et al., 2004, p. 221). Thus, a method whereby the patient’s lived experience is validated, rather than ignored is required. Instead of being reduced to body parts or a symptoms list, the individual needs to be received as a suffering individual, one who wants to be recognized and validated.

The medical field is aware that they have separated patient from their ailment. In fact, the reduction of illness to an identified, specific, anatomical breakdown is felt to be a great accomplishment of the twentieth century. However, while it has provided great gains, this view of the sick has also meant that much has been lost.

A byproduct of our ever-sophisticated understanding of the biological basis of the human body may be that those people whose illnesses are not medically explained, may actually fare less well today than in times when medical knowledge was less developed because doctors may now be less skilled in providing support and ongoing care against a background of diagnostic certainty (Nettleton et al., 2005, p. 209).
Although an ill person cannot prove they are suffering, it is highly likely that the patient with CD would appreciate those listening to their descriptions of symptoms, as if they appreciated their struggle. Nettleton et al., (2005) found that “above all it seems that people who suffer from undiagnosed illness want their symptoms to be acknowledged as ‘genuine’” (p. 209).

It could be argued that the desire to be received and understood when one is ill is a very basic and legitimate need. That this is in question, or needs to be emphasized to physicians seems ironic, as they are in a profession that is founded on the premise of care. Yet, the literature on the treatment of CD is filled with the call for GP’s to receive better education on how to care for these patients and for doctors in specialty care to thoughtfully consider how they communicate with their patients (Edwards & Bhatia, 2012; Fink & Rosendal, 2008; Howman et al., 2016; Jackson & Kay, 2013; Johansen & Risor, 2016; Kirmayer et al., 2004; Lidén et al., 2015; Rosendal et al., 2016; Stone, 2014).

Our understanding of the nature of disease is limited by our model, and entire aspects of the phenomenon of illness remains inaccessible or incomprehensible to us. We seem to have a great deal of difficulty taking seriously any human suffering that cannot be directly related to anatomic or pathophysiologic derangement. It is as if this suffering had a value inferior to that associated with “real disease.” If anyone doubts this, let him consider our attitude towards such diagnostic entities as irritable bowel syndrome or fibromyalgia or hiatus hernia, each of which represents a disease in search of anatomicopathologic facts. In a sense, we seem obliged to remove ourselves from the world of our patients in order to categorize their diseases in a technologic manner. We cannot hear them while we are listening (Baron, 1985, p. 607).
Therefore, the imperative for counsellors is to set aside any preconceived beliefs about what is happening for the patient, and instead actively attune to what they are saying and offer them your attention, concentration and openness.

The diagnosis of CD could be the perfect opportunity to step back from pathogenesis and embrace salutogenesis, for at the heart of this model is the construct, sense of coherence. And “sense of coherence consists of three elements: comprehensibility, manageability and meaningfulness” (Eriksson, 2017, p. 95). All three of which are central to the care of persons diagnosed with this illness. Lidén et al., (2015) conducted a phenomenological-hermeneutic study with patients with MUS and came to the same conclusion: they related the subtheme “searching for explanations” to comprehensibility, “learning to take care of oneself” with manageability and “learning to accept and become mindful” with the search for meaning.

The central finding of this thesis is that for too long the focus with patients with a diagnosis of CD has been on their symptoms and not on their suffering. If the name of an illness holds its etiology, then this thesis argues that it is time to use a term that reflects the change in self and world that occur when someone receives the diagnosis. Rather than using words that try to distinguish which part of the body is unwell such as conversion disorder, functional neurological symptoms, functional somatic symptoms, psychogenic or medically unexplained symptoms, what is needed is a term that denotes to all professionals across all medical disciplines that the individual with CD, FNS, FSS OR MUS requires care that is founded on patience, compassion and understanding. The five themes outlined in chapter four articulate the “being-in-the-world” experience of the condition. They relate what has changed for the individual with CD and how it impacts them. Each theme clarifies that it is not only the
symptoms themselves that are challenging, but it is the impact the symptoms have on the daily lived experience that need to be heard and understood.

**A Disintegrated Self and World**

In chapter four, the five themes discovered through a hermeneutic-phenomenological inquiry were articulated. They are: 1) a break in the sense of coherence and self-concept; the subjective experience of a sudden, significant, alteration of physical capacity and wellness. This includes perceptual confusion and emotions such as fear, that arise from such a change 2) the negotiation of emotions of guilt, shame and vulnerability resulting from illness 3) the change in self-concept as a direct consequence of illness that is not biological in origin or attributed to volition 4) the need for support to navigate the significant change in self-concept, break in sense of coherence and self-efficacy 5) acceptance as the means to create a continuation of self from the past into the future. These five themes reflect the essential or “eidetic” characteristics of illness, “they reveal what illness means to the patient” (Toombs, 1987, p. 234).

1) **A break in the sense of coherence and self-concept: the subjective experience of a sudden, significant, alteration of physical capacity and wellness or the “loss of wholeness”** (Toombs, 1987, p. 229).

   Typically, the loss of the taken-for-granted body, is the most recognizable part of being ill. Most people are familiar with the experience of what their body is like, before, during and after a cold or flu. Suddenly, their body, which was considered immutable, does not act immediately, fully, or as wanted. It is weak, sore and tired. In these moments, an awareness of the fragility of the body arises along with reflections on what the loss of its strength and abilities could mean. “The body-in-pain or the body-malfunctioning thwarts plans, impedes choices, renders actions impossible” (Toombs, 1987, p. 229). For patients diagnosed with CD, there is
first, the experience of difficult and at times painful physical symptoms, but what happens second, must be emphasized. If one is ill with a cold, the changes in the body can interrupt daily function, but it is probable that the individual trusts they will get better. For the person with CD, they do not know why their body no longer functions “normally”, nor how to stop it from acting as it is, nor why it started to act this way. For these individuals, life, as it was once known, is gone. “Learning to live with MUS seems to be about coming to terms with shattered opportunities for ordinary daily life” (Lidén et al., 2015, p. 4). There is the complete dissolution of what was “true” or could be counted on. All frames of reference are now questionable and all beliefs found faulty. Lidén et al., (2015) found learning to live this way was “a great and difficult challenge that involves losing control over life, becoming disoriented, and then a battle to reorient” (p. 7). Part of this battle involved questioning “assumptions previously taken for granted: truths about themselves as people, their relationships, and circumstances in their sociocultural context” (Lidén et al., 2015, p. 7). This mirrors what Toombs (1988) found, and described in the following way: “In order to address the patient’s experience of disorder, attention must be paid not only to the physical manifestation of disease state but also to the changing relations between body, self and world” (p. 221). Thus, what is revealed by looking at the lived experience of CD, rather than symptoms alone, is the complete dissolution and then the re-conception of the individual’s self and world.

2) The negotiation of emotions of guilt, shame and vulnerability resulting from illness or the “loss of certainty” (Toombs, 1987, p. 229).

Any breakdown in bodily function can cause a person to have some “body doubt” which is described “as anxiety on a physical level, hesitation with respect to movement and action, and a deep disturbance of existential feeling (Carel, 2013, p. 9). The lived experience of CD, by its
very nature, produces body doubt. To have one’s body act as it as has a “mind-of-its-own” and thus produce life-changing symptoms that are not attributable to known disease, can leave a person feeling bewildered, anxious and ashamed. Western culture frames illness as “failure” (Gunderman, 2000) and mental illness with even less tolerance (Edwards et al., 2014; Friedman & LaFrance, 2010; Kornelsen et al., 2016; Sharpe & Carson, 2001). The focus of Western culture on autonomy and self-sufficiency allows us, as a society, to ignore, dismiss, and deny that as soon as we are born, our physical body begins to breakdown and decay. It provides the means to act as if we are not innately vulnerable and thus, to move through our days and our life with competence and confidence. However, sickness irrevocably changes this belief.

In the experience of illness the individual is forced to surrender his most cherished assumption, that of his personal indestructability. And if this most deeply held assumption is no more than an illusion, what else in his hitherto taken-for-granted existence can remain inviolate? The person who is ill comes face-to-face with his own inherent vulnerability (Toombs, 1987, p. 230-231).

The person with CD or medically unexplained physical symptoms (MUPS) feels their vulnerability very deeply. The essence of the diagnosis, the lack of clear trajectory for treatment and the experience of not being “believed” by medical experts all heighten the sense of uncertainty.

The lived experience of MUPS is rooted in uncertainty: uncertainty of what may be causing symptoms, uncertainty about if or how symptoms may progress, uncertainty of how the illness may affect all facets of life and ultimately, uncertainty about the future. This uncertainty ranges from discomfort to devastation (Kornelsen et al., 2016, p. 6).
Yet, this “uncertainty” seems to be something that physicians do not want to directly address. Gunderman (2000) notes that this may stem from “health care professional’s psychological impulse to suppress a disturbing realization of personal vulnerability. From a caregiver’s point of view, it is unnerving to realize that “I, too, could fall ill and die” (p. 9). It is also likely that in the case of CD “that certainty of causation may never be achieved” (McNair & Jindal, 2010, p. 106). Thus, patients and physicians are left without an explanation and nothing to blame.

3) The change in self-concept as a direct consequence of illness that is not biological in origin or attributed to volition/ or the “loss of control” (Toombs, 1987, p. 229).

The patient with CD, by the illnesses very own label, declares that they have lost control. A control that is illusionary, but one that had supported them in their everyday lived experience. Carel (2013) explains it simply and beautifully, stating “the ‘I can’ feeling implicitly underlies all our movements and plans. If I plan to walk the dog, implicit in that plan is my ability to walk” (p. 4). If this confidence is shattered, because one day, you cannot walk the dog, then our human vulnerability is suddenly not in the background but very much, in the forefront of every thought, action and belief. In illness, every aspect of our taken-for-granted confidence is deeply and thoroughly, brought into question.

Even if the body is eventually restored to health, the perceived loss of bodily integrity remains. For the individual who has experienced illness recognizes he has only a limited control over the functioning of his body; that at some future date it may again come into opposition with the self. He can no longer take the body’s compliance for granted (Toombs, 1987, p. 230).

Where once there was an unconscious acceptance of ability and strength, now the “most basic assumptions about the regularity, predictability and benevolence of the world” (Carel, 2013, p. 8)
are questioned and feel uncertain. Lidén et al., (2015) argue “living with MUS means struggling to find plausible explanations for one’s suffering” (p. 9). Yet, however the individual “makes sense” of what has happened, they can never again return to a state where the body is taken for granted. For the individual with CD fundamentally knows they were unable to prevent their physical changes or stop themselves from becoming ill, and thus experienced “their” inherent vulnerability.

4) **The need for support to navigate the significant change in self-concept, break in sense of coherence and self-efficacy or the “loss of freedom to act” (Toombs, 1987, p. 229).**

The person with CD experiences a substantial change in how the body “functions.” The changes may be sudden or a slow acceleration of decline. No matter the timeline, patients seek counsel on what is happening and how to address the changes.

Illness, in its various forms, always impedes the ability to be self-reliant, to act on one’s own behalf. The ill person must not only seek the help of others for physical assistance but he must also rely upon the help of a trained healer, a physician (Toombs, 1987, p. 232).

It is reasonable to seek out the medical community, as they are those who supply healing and help to “make sense” of the drastic change in how the body “is.” The literature attests that doctors are aware of this need and that they want to support and adequately communicate with patients (Claassen-van Dessel et al., 2015; Edwards & Bhatia, 2012; Kirmayer et al., 2004; Kornelsen et al., 2016; Rikards & Silver, 2014; Stone, 2013; Stone, 2014; Stonnington et al., 2006; Rosendal et al., 2017). Kurlansik & Maffei (2016) state “a strong, positive relationship between the physician and patient is essential” (p. 53). As well, Isaac & Paauw, (2014) found “the most powerful tools available are the ability to communicate the limits of current
understanding, acknowledge the difficulties faced by patients with this disorder, and reinforce the willingness and desire of clinicians to partner with patients” (p. 669). Therefore, if doctors would adopt a frame that sought an embodied experience of illness rather than a pathogenic view, the partnership between patient and physician could be that much more amicable. Butler et al., (2004) state this might occur if

- instead of trying to sort out ‘real’ disease from the rest (in the biomedical model), or to get patients to recognize that their symptoms arise more from personal and contextual than from physical factors (biopsychosocial model), clinicians (could) focus on helping their patients ‘make sense’ of their symptoms (p. 220).

Further to this Schröder & Fink (2010) who embrace the biopsychosocial model, still argue “that full and explicit acknowledgement of patients' suffering and disability is an essential first step toward improving management and treatment of functional disorders” (p. 95). This would seem to be a much more ethical, kind, supportive and feasible type of care than attempting to force patients into a belief that the cause of their illness is some form of a psychiatric malady.

5) **Acceptance as the means to create a continuation of self from the past into the future or the “loss of the familiar world”** (Toombs, 1987, p. 229).

Acceptance, by the patient, of their altered person and world has been linked to a positive prognosis (Claassen-van Dessel et al., 2015; Edwards et al., 2014; Gelauff et al., 2013; Kornelsen et al., 2016; Stone & Edwards, 2012; Stone, 2013; Stone, 2014). However, how to help patients move towards acceptance is still unknown. Oliver Sacks (1933-2015) is a well-known doctor and neurologist. He fell and injured his leg in the early 80’s and in 1982, he wrote an essay entitled “The Leg”. In this piece and later on in his 1984 book, “A Leg To Stand On” Sacks describes his psychosomatic experiences along with an intense need to be believed and to
not be found “hysterical”. Stone et al., (2012), when reviewing the incident noted that “Sack’s frustration in finding a health professional to understand his frightening symptoms is common, as too is his rejection of the possibility of a psychological component to the problem” (p. 866). That Sacks, a preeminent physician felt this way and had this experience can give some indication how daunting the prospect that the average person faces when attempting to understand and integrate their illness experience. It is important to consider that

the patient does not feel free to reject the advice of the physician. To do so would seem to be irrational in the face of inadequate knowledge he feels himself to possess. To do so would also be to risk alienating himself from the one who promises to alleviate his distress” (Toombs, 1987, p. 233).

Yet, “patients often regard psychological treatments as inappropriate and referral to mental health services as unacceptable” (Sharpe et al., 2011, p. 564). Compounding this difficult circumstance is the experience that

illness truncates the experiencing of the individual. It imprisons him within the present moment. The future is suddenly disabled, rendered impotent and inaccessible. This loss of the future serves further to isolate the one who is ill and separate him from his hitherto familiar world” (Toombs, 1987, p. 234).

Thus, the patient with CD can feel as if they have no method to orient themselves or the world around them. And, it is exactly at this point, when all seems lost, that the individual’s willingness to tolerate this level of disorientation and disorder is so fundamental. If the ill person can be supported in this state they then can learn to accept two things a) “that life is a chaos in which we must constantly relate to change” (Eriksson, 2017, p. 93) and b) it is “vital how we are able to
manage this chaos” (Eriksson, 2017, p. 93). These two factors are at the heart of the salutogenic view, for within them are the means to find and create acceptance.

Each of the five themes hold critical information for the physician or therapist who cares for the patient diagnosed with conversion disorder. They give them a window to see into the lived experience of the illness.

**Areas of Future Research**

This thesis has explored conversion disorder using a qualitative method. During the research for this work other qualitative studies were discovered and read. However, no other hermeneutic-phenomenological study that employed an interpretive phenomenological analysis (IPA) that investigated conversion disorder was found. It is recommended that further qualitative studies using IPA and study CD be conducted to further verify if the preliminary findings presented here have validity. This work could expand the overall understanding of CD if the Dasein or individual’s lived experience of patients was sought and recorded. This is especially important because “the great achievement of Dasein is that it replaces the individual predicated on Cartesian dualism (person/world, subject/object, mind/body and so on) with people Being-in-the-world with things and others” (Eatough & Smith, 2017, p. 194). It is possible that if more individual or group studies that gathered this type of information were collected, that the picture of the experience of CD would significantly expand. However, it must also be noted that qualitative studies that gather the physician’s experiences are also required. When referring to the frequently used word “difficult” in relation to MUS, Maatz et al., (2016) found taking seriously the common conceptualization that this is a ‘difficult’ area of medicine, or a ‘difficult’ group of patients means that qualitative research which gives voice to the subjective experiences of health professionals is clearly needed. This is important not
only for understanding the ‘the problem’ from health professionals’ own perspectives in their own words, but also for exploring possible ways of improving those experiences (p. 2).

I agree with this recommendation by Maatz et al., (2016), and hope that such research is completed soon.

Another area for future research is the inclusion of the phenomenological view of illness in the education of doctors, especially in regard to somatoform disorders. Carel (2011) suggests that “by drawing attention to the lived experience of illness and to the pervasive impact of illness on the patient’s life-world, new insights and sensibilities can be developed in medical staff and students (p. 14-15). Changing the education doctors receive about MUS has been identified as a priority (Howman et al., 2016; Morriss & Gask, 2009; Shattock et al., 2013; Yon et al., 2017). However, what this training should encompass needs further study. For at present, there continues to be a focus on pathogenesis and the biomedical model. If this conceptualization of the illness has not been found helpful in the past, it begs the question how it would be beneficial in the future, whether for doctors or their patients. Still, it could be argued that any training would be better than no education and at present, Shattock et al., (2013) found for new medical trainees “despite being a common disorder, students reported having no formal training in MUS” (p. 253). As well, Howman et al., (2016) found “there is no strong evidence base for how teaching about MUS should be conducted” (p. 8). Both areas deserve attention.

Lastly, the salutogenic model needs to be researched. It is possible that this frame could provide the needed conceptualization for understanding CD. Within this model is the potential to have “health defined as something other than the absence of disease” (Mittelmark & Bauer, 2017, p. 8). This may be exactly the right lens to investigate and make sense of conversion
disorder. However, it is noted that salutogenesis “still is a social science idea in infancy. Mainstream health professions and disciplines have yet to be strongly touched by salutogenesis” (Mittelmark & Bauer, 2017, p. 8). Thus, there is a great deal of work to do.

**Reflecting on the Process**

I begin this section with a quote:

In our society we believe that once we have the words to describe a phenomenon, we understand it, but although the words are necessary, they are insufficient. Meaningful discovery becomes possible only when knowledge is enlivened by experience that is lived through the body. If an experience is coming from the body, then it is now known.

To know something in our head does not change our life (Woodman, 2015, p. 76).

These words express my feelings about being a person who was diagnosed with CD. CD, as a condition, is very challenging to understand and work with. It is also an illness that many people will experience in their lifetime. As a clinical counsellor I now bring my lived experience of CD with me into my work. It has made me a more patient and compassionate therapist.

Reseaching this 4000-year-old construct was an amazing experience. Daily, I would find myself reflecting on how pervasive and multifaceted the disorder is and how it continues to confound the scientific community. In many ways this illness tests our ability to be with uncertainty. While humans, generally, walk through life conscious and/or unconscious of the desire for control, CD instantly asserts that whatever “control” we think we have, it is illusory. Once this belief has been challenged, the ground for a whole new way to be in life has been tilled.

I think that I gained compassion for doctors and medical professionals in the process of writing this thesis. In my experience, most work from a place that has little room for
vulnerability or uncertainty. This is likely why they find the disorder difficult. I often felt, when I was under their care, that my symptoms were seen as a smoke alarm, and physician skills were, metaphorically, a fire extinguisher. When my symptoms “sounded the alarm” doctors would train “the extinguisher” on them with all their might. I believe this action was taken with the hope and the belief that this would “put them out.” Yet, as this image explains, this meant that nothing was focused on the “fire” and consequently, “the house was burning.” It took a long time, on my journey with CD, to realize that the “fire” was a break in my self-concept, sense of coherence and self-efficacy. I will be forever grateful that I found a therapist who saw this, and helped me put out the flames.

The years I was ill with CD were some of the most difficult of my entire life. Yet, I would not change them. It was through this ailment that I discover a great deal about myself: how to stay with a sense of disorientation, bewilderment and fear, how to be with shame until it shifted, and how to embrace rather than deny or reject my inherent vulnerability. These teachings helped me differentiate and individuate, become a more attuned mother and a more skilled counsellor. I hope this work gives the reader a sense of the dynamic transformation process that I underwent.
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