An Autoethnography of a Registered Nurse Living with Chronic Undiagnosed Illness

Frances M. Ricker

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AN AUTOETHNOGRAPHY OF A REGISTERED NURSE
LIVING WITH CHRONIC UNDIAGNOSED ILLNESS

BY

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DISSERTATION
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Finally, I dedicate my dissertation to my parents, Joseph Lee Martine and Ofelia Drusila Martine. My Hispanic mother valued education highly despite never obtaining a college degree herself. My father struggled with an unknown illness much of his later life. This study details some exploration of a possible relationship between his illness and mine, and reflects my mother’s love of the pursuit of knowledge. I know both of them would have been very proud of my obtaining my PhD from the University of New Mexico, having lived in Albuquerque for many years.

A last word of appreciation to my husband, Thomas Ricker, for his presence and kindness during my decades of illness and for emotional support during my years of doctoral study. I could not have completed this journey without him.
AN AUTOETHNOGRAPHY OF A REGISTERED NURSE LIVING WITH CHRONIC UNDIAGNOSED ILLNESS

by

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ABSTRACT

This autoethnographic study examines a registered nurse’s experience living with chronic undiagnosed illness. The number living with undiagnosed illness is unknown and little is understood about living with chronic undiagnosed illness.

This analytic autoethnography (Anderson, 2006) used multiple data sources: my journal, medical history narrative, and artifacts including my handwork, examples of my father’s handwriting, and family photographs. Narrative analysis, thematic analysis, and visual analysis were conducted.

My experience of living with chronic undiagnosed illness was characterized by three themes that reinforced isolation: not knowing, loss, and hidden secret self. Family context evidenced diverse themes of not being believed, hidden secret self, diminished self-identity, and diminished family role. Social context featured hidden secret self, diminished social role, and hidden Hispanic identity. Professional context themes were hidden secret self and impact on professional role.
There is a need to define nursing’s role in caring for and identifying interventions for patients with chronic undiagnosed illness. Health professionals need educational content on undiagnosed illness and atypical presentations of disease. Further quantitative and qualitative research is needed in real world practice settings, capturing cultural contexts of the patients’ experience. Advocacy in health care and public policy analysis are needed for this population.
# TABLE OF CONTENTS

LIST OF TABLES ........................................................................................................... xiii

LIST OF FIGURES ........................................................................................................... xiv

CHAPTER 1 INTRODUCTION ...................................................................................... 1

Origins of the Research ............................................................................................... 1

Being a Nurse with Chronic Undiagnosed Illness ...................................................... 8

Statement of the Problem ........................................................................................... 10

Undiagnosed Illness ................................................................................................... 10

Illness Narratives ........................................................................................................ 12

Medical Paradigm ........................................................................................................ 13

Social Construction of Illness .................................................................................... 15

Autoethnography ........................................................................................................ 10

Personal Knowing and the Generation of Nursing Knowledge ............................. 19

Purpose ......................................................................................................................... 22

Research Questions ..................................................................................................... 23

Significance .................................................................................................................. 24

CHAPTER 2 REVIEW OF THE LITERATURE ............................................................ 26

Undiagnosed Illness ................................................................................................... 26

Critical Social Approaches to Understanding Illness ................................................ 31

Influences from the History of Medical Education and Philosophy ...................... 31

Immunology .................................................................................................................. 34

Social Construction of Illness: Philosophical Underpinnings ............................... 38
Meaning of Chronic Illness and Qualitative Research ........................................ 40
Illness Narratives ........................................................................................................ 42
Qualitative Research and Undiagnosed Illness ....................................................... 45
Autoethnography as a Research Approach ............................................................ 46
The Development of Autoethnography .................................................................... 46
Definition of Autoethnography ............................................................................... 49
Autoethnography: Incorporating Culture and Meaning ........................................... 50
Features of Autoethnography ................................................................................... 54
Nursing’s Use of Autoethnography to Understand Personal Illness ....................... 56
Analytic Lens for My Autoethnography .................................................................... 61
Arthur Kleinman ......................................................................................................... 61
Arthur Frank ............................................................................................................... 63
The Restitution Narrative ......................................................................................... 64
The Chaos Narrative ................................................................................................. 65
The Quest Narrative .................................................................................................... 66
Testimony .................................................................................................................... 67
Synthesis of Literature ............................................................................................... 68
Key Concepts .............................................................................................................. 68

CHAPTER 3 STUDY METHODS .................................................................................. 72
Introduction ................................................................................................................ 72
Autoethnography ...................................................................................................... 73
Evocative Autoethnography ...................................................................................... 73
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analytic Autoethnography</td>
<td>74</td>
</tr>
<tr>
<td>My Study’s Autoethnography Approach</td>
<td>78</td>
</tr>
<tr>
<td>Study Setting</td>
<td>80</td>
</tr>
<tr>
<td>Sampling</td>
<td>81</td>
</tr>
<tr>
<td>Recruitment</td>
<td>81</td>
</tr>
<tr>
<td>Ethical Considerations and Human Subjects Considerations</td>
<td>81</td>
</tr>
<tr>
<td>Participants</td>
<td>82</td>
</tr>
<tr>
<td>Data Sources and Collection</td>
<td>83</td>
</tr>
<tr>
<td>Data Management</td>
<td>85</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>86</td>
</tr>
<tr>
<td>Process for Analyzing Data</td>
<td>88</td>
</tr>
<tr>
<td>Triangulation</td>
<td>88</td>
</tr>
<tr>
<td>Constant Comparison</td>
<td>90</td>
</tr>
<tr>
<td>Coding</td>
<td>90</td>
</tr>
<tr>
<td>Thematic Analysis</td>
<td>91</td>
</tr>
<tr>
<td>Visual Methodologies</td>
<td>92</td>
</tr>
<tr>
<td>Merging Data Sources</td>
<td>95</td>
</tr>
<tr>
<td>Rigor of the Study</td>
<td>95</td>
</tr>
<tr>
<td>Limitations</td>
<td>100</td>
</tr>
<tr>
<td>Conclusion</td>
<td>102</td>
</tr>
<tr>
<td><strong>CHAPTER 4 INTRODUCTION</strong></td>
<td>105</td>
</tr>
<tr>
<td>Narrative of My Medical History</td>
<td>105</td>
</tr>
<tr>
<td>Analysis of My Medical Narrative</td>
<td>112</td>
</tr>
</tbody>
</table>
Tension Between Being a Patient and Being a Nurse .................................112
Living with “Not Knowing” the Diagnosis ................................................114
Progression of Symptoms Over Time from Observable to Others to Less Visible to Others .................................................................115
Considering and Reflecting on the Observation of Other Nurses .............115
Researching the Medical Literature Behind the Scenes ..........................116
Journal Entries (2018-2019) ......................................................................117
The Emergence of a Nurse Researcher .........................................................117
Emergence of Nurse as Expert ....................................................................119
Observation ..................................................................................................121
Observing Physical Pattern of Symptoms ..................................................121
Observing as a Nurse ..................................................................................123
Observing Variability versus Archetypes .....................................................123
Observing Cultural Objects ........................................................................125
Observing Changes in Handwork ...............................................................126
Observing and Analyzing Handwork Photographs ......................................128
Observing Family Photos and Handwritten Artifacts ..................................136
  Wedding Photograph 1977 .......................................................................137
  Photograph of Father Lifting Wood ...........................................................138
  Photograph of Father’s Facial Expression ..................................................139
  Photographs of Paternal Grandfather .......................................................140
  Photograph of Grandmother (Paternal Aunt) .........................................141
My Illness Narrative and Frank’s Typologies .................................................. 167

Implications ........................................................................................................... 169

Clinical Implications .......................................................................................... 169

Research Implications ........................................................................................ 174

Context Critical to Studying Illness Experience .............................................. 177

Autoethnographic and Ethnographic Research on Illness Experience ............ 178

Policy Implications ............................................................................................. 181

Limitations ........................................................................................................... 182

Summary and Conclusions .................................................................................. 183

APPENDIX .......................................................................................................... 186

REFERENCES .................................................................................................... 187
LIST OF TABLES

Table 1: Data Analysis Plan.................................................................94
LIST OF FIGURES

Figure 1. Applique quilt block.................................................................129
Figure 2. Handwork detail back of quilt....................................................130
Figure 3. Sample of basic knitting graph..................................................131
Figure 4. Baby quilt................................................................................132
Figure 5. Nine patch layout.................................................................133
Figure 6. Unfinished projects...............................................................133
CHAPTER 1

Introduction

This chapter introduces the dissertation study. It begins with the origins of the study, and elaborates on the context of the study and the situated experience of being a registered nurse living with chronic undiagnosed illness. The statement of the problem reviews the topics of undiagnosed illness, patient stories of undiagnosed illness, medical paradigm, and social construction of illness. Autoethnography is proposed as the research approach. This autoethnography is not a medical investigation, but rather a study of the experience of living with chronic undiagnosed illness. The introduction concludes with the research questions for the study.

Origins of the Research

My story of illness first begins in 1981 with a neurological attack in my late twenties when my daughter was barely one year old. I woke one morning unable to speak clearly and unable to close my left eye. My tongue would not work properly, and my speech was slurred and garbled. Accompanying these symptoms was a profound disabling weakness in my arms and legs. By the time I drove myself to my generalist physician’s office, I could no longer stand and was lying against the wall when the office staff arrived. Realizing that I was presenting with a neurological emergency, my husband was summoned to take me to the nine-hundred bed hospital where I worked as a young registered nurse in North Dallas. My subsequent years were spent dealing with ongoing and emerging symptoms and the search for a definitive diagnosis.
I began my doctoral studies as the University of New Mexico with a strong interest in health policy, having served in formal and informal roles advocating for professional nursing issues in the state of Colorado for many years. I served for six years as the Executive Director for Colorado Nurses Association and spent two of those years as the professional lobbyist representing the association on nursing issues at the Colorado state legislature.

I am also part Hispanic and felt in my first years in the program that I would focus on issues that affected Hispanics, in particular Mexican Americans. My mother had been born in Mexico and later became a naturalized US citizen. My mother’s family had been involved in politics at a high level. My grandfather had also been involved in politics in Mexico at one time and was a National Dean of Law in Mexico, which I was told was equivalent to a Supreme Court justice in the United States. Politics had often been discussed in my family growing up with the family influences. This family background also influenced my sister’s husband to run for Congress in the United States. He has served multiple terms representing California in the U.S. House of Representatives. Thus, politics and policy were an important piece of my personal identity.

I had been monitoring issues like DACA and immigration issues were beginning to build that targeted Hispanics. I wanted to make a difference on these issues. I knew my own grandfather had been granted political asylum in the United States, although, I knew his journey was so different from the challenges many were facing today. I was also engaged on the topics of health disparities and social determinants of health. I saw one way of honoring my Hispanic heritage as focusing my doctoral studies in this area.
As my symptoms with my undiagnosed illness worsened during my first three years in the program, they were impacting my studies. Fatigue, dizziness, blurry vision, and problems concentrating made several of my courses more challenging. I remember in particular struggling with the quantitative research course. I also began to notice some problems interpreting graphs which puzzled me. I also remember wondering why I was having to extend so much effort on any of my written assignments. Assignments which normally would have taken me a few hours in earlier years were now taxing me heavily and taking much longer to do. Mental fatigue and physical fatigue, combined with blurred vision posed real challenges. There were times when I would reread a paragraph multiple times, struggling to grasp what was being communicated conceptually. This was a change for me that I really struggled with: I had always seen myself as a strong student academically, who loved both reading and writing.

I reached out to faculty only when I absolutely had to. Each deadline for a course or assignment began to stress me inordinately because I could not predict the “bad periods” I was experiencing on a recurring basis. If at all possible, I tried not to indicate my health struggles with faculty but when it became impossible, I had no choice. Each time I had to ask for an extension, I felt defeated and my self-concept suffered. As I struggled with doctor appointments, ongoing medical tests, working full-time teaching in a baccalaureate nursing program, taking PhD courses, and my declining health, I began to realize my “illness” had become the central focus of my life. I struggled on a daily basis just to manage my life and my symptoms.

At the same time that I was undertaking my course work in nursing, I was informally researching a multitude of diseases which each represented a disease I was
tested for in the search for my elusive diagnosis. I have folders on my computer with numerous articles on different diseases such as: Lupus, Lyme disease, multiple sclerosis, Guillain Barre, myasthenia gravis, sarcoidosis, Sjogren’s syndrome, neuromyelitis optica, Lambert Eaton, dysautonomia, chronic inflammatory demyelinating polyneuropathy, interstitial cystitis, subacute-myelo-optico-neuropathy, and more.

Some conclude that I learned to be a “researcher” because of my nursing education. However, it’s more complicated than that. I learned some skills related to conducting literature searches in college, but what developed my habit of inquiry stemmed from having this “mystery disease” that no one could identify with absolute certainty. This began right after my initial neurological attack in my late twenties. I began to frequent the medical library at Southwestern Medical School in Dallas. When I flew home to Albuquerque, I would check out topics at the University of New Mexico Medical Library. I date myself in relating this, as I was physically pulling the journals and the articles from the shelves and in the stacks. I loved the many bound volumes of journals lined on the shelves. I can remember what an index is and how to use one, a lost art. Thus, having an unknown illness consolidated my identity as a researcher, and wish to become a researcher.

I continued to informally research over the years because of ongoing symptoms and the emergence of new symptoms. Modern search techniques replaced old ones, but the ongoing research continued. I also began to search the internet as those technologies evolved. I have found the internet of particular interest as it relates to those that struggle with undiagnosed illness. It has become a medium of connection and information for many.
Towards the end of my coursework, I completed my health policy field placement in Telluride, Colorado, looking at the issue of inclusivity in the community supported by Tri-County Health Network. I interviewed Hispanic immigrants as part of that experience and loved the exposure to understanding the social determinants of health that impacted that community. I made two site visits, but did find I was struggling physically with the nature of the experience-- the long drive, etc. My illness was impacting even the things I was most passionate about doing.

It was about this time that I began to realize the experiences in my life that had been most pivotal related to this chronic unknown illness I had struggled with most of my life. I really had done more ongoing research over the course of my life related to this than anything else.

I began to reflect more on the process of seeking “diagnosis” in our health care system, the challenges for those who seek an obscure diagnosis, the barriers those without a diagnosis face in managing symptoms, and some of the social pressures experienced by those without a diagnosis. I began reflecting on how much living with an undiagnosed illness had impacted so many dimensions of my life. My life had slowly, insidiously changed through this illness experience.

This marked the beginning of changing my PhD dissertation to focus instead on the experience of living with chronic undiagnosed illness as a nurse. It was at this point that I began journaling on my experience. Dr. Dorinda Welle, a medical and cultural anthropologist, agreed to serve as my dissertation chair. Dr. Welle had also struggled with chronic undiagnosed illness and felt that my experience of undiagnosed illness could be the topic of an autoethnography for my dissertation. We began weekly Zoom
discussion sessions at this time to review journal entries, to discuss scholarly articles, to
reflect on the illness experience, and to explore other possible sources of data for the
dissertation. Our dialogue continued for over a year and a half. I continued journaling
during this time: the first source of data for my autoethnography. I discovered the
dialogue proved as pivotal as the journaling for me. I remember starting to cry the first
time I read one of my early journal entries to Dr. Welle. It was a significant emotional
release in beginning to share my illness experience.

In these discussions we also explored topics related to my identity. Some of the
topics we discussed were my role as a registered nurse, as a nurse educator, as a mother
of two adult children, and my role as a daughter. In fact, there were quite a few
discussions relating to my father, as I believed he may have lived with an undiagnosed
illness himself which also had neurological symptoms. I explored in our dialogue some of
his symptoms, and related some of my regret in not being able to help my father more in
pinning this down, especially since I was a nurse. I felt my father’s experience related
some potential clues to what might be happening with me.

I have always had a strong passion for creative outlets outside of nursing. For
many years, nursing felt very scientific, technical, and procedural to me. I leaned toward
creative pursuits outside of nursing to balance myself. I loved any creative handiwork
that involved texture and shape and form. I became an advanced quilter in my thirties.
Executing fine applique by hand was one of the skills I took great pride in. In our
discussions on my illness, we explored the changes in my fine motor abilities that were
now taking away my ability to do these things I loved. This was also evident in my
knitting. I was not surprised to learn later in my life that I am a kinesthetic learner: I have to write things down, and feel and see the words to process my learning.

Our discussions about my declining abilities brought these issues to the forefront. Illness receded into the background and our discussions illuminated my changing sense of self identity. I relived also the personal losses that were impacting my life. When Dr. Welle later shared her own experiences with chronic undiagnosed illness, her openness allowed me to share my own vulnerability. I began to share openly experiences that I had not allowed others to know about living with my illness. Our common bond allowed me to trust someone with what I was feeling and experiencing. This was an emerging process through the journaling and our reflexive discussions.

Guided by Dr. Welle, our webinar discussions explored both illness and medical narratives. Dr. Welle also shared literature that looked at the anthropologic perspective on medical narratives. The topic of immunology became a focus for our webinar after I shared that I believed my illness had an autoimmune basis. This further extended into reading literature that explored the conceptual framework for immunology that currently informs bio-medical and nursing education. Another component of our webinar dialogue related to “the meaning of illness,” which introduced the field of medical sociology and began an extended search into the literature.

As we continued with the webinar sessions, I also continued my journaling several days each week, documenting and reflecting on my life with chronic undiagnosed illness. I continued my readings in the research literature and also in popular literature. One nonfiction book, “My Imaginary Illness: A Journey into Uncertainty and Prejudice in Medical Diagnosis” (Atkins, 2010), particularly struck a familiar note, because the
author was dealing with an undiagnosed neurological disease, which later was treated as myasthenia gravis. I perused social media sites, trying to get a sense of patient’s struggles with being undiagnosed. The social media sites supported my concerns that there appeared to be others out there also struggling with a lack of diagnosis. I concluded I was not alone in dealing with chronic undiagnosed illness, but an increasing awareness of the magnitude and complexity of the problem was emerging, including the lack of patient voices who were struggling with chronic undiagnosed illness in the health care literature.

**Being a Nurse with Chronic Undiagnosed Illness**

I am a nurse that has lived with a chronic undiagnosed neurological disease for most of my life. My education in nursing has prepared me to deal with clients who have diagnosed diseases. When I know what disease a client has, I know the interventions, the pharmacologic approaches, and what education is required for them. I can evaluate their symptoms, plan, and evaluate their care. I can care for them effectively. A diagnosis, thus, is the framework around which I have been taught that medical and nursing care for the client is organized.

I am a nurse who is also a client, or patient. I know “client” is in vogue now as the accepted terminology. Since it is my illness experience, I prefer to call myself “the patient.” As I struggled with a lack of diagnosis and ongoing symptoms, I experienced many frustrations in interactions with providers and with the health care system. The current health care system is not well suited to addressing chronic, unknown, or rare diseases. I began to understand there are nuances in “categories” of illness. The length of time I have been managing symptoms and seeking formal medical care allowed me to conclude my illness was “chronic.” Despite an early label for the initial presentation of
my disease of Guillain Barre, I knew the ongoing and changing nature of my symptoms made it more likely that I was dealing with an unknown disease which was evolving. When years passed without an adequate medical explanation or diagnosis, I began to falsely conclude that I might also suffer from a rare disease. Why else would it have taken so long to find an answer?

I also found myself sometimes in conflict with dual roles. I wanted to be a good patient, and wondered if, initially, this sometimes limited my ability to question and challenge physician presumptions. I wondered how much of my subordination to physician’s opinions and judgements might relate to conditioned social roles regarding physicians as authority figures. Was I also subconsciously subordinating to physician authority as a nurse? It took some time for me to begin to assert my own knowledge, research, and understanding of different diseases and the research literature I had amassed for each one. I was becoming more “expert” in neurological diseases than most nurses generally are. I was discovering the fine critical points for different diseases from my readings of the medical literature. I was able to identify when a neurologist made an incorrect statement based on the latest evidence.

Another aspect my professional career was in a nursing faculty role teaching in an accelerated BSN program in Denver. Some of the content I have taught in the past to students in my prior Medical Surgical II courses relate to topics that are relevant to the dissertation, specifically neurology and immunology. I have taught nursing students about many of the diseases I have been tested for, and am familiar with, archetypical presentations for each of them. These include such diseases as Guillain Barre, multiple sclerosis, myasthenia gravis, and Parkinson’s disease.
Statement of the Problem

Undiagnosed Illness

According to one source, undiagnosed diseases are common, affecting 30 million people in the United States (Spillman et al., 2017). Undiagnosed diseases may include rare disorders, common disorders with atypical presentations, and conditions that cannot be explained by a medical diagnosis. Neurology patients are reported to have a higher prevalence of unexplained illness, and it is estimated that 20-40% of patients referred to neurology have medically unexplained symptoms (Nettleton et al., 2004).

Yet, undiagnosed illness is a hidden problem. It is not possible to know with absolute certainty how many people overall are living with undiagnosed illness. Compounding this uncertainty is the lack of clarity in defining “undiagnosed illness.” Undiagnosed illness may be chronic in nature, yet not all chronic illness is undiagnosed. Some may be undiagnosed because they have rare diseases, yet not all undiagnosed illness can be presumed to stem from rare disease.

Rare diseases affect approximately 25 million in the United States and include 6,000 rare diseases that lead to increased morbidity and mortality (Groft & Rubinstein, 2013). A rare disease is defined under the Orphan Drug Act as a condition affecting 200,000 Americans or a disease with a greater prevalence but for which no reasonable exists that the costs of developing or distributing a drug can be recovered from the sale of the product in the United States (Orphan Drug Act, 1983).

Those that live with undiagnosed illness and rare diseases often undergo multiple encounters with providers and numerous tests and procedures to secure a diagnosis (Reid et al., 2001). Reid, et al. (2001) relate that frequent attenders in all medical settings
account for a disproportionate amount of health care resources, and in primary care, frequent attenders commonly present with symptoms that are medically unexplained. Their retrospective cohort study found that medically unexplained symptoms are also common in frequent attenders in secondary care and present in most specialties. Specialties that presented with higher frequency of medically unexplained symptoms in the study are gastroenterology, cardiology, and neurology (Reid, et al., 2001).

This also contributes to higher economic costs for the health care system (Angelis, Tordrup, & Kanvos, 2014). There may be fragmentation of care and lack of coordination in delivery of care, further contributing to an elusive diagnosis. Being uninsured also increases a person’s chance of going undiagnosed, or if diagnosed, going untreated, especially for three chronic health conditions of hypertension, diabetes, and elevated cholesterol (Wilper et al., 2009).

One effort to provide a resource for those who struggle in attaining a diagnosis is the Undiagnosed Diseases Network (National Human Genome Research Institute, 2019). The Undiagnosed Diseases Network (UDN) was organized and established by the National Human Genome Research Institute (NHGRI), the National Institute of Health Office or Rare Disease Research (ORDR), and National Institute of Health Clinical Center. Founded in 2008, goals of the UDN focus on improved diagnosis and care for patients with rare diseases, facilitating research, and creating integrated collaborative clinical sites across the country. Seven research centers were initially established to serve as clinical sites. In 2018, twelve clinical sites were designated to serve as clinical sites.
Illness Narratives

While initiatives like the UDN and other research studies try to quantify or predict the number who are undiagnosed or make integrated efforts to diagnose them, the experience of living with an undiagnosed illness is less well understood. To date there are no studies of the narratives of patients living with undiagnosed illness. Illness narratives are one way to understand the meaning of illness and how people structure a chaotic experience through a narrative (Ellis, 2004; Frank, 1995, 1998; Kleinman, 1988).

Illness narratives are also being incorporated into modern medicine and medical education with the belief that understanding of the meaning of the patient’s illness experience will allow the medical provider to engage more effectively with the patient (Arntfield, Slesar, Dickson & Charon, 2013; Charon, 2001, 2005; Kleinman, 1988). These medical narratives then ideally would inform more holistic care and allow the provider to better understand the patient’s experience of illness.

Nursing also has explored the use of narrative as a qualitative approach to understand patient’s experiences and their own illness experiences, beginning in the 1970s-1980s. There was some lapse in focus on narratives after that time, with a reemergence of interest in the late 1990s (Edward, Giandinoto & McFarland, 2017; Holloway & Freshwater, 2007; Guzman, 2009; Keim-Mapass & Steeves, 2012; Knight, 2018; Overcash, 2004).

Narratives can range from basic descriptions or summaries of experience to narratives that are documented in qualitative nursing research, with formal analysis. Narrative analysis may be based on the written documentation by the individual or on the text of oral interviews that provide narrative data. Through communicating stories of
their experience, narrative research participants may come to organize and understand their experience, share their emotional experience in a more holistic form, and potentially regain the ability to reshape their world and identity (Holloway, 2013). Narrative research has potential to enhance professional’s engagement and understanding of those who are vulnerable (Holloway, 2013). An example of nursing’s use of narrative research is Keim-Malpass and Steeves (2012) analysis of women’s online narratives of cancer.

Nurses have also used narrative as a naturalistic form of inquiry regarding their own illnesses. Knight (2018) utilized narrative to explore her experience with breast cancer. Guzman (2009) utilized a diary to record her narrative as a nurse educator with breast cancer. As with patient narratives, nursing narratives can range from a descriptive sharing of an illness experience to more formal qualitative research with thematic and narrative analysis.

Illness narratives are more than a description of one’s illness experience. They may have therapeutic value and allow the person experiencing illness to make sense of his/her life (Custer, 2014; Ellis, Adams, & Bochner, 2010; Frank, 1995; Hyden, 1997; Kleinman, 1998; Le Roux, 2017; Overcash, 2004; Schultz & Flasher, 2011; Spillman, et al., 2017). Research literature on illness narratives as interventions support these positive outcomes (Frank, 1998; Mazanderani, Lococh, & Powell, 2013; Spillman, et al., 2017).

Medical Paradigm

Some of the challenges medical providers have in understanding the meaning of illness experience for their patients relate to their philosophical underpinnings. There are strong empirical and positivist influences that inform medical epistemology (Dunn & Ives, 2009; Tonelli, 1998). Additionally, there are influences from philosophy and
Western culture that have introduced and solidified a form of binary thinking where
dichotomies predominate (Stoller, 2012). Cartesian dualism is evident in a mind-body
dichotomy. Medicine and nursing are influenced by the dichotomous concepts of
subjective and objective data. Illness and wellness also form conceptual dichotomies that
categorize individuals.

The underpinnings of diagnosis have their roots in the subjective. The patient
history, which includes the patient’s description of their symptoms and the chronology of
illness events, is actually a story we start from (Kleinman, 1988). Yet, diagnosis is often
more often confirmed by what is objective – a reliable diagnostic test, definitive imaging,
and conclusive laboratory results. Diseases that are difficult to diagnose often have a
combination of subjective symptoms and more objective diagnostic testing procedures or
methods. To meet diagnostic criteria for more complex diseases, multiple criteria often
have to be met. There is an ontological tension between what is “real” and what is
perceived by the patient.

A diagnosis ultimately reflects a categorization of the patient’s symptoms into a
label (Brown, 1995; Conrad & Barker, 2010; Kleinman, 1988; Noah, 1999). That label is
socially constructed by the scientific and medical experts in a region at a given point in
time (Brown, 1995; Kleinman, 1988). The label has further social implications for the
individual who reacts to the label based on social norms regarding the illness or disease
(Goffman, 1963). Some diseases or illnesses carry stigma attached to them, such as
leprosy for example (Goffman, 1963; Kleinman 1985). While there are other factors that
contribute to the social construction of illness, the diagnosis is a major factor.
Social Construction of Illness

During the 1960s and 1970s, there was an emergence of literature that reflected on the cultural meaning of illness. This was influenced by the framework of social constructionism, emphasizing the belief that meaning of phenomenon are not inherent to the phenomenon themselves, but that they develop through social context (Conrad & Barker, 2010). Thus, the early research on social construction of illness had its roots in medical sociology. Symbolic interactionism and phenomenology also influenced the social constructionist approach to illness (Charmaz, 1991; Glaser and Strauss, 1965; Goffman, 1963). The writings of Michel Foucault in examining how medical discourse informs knowledge about the body including disease were also influences (Conrad & Barker, 2010). The movement toward illness narratives in the 1980s and 1990s was an outcome of the wide-ranging and interdisciplinary work on meaning of illness. Frank’s (1995) work on illness narratives is one example.

The cultural meaning of an illness affects how the illness is experienced, perceived, and depicted (Kleinman, 1988). The cultural orientations or patterned ways we have learned to think and act in our social worlds influence our common beliefs about how to understand and treat illness. Thus, Kleinman emphasizes that the illness experience is always culturally shaped.

The cultural meaning of an illness affects the social response and interpretation of the illness (Brown, 1995). Social response to illness is relevant and relates to other research on the stigmatizing nature of some illnesses. Thus, research on stigma has also linked to understanding of illness identity, impairment, disability identity, and stigmatization of illness. Goffman’s work (1963) on Stigma highlight that the social
meanings of impairment derive from social interaction. Some diseases are socially more stigmatizing, such as AIDS and leprosy (Kleinman, 1988). Fear of contagion may also contribute to the stigmatization of some diseases.

Nursing culture, including the values, beliefs, traditions, rituals, engrained norms, organizational culture, and practices of the profession, can influence the profession’s views toward illness and the individual patient’s experience of illness. Leininger (1994) historically, was the first to examine nursing’s professional culture. Culture of nursing, which was studied in the 1990s, has not been as extensively studied in more recent times, according to Strouse and Nickerson (2016). They examined the process of enculturation to professional nursing culture, identifying the importance of professional socialization to professional identity and the critical role of nursing faculty in facilitating enculturation of nursing students. Nursing culture can have both positive and negative influences on the patient experience. Nursing culture has been identified in one study as a theme in nurse’s barriers to implementation of evidence-based practice (Henderson & Fletcher, 2015). More research is needed to identify the relationship between nursing culture and patient’s experience of illness, in particular with undiagnosed illness.

The nursing profession can stigmatize illness. There is research literature on health professionals and the nursing profession’s stigmatization of mental illness (Hansson et al., 2011; Ross & Goldner, 2009). Stigmatization of overweight patients by nurses and health care providers has been reviewed in the literature (Creel & Tillman, 2011; Phekin et al., 2015).

It is important to note that those dealing with chronic neurological illness also experience stigmatization. Stigma has been shown to be key determinant in quality of life
for those dealing with Parkinson’s Disease (Ma et al., 2016). This study noted that the physical visible symptoms of Parkinson’s such as abnormal movements and difficulties with communication as contributing to the stigma for individuals with the disease.

There are illnesses that many physicians perceive to lack legitimate medical standing, such as chronic fatigue syndrome, fibromyalgia, and irritable bowel syndrome (Conrad & Barker, 2010). Sometimes the lack of standing relates to lack of confirmatory empiric evidence of disease. They showcase the tension between the lay experience of illness and medical knowledge with respect to cultural legitimization of illness.

The person who lives with undiagnosed illness lacks legitimate medical standing. Those with undiagnosed illness may face questioning regarding the authenticity or legitimacy of their symptoms (Conrad & Barker, 2010; Swoboda, 2006). The lack of physical empiric evidence of disease in a high-tech bio-medical era threaten those dealing with undiagnosed illness. A lack of diagnosis may result in failure to acknowledge and treat their symptoms. This may also lead to questions regarding the mental stability of the person or whether there is underlying mental illness (Frank, 1995; Kleinman, 1998). These factors related to stigma may inform the near silence of nurses regarding their own experiences of undiagnosed illness.

**Autoethnography**

Autoethnography is a form of qualitative inquiry that is written by the individual who is also the subject of the study (Ellis, 2004). It includes the personal story of the author and also contains the larger cultural meanings of the individual’s story (Creswell, 2013). It is a research approach that is both process and product, utilizing a systematic
approach to describe and analyze personal experience in order to understand its cultural context (Ellis, Adams, & Bochner, 2011).

Wolcott (2008), an ethnographer, explains autoethnography as a reporting style dealing with the experience of the researcher(s) themselves, advocating for autoethnographers to shore up their writing by focusing on the cultural context to fulfill the ethnographic component. They should place themselves squarely within the cultural setting in their account (Wolcott, 2008). My autoethnography will examine the situated context and cultural elements of living with chronic undiagnosed illness, thus incorporating ethnographic elements.

Autoethnography combines elements of both autobiography and ethnography. The author usually is writing about experiences that are crucial moments in their lives, sometimes described in the literature as “epiphanies” (Ellis, Adams, & Bochner, 2011). Those writing autoethnographies may or may not include interviews with others, however the use of other texts such as journals, photographs, and recordings can help capture the full experience and provide additional data sources to analyze (Ellis, Adams, & Bochner, 2011).

In the classic quantitative research tradition, writing is viewed as a tool to communicate the steps of the research process. In autoethnography, writing is less about a mechanistic mode of written communication and more of a method of research inquiry. Bochner and Ellis (2016) lament social sciences reliance on academic dialect as often depersonalizing the individual, with focus on the theoretical versus the human aspect of experience. Autoethnography, they argue, makes writing part of the research process. The writing does not stand apart from the research process, it is instead an inherent part of the
research process. The core data in an autoethnography is what one writes about one’s self and one’s experiences.

Van Manen (2014) emphasizes the importance of writing to all qualitative inquiry, explaining that research does not merely involve writing; research is the work of writing. Writing is the method by which the writer produces himself or herself, and strong qualitative writing is able to capture inner speech or thoughts: the thought process that informs research. In order to write in this way, one has to withdraw from the world where the writer dwells to an inner space inside the self (Van Manen, 2014). According to Van Manen, it is in this “solitary experience” that insight and depth of meaning can be written about. An autoethnography captures this element of self-withdrawal in order to document meaning making.

A history of the evolution of autoethnography, and definitions and characteristics of autoethnography, will be detailed in the literature review. Autoethnography has been influenced by other disciplines including anthropology and sociology. Further, autoethnography is also informed by other approaches in qualitative inquiry including ethnography, phenomenology, grounded theory, and critical social approaches. The movements toward understanding the meaning of illness and toward human caring in nursing also are pertinent to this study examining personal experience of illness and will be presented in the literature review.

**Personal Knowing and the Generation of Nursing Knowledge**

Personal knowing as a means to generate concepts and knowledge development is not new to nursing. It is one of Carper’s fundamental Patterns of Knowing presented in 1978, which identified ethics, aesthetics, and personal knowing as patterns that are
interrelated, interdependent, and overlapping with empirical knowledge to create the whole of knowing (Mantzorou & Mastrogiannis, 2011). Parse (1987) describes the “art of nursing” that include valuing human presence and one’s connection to the person.

Moch (1990) argues for personal knowing as essential to development of knowledge central to nursing practice. In personal knowing, discovery of self and others is essential to nursing and is derived through reflection, synthesis of perceptions, and connecting with what is known. This argues against an impersonal objective orientation in nursing and establishes valid connection to inner experience. An autoethnography about a nurse’s experience with illness is a valid form of knowledge, based on Carper’s fundamental patterns of knowing which include personal knowledge.

Chinn and Kramer (1999) bring in the concept of knowing the self as critical to knowing another person. Carper, and Chinn and Kramer both support the therapeutic use of self and nurses bringing self into relationships with patients as part of personal knowing (Mantzorou & Mastrogiannis, 2011). In order to achieve personal knowing, nurses need to be authentic, reflecting their true selves, and must engage in self-reflection and openly disclosing oneself. Chinn and Kramer (1999) extend this to full understanding of the moment and the context of interactions: a key component of autoethnographic research. Despite a history of acknowledging personal knowledge as a valid form of knowledge in nursing, tension exists between empirical positivist forms of knowledge and aesthetic knowledge. This is exemplified by the dichotomies and in the conflicting paradigms of quantitative and qualitative methodologies in nursing.

Experience is also viewed as a valid form of generating nursing knowledge. Benner (1982) supports that through clinical knowledge and experience nurses develop
an intuitive grasp of situations that informs a more holistic view of situations in practice. A nurse’s personal experience of chronic undiagnosed illness can inform a holistic view of the illness experience.

An autoethnography makes tacit knowledge explicit, lending itself to scientific data analysis. In other words, personal knowledge is tacit until it is written down and made explicit. Without explication, it can be dismissed as intuition and considered vague or unconfirmable (Mantzorou & Mastrogiannis, 2011). Thus, an autoethnography explicates personal knowledge for the purpose of systematic analysis and the generation of findings.

An autoethnography, further, allows a researcher to describe and analyze both insider (emic) and outsider (etic) perspectives. Whereas historically, anthropology and sociology initially favored an objective etic perspective, modern approaches value the insider perspective and a holistic approach would value knowledge gained through both perspectives. As a nurse who is chronically ill, I have an insider view of the patient experience. As a nurse, educated to objectively assess, analyze, and evaluate experiences from an external detached perspective, I also view my illness experience from that outsider “lens” as well.

Despite a current surge in interest in medicine and nursing towards evidence-based practice, much of the research evidence to support it has systematically excluded evidence based on perceptions, practices, or contexts, according to Leeman and Sandelowski (2012). There has been a relative lack of attention to evidence from practice and to qualitative research as primary sources of evidence for evidence-based practice. The authors suggest the terminology used should change from “evidence-based practice,”
to “practice-based evidence.” Health care providers and recipients of care operate within social contexts. Qualitative research, in particular ethnographic, descriptive, narrative, and discourse approaches are suited to understanding how the social world is interpreted, experienced, and constituted (Leeman & Sandelowski, 2012). An autoethnography by a registered nurse living with chronic undiagnosed illness represents a legitimate qualitative study to provide “practice-based evidence” that expands nursing knowledge.

This proposed study highlights another missing perspective in the medical and nursing research literature. My autoethnography will address a gap in first person studies on chronic undiagnosed illness conducted by a nurse. I only found five examples of nurses’ use of autoethnography to explore their own illness (Allbon, 2012; Peterson, 2017; Sealy, 2012; Smith, 2015; White, 2003). A review of the literature yielded no studies utilizing autoethnography to explore living with undiagnosed illness.

Further, I propose to apply a systematic analytic approach including thematic analysis to strengthen the rigor of the autoethnographic study. Despite autoethnography’s increasing application in other disciplines of research and its inclusion in many sources on qualitative research methods, nursing has not extensively used this approach to study experience with illness. To my knowledge, no autoethnographies have been conducted by a nurse living with chronic undiagnosed illness.

**Purpose**

The purpose of the study is to address scientific gaps in knowledge regarding the experience of living with chronic undiagnosed illness and to describe how the cultural context of health care, family, and the nursing and medical professions impact that
experience. There is absence in the medical and nursing literature on what it is like for a registered nurse to experience living with chronic undiagnosed illness.

The study will employ qualitative research methodology to systematically analyze narrative and social context on living with chronic undiagnosed illness, contributing to nursing knowledge on the personal experience of illness.

This autoethnography of my experience as a registered nurse who has lived with chronic undiagnosed illness will help inform a research agenda (implications for future research) for the study of patients and health care providers experience with chronic undiagnosed illness. In addition, this study will help to identify the implications for a) health care practice, b) identifying needs of individuals with chronic undiagnosed illness, and c) improving medical and nursing education to provide more person-centered holistic care.

**Research Questions**

The research questions for the study are:

1. What is it like to be a registered nurse living with chronic undiagnosed illness?
2. How is the experience of chronic undiagnosed illness shaped by cultural contexts of health care, family, and profession?
3. What are the implications of my autoethnography for future nursing research, nursing and medical education, healthcare delivery, and patient empowerment and advocacy?
Significance

The story of having a chronic undiagnosed illness as experienced by a registered nurse has not been told in a systematic way, and this autoethnography may lend insight into how to better support clients and nurses who are experiencing chronic undiagnosed illness, and how to manage their care more effectively.

The study may provide recommendations for education and training of medical and nursing providers. Current education for providing nursing care is organized around categories framed largely by diagnostic disease categories. Nursing texts may address chronic illness specific to disease conditions such as cancer, but there is little guidance on nursing interventions for the client with no diagnosis. Autoethnography may lend insight into how the use of autoethnography benefits or has therapeutic value for the individual living with chronic undiagnosed illness: in other words, this method may help on future intervention design for patients. An undiagnosed illness also affects how others view one, and how one views oneself. It is important to understand how undiagnosed illness can inform sense of identity, including one’s identity as a nurse.

There is also potential benefit in improving the physician-client and nurse-client relationship. The “patient history” and description of their symptoms are the subjective elements, a beginning “story” that may help inform their diagnosis. An autoethnography extends that beginning framework to allow a holistic understanding of the illness experience. The proposed autoethnography can enhance the provider’s understanding of the personal experience of illness and help to promote a therapeutic relationship.

An autoethnography of undiagnosed illness goes beyond just relating the story of the illness episode and includes the broader sociocultural context, including medical and
nursing cultures. While some nurses have shared their experiences with specific illnesses using autoethnography as method, there are no autoethnographic studies of a registered nurse living with undiagnosed illness. It is not possible to know how many individuals (let alone nurses) actually living with undiagnosed illness, but there could be a significant number needing support and direction to guide their healthcare experience. This autoethnography may strengthen understanding of the “dual experience” of being a nurse and a patient.

While the predominant focus in both medical and nursing education prioritize interventions for disease, there is a need for knowledge based on research of how to manage care for those dealing with undiagnosed illness, who often seek many medical consultations and undergo repeated testing and procedures. Nursing practice needs to have evidence-based strategies and knowledge to address those living with undiagnosed illness. This autoethnography is a first step in building an evidence base, and identifying key topics for future research.
CHAPTER 2

Review of the Literature

This chapter begins by examining the literature pertinent to undiagnosed illness. The next section explores critical social approaches to illness, including influences from the history of medical education and philosophy, immunology, illness narratives, and the social construction of illness. Arthur Kleinman’s work on illness narratives is reviewed and a conceptual framework for the dissertation is introduced based on Arthur Frank’s work on illness narratives. Frank’s typology of restitution, chaos, and quest narratives are presented. The chapter concludes with key concepts for the dissertation.

Undiagnosed Illness

As previously stated, there is no data source that can identify exactly how many individuals there are with undiagnosed illness in the United States. It is possible to review data for some of the categories of illness that may include individuals with undiagnosed illness. There is also data on rare diseases and chronic diseases.

There are approximately 7000 rare diseases affecting one in ten Americans (Shen et al., 2019). Approximately 25 million people in the US are affected by rare diseases (Groft & Rubinstein, 2013). Each year, there are 250-280 new rare diseases described annually, internationally (Gainotti et al., 2018). It takes an average of 6 years or longer for someone to get a rare disease diagnosis, with an estimated 350 million living worldwide with rare diseases (Groundbreaking documentary on undiagnosed diseases, 2014), affecting 6 to 8 percent of the world’s population (Angelis, Tordrup, & Kavanos, 2014). Forty percent of rare disease patients are diagnosed incorrectly before receiving a final diagnosis, and 25 percent spend between five and 30 years experiencing numerous
referrals and tests (Shen et al., 2019). Many rare diseases are misdiagnosed as common
diseases due to their rarity (Shen et al., 2019).

Patients that are seeking a diagnosis for disease become “medical orphans” and
deal with “medically unexplained symptoms” (Nettleton et al., 2005, p.205). Neurology
is one medical field that has a high prevalence of unexplained illness.

Chronic disease is defined as a condition that lasts one year or more and requires
ongoing medical attention or limits activities of daily living or both (CDC, 2019).
Chronic conditions are a leading driver of annual health care costs, accounting for 90% of
the nation’s $3.5 trillion in annual health care expenditures for people with chronic and
mental conditions (CDC, 2019). Chronic disease data include those with specific
diagnosed conditions, such as heart disease, cancer, and diabetes. Those living with an
undiagnosed illness may be experiencing chronic disease by definition, but are not
captured in the data on chronic disease. According to the CDC (2019), 6 in 10 adults in
the United States have a chronic disease, and four in 10 adults have two or more chronic
diseases.

Current methods of capturing occurrence of disease are based on having an
established diagnosis, for example, measures such as incidence and prevalence.
Prevalence (per 1,000) is defined as the number of cases of a disease in a population at a
specific time divided by the number of persons in the population at the specified time
(Gordis, 2014). Incidence rates are based on the number of new cases of a disease that
occur during a specific time period in a population at risk for developing the disease.
Incidence rates capture new cases of disease (Gordis, 2014).
In reviewing problems with incidence and prevalence measures, Gordis (2014) cites the first problem is identifying who has the disease. Thus, diagnostic criteria play a crucial role in the numerator for calculating both prevalence and incidence. Some diseases may have multiple sets of diagnostic criteria for diagnosis. These factors particularly play a role in estimates of prevalence. A second challenge in disease surveillance identified by Gordis (2014) is in finding the cases that need to be included in the numerator. Some options include using available data or conducting studies to gather data to estimate incidence or prevalence. Difficulties in diagnosis, such as the patient not knowing the name of the disease, not receiving diagnosis, or the patient having the disease without awareness or manifest symptoms of the disease can contribute to errors in estimating the occurrence of individual diseases and in determining the overall magnitude of the problem (Gordis, 2014).

In reviewing the literature, it became clear that terminology used to describe undiagnosed illness present several challenges. Some terms that are often used in the literature are undiagnosed illness, chronic disease, and rare disease. A person with an undiagnosed illness may have a chronic condition, but chronicity of illness also happens with established disease. Those with undiagnosed illness may also present acutely with an initial presentation of the condition. A condition may be undiagnosed or difficult to diagnose because it is a rare disease, but not all undiagnosed illness stems from rare diseases. Common diseases can also be overlooked in the search for a diagnosis.

Some definitions of rare diseases include undiagnosed illness as one type of rare diseases (Spillman et al., 2017). Rare diseases according to this source include 1) rare and difficult to diagnose conditions, 2) atypical presentations, 3) conditions yet to be
described, and 4) manifestations that cannot be explained medically. Thus, undiagnosed illness is presented as a subcategory of rare diseases. This would presume that all undiagnosed illness is a form of some rare disease which may be a false assumption.

The terms undiagnosed illness, chronic illness, and rare diseases are sometimes used interchangeably in the literature. Spillman et al., (2017) relate that “undiagnosed diseases” are common, affecting 30 million Americans. When the original source for their statement was examined, it actually referred to rare diseases, not to undiagnosed diseases (Eurordis, 2005).

A lack of commonly accepted search terms presented additional challenges in locating literature. One example, is the search term “medically unexplained symptoms.” Another search term that was hard to identify early in the process was “orphan diseases.” After extended searching, another search term “invisible chronic illness” revealed more literature, but this term generally refers to those with a diagnosed chronic illness but with invisible symptoms. The words used to describe undiagnosed and rare diseases evoke emotion, such as “orphan”, “medically unexplained” and “invisible”; yet the literature fails to address these emotional and social dimensions.

This introduces the distinction between illness and disease where an individual’s experience of disease may not correlate with the biomedical label or interpretation of the disease. Disease is based on diagnosis, whereas, illness captures the individual’s perception and experience of illness (Giger, 2017). Kleinman (1988) argues that illness is culturally shaped, largely by the individual’s perceptions. He further describes how this emphasis on diagnosis turns out medical school practitioners viewing disease as a
“physical entity to be discovered or uncovered” (Kleinman, 1988, p.17). He depicts diseases as socially constructed categories.

Further, illness in general may occur in the absence of disease and often, visits to a physician may be for complaints without a biological basis (Kleinman, Eisenberg, & Good, 2006).

The term “undiagnosed disease” is also confounding. How can one have a disease without the label of disease? Thus, the term undiagnosed illness may present a more accurate descriptor for the patient’s experience.

Given the limited research that identifies how many individuals overall may be undiagnosed, there are examples in the research literature that try to project how many may have undiagnosed illness with specific disease conditions in select settings. One example of a disease condition where studies have tried to evaluate the extent of undiagnosed cases is with diabetes. Population surveys for diabetes have shown the 24 to 75% of prevalent cases across different countries have gone undiagnosed, and the diagnosis for diabetes has been estimated to lag from three to seven years (Porta et al., 2014). Other studies that have attempted to estimate undiagnosed cases for specific conditions include those on HIV (Eyawo, Hogg, & Montaner, 2013) and on dementia (Shao et al., 2019).

Illness-death models are sometimes used to approximate undiagnosed illness. Brinks et al. (2015) propose a state model which may have utility for estimating the incidence of partly undetected chronic disease. This model is proposed for irreversible chronic diseases with a preclinical state preceding a diagnosis. They propose incorporating undiagnosed disease into an illness-death model using information on
prevalence and mortality. Those undiagnosed are partitioned into categories of normal, undiagnosed, diagnosed, and dead. Complex epidemiological calculations are then applied to the condition of diabetes using the Health and Retirement Study. Again, these studies typically look at one or several disease categories, but cannot capture the overall number of those that have undiagnosed illness.

Resources for those dealing with undiagnosed illness include the previously mentioned Undiagnosed Diseases Network (UDN, 2019), a clinical research initiative funded by the National Institute of Health (NIH), which oversees a coordinating center affiliated with the Department of Biomedical Informatics at Harvard Medical School. Twelve clinical sites around the United States provide access to services, which also include care facilities. The UDN was founded in 2014, and has evaluated 1258 participants with 353 participants diagnosed (UDN, 2019).

The International Rare Disease Consortium was founded in 2011, representing a collaborative between the European Commission and the National Institute of Health to foster international collaboration in rare disease research (IRDiRC, 2019). Objectives of the IRDiRC are to diagnose all patients coming to medical attention within one year, to approve 1000 new therapies for rare diseases, and to develop methodologies to assess the impact of diagnoses and therapies on rare disease patients (IRDiRC, 2019).

Critical Social Approaches to Understanding Illness

Influences from the History of Medical Education and Philosophy

The beginnings of medical education in the United States help to demonstrate how early conceptualizations of disease have influenced and dominated modern medicine and nursing. Abraham Flexner was a former schoolmaster with no background in
medicine, who was chosen by the Carnegie Foundation to head up a commission to assess U.S. medical education (Lewis, 2010). Flexner used as his framework the medical education practices that were inspired by German university education and scientific research methods, then practiced at the Rockefeller Institute for Medical Research, where his brother worked.

The Flexner Report, issued in 1910 by the Carnegie Foundation, identifies the proper goals of medicine as the “attempt to fight the battle against disease” (Lewis, 2010). These early metaphors linking medicine to waging war influence recent conceptualizations in immunology. Flexner argued for medical training to be founded in the methods of natural science, viewing the human body as belonging to the animal world and their tissues and organs belonging to the domain of biology (Lewis, 2010). His argument that biological sciences provided the basic content for medical education is the origin of the pre-med emphasis on chemistry, biology, and physics. The Flexner Report transformed medical school education and created the curricular structure largely in use today.

Decades later, an emerging understanding that humans are not simply animals or physical beings and that they also live meaning-centered lives arose to challenge traditional medical education. In the 1970s and 1980s, resistance to the preoccupation with biology arose which introduced a more psychosocial and person-centered approach (Lewis, 2010). Medical scholars also began to take interest in other fields in the humanities such as philosophy, anthropology, and literature. Journals that reflected interdisciplinary areas began to appear, such as The Journal of Medical Ethics (1975), The Hastings Center Report (1975), The Journal of Medicine and Philosophy (1976),
The early works involving philosophy and medicine began to focus on the ethical aspects of the clinical encounter. These often dealt with conflicts between medical values, patient autonomy, and social justice. Medical practice in this time was viewed as needing to incorporate a moral relationship between patient and provider (Lewis, 2010).

The emergence of phenomenology which sought to understand the meaning and experience of illness is also a historical influence. The German philosopher, Edmund Husserl (1859-1938), did much of his work at the same time that the Flexner report was being issued (Lewis, 2010). Husserl viewed the flaws in science as stemming from the obsession with the objective, while ignoring the subjective. He viewed this objectivism, happening on the eve of Nazi atrocities, as contributing to a crisis in humanity (Lewis, 2010). The U.S. medical system was founded largely on the beliefs of European science; thus, it continues to promote objectivism which further places more emphasis on cure or symptom management and lack of attention to the personal and sociocultural (Lewis, 2010). Thus, there was the loss of the human aspects of care and medicine in its early roots emerged more in the United States as a form of applied biology.

It occurs to me that nursing science initially, for a few decades, provided a corrective intervention by embracing interest in studying the patient’s subjective experience, but as nursing re-oriented nursing science to conform more with medical science, an objective perspective became dominant in nursing science as well.

Phenomenology served to introduce a more humane understanding of the illness experience. When one is ill, there is more occurring than a biological event. The
patient’s experience of illness and their suffering need to also be understood both by the patient and the clinician. The idea of a wounded humanity becomes central to the healing relationship (Lewis, 2010).

**Immunology**

Critical interpretive approaches from medical anthropology and medical sociology later supported many of the same conclusions as phenomenology. Medical anthropology and medical sociology have critically examined some of the medical narratives that inform many of the concepts that relate to undiagnosed illness, particularly in immunology and neurology. An example of this is self-non-self theory, a major influence on immunology for over sixty years (Napier, 2012; Pradeu & Cooper, 2012).

In the 1960s, Peter Medawar and F. Macfalane Burnet received the Nobel Prize for Medicine for their work on immunity and introduced the concepts of self and non-self (Napier, 2012). Non-self was viewed as foreign. The body was seen to produce a protective antibody or defender of self, the “anti-foreign body”, that recognizes a foreign “antigen” (non-self). These terms were the conceptual building blocks of a medical narrative to describe immunologic processes understood as defensive and combative biological processes. These informed how clinicians interpret illness episodes and understand the symptoms.

These war-like metaphors used to describe immunologic processes also connote physical activity as battlefield tactics. Examples of metaphors are: recognize, scout, trick, discover, alert, evade, sense, recruit, mobilize, prod, defend, mask, scavenge, attack, invade, sacrifice, and kill (Napier, 2012). These metaphors can also imply that viruses
have agency and that they can physically move. Napier (2012) notes that viruses cannot move and require cells to come alive.

Anthropology has helped to illuminate this militarization of medical thinking (Stoller, 2012). Other examples of terms reflecting military descriptors include fighting cancer, battling disease, and the use of the term “survivor” for those that transcend their disease encounters. Stoller further critiques medicines tendency toward categorization and the imposition of a narrative as limiting our understanding of health and illness.

In spite of extensive critiques, and new narratives of immunology, these metaphors of immunology as a war-zone still pervade nursing and medical textbooks. For example, the following excerpt describing human leukocyte antigens (HLA), a person’s “universal product code”, is from a current baccalaureate medical surgical nursing textbook (Ignatavicius, Workman, & Rebar, 2018):

The HLAs are key for recognition and self-tolerance. The immune system cells constantly come in contact with other body cells and any invader that enters the body. At each encounter the immune system cells compare the surface protein HLAs to determine whether the encountered cells belong in the body. If the encountered cell’s HLAs match the HLAs of the immune system, the encountered cell is ‘self” and is not attacked. If the encountered cell’s HLAs do not perfectly match the HLAs of the immune system cell, the encountered cell is non-self or foreign. The immune system cell then takes action to neutralize, destroy, or eliminate this foreign invader (Ignatavicius, Workman, & Rebar, 2018, p. 290) (italics added).
There are also sociocultural connotations in this use of language. That which is foreign must be eliminated, eradicated, or destroyed. Current immigration issues in the United States also reflect the sociopolitical narrative to eliminate, restrict, or reduce the numbers of those who are foreign, and thus dangerous. There is again the theme of eliminating non-self. Napier (2012) argues that the tendency to view viruses as active agents stems from cultural beliefs that see otherness within us as dangerous, and underly the belief that self must be protected from all things foreign, including for example, viruses originating from “foreign” countries, contributing to a political ideology “infecting” medical narratives.

Contemporary immunology has replaced these outdated concepts that still pervade nursing and medical literature. In a more informed model, the body is viewed to actually create new versions of otherness rather than mutations of self. Bone marrow (B) and thymus cells (T) explore otherness, rather than defend self (Napier, 2012). In Napier’s view, the outdated model is replaced with a view of the immune system functioning as more of a search engine versus an eliminator of difference. Immunology, according to Napier, may be seen less as a battle against non-self and more as the body’s creative attempts to engage difference much like a system of information assessment and creativity. Antigens may develop from nucleic acids of normal cell genes, i.e.; from former selves (Napier, 2012).

Another immunologic theory which emerged to challenge self-non-self theory is danger theory (Pradeu & Cooper, 2012). Danger theory views immune responses as triggered by danger signals released by the body’s cells. Immune response is seen as more of a response to damage to the organism’s cells or tissues. Damage signals cue the
cellular distress and immune responses. Despite danger theory’s emergence in the 1990s and 2000s, nursing texts still lag in incorporating these theories, still perpetuating the self-non-self narrative.

Medical narratives about neurology also influence understanding of illness. Medical anthropology is seeking to understand the relationships between neuroscience, the self, and society (Gardner et al., 2018). Early influences in neurology focused primarily on the physical brain and tended to support brain-based explanations for behavior (cognition). Neuroanthropology is a developing field that recognizes the brain as dynamic and responsive to context. There is now blurring of the traditional distinctions between biology and culture with opportunity to better collaborate among the fields of anthropology, neuroscience, and psychology (Gardner et al, 2018).

Bridging this new narrative in neurology is the concept of neuroplasticity. Neuroplasticity is a concept based on the emerging evidence that the brain has capacity to reorganize itself following brain damage (Fischer-Baum & Campara, 2017). It is not certain whether this reorganization of the neural system following damage relates to whether the function reorganizes to another region that typically doesn’t carry that function or whether it could be due to refinement of an alternative neural pathway (Fischer-Baum & Campara, 2017). There may be support for the role of environment in rehabilitation and optimization of recovery following neurological injury whether from stroke, multiple sclerosis, or Parkinson’s disease (Khan et al., 2017). In Khan’s et al. study, exercise is an example of an evidence-based intervention that demonstrates some capacity to enhance neuroplasticity in certain neurological conditions. Thus, neuroplasticity informs the medical narrative about neurological illness and brain
function by introducing ideas such as rewiring, connectivity, improved connection, and remyelination. It is a transformative, connective, regenerative narrative.

**Social Construction of Illness: Philosophical Underpinnings**

Today, the social construction of illness is a major research area, particularly in medical sociology and medical anthropology. However, the origins of social constructionism go back much further, influenced by early anthropologists and sociologists; followed by contemporary approaches to an emerging “qualitative research” framework. Grounded theory, symbolic interactionism, and phenomenology developed in the 1960s (Conrad & Barker, 2010).

Parson’s sick role theory, which was published in the 1950s, established an early framework for looking at sickness behavior (Conrad, 1990). Sick role theory was taught in nursing programs for decades and influenced the belief that return to state of wellness was the preferred normalcy. Sick role theory also limited the patient’s own agency, placing the health provider in the primary role.

Nursing research on the experience of illness has utilized grounded theory, phenomenology, ethnography, narrative, case study, and autoethnographic approaches. Grounded theory was one of the earlier qualitative research approaches to studying chronic illness. Charmaz (1980) utilized a social constructionist grounded theory approach to understand meaning of illness in chronic illness. Chronically ill people experience their constructions as reality. Their constructions reflect understanding of their experiences in varying situations in which they experience them, according to Charmaz (1990). One of the areas where Charmaz extended understanding with respect to chronic illness is in sense of self and the experience of illness (Gerhardt, 1990).
Symbolic interactionism asserts that human actions depend on the meanings that people ascribe to their situations (Charmaz, 1990). These meanings derive from shared interactions, and language plays a key role. This philosophical approach has influenced diverse efforts to understand meanings of the illness experience.

Stigma emerges as a key concept in understanding illness experiences. Irving Goffman (1963) helped inform this tradition emphasizing that individuals actively participate in the construction of their social worlds and introducing the conceptual of stigma, and highlighting that not all meaning is affirmative or positive, but can confer shame.

The writings of Michel Foucault in the 1970s also contributed to a social constructionist approach. Foucault related how medical discourse constructs knowledge about the body and disease (Conrad & Barker, 2010). More recently, individual studies are emerging that look at the experiences of living with different specific illnesses (Conrad & Barker, 2010). However, most patients do not have formal exposure or training in the discourses (or narratives) that shape medical practice.

Some of the implications of these qualitative approaches are that they illuminate the perspective of those who are ill and bring the focus of health care back to the person who is receiving care. They treat the individual as less of an object for study and incorporate a view of the illness experience as multidimensional. These approaches also help to inform on relevant concepts to an illness experience, such as the concepts of loss of self and an illness identity.
Meaning of Chronic Illness and Qualitative Research

Some of the first efforts to understand chronic illness through a qualitative lens began around the 1960s with Anselm Strauss and the University of San Francisco School of Nursing (Gerhardt, 1990). These efforts emerged from Grounded Theory and concepts around life management. Strauss and Glaser (1975) described the effects on life management when dealing with a chronic condition. This next led to written works on life management based on patients with the same diagnosis (Gerhardt, 1990).

Charmaz extends earlier work on life management in chronic illness further by focusing on how illness and suffering undermine a person’s sense of self and their ability to execute effective strategies for life management (1980). Suffering loss of self is seen to arise out of daily life in chronic illness, existing due to social isolation, and leading to discredited definitions of self where one becomes a burden (1983). Illness was believed to be experienced in the context of daily interactions which altered performance of self (Charmaz, 1991; Glaser & Strauss, 1965). Themes that Charmaz identified across several studies on diverse illnesses included: self-esteem, continuing and changing self-concept, and relations between time and identity (1990).

Charmaz’s later work in the 1990s focused on how individuals construct and manage their illness (Conrad & Barker, 2010). Charmaz documented how persons managing chronic illness find their worlds shrink when challenged with day to day management of chronic illness and their foundation of sense of self can be lost with nothing to look forward to (Conrad & Barker, 2010). Charmaz continued research on meaning of illness and studied other aspects of chronic illness including disclosure of illness to others in addition to continued work on identity and chronic illness (1990). Her
work on chronicity of illness affecting self-concept has influenced subsequent qualitative studies on illness.

In the 1970s Grounded Theory became a less dominant paradigm in medical sociology, somewhat overshadowed by interest in Phenomenology (Gerhardt, 1990). Phenomenology, which emphasizes studying objects of consciousness, allows one to study emotions which have applicability in understanding an illness experience (Charmaz, 1990). This leads the researcher to examine the participants interpretation of experience and action. In 1975, the first work using ethnomethodology to focus on the process of illness management was published: *Chronic Illness and the Quality of Life* (Gerhardt, 1990). This was followed by a focus on families’ experiences with illness and later by more avid interest in lay knowledge of illness and their relationship to medical encounters (Gerhardt, 1990).

A phenomenological approach focuses on how the body is experienced in illness and in health along different dimensions of illness such as: as an aspect of the world, as reflective, as observed, as focus of appreciation, and as call (Van Manen, 2014).

Cultural context is not a focus in this approach. An example of a work that incorporates phenomenologic writing is Carol Olsen’s *The Life of Illness*, where she remembers tales of the body in living with dialysis for several decades (1993). Van Manen’s more recent text on how to research lived experience supports the need to investigate experiences as we live them, citing biographies as a resource and also noting diaries, journals, and logs can be meaningful sources of lived data on experience (2015).

In nursing, the movement to include caring as a central nursing concept enables a broad research approach to the illness experience that can examine diverse forms of
knowledge. The philosophical foundations for Watson’s theory of caring allow for multiple forms of knowing and knowledge sources. Her work calls for a caring science to go beyond conventional reductionistic scientific epistemology (Watson, 2012). Watson expresses that health illness and healing experiences are concepts that may be better researched in the context of caring science and by considering knowledge and theory along a continuum, which allows for a range from the concrete to the abstract in nursing concepts. Watson also supports the use of self and believes that feelings, experiences, and transcendental understanding inform nursing knowledge and caring science. The work of Patricia Benner also supports the linkage between caring and the understanding of health and illness (1994; Spichiger et al., 2005). Patricia Benner has used phenomenology as an approach for developing caring science.

**Illness Narratives**

Around the 1980s, Arthur Kleinman’s work on illness narratives was published which reemphasized consideration of the illness experience from a narrative research perspective (Kleinman, 1988). The narrative became more than just the content of the story, serving to illuminate suffering and give patients a voice. Arthur Frank (1995) further extended this work on narratives. For decades, illness narratives occupied a more peripheral position in social scientific study; today it plays a central role documenting the illness experience in a social context (Hyden, 1997).

Illness narratives serve several different functions: to construct the illness experience, to reconstruct life history, to help make disease and illness understandable, and to share the collective experience of illness. They also express the challenge of giving voice to the experience of being ill in modern society (Hyden, 1997).
Wideman-Johnston (2016) published her dissertation using narrative inquiry to look at her chronic illness experience living with Diffuse Irritable Gastrointestinal Tract Syndrome. Findings from the study focused on issues of identity, extraordinary gifts received (secondary to illness), and tensions in understanding chronic illness. A recommendation of the study is for the need for continued illness narrative research and for providing authentic accounts of what living with chronic illness entails.

Illness narratives gained interest by the field of medicine in the early 2000s. However, in this shift, the term illness narratives was changed to “medical narratives.” Medical narratives can take the form of a number of different types such as medical fiction, lay exposition in the form of published essays in lay journals, medical autobiography, stories from practice, and also writing exercises used as part of medical training. (Charon, 2001). Illness narratives and findings from illness narratives research are being used in medical education to improve physician communication skills, enhance empathy, and to promote physician self-reflective practice (Arntfield et al., 2013; Brown & Garden, 2017; Charon, 2001; Hatem & Rider, 2004; Pearson, McTigue, & Tarpley, 2008). Findings from medical narratives research are also utilized to enhance the doctor-patient relationship (Charon, 2001; Coulehan, 2003; Harter & Bochner, 2009) and further serve to document suffering of patients (Harter & Bochner, 2009). It should be noted that in changing the terminology from illness narratives to “medical narratives”, medicine exhibits a form of paternalism, inferring that the illness narrative derives from the practice of medicine rather than from the patient’s story.

Physicians’ interest in illness narratives legitimated an approach of research that nurses had been doing prior to that for approximately twenty years. Hutchison (1999)
provides evidence of this in a historical review of qualitative nursing research. In the 1960s, nurses applied to do PhDs in social science areas funded by the federal nurse scientist program. By the 1980s, many of the schools of qualitative inquiry were emerging: ethnography, grounded theory, and phenomenology. The 1990s saw the early publication of textbooks on qualitative health research. Morse and Johnson (1991) published *The Illness Experience: Dimensions of suffering*, based on grounded theory research exploring different types of illness experience in patients (Hutchison, 1999). Clearly, nursing’s focus on qualitative methods and the illness experience predates the emergence of medical narratives.

Nursing has utilized narrative method as a way to inform understanding of the patient experience and also to better understand nurse’s own personal experience of illness. Narrative research was advanced as an appropriate qualitative methodology in the nursing profession (Holloway & Freshwater, 2007; Overcash, 2004). Guzman (2009) examined a nurse educator’s experience as a breast cancer patient using a narrative research approach. The genre of nursing narratives exploring a nurse’s experience with illness vary from informal personal essays to more structured qualitative studies. Women’s online narratives of cancer have been studied by nurses (Keim-Malpass & Steeves, 2012). Knight (2018), a nurse, utilized a personal diary to document and analyze her breast cancer experience.

Joyce (2015) argues for narrative’s place in nursing research, which can take the form of life history, recollection of life incidents, patient’s storytelling of their experiences, biography, and also autobiography. Narrative occurs in both clinical and
therapeutic settings for nursing, allowing patients to create meaning of their experience through narrative (Joyce, 2015).

**Qualitative Research and Undiagnosed Illness**

There are few qualitative studies on living with undiagnosed illness. Nettleton et al. (2005) did undertake a study exploring narratives of people living with medically unexplained symptoms that had not been diagnosed. Three features they identified were the chaotic structure of their illness narratives, concern that their symptoms may be “all in the mind”, and their status as marginalized by doctors. Despite their desire to secure a medical diagnosis, the individuals in the study were more concerned to receive ongoing medical and social support.

One of the practice recommendations from this study is for health practitioners to understand that a patient narrative that is chaotic does not indicate the patient is confused, but rather, it may tell more about the social expectations around being sick. An undiagnosed patient is unable to legitimately enter the sick role. Physicians are also urged to provide more patient centered care to those with medically unexplained symptoms. Patient centered care that is more focused on the illness experience may provide a better framework for support (Nettleton et al., 2004).

The issue of how to handle those with medically unexplained symptoms is not prevalent in the medical and nursing literature, in particular in the United States. One study from Norway conducted a metasynthesis of qualitative studies looking at how general practitioners manage patients with medically unexplained symptoms (Johansen & Risor, 2017). Concepts were analyzed across 13 qualitative studies on unexplained medical symptoms.
This synthesis found that there is epistemological incongruence between the concepts of disease used by doctors and patients (Johansen & Risor, 2017). Physicians who could not identify the diagnosis or source of the patient’s complaint experienced helplessness, frustration, and failure, reflective of a lack of power to solve the patient’s problems. Flexible approaches to patient management that take the patient’s social background and life into account were recommended. Another suggestion is the need to reframe understanding and management for those with medically unexplained symptoms and the need to balance the ideal with the real, where ideal is presented as biomedicine as a learned discipline and the real is experience-based knowledge. A psychosocial model is presented as more appropriate for reframing of the illness experience in these instances, where there is a move from curing to caring and coping with illness.

**Autoethnography as a Research Approach**

**The Development of Autoethnography**

There are competing versions of how autoethnography developed. The discipline of anthropology provides the true early origins of autoethnography. The branches of evocative and analytic autoethnography associated with the discipline of sociology evolved later.

Reed-Danahay (1997) is credited with writing the first historical overview of the term “autoethnography”. David Hayano, a cultural anthropologist, published an essay on autoethnography in 1979 that detailed the use of self-observation in ethnographic research (Anderson, 2006). The origins go back even further, with Hayano explaining that “autoethnography” as a term was first coined in 1956 and was based on a seminar by Raymond Firth detailing an argument regarding Kikuyu practices in Kenya between two
sources that each claimed native knowledge of Kikuyu practices (Reed-Danahay, 1997). This story set the stage for the early origins of autoethnography as a form of self-representation by trained anthropologists that include criticism of privilege from an outsider’s perspective and which incorporate resistance to structures of knowledge as power (Panourgia, 2000). Thus, the early definitions of autoethnography, as viewed by anthropologists, directed researchers to the study of one’s own people.

A second interpretation of the meaning of autoethnography is in the use of personal narrative in ethnographic writing (Reed-Danahay, 2017). There is controversy and difference of interpretations between the two definitions. It is generally agreed that autoethnography places self as researcher or narrator in a social context, but there is continued tension between dichotomies of insider versus outsider, and objective observation and participant experience (Reed-Danahay, 2017).

Reed-Danahay (2017) more recently concludes that autoethnography today includes three separate genres: portraits of a social group the author-anthropologist is familiar with, life writings or autobiographies that include ethnographic description of their social group, and anthropological writing including reflexive descriptions during ethnographic fieldwork.

After the developments in anthropology, the discipline of sociology continued to expand autoethnographic approaches. This was aided by researchers and scientists in sociology with the University of Chicago (Anderson, 2006). This interest in biographical research, more a form of sociological ethnography, was further developed under what is known as the Second Chicago School. In this approach, the ethnographies produced
tended to not include any personal narrative or personal notes in their writings (Anderson, 2006). These studies more accurately resembled ethnographies.

In the 1960s and 1970s, sociologists began to experiment more with self-observation methods. In 1975, Karl Heider asked 50 Grand Valley Dani school children, ‘What do your people do?’ in the Grand Valley of West New Guinea, and called their collective responses autoethnography (Ellis, 2016). In 1979, cultural anthropologist David Hayano’s published essay on autoethnography established the argument for autoethnographic method and he is also given credit for the early use of the term, autoethnography (Anderson, 2006). Hayano later published his personal account as a professional poker player. Other social scientists, including Louis Zucher in the 1980s, continued to expand the role of autobiographic and self-observant research. These social scientific traditions have been influences in the emergence of what is known as the realist or analytic tradition in autoethnography (Anderson, 2006).

A second approach to autoethnography known as evocative autoethnography, also derived from the fields of sociology and communications in the late 1990s at around the same time as analytic autoethnography. Recognized scholars that are proponents of evocative autoethnography are Carolyn Ellis, Norman Denzin, and Arthur Bochner. Carolyn Ellis began her exploration into the genre of autoethnography studying her personal grief and loss after the sudden death of her brother, and also her partner's traumatic experience with a terminal illness, end stage emphysema (Ellis, 2004; Ellis, Adams, & Bochner, 2011). Evocative focuses on the emotional dimension of experience. The differences of these two approaches and their considerable overlap will be detailed below.
Definition of Autoethnography

Autoethnography is a form of writing that combines an ethnographic look at one's outer world with and looking inward towards one's own autobiographical story of self (Schwandt, 2007). Custer (2014) explains autoethnography as a style of autobiographical writing and qualitative research that explores individual life experiences in relation to social and cultural institutions. Ellis, Adams, and Bochner (2011), adherents to evocative autoethnography, define autoethnography as “an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (p. 273).

Autoethnography is also a method of qualitative inquiry that utilizes data about self and context to gain understanding regarding connectivity between self and others in a given context (Ngunjiri, Hernandez, & Chang, 2010). In this approach, the researcher is both research participant and researcher using narrative of one’s experience to generate greater self-understanding. Interpretive approaches to qualitative inquiry, including symbolic interactionism, seek to understand the meaning of experience (Denzin, 1989; Thorne, 2016). Social constructionism, which posits the belief that reality does not just exist, but is actively and continually constructed, is a philosophical approach compatible with autoethnographic method. Self is believed to be interwoven with social exchange, and self then belongs to “other” as much as to oneself (Foster, McAllister, & O’Brien, 2006). Thus, autoethnography can illuminate not only subjectivity, but also intersubjectivity.

The act of writing itself can be seen as a way of knowing and a form of inquiry (Ellis, 2004; Ellis, Adams, & Bochner, 2011). Stories can be viewed as theoretical in
their attempt to explain life (Ellis, 2004). Further, narratives can be viewed as having a mode of reasoning (logico-scientific) and a mode of representation. The logical scientific approach looks for universal conditions of reality, and the mode of representation examines connections between events. This approach validates autoethnographic writing not just as a style, but as a form of research inquiry.

Carolyn Ellis and Arthur Bochner define autoethnography as “an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural” (2016, p. 65). They describe autoethnography as using an ethnographic wide lens to focus outward on social and cultural aspects of personal experience and then focusing inward on a vulnerable self that is moved by and moved through cultural interpretation. The “multiple layers of consciousness” in Ellis & Bochner’s (2016) definition is poorly defined.

**Autoethnography: Incorporating Culture and Meaning**

Amanda Coffey (1998) in *The Ethnographic Self*, examines the role of the ethnographer’s personal experience and presence in relation to fieldwork. Tracing the early history of ethnography which positioned the researcher’s emotional experience as either absent or included in a more distant peripheral position, Coffey speaks to a new wave of ethnographic writing which is placing more emphasis on body and self, and uses the ethnographic writing and analysis to explore the self. This work supports that it is possible to put the emotional personal experience of the researcher as central in an ethnography. Fieldwork entails both the cognitive and the emotional, and the ethnographer has to be committed to conveying the effect of lived experience, not separating cognitive and the emotional (Coffey, 1998).
Coffey (1998) also speaks to the autobiographical side of fieldwork and ethnography. Similar to autobiography, ethnography is about experience, remembering, ordering, and giving a framework to one’s memories. Ethnography is an act of memory, both individual and collective and tied to cultural meanings and language shaping memories. Despite establishing linkage in her writing to going beyond ethnography in newer forms of autobiographical writing, her final conclusion in the book expresses hesitancy to fully embrace some forms of autobiographical writing as ethnographic. This book was published immediately prior to the emergence of focus on narrative medicine, and predates more recent work on autoethnography.

A how-to handbook on conducting an autoethnography was introduced by Chang (2008). This is a frequently-cited work by other researchers and provides detail specific to method, including how to collect autoethnographic data, how to analyze and interpret autoethnographic data, how to collect self-observations and self-reflective data, and includes writing exercises for autoethnography. Chang proposes that self narrative can be used as a cultural text through which cultural understanding can be gained (2008). However, it is critical to note that telling one’s story alone does not provide cultural understanding. That is gleaned through in-depth cultural analysis and interpretation. This source also supports the position that autoethnography is an excellent tool for use with medical personnel and human service workers to help gain understanding of others (Chang, 2008).

Madison’s (2012) book on critical ethnography prompts two questions. The first is whether autoethnography could be considered critical ethnography. A critical ethnography defends those who are out of reach, and as such an autoethnography about
those living with undiagnosed illness helps to make visible their needs and challenges. Madison quotes Habermas’s three positions of social inquiry: 1) the natural science model of empirical analysis, 2) the historical and interpretive model, and 3) the critical theory model (Habermas, 1971). An autoethnography on chronic undiagnosed illness exemplifies the historical and interpretive model by describing the sociological factors that impact the illness experience.

This autoethnography may show how social life can overcome social oppression: in this case, the components of social life being the cultural elements and social oppression may be illustrated in how society and its subcultures respond to those with chronic undiagnosed illness.

Madison’s (2012) work states the requirement that critical ethnography requires dialogue with others, raising the question of whether an autoethnography would meet that criteria. An autoethnography may begin with a focus on self, but as it is discussed and debated with others, and is experienced by the reader; it moves beyond the subjective self to show how an autoethnography extends to others and is not just an exclusive experience.

Autoethnography is an ethnography of one’s own cultural group or an autobiographical focus with an ethnographic or extended contextual interest (Madison, 2012). John Van Maanen (1988) proposed four alternative ethnographies that extend beyond traditional realism of ethnography. There is confessional ethnography where there is focus on oneself. My autoethnography illustrates that. Dramatic ethnography takes the form of dramatic narrative of performance. The third, critical ethnography has a guiding purpose or advocacy agenda. There are elements in my autoethnography that
meet that form in that I want to identify how to better care for those with chronic undiagnosed illness, both individually and as a collective health care system, and also to raise awareness of a group that is not well addressed in health care literature. The fourth alternative autoethnography Van Maanen identifies is autoethnography itself, combining autobiography with ethnography. This autoethnography meets three of the forms of alternative ethnography.

Elements of autoethnography are also informed by other qualitative schools of thought. Van Manen (2014) describing phenomeonologic practice speaks to wonder as being a central method of phenomenologic inquiry. Philosphic reflection, he explains, results from wonder. One uses reflexivity of experience to answer broader questions that seek to find meaning. An autoethnography examining undiagnosed illness begins with this “wonder” about what that experience is like and seeks to answer what is the underlying meaning of the experience.

Specific to writing, Van Manen (2014) explains that writing creates a different temporal spatial quality, an immediacy of presence, that is both near and distant at the same time. In addition, he explains, reading a text oralizes it, further contributing to immediacy of presence. An autoethnography, being a written description of experience meets this description. Further, as there are elements of past and present in the capturing of memory, it exemplifies the quality of being near and distant. The reader of an autoethnography is further “oralizing” the text.

Early ethnography with its early influences from anthropology emerged as a method for studying the “other”, also known as the etic perspective (Patton, 2018). What began as interest in exotic cultures later extended in the U.S. to studying others such as
African Americans, American Indians, immigrants, working class families and the poor. In contrast to the focus on other, an emic perspective emerged which looked at the insider’s perspective. Giving a voice to the researcher; the role of the researcher is expected to be visible, described, held responsible for developing findings about “the other.” This has called into question the relationship between the observed and the observer in the postmodern world (Patton, 2018).

An additional question is how the ethnographer can study one’s own culture. Autoethnography is one approach to this and is referred to by Goodall (2000) as the new ethnography where use of creative narratives based on the writer’s personal experiences within a culture is addressed to academic and public audiences (Patton, 2018).

**Features of Autoethnography**

A commonality to the many definitions for autoethnography are the concepts of personal experience and culture (LeRoux, 2017). Autoethnography is written in first person voice and can take a variety of forms including: short stories, poetry, fiction, novels, photographic essays, scripts, personal essays, journals, fragmented writing, and social science prose (Ellis, 2011).

The goal of an autoethnography is to articulate an expanded knowledge of self in a situated context. Anderson (2006) reflects that autoethnography provides opportunity to explore some aspect of one’s social life in a deeper manner to inform broader social understanding. Ellis, Adams, and Bochner (2011) note that autoethnography combines features of both autobiography and ethnography. They relate that autobiographers often write about “epiphanies” highlighting times of crisis that compel a person to analyze lived experience. In ethnography, a culture’s practices, common values, beliefs, and
experiences are studied to help insiders (members of the culture) and outsiders (cultural strangers) better understand the culture and the conditions that shape it (Ellis, Adams, & Bochner, 2011).

One of the ways this knowledge of self is achieved is through reflexivity. Reflexivity is a central concept in both the evocative and analytic approaches to autoethnography (Anderson, 2006; Custer, 2014; Ellis, 2004). Reflexivity is a self-conscious introspection aimed at understanding one’s connection to others in the research situation and also one’s effect upon it (Anderson, 2006). There are reciprocal influences between the ethnographer, their settings, and informants (Anderson, 2006). Ellis and Bochner (2016) describe this as a shift in ethnography from participant observation to a focus on observation of participation where ethnographers reflexively write about themselves as participants who speak, ask questions, make comments, have feelings, and tell stories.

Writing personal stories is seen as making “witnessing” possible (Anderson, 2006; Ellis & Bochner, 2006). This witnessing refers to the ability of the participant and the reader to listen to, or speak about, observe, and subsequently, better testify on behalf of an experience (Adams, Ellis, & Bochner, 2011).

Autoethnography is considered transformative in several ways. One way explained by Custer (2014) is in its ability to change time by altering an individual’s perception of the past, inform their present, and reframe their future. In entering situations again by writing about them, there is a reformation of the way one views something experienced (Custer, 2014). Anderson (2006) affirms that analytic autoethnography expands knowledge of self, transforming the researchers own beliefs,
actions, and sense of self. According to Anderson (2006), this happens largely in part because the researcher is not a distant observer, but is being reflexive, self-introspective and examining reciprocal influences between self, settings, and informants.

Writing personal stories can also be therapeutic for both the writer and the reader (Adams, Ellis, & Bochner, 2011; Anderson, 2006; Custer, 2014; Ellis, 2004; Frank, 1995; Kleinman, 1998). Autoethnography not only allows one to work with others to validate the meaning of their experience, but also to feel validated or better able to cope with their circumstances (Bochner, Ellis, & Adams, 2011). Ellis (2004) affirms that autoethnography is therapeutic for writer, participant, and the reader. Autoethnographies about illness, in particular, can be therapeutic, as in Caroline Allbon’s (2012) autoethnography of dealing with multiple sclerosis, which made the invisible aspects of chronic illness visible.

**Nursing’s Use of Autoethnography to Understand Personal Illness**

Autoethnography has been used to document and analyze personal experience of illness by non-nurses. For example, Simeus (2016) in her dissertation uses the autoethnographic method to narrate her experiences with cancer and identify the theme of dance to describe her experience of treatment and survival.

There are, however, very few examples of nurses’ use of autoethnography specifically to study their own illness. Only five autoethnographies by nurses specifically analyzing their own illness were located (Allbon, 2013; Peterson; 2017; Sealy, 2012; Smith, 2015White, 2003). Cotter (2017) writes an autoethnography related to her experience with Crohn’s disease, with the autoethnography focused on developing autoethnographic method.
There are common elements in the autoethnographies written by nurses including the concepts of identity, transformation, embodiment, invisible illness, symptom management, and empathy (Allbon, 2013; Sealy, 2012; White, 2003). Several of the autoethnographies examine the physician-client role and critique the health care system’s effectiveness in meeting their needs (Allbon, 2013; White, 2003). Unlike patient narratives, nurses’ autoethnographies document their extensive insider or provider knowledge of the health care system.

In 2013, Caroline Allbon, a nurse and educator, wrote her dissertation using autoethnography as her methodology analyzing her transformation from being a person without multiple sclerosis (MS), to being a person with MS, to culminate in living creatively with MS. She analyzed personal journal entries to examine her embodied experience of MS. Her autoethnography illustrates the contextual issues surrounding living with an illness with invisible symptoms. Her autoethnography analyzes the role of medicine as a form of social control and challenges the biomedical dualism in medicine which separates out her psychological, emotional experience of living with MS from the physical aspects of disease. She challenges medicine’s view of the medical encounter as “surveillance” which treats the physician as the investigator and the patient as a passive object (Allbon, 2013)

This autoethnography dissertation (Allbon, 2013) presents an “Alice in Wonderland” type narration to tell her story of living with multiple sclerosis. Her study findings focus on implications for organizational learning and leadership development. The analysis of narrative highlights the need for leadership and institutional change for those who care for individuals with chronic illness. One recommendation from her study
is for physicians to better learn how to manage patients facing clinical uncertainty. She advocates strongly for the use of narrative and autoethnography vignettes to enhance representation and reflexivity in qualitative research (Allbon, 2013).

White’s (2003) autoethnography documents her experience with chronic nonmalignant back pain. White relates that chronic pain sufferers represent a marginalized group and that her personal hospital experience was not positive, influenced by nurses treating patients based on negative stereotypes and attitudes. White first began her study as a grounded theory design with interviews, in which she identified the following themes: 1) loss of control, 2) speaking into the void (health care workers not listening), 3) body image distortion, 4) stigma, 5) fear of addiction, and 6) everyone else knows best (patient viewed as incapable of making own decisions). She then shifts to autoethnographic findings, yet does not detail the specific autoethnographic findings. This is a less compelling use of autoethnographic method.

An autoethnography on the use of reflexive journaling and meditation to cope with breast cancer was published by Sealy (2012). The findings from Sealy’s autoethnography supported the following implications for practice. First, unresolved emotional issues from the past can complicate treatment and recovery for locally advanced breast cancer. Secondly, cognitive awareness of unresolved emotional trauma alone may not be sufficient to reduce emotional pain. Third, reflective journaling and meditation can provide an opportunity to socially reconstruct past psychological injury. Sealy posits that both patients and nurses may be hesitant to share past traumas out of being ashamed of what happened to them. Autoethnographies, she argues, may be a way to compare personal experience to others’ stories, leading to personal life transformation,
enhanced self-awareness, therapeutic use of self, and to enhance empathy. Identity is also an evident theme in the autoethnography, with Sealy analyzing her mothering role and her own concepts of self-acceptance and self-worth.

Living with kidney disease, end stage renal failure and the lived experience of kidney donation within a First Nations context (indigenous peoples in Canada) was explored by a nurse in an autoethnography (Smith, 2015). The author used journal records of her medical trips and appointments with specialists as her data. Her son is the one with end stage renal failure and she donated her kidney to him. This autoethnography details the author’s experience, but unfortunately does not demonstrate systematic analysis or thematic integration. It serves primarily as narrative of the experience. The main cultural context explored is the First Nations perspective.

Peterson (2017), in her autoethnography, documents a first-person account of the experience of stigma as a nurse with mental illness, using autoethnography. Peterson uses the literature on stigma and mental illness to compare and analyze her personal experience. Her autoethnography documents themes regarding work colleagues knowing about her mental illness; experiencing stigma by regulatory agencies that required disclosure of mental illness; but not physical illness, the tendency to view a person with mental illness as dangerous. She details experience of nursing management actions and analyzes power differentials between those who have mental illness and those who treat or employ people with mental illness. Implications for this autoethnography focus on the need to raise nurse’s awareness of stigmatizing those with mental illness, in particular, their peers with mental illness. The autoethnography’s data includes written notes by the author, but the researcher does not detail the specific handling of autoethnographic data,
or how data was extracted and analyzed. Although the conclusion section relies on
literature support, the researcher relies less on findings from the autoethnography to
support conclusions.

A nurse with Crohn’s disease conducted an autoethnography on the history of
autoethnography as method (Cotter, 2017). More a reflection on autoethnographic
method than on the author’s illness, the study does not extend particular knowledge on
living with illness. It is, however, an insightful work on the challenges of first-person
research. The author notes that silence surrounds many experiences that do not fit within
cognitive or rational paradigms of health care. Through her life experience, including her
eyearly nursing studies, later PhD pursuit, and work in public health, she illustrates how
personal and non-rational aspects of life can be left out of research. Autoethnography, she
explains, is one way to use story to illuminate and develop methods to address these
missing areas in research (Cotter, 2017).

Etorre (2006), a sociologist, produced an autoethnography detailing her
experience with acute thyrotoxicosis. While not a nursing autoethnography, it is a work
focused on illness through a sociologic and cultural lens. Through her personal narrative
she explores how medicine’s views toward mind-body dualism and gender impact her
experience. She analyzes the impacts on her self-identity and loss of self that
accompanied her illness. Another key finding is the understanding that a single cultural
perspective cannot, by itself, reveal truth. She argues that narrative allows for a plurality
of truths which align with her study’s theme of multiple fractured aspects of self (Etorre,
2006).
All of these autoethnographies try to form a holistic perspective on an illness experience in diverse cultural contexts. In narrating the multiple identities that the nurse occupies through multiple health encounters, these autoethnographies generate of findings that support recommendations for reforms for a fragmented health care system. In addition, those autoethnographies that applied an analytic approach demonstrated the strongest findings with implications for nursing.

**Analytic Lens for My Autoethnography**

Although the aim of my autoethnography is not to develop theory, the work of two scholars informs the general analytic lens for my study.

**Arthur Kleinman**

Two classic authors that exemplify the medical sociology and medical anthropology approach using illness narratives are Arthur Kleinman (1988) and Arthur Frank (1995). Arthur Kleinman, who is identified as one of the founders of research on illness narratives, examines the personal and social meanings of illness through illness narratives.


It is Kleinman that advocated for a return to the illness experience. He promoted an emphasis on the need for meaning-centered medical practice that focused on more than just the physical body and included an empathic understanding and witnessing of the
experience of suffering (Lewis, 2011). He critiques the patient-clinician experience as missing this critical understanding of the personal meaning of illness. In fact, he argues that the patient-physician interaction is organized as more of an interrogation.

Practitioners, in his view, have not been trained to be “self-reflective interpreters of distinct systems of meaning” (Kleinman, 1988, p. 17). Instead, physicians view disease as an actual physical entity to be discovered and cured.

Kleinman brings forward in his writings the distinction between illness and disease, as explanatory models one uses to conceptualize sickness (Kleinman, 1988; Kleinman, Eisenberg & Good, 2006). Disease according to the paradigm of Western medicine refers to “malfunction or maladaptation of biologic and psychophysiologic processes in the individual; whereas illness represents personal, interpersonal, and cultural reactions to a disease or discomfort” (Kleinman, Eisenberg, & Good, 2006, p.141). When doctors tend to look at the disease as the disorder they are treating, they can tend to overlook and disregard illness problems (Kleinman, Eisenberg, & Good, 2006).

Illness is thus culturally based, according to Kleinman, and shapes the way one perceives, experiences, and copes with disease (Kleinman, Eisenberg& Good, 2006). Included in the cultural meaning of illness are the explanations of sickness, explanations related to social position one occupies, and systems of meaning employed. How one communicates and presents their symptoms and illness story is influenced by cultural beliefs. Illness behavior is also governed by cultural rules and norms. According to the authors, we learn approved ways of being ill (Kleinman, Eisenberg, & Good, 2006).
Kleinman (1988) argues it is not just the label of the disease that is value based, but that symptoms too can carry cultural significance. For example, in the non-industrialized world pain is an expected component of living that is endured in silence. In the Western world, pain is perceived differently perhaps, according to Kleinman, based on the belief in the pursuit of happiness. In the Western world, alleviation of pain is the expectation.

Kleinman’s contribution to the understanding of the illness experience stems from the belief that sickness is experienced as more than a disease episode, and incorporates the meaning of the experience, including the social elements that are part of the experience. He further helps elucidate the tension between classic empirically based medicine, its nosology, and attempts to categorize and define disease with emphasis on intervention and cures, with the personal experience of having an illness influenced by cultural elements and trying to manage a chronic illness and integrate it with daily life. It is a bit ironic that the focus on distinguishing between illness and disease may reflect further attempts to categorize and label the illness experience. This may reflect the influence of his own medical training and professional paradigm.

Arthur Frank

Arthur Frank is a medical sociologist who survived a heart attack and then cancer which influenced his work in examining illness narratives. Arthur Frank’s classic work, *The Wounded Storyteller* (1995), introduces a categorization of types of narratives as being 1) restitution narratives, 2) chaos narratives, and 3) quest narratives.

In the early chapters of the book, Frank (1995) explores why ill people need to tell their story as part of constructing new understandings of their relationships to the world.
A critical point is made by Frank in stating that the stories told about our lives are not necessarily the lives as they are lived, but that the stories are about the experience of those lives. The stories themselves shape the perceptions of the experience over time.

These “self stories” also are transforming, extending beyond the description of the illness. “The self is being formed in what is told” (Frank, 1995, p.55). This perspective compliments nursing science perspectives on documenting transformation of knowledge that can inform and improve patient care (Chinn & Kramer, 1999). A common theme in illness stories is the loss of voice that has been taken away. In telling an illness story, the ill person becomes a “witness” to his/her own illness. There is also a need on the part of the ill person to understand the genesis of why illness is happening to them and to interpret the meaning of the experience.

Frank categorizes the types of illness narratives as 1) restitution narratives, 2) chaos narratives, and 3) quest narratives. An important point by the author is that no illness telling conforms completely to any of the three narratives, with actual telling including elements of all three.

**The Restitution Narrative**

The restitution story is one of health and recovery. It affirms that one is normally healthy and that illness is transitory, concluding in healing and wellness after treatment. Frank (1995) asserts that people learn this narrative from institutional stories that model how illness is to be told. Institutional medicine exerts its preference for this form of narrative. Commercials also condition the public to the expectation for how illness should progress from illness to cure. Illness can be seen as a puzzle which can be solved if one finds the solution.
Frank (1995) also critiques that this tends to depict the body as a commodity like a car that is broken down and in need of repair. Restitution can therefore by purchased and modified. A classic example of the restitution “philosophy”, according to Frank, is Parson’s Sick Role Theory which emerged from the 1950s-1970s. This theory was frequently presented in nursing curriculums during that time period.

Parson’s sick role included three assumptions: 1) illness is not a person’s fault, 2) being sick exempted one from normal responsibilities at work and home, and 3) the ill person was obligated to place self under the authority of a medical professional. According to Frank (1995) this sick role model was a narrative of social control where getting well was the only outcome. The theory aligns with the restitution category where recovery and cure is the ultimate outcome.

The Chaos Narrative

A true chaos story cannot be told, according to Frank (1995), because of its chaotic body and lack of voice. It is disorganized and lacks coherence. An element of a chaos story is its immediacy. The person experiencing a chaos story lives in the present with little linkage to a future or a past. There is no genesis in a chaos story and there is no hope for a sense of future. A chaotic story frequently demonstrates interruptions. Another characteristic of a chaos story is the loss of agency and lack of control. Whereas, the restitution story presumes life to get better, the chaos story presumes life will never get better (Frank, 1995).

When the ill person is in the midst of chaos, the story cannot be told, according to Frank (1995). It is only retrospectively after reflection that a narrative with temporal dimensions can be told. The ill person desires to get out of chaos, but can only be helped
when others are willing to become witnesses to the story. The worse thing someone can do to someone in a chaos story is to rush them to move on. The importance of hearing and listening to someone in the midst of a chaos story is emphasized by Frank (1995).

**The Quest Narrative**

It is only in the quest story that the teller has a story to tell (Frank, 1995). In a quest story, suffering is dealt with directly, there is acceptance of the illness, and there is an underlying belief that something is to be gained from the experience. In the quest story, the ill person seeks to use their experience of illness in some meaningful way. Frank (1995) relates that most published illness stories are quest stories.

The experience of illness in a quest story is seen as a journey, often analogous to a hero’s journey where there is a departure with a calling (illness), initiation and a period of trials, culminating in the final stage of return. In the quest narrative there is the element of transformation where the teller has been changed by the experience, with a resulting insight to be shared and passed on. There is an underlying theme of “conquering” illness which can be perceived as a masculine oriented conceptualization of illness.

Three facets of the quest narrative in Frank’s (1995) conceptualization are memoir, manifesto, and automythology. The memoir component is the telling of the story and other events in one’s life. The story is not told chronologically, but instead is recollected from present circumstances with illness interrupting the telling of the story.

A manifesto narrative is more prophetic in nature, demanding some form of social action. It includes how society has added to the experience of illness. Illness is seen as more of a social issue, not just an ailment or affliction.
Automythology is the third facet of quest narratives. The metaphor describing this is the Phoenix, reinvented from the ashes of fire. The person experiencing illness has not only survived, but they are reborn in some way. The focus in this facet of narrative is on individual change versus social reform. Identity can be changed in the more extreme forms of a quest story. There is regeneration in some way.

**Testimony**

Frank (1995) characterizes the individual who is telling an illness story as a “witness”. Each of the different types of narratives become a form of testimony. The illness story contains the body’s testimony. Stories are turned into testimony largely by the call upon another person to receive or hear the story.

Frank (1995) links testimony to a broader ethic. Self-stories are seen as moral acts of personal becoming. A main point is not dealing with health care conflicts, but to determine how to live a good life while being ill. The ill person is deciding what they wish to become in the experience and determining what story they wish to tell of oneself. Telling of the story becomes the final discharge of moral responsibility. Then, linking to the reader, Frank (1995) concludes the moral purpose of reading an illness story is to witness change of character through suffering.

Frank’s work focuses heavily on categorization of illness stories by type, as in his categories of restitution, chaos, and quest narratives. There is emphasis more on the structures of illness narratives versus the meaning for the individual teller. However, because they draw from real illness narratives, they may capture an authentic element of the illness experience.
Frank’s typology of restitution, chaos, and quest narratives will be used as a conceptual model to inform data analysis for the dissertation. The terms used by Frank are gender-laden. The term “restitution” implies someone is being saved and the term “quest” conjures image of conquest and discovery historically associated with male gender. The category terms invoke an imagery of “white knights” restoring health. It should be noted that despite a common critique of medicine’s tendency to categorize, classify, and label disease, Frank resorts to categorization to describe the illness experience. One form of categorization is replaced with another.

His additional concepts of memoir, manifesto, and automythology also reflect themes from his work (Frank, 1995). I will look for these and other themes that may emerge from my personal data sources in my data analysis.

**Synthesis of Literature**

There is strong support in the literature for use of narrative in the personal experience of illness. Autoethnography as an accepted scientific approach to qualitative study is also substantiated. The particular limitations evident in the literature relate to qualitative research on the experience of living with chronic undiagnosed illness. There are published non-fiction stories of this experience, but little formal research. The medical and nursing literature has very few autoethnographies by registered nurses on their own illness. There are no qualitative studies on nurse’s experience of living with chronic undiagnosed illness, including autoethnographies.

**Key Concepts**

**Culture**: beliefs and behaviors that are shared by members of a group (Galanti, 2015). A more complex definition, incorporating concepts from other historical definitions offered
by Bertsch (2011) is that culture is the collective “programming” (organizing) of the mind that distinguishes the members of one human group from another. Culture is a system of values which influence the norms, beliefs, and choices necessary to address the problems presented in the environment. This collective culture is socially passed from established members of the group to new members of the group (Bertsch, 2011).

**Professional Culture:** the shared and fundamental beliefs, normative values, and related social practices of a group, in this case a professional group, that are so widely accepted that they are implicit. These include three levels of artifacts, espoused values, and tacit assumptions shared by the group (Shanafelt et al., 2019).

**Familial Culture:** attitudes, assumptions, values, and beliefs which a person inherits from his or her parents or ancestors. Family is a culture bound phenomenon where culture provides norms for behaviors having impact on family member roles and power dynamics, and is mirrored in communication interactions (Johnson, Radesky., & Zuckerman, 2013).

**Ethnicity:** groups whose members share a common social and cultural heritage passed on to each successive generation (Giger, 2017). According to Giger (2017), the most important characteristic of ethnicity is the shared sense of identity by members of the ethnic group.

**Narrative:** narrative is a socially-constructed story of how humans experience the world and how they interpret this experience (Joyce, 2015). Narrative research is considered an interpretive approach in the qualitative research paradigm.
**Medical Paradigm:** Western medical paradigm includes the theories from physics, chemistry, and biology which form the basis for an explanatory model of disease (Lake, 2007). In this model symptoms are seen as subjective descriptions of effects caused by empirical factors. Western medicine views all causes of illness as based on biological processes that can be described in a reductionist approach and based on the language of Western science (Lake, 2007).

**Illness:** the innately human experience in which the sick person, their family members, and their social network perceives, lives with, and responds to symptoms and disability (Kleinman, 1988).

**Disease:** the medical paradigm defines disease as a malfunctioning, or maladaptation, of biologic and psychophysiologic processes in the individual (Kleinman, 2006). Frank (1995) distinguishes disease as a physiological process from illness which is the social experience of a disease.

**Diagnosis:** the process of identifying a disease, condition, or injury from its signs and symptoms. A health history, physical exam, and tests such as blood tests, imaging tests, and biopsies may be used to help make a diagnosis (National Cancer Institute, 2019). Further, nosology is defined as a classification or list of diseases and a branch of medical science that deals with the classification of disease (Merriam-Webster, 2019).

**Illness Identity:** an incorporation of chronic illness or disability into one’s sense of self (Charmaz, 1995). It builds from the concept of identity which is the way an individual defines, locates, and differentiates self from others (Hewitt, 1992). It includes the roles and attitudes that people develop about themselves in response to being ill.
**Immunology:** the study of the body’s immune system and its functions and disorders (Hopkins Medicine, 2019). It focuses on identifying antibodies, investigating problems with the immune system, and determining organ, tissue, and fluid compatibility for transplantation. For the immune system, it includes when the body attacks its own tissues (autoimmune) or is underactive (immunodeficiency disorders).

**Stigma:** an attribute that is deeply discrediting (Goffman, 1963).

**Social Construction of illness:** a research perspective largely influenced by medical sociology focusing on the cultural meaning of illness, viewing the illness experience as socially constructed, and positing that medical knowledge is also socially constructed (Conrad & Barker, 2010).
CHAPTER 3

Study Methods

Introduction

The research approach for the study was autoethnography. Autoethnography was the most appropriate design to investigate my research questions. Autoethnography allows an examination of the personal and cultural dimensions of living with undiagnosed illness. The qualitative researcher is multi-method in focus, and according to Denzin and Lincoln (2005), a “bricoleur,” or a maker of quilts. This autoethnographic study pieced together the diverse elements that were part of my overall illness experience. Since I am a quilter, whose illness has impacted my physical ability to execute handiwork in different forms, this description by Denzin and Lincoln (2005) seemed particularly appropriate. Within the framework of autoethnography, multiple qualitative data sources were incorporated and analyzed including my journal entries, notes from dialogue sessions with my chair, handsewn artifacts, and photographs. In selecting a design, it was necessary because of underlying illness to consider a design that is feasible and that will enable completion of the study.

Utilizing autoethnography as an approach to understanding the illness experience of a registered nurse living with undiagnosed illness moved beyond a lived experience, and allowed me to analyze the meanings of my experience and the aspects of my narrative in a sociocultural context, including the cultural contexts of health care, family, and profession.
Autoethnography

Autoethnography as a method of qualitative inquiry is being used by a variety of disciplines. Approaches to autoethnography reflect tension between the two more dominant schools of autoethnography: analytic autoethnography and evocative autoethnography. Whereas analytic autoethnography advocates for a systematic analytic approach, evocative autoethnography has less structured criteria, emphasizing more the aesthetics of writing. Sarah Wall (2016), a nursing scholar, has proposed an alternative moderate approach to autoethnography based on her expertise in reviewing autoethnography manuscripts. Her approach aims to maintain the quality, rigor, and utility of autoethnography for academic research.

Evocative Autoethnography

The goal of evocative autoethnography is to use narrative to bring forth emotion, taking the reader to the depth of personal feelings and to generate empathy for another (LeRoux, 2016). This approach rests on thick description, aesthetics, evocative, and vulnerable stories. Ellis (2004) describes good autoethnographic writing as truthful, vulnerable, evocative, and therapeutic.

A characteristic of evocative autoethnography is its ability to elicit empathy. This is accomplished in part by the writer’s demonstration of vulnerability (Custer, 2014; Ellis, 2004). Vulnerable writing should make one feel as if they were there and allow one to feel for another, and also with another. There are elements of disclosure that can enhance the vulnerability (Ellis, 2004). Evocative autoethnography blends social science and art, ultimately creating something all its own (Ellis, 2004).
Criticisms that have been leveled at evocative autoethnography relate to its lack of systematic analysis and standards for rigor (Anderson, 2006; Wall, 2016). Another criticism is that it emphasizes the aesthetics and mechanics of the writing in an autoethnography over a systematic disciplined qualitative approach.

**Analytic Autoethnography**

Anderson (2006), a sociologist, proposed analytic autoethnography as an alternative to evocative autoethnography. Five key features of analytic autoethnography are identified as: 1) complete member researcher status, 2) analytic reflexivity, 3) narrative visibility of the researcher’s self, 4) dialogue with informants beyond the self or dialogue across sources of data, and 5) commitment to theoretical analysis (Anderson, 2006).

The first criteria is that the researcher is a complete member of the social world under study (Anderson, 2006). The group membership precedes the decision to conduct research on the group and allows the ethnographer to be there in the research. The researcher is both member and participant in the social community. As a registered nurse living with chronic undiagnosed illness, I write about the social world of illness in which I am a participant in the experience.

The second criteria, reflexivity, is the researcher’s awareness of their connection to the research situation and their effects on it (Anderson, 2006). In my study, reflexivity was evidenced in analysis of journal entries with reflective quotes, reflections captured in the audit trail, and in debriefing sessions with select committee members and my Chair.

The third criteria is the narrative visibility of the author’s self (Anderson, 2006). In traditional ethnography, the researcher is largely invisible. According to Anderson
(2006), a central feature of autoethnography is that the researcher is a highly visible social actor in the written text. The researcher should demonstrate analytic insight in the telling of the personal experience including changes in beliefs and relationships. In my autoethnography, the researcher was positioned centrally in the research. I was the research subject and source of data.

The fourth criteria of dialogue with informants beyond the self is in contrast with evocative autoethnography, where dialogue with others is not requisite. As Anderson (2006) argues, ethnography calls for dialogue with “data” or “others”. Autoethnography should also be a relational activity that seeks interrelationships between the researcher and others or between sources of data to inform a broader social knowledge. This fourth criteria represents one of the more controversial of Anderson’s criteria, and has been challenged by other researchers (Denzin, 2006; Vryan, 2006).

My study demonstrated dialogue across sources of data in my using multiple sources of data to triangulate findings. My study was multimethod, using multiple data sources, and analogous to Denzin and Lincoln’s description of qualitative research as multimethod in focus and viewing the researcher as a bricoleur or a maker of quilts. While I did not interview others with undiagnosed illness, my journal documented my years of dialogue with healthcare providers, family members, and colleagues, as well as more than 30 years of engagement with the research literature related to various symptoms and diseases. My notes documented dialogue with my dissertation committee chair in planning this study.

Anderson’s (2006) final criteria is a commitment to an analytic agenda versus simple documentation of personal experience. Analytic autoethnography is rooted in
analytic social science using empirical data to gain insight into social phenomenon, broader than the data. Analytic autoethnography does not simply capture what is going on in the individual or social environment, but moves further to transcend the world through broader generalization (Anderson, 2006). The goal is refinement, elaboration, and enhancement of theoretical understanding. I met the fifth criteria by using formal qualitative methods for coding and thematic analysis of my data. The themes identified were examined for relationships and linkages across data sources to inform integration of the findings.

Other researchers have raised challenge to Anderson’s (2006) fourth criteria of dialogue with others as seemingly restricting any form of self-study or labeling forms of evocative writing as non-analytic. Vryan (2006) argues for a definition of analytic autoethnography that is less restricted, more inclusive and flexible. Vryan supports that it is possible to study the experience of a single life, which after analysis, can have social science relevance and utility in practical social and systems problems. Analytic product, he argues is more appropriately determined by usefulness to others, and whether the work helps to understand or better explain other people, experiences, and contexts. The work should further contribute to collective knowledge. He challenges the dichotomy created between evocative and analytic autoethnography, reminding that analytic work can include evocation and that creative rich text is compatible with analysis (Vryan, 2006).

Denzin (2006) also challenges the restrictions in the analytic approach (Anderson, 2006). He critiques Anderson’s approach as influenced and dominated by symbolic interactionism and early traditions in ethnography. He argues, “through our writing and our talk we enact the worlds we study” (p.422). Description of these enactments are
folded through an autoethnography. In my study, analysis of these enactments aimed to deconstruct cultural and methodological practices to inform recommendations for a more responsive approach to health care for people with chronic undiagnosed illness.

Sarah Wall (2016), a nurse, is an autoethnographer and qualitative methodologist, who has reviewed autoethnographies for many years. She finds middle ground in the methodological debate between analytic autoethnography and evocative autoethnography. Concerns that she cites regarding the quality of some autoethnographies relate to terminology, clarity of purpose, appropriate application of method, quality of data, analysis, presentation style, and ethical issues. The strongest concern is related to lack of analysis in some works. She views autoethnography as a form of scholarly research, and as such, the work needs to exhibit evidence of a systematic approach using ethnographic strategies (such as observation and participation in a context), needs to link personal experience to social, cultural, and political issues, and last, the work needs to establish connection to the research method (Wall, 2016). The raw data of the autoethnography needs to be analyzed to meet the purpose of the method.

While Wall (2016) critiques Ellis and Bochner’s (2006) criteria for evocative autoethnography as ambiguous, she does acknowledge that personal experience needs a method for representation and can inform building of sociological knowledge. Wall further relates that there are marginalized perspectives on certain topics that are given voice through autoethnography.

Wall (2016) further shares the view that autoethnographies on understudied topics, including those that share the patient perspective, have the potential to inform health professionals about the patient experience and to contribute to knowledge on how
those particular medical issues could be better managed. One autoethnography she reviewed related to a profound health experience, that she relates was told “artfully” but that was also analyzed systematically, making a significant and useful contribution to academic knowledge and professional knowledge development. My autoethnography of a nurse living with chronic undiagnosed illness fell under the categories of subjects that are enhanced by an autoethnographic approach, according to Wall (2016).

Duncan’s (2004) criticism of evocative autoethnography relates to Wall’s expressed concerns on the lack of analysis in the approach. Duncan (2004, p.11) is critical of “an overreliance on the potential of personal writing style to evoke direct emotional responses in readers but offer no deeper levels of reflection of analytic scholarship.” Instead, Wall advocates for a more scientific, analytic approach including justification of method, methodological description, multiple sources of evidence and clear account of the outcomes of the study and the clarity provided (Wall, 2016).

Winkler (2018) offers a balanced perspective of criticism on both sides of the debate between evocative and analytic schools of thought. Rather than choosing one side versus another in the debate, Winkler (2018) argues for embracing the plurality and multiplicity of approach in autoethnography by utilizing techniques such as debrief and triangulation. I incorporated some of these recommendations in my data analysis.

**My Study’s Autoethnography Approach**

This study incorporated the moderate approach to autoethnography (Wall, 2016; Winkler, 2018) and Anderson’s analytic approach criteria (2006) previously detailed. As recommended in Wall’s approach, I do not use terms like narrative and autoethnography interchangeably, recognizing that autoethnography has to include an ethnographic
analysis of cultural context. I endeavored to make the research purpose clear in the study, and to ensure linkage to autoethnography (Wall, 2016). Moderate autoethnography requires the elements of story, systematic analysis, and dissemination (Wall, 2016). Analysis should include analysis of themes across multiple data sources along with explication arising from the themes (Wall, 2016).

Since consideration of sociologic context is a necessary component of an autoethnography; the cultural elements I identified for this study are healthcare culture, professional culture, and family culture. In my autoethnography, I utilized narrative analysis, thematic analysis, and visual source analysis to examine these cultural elements.

The findings from the autoethnography should be clearly stated, not leaving the reader to guess regarding the findings (Wall, 2016). The discussion and analysis components should form a substantive section of the work. This research dissertation included a thorough data analysis based on qualitative research methods, a complete discussion of findings, and a conclusion that developed implications of the study.

Wall’s (2016) moderate approach also requires consideration of the plan for dissemination of the autoethnography. Ethical concerns in moderate autoethnography focus on how others are represented and their privacy protected. An autoethnography can result in significant personal disclosure which also raises concerns regarding the protection of oneself (Wall, 2016). With respect to this study, I considered the degree of disclosure necessary to document and report dimensions of my experience, while gauging the degree of personal risk in the disclosure.

Multiple sources of data were utilized for the study which enhanced triangulation (Wall, 2016; Winkler, 2018). I included material and visual sources of data, as
recommended by Anderson (2006). Reflexivity is common to all autoethnographic approaches (Anderson, 2006; Denzin, 2006; Ellis, 2004; Wall, 2016; Winkler, 2018), and reflexive statements were included in journal entries, personal reflection notes, and the audit journal.

One thread that was incorporated in the study was the concept of studying “one’s own people,” as part of the ethnographic cultural context. In this study, my people included my role as a nurse and healthcare provider. I was also a patient—these were also “my people.” Then there is the thread of my Hispanic ethnicity that also informed my experience and community.

My autoethnography approach was anchored in the qualitative research tradition and used standard qualitative data analysis methods. The moderate approach to autoethnography proposed by Wall (2016) and Anderson’s (2006) approach to analytic autoethnography conform to higher standards for autoethnographic inquiry and are aligned with established qualitative research methods.

**Study Setting**

The study setting included the various locations for my personal experience over many years, such as my residence, my work location, physician offices, hospitals or centers for diagnostic testing, and other physical locations described in the course of routine journal entries. I resided in a suburb of Denver, Colorado in the United States. Other physical locations referenced were places I have lived before such as Albuquerque, Los Alamos, and Dallas. The work location was at a college of nursing program in Colorado.
Sampling

The study did not involve collection of data from other human subjects.

Recruitment

Recruitment was not required and was not conducted for this study.

Ethical Considerations and Human Subjects Considerations

Dissertations in oral history and in autoethnography are not always required to apply for Institutional Review Board (IRB) status (Bochner & Ellis, 2012). This is true, in particular, if there is no intent to generalize beyond the individual (Bochner & Ellis, 2012). The UNM HSC consultant has advised the study will be a non-human subjects study. The requisite non-human subjects research letter was obtained by the UNM HSC IRB. This status reflected the two-part IRB definition of non-human subjects research: the study examined “personal history” (i.e. not involving human subjects) and involved systematic analysis, recommendations e.g. for health care practice, and aimed to contribute to the published scientific literature (i.e. constitutes research).

This does not release the researcher from ethical considerations. In an autoethnography, the researcher has an obligation to a “relational ethics of care” (Bochner & Ellis, 2012, p. 154). A relational ethics of care refers to how people connect to each other in their various roles and relationships from moment to moment (Bochner & Ellis, 2012). Relational ethics is taking responsibility for the impact of the research on another. There is a thoughtful reflection of the potential impacts on those involved.

One of the ethical quandaries in writing an autoethnography is that in telling my story I write about others who might be recognized. My journal entries did include descriptions of interactions with family members, coworkers, physicians, healthcare
workers, and others. I had an obligation to protect the individual identities of those described in my data. In order to protect the privacy of individuals in my autoethnography, I de-identified names, some locations, and other descriptive information that could reveal identity before sharing the text materials with others. I deleted protected health information that could identify the person. For the write-up on family relative photos, photographs were described and not shared visually with others. As these included persons who were no longer living, I protected their identities by referencing them generally as relatives, where possible.

Journal entries will be stored on a password protected laptop computer. With autoethnography, one has to consider the implication of the writing on others, while still preserving the reality one is seeking to depict (Bochner & Ellis, 2012). Morse et al. (2002) critique autoethnography for its inability to protect other’s confidentiality. In instituting the measures identified, I endeavor to address concerns regarding confidentiality.

A significant ethical concern that is sometimes overlooked with autoethnography is the risk to the researcher themselves (Wall, 2016). Autoethnographers make themselves vulnerable in sharing their private stories (Tullis, 2013). Yet, conventional research ethics and research ethics boards tend to overlook the impact the research process has on the researcher, within qualitative research and within autoethnography specifically (Dickson-Swift et al., 2008; Tullis, 2013).

**Participants**

I was the sole participant in the study.
Data Sources and Collection

In an autoethnography, one writes about one’s experiences. The writing aims to obtain perspective and may include elements of past, present, and future. Autoethnography incorporates elements of biography and ethnography. The biography component often relates to an experience of crisis (Ellis, Adams, & Bochner, 2011). For my study, the sources of data helped illuminate an emic perspective, the insider’s perspective. The insider in this case was someone living with chronic undiagnosed illness who is also a registered nurse.

Similar to ethnography which captures diverse elements of culture, autoethnography can encompass many different data modalities. Song, poetry, plays, stories, talking, dance, music, yoga, media, journaling, art, role play, history, cinematherapy, bibliotherapy, painting, novels, comics, and conversation are examples of some of the possible types of data in autoethnography (Custer, 2014).

For my autoethnography, the primary sources of data were autoethnographic writing in a journal, photos, reflection notes, and examples of my handwork. I first began keeping a journal in April of 2018. The journaling was done on a regular basis to capture moments of reflection on living with undiagnosed illness. The journaling continued for over a year and a half, encompassing largely a time period in which I remained undiagnosed for evolving and worsening neurological body symptoms. A working diagnosis did occur in the final stages of preparing this dissertation proposal, and there were some journal entries in this later time period documenting and reflecting on that stage of the illness experience.
My journal entries were catalogued on my computer by date, month, and year. They captured daily life, physical and mental challenges of dealing with my illness, and my interactions with work, medical visits, diagnostic testing, and family. They were a core element of data for understanding what it was like to be a registered nurse with a chronic undiagnosed illness. After I had journaled for a couple of months, I shared my first few journal entries with my dissertation chair. The first reflections on my journal entries became a highly emotive experience, in which I began to cry as I read several passages slowly. An additional source of data were my reflection notes, including reflections from the interactive sessions with my chair where I began to interpret the meaning of my experience.

Examples of my handwork became an important source of data for me as they allowed me to examine more specifically the loss of fine motor skills occurring in my hands. Quilting is a form of handwork that has ties to my grandmother, who introduced me to quilting. In my twenties and thirties, I delved heavily into intricate forms of quilting which all incorporated fine handwork, including very detailed applique, piecing, and hand-applique. As my neurological illness progressed, I noted a loss of fine motor skills, for example difficulties in placing pins into fabric. I could no longer work a needle well with my hands. One source of my data included photographs of samples of my work that showed my early abilities with handwork, and how these had changed over time with the illness.

Later, in my fifties I began to explore knitting. I am kinesthetic, and have always pursued handwork which is tactile. I love feeling the texture of a quilted piece, and love the texture of yarns as well. One of the things I noted as I tried to advance my skill in
knitting is that I was making errors pretty frequently, and I had noted trouble reading graphs used in knitting for color patterns and lace knitting. These photographic examples helped detail a growing concern about cognitive challenges I experienced.

An ongoing concern for me related to whether this illness I was dealing with might have a genetic basis, and whether it might be inherited by my two adult children. This was a particular concern because of the belief I had that my father may have lived with an unknown undiagnosed illness with some similarities, and some differences, to my illness presentation. There were signs of possible neurological illness such as loss of balance, choking, changes in handwriting, nightmares, heat intolerance, seizures, etc. I examined photos of my father, grandparents, and other family members for clues to what might be happening. I do believe this interest in family history was informed by a nurse’s background knowledge of epidemiology and genetics in disease. These photos are a data source that helped elicit observation and my own memories. I referred to these photos in my write-up as relatives’ photographs, and omitted references to the specific family relationship to protect individual identity.

The photographs of my handiwork and photographs of my family are artifacts that captured cultural elements of my experience. Autoethnography (as a “relative” of ethnography) can include observation of cultural objects as pertinent to the research (Glaw, Inder, Kable, & Hazelton, 2017).

**Data Management**

Journal entries were logged by date on a password protected computer. The names of persons mentioned in the journal entries were de-identified. Entries were dated and sorted by months in folders.
Scanned digital photographs were labeled, and wherever possible, dated. They were stored on a password protected computer. Other visual artifacts, such as samples of my father’s handwriting were kept in a secure location. Photographs of family members were described. Photographs of handwork were presented visually and described as part of the data analysis.

The audit file, a notebook which documents the audit trail, were kept in a locked file cabinet. Entries were dated. The audit file documented self-reflection, research decisions, questions that arose in the course of data analysis, and details related to the process of the research.

**Data Analysis**

This autoethnography was analyzed using narrative analysis, thematic analysis, and visual analysis. The Data Analysis Table at the end of this section illustrates the three forms of analysis that were utilized, their source, and the detail for each of the methods of analysis. In order to strengthen the rigor of the data analysis phase, investigator triangulation and methodological triangulation were incorporated (Fusch, Fusch, & Ness, 2018; Thurmond, 2001).

Investigator triangulation was achieved in this study by having more than one person review the coding categories and themes derived from the coding. The Chair of the dissertation committee reviewed transcripts of the journal entries and verified coding decisions.

In a study with just one individual, one wants to mitigate bias where possible. Fusch, Fusch, and Ness (2018) recommend use of interview protocols, member checking, and data saturation as possible strategies to reduce bias. Involving others in the data
analysis process during the analysis and then later in the study via debriefing help ensure the interpretation of findings are confirmed by others. Winkler (2018) supports incorporating other’s perspectives in an autoethnography, such as asking colleagues for comments, or debriefing as valid strategies to strengthen an autoethnography. Cross-checking and verification of data by more than one researcher increases the value of the findings (Thurmond, 2001). Ensuring data saturation is also a strategy to reduce bias.

Methodological triangulation is demonstrated by two data collection procedures from the same design approach (Fusch, Fusch, & Ness, 2018; Thurmond, 2001). In the case of my autoethnography different data sources (journal, medical history narrative, photographs, letters and handwork) were analyzed. This would be considered a between method of triangulation for methodological triangulation. Denzin (1970; 1989) contributed to early definitions for the types of triangulation and supports that multiple external data collections and multiple analysis methods strengthen rigor.

For structural analysis of the narrative, Frank’s (1995) typologies of the three types of illness narratives will be one of the frameworks for analysis of my autoethnography. The three types of illness narratives are the restitution narrative, the chaos narrative, and the quest narratives. I compared and contrasted my narrative against these typology categories.

Narrative analysis includes how the participant tells their story and assigns meaning to their story (Ellis, 2004). There is also an ethnographic component to narrative analysis, in which the social context and use of social science and health care concepts are examined in a narrative.
Ellis (2004) sees narrative analysis as an inductive process, where themes emerge from the data. In analysis of narrative there is reduction of the stories content to analyze in effort to find categories, themes, or subpatterns (Ellis, 2004).

**Process for Analyzing Data**

An overview of the process for data analysis helps delineate how linkages evolved. The initial steps involved reading of the journal entries, describing and showing handwork artifacts, and writing descriptions of family photographs. All journal entries were shared with my dissertation chair for comparison analysis. Journal entries were read to identify themes. This initial attempt at coding of themes resulted in a lot of disjointed potential topics. A different approach was agreed on in consultation with my chair. I reviewed all my journal entries and selected all quotes for two different topic areas—nursing and family. Then these quotes were all analyzed together. This secondary analysis resulted in identified common areas or categories from the subsets of data. The journal entries were read again multiple times and the themes which had emerged from the subset were found to be consistent across other journal entries.

**Triangulation**

The next step in the data analysis process after reviewing journal entries was to consider how the other sources of data related to the journal data. A consistency across the data sources is that they all confirm an evolving worsening chronic illness that decreased physical abilities and that changed self-image. In the case of photographs of family members, I was observing for examples of that type of patterning and do believe there is evidence from historical memory that supports a declining physical pattern and
some evidence of physical symptoms suggestive of a possible neurologic illness for most of the family photographs.

Looking across all sources of data contributed to triangulation for the study. Observations from journal entries were compared to photographs and artifacts. An example of confirming findings is when the photograph of my paternal grandmother is compared to journal entries describing her physical symptoms, confirming across sources of evidence.

Triangulation is the use of two or more data sources, investigators, methodologic approaches, theoretical perspectives, or analytic methods within a study (Denzin, 1970; Kimchi et al., 1991). These combinations result in the four forms of triangulation espoused by Denzin (1970): data triangulation, investigator triangulation, methodological triangulation, or theoretical triangulation. Benefits of triangulation include adding depth to a study, helping to confirm data saturation, and mitigating researcher bias (Fusch et al., 2018). The forms of triangulation used in this study were data triangulation, researcher triangulation, and methodological triangulation.

Data triangulation occurs in the study because there is different data for the same event, in this case chronic undiagnosed illness. There is written and photographic data. Researcher triangulation is accomplished through the guiding supervision of my dissertation chair who had access to all journal entries, read the entries, and compared her analysis to mine. This study exemplifies within method triangulation because data was triangulated with multiple data collection methods– journals, photo elicitation, and observation of artifacts.
**Constant Comparison**

Throughout the study there was a process of emergent analysis where I repeatedly went back to the data to validate interpretations and compared across data sources for similarities and differences. Glaser and Strauss (1965) are credited with development of the method of constant comparison where sections of data are continually compared with each other to allow categories to emerge and for relationships between categories to become apparent. While this method is historically associated with grounded theory it is considered a tool for inductive reasoning in qualitative inquiry.

**Coding**

One of the early stages in data analysis involves coding of the data. Coding is a labeling of text data to establish what the passage is about and to assign a location for the data (Bazely, 2013). Codes can be descriptive (structural) when they describe actions or events, or they can be interpretive (analytical) (Bazely, 2013). Whereas, some qualitative studies establish codes prior to review of data, for the autoethnography, coding will be used to identify initial key concepts and phrases related to the research question(s), to sort data, and to assign a location for ease of retrieval.

My journal entries were initially hand-coded by highlighting, underlining key statements or phrases in text. Pencil and paper strategies for coding are accepted methodology for coding of qualitative data (Bazely, 2013). I made notes in the margins of possible labels for related content. I reduced written passages into categories that relate to the three research questions asked. I used 3 by 5-inch notecards to write down the categories. These categories were used to help develop and organize themes that relate to the research questions.
Some of the “best practices” for coding (Bazely, 2013) which I utilized included 1) systematic analysis of each source of data, 2) repetitive reading and re-review of data content, 3) marking of transcripts or physical data, 4) indexing of data, 5) sorting of data to create codes and 6) writing analytic memos in an audit trail. Microsoft Office software and handwritten notation were used to organize themes and to compare data. Bazely (2013) suggests inserting keywords into text can also be used to help locate relevant passages using Word’s find function.

On reliability of coding, Bazely (2013) does not advocate for multiple coders, instead arguing that the strength of one’s argument and the clarity and comprehension of evidence is the best measure of reliability. Part of a convincing argument is to establish a clear audit trail of coding decisions linked to the data. Coding and thematic analysis were conducted with the other sources of data in the study.

Thematic Analysis

For my study, thematic analysis was conducted according to Ellis’ (2004) guidelines and based on the phases of thematic analysis proposed by Braun and Clark (2006, 2012). As previously described, the emphasis was on using inductive thinking to analyze data to identify patterns and themes.

Thematic analysis is a method for “systematically identifying, organizing, and offering insight into patterns of meaning (themes) across a data set” (Braun & Clarke, 2012, p. 57). The purpose of analysis it to identify what may be relevant to answering the research question(s). This study will use an inductive experiential approach to thematic analysis. Braun and Clarke (2012) recommend that researchers identify the type of thematic approach to be utilized. Inductive thematic analysis, is often experiential in
orientation and assumes a knowable world giving “voice to experiences and meanings of that world, as reported in the data” (p.59).

Six phases of thematic analysis are proposed by Braun and Clark (2012). They are 1) familiarizing yourself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing potential themes, 5) defining and naming themes, and 6) producing the report. I used these phases in my study to perform thematic analysis. Their guidelines also provide examples of how to organize thematic data in tables.

Thematic analysis focuses on identifiable themes and patterns of living and/or behavior (Aronson, 1994). Themes are then “pieced together to form a comprehensive picture” of the experience, resting on the researcher who analyzes how the different ideas fit together in a meaningful way when put together (p. 3).

Visual Methodologies

Visual methodologies were included as sources of data for my autoethnography. These included photographs of my handiwork, photographs of family members, and photographs of some of my father’s letters. Visual methodologies have been used for a long time in anthropology and sociology, but are relatively new to health research (Glaw et al., 2017). Two methods I used in the study are autophotography and photoelicitation. The visual data for the autoethnography was analyzed according to criteria for visual displays of data (Scagnoli & Vertinelli, 2017).

Autophotography is asking the research participant to take photographs of their environment or an aspect of their life and using the photograph as the actual data (Glaw et al., 2017). In my study, photographs of my handiwork illustrated declining physical
and cognitive abilities due to a health condition. Photographs provided understanding of the specific types of cognitive tasks that I began to have challenges with during the evolution of my illness.

Photo elicitation is using a photograph or other visual mediums to generate verbal discussion and to create data and knowledge (Glaw et al., 2017). Different layers of meaning can be discovered, memory stimulated, and new ideas generated. I used photoelicitation in my study to examine photographs and artifacts to explore my family health history. Photographs helped elicit my awareness of clues and patterns in my family health history, in the absence of established diagnostic medical history for certain family members. Samples of my father’s handwritten letters in the last years of his life were a source of photo elicitation.

A qualitative descriptive design study was conducted by Scagnoli and Verdinelli (2017) to explore what constitutes effective use of visual displays in qualitative studies. The study concluded that visual displays should be included in qualitative studies and provided a list of criteria used by editors to assess the validity of visuals in qualitative research articles. The criteria include: does the visual provide communication beyond the use of words, creating a metalevel of meaning and add value? Another criterion relates to having a logical and coherent structure to the visual displays. The use of color and flow is another element examining the aesthetics of diagrams. Finally, simplicity is also a feature recommended. The visual display should transmit quickly and easily the information to be shared with readers (Scagnoli & Verdinelli, 2017). These guidelines informed my use of visual displays in Chapter 4.
<table>
<thead>
<tr>
<th>Type of Analysis</th>
<th>Source</th>
<th>Characteristics</th>
<th>Evidence from the Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Narrative</td>
<td>Frank (1985)</td>
<td>Typologies: Restitution, Chaos, Quest</td>
<td>Reading my story sources, comparing amongst Frank’s existing typology, and identifying existing or other terminology to describe the type of narrative.</td>
</tr>
<tr>
<td></td>
<td>Ellis (2004)</td>
<td></td>
<td>How does the narrative depict context and illuminate social science and nursing science concepts?</td>
</tr>
<tr>
<td>Thematic</td>
<td>Bazely (2013)</td>
<td>Coding</td>
<td>Coding Principles and Practices</td>
</tr>
<tr>
<td>Visual</td>
<td>Glaw et al. (2017)</td>
<td>Autophotography</td>
<td>Examining samples of my handwork to identify examples of possible physical and cognitive decline.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Photo elicitation</td>
<td>Examining family photos to identify physical features that relate to possible hereditary neurological illness. Examining one relative’s letters and handwriting to identify features of possible neurological decline.</td>
</tr>
</tbody>
</table>

Table 1: Data Analysis Plan
Merging Data Sources

Whereas triangulation of data sources strengthens a study, the different sources of data in my study were compared and analyzed across the sources for congruence. Thurmond (2001) identifies an important component of triangulation of data is identifying areas of convergence and divergence between the sources. Each of the different sources of data (journal entries, photos, handwork photos, audit notes) was analyzed individually and then compared and contrasted as the findings from the study were emerging.

Rigor of the Study

The primary sources for evaluating rigor of this autoethnography were based on criteria established by LeRoux (2017), Wall (2016), and Chang (2006). Their criteria are specific to autoethnography and each of these authors support the inclusion of systematic analysis of data as central. Chang (2008) and Wall (2016) share commonality in their emphasis on the study of culture in an autoethnography as a necessary element. Rigor of the data analysis has been already addressed in that section by application of investigator and methodological triangulation of data (Denzin, 1989; Fusch, Fusch, & Ness, 2018; Thurmond, 2001).

Traditionally with autoethnography, there have been two approaches to rigor. One uses established classic qualitative techniques such as Lincoln and Guba’s (1985) criteria for trustworthiness and authenticity. The alternate view is that criteria should be used specific to the design. Thus, for my autoethnography I used criteria that were specific to autoethnography as the predominant approach to evaluating rigor. Lincoln and Guba’s
(1985) criteria for qualitative studies will be briefly summarized as they relate to the study after the primary sources for autoethnography rigor are presented.

LeRoux’s (2017) criteria are informed by her research with qualitative researchers who helped generate criteria for rigor relevant to autoethnography. LeRoux conducted a literature review and survey on rigor in autoethnography, and concluded it is possible to establish a set of general criteria for rigor in autoethnography. The five criteria proposed are 1) subjectivity, 2) self-reflexivity, 3) resonance, 4) credibility, and 4) contribution. LeRoux (2017) adds the additional expectation that the research should be ethical.

Subjectivity refers to the presence of the self as visible in the research (LeRoux, 2017). In using a personal journal for my data collection, the self is apparent in the study. It is a story of my personal experience, and meets the criteria of subjectivity. Self-reflexivity is captured in statements that support my self-awareness, self-exposure, and introspection regarding my experience. These were in the journal entries, reflection notes, and the audit trail.

If those reading the study can connect to my story intellectually and emotionally, I have then demonstrated resonance. Can those reading about my experience understand a common link between us? That is resonance (Polit & Beck, 2017).

Le Roux’s (2017) final criteria is that of contribution. The study should extend knowledge, improve practice, or make a contribution to social change (LeRoux, 2017). The study informed a holistic understanding of the illness experience in undiagnosed illness, identifying the cultural context and influences. My study informed better approaches for supporting those with chronic undiagnosed illness for health care
professionals. My study captured the challenges and barriers that someone with chronic undiagnosed illness encounters on a routine basis.

Wall (2016), a nurse educator, an autoethnographer, and qualitative methodologist has reviewed many autoethnographies for publication and has developed recommendations for rigor in autoethnography. She has particular concern with lack of data analysis in some autoethnographies. Her recommendations include 1) evidence of a systematic approach to analysis of raw data using ethnographic strategies, 2) demonstration that the personal experience related links to social, cultural, and political issues, and that 3) the work needs to connect to the research method (Wall, 2016). My autoethnography will use established qualitative methods for data analysis of raw data. My study examined the cultural elements of health care culture, professional culture, and family culture.

Chang (2003), in a step by step guide to writing autoethnography, also places emphasis on the importance of an autoethnography providing cultural understanding. Critical to that cultural understanding is cultural data analysis and interpretation. Thus, rigor is demonstrated by the inclusion of those elements. Chang (2006) differentiates data interpretation from data analysis, explaining data interpretation involves finding cultural meaning in e.g. the themes and other findings of the data. Interpretation involves making sense of the data while examining relationships between meaning and text (Chang, 2006). By moving from identification of themes or categories to examining broader patterns and relationships in the data, this study was able to provide interpretation of data, particularly in describing cultural context.
An opposing view to the belief that reliability and validity (quantitative measures for rigor) have no place in qualitative studies is advocated by Morse et al. (2002). Not only do they support that validity and reliability are necessary in qualitative research, they propose that one way to enhance qualitative studies rigor is by inclusion of verification strategies during the conduct of a study. I included three of their recommended verification strategies. First, I collected and analyzed data concurrently. I also incorporated their recommendation on thinking theoretically by making sure that ideas that emerge from the data were reconfirmed in new data and in turn were verified in data already collected. The third recommendation I incorporated was to make sure there was methodological coherence by examining congruence between the research question and the method.

Lincoln and Guba (1985) proposed the concept of trustworthiness as a way to assess the rigor of qualitative research. The concept of trustworthiness largely replaced the quantitative assessment criteria of reliability and validity in qualitative research. Trustworthiness includes the criteria of credibility, transferability, dependability, and confirmability. Later, Guba and Lincoln (1989) added the criteria of authenticity.

The criteria for establishing credibility according to Lincoln and Guba (1985) are prolonged engagement, persistent observation, and triangulation. Prolonged engagement is demonstrated in my study by the length of time I have been dealing with a chronic undiagnosed illness, since my early thirties. I have been personally researching neurological and rare diseases in that time frame. The journal I kept during the dissertation begins in April 2018 to the present time, but also recalls earlier experiences in my life. Persistent observation in my study was demonstrated by my observation of
my symptoms and health condition for decades, as detailed in my journal notes. The third way my study demonstrated credibility was by triangulation in the use of multiple sources for data and multiple methods (Lincoln & Guba, 1985) I used multiple sources of data in my autoethnography which included my journal entries, photographs, and cultural artifacts such as my handwork.

Dependability and credibility go together, with no credibility a study’s dependability is in question (Lincoln & Guba, 1985). The use of multiple data sources, overlapping methods, and an inquiry audit help establish dependability. Examples of the type of audit trail materials I included are raw data, data reduction and analysis products, process notes, notes on data reconstruction and synthesis, and reflexive notes. An audit trail is a major technique for establishing confirmability. I kept an audit journal and notes from data analysis sessions. Lincoln and Guba (1985) also identify triangulation and the keeping of a reflexive journal as two other methods for demonstrating confirmability.

Thick rich description was one of the ways I demonstrated transferability in the study (Denzin 1989; Lincoln & Guba, 1985). Providing thick description allows one to reach conclusion regarding whether transfer is possible. I tried to capture not only physical detail, but the emotional and personal aspects of my illness experience, in order to reflect on how my story might relate to the experience of other registered nurses with chronic undiagnosed illness.

Conrad and Barker (2010) argue that rather than seeking generalizability in qualitative research, that generalizability in qualitative research should be in terms of concepts rather than in terms of data. Generalizability, according to them, should be measured in terms of applicability of the concepts (which includes themes, including
those relating to cultural context) to other samples, settings, and situations. In my
Conclusion chapter, I discussed how the concepts identified would apply to other people,
situations and settings.

Authenticity refers to whether the researcher fairly and faithfully show a range of
different realities and capture the experience of the life or lives being portrayed (Polit &
Beck, 2017). Ways to enhance authenticity include reflexivity, prolonged engagement,
persistent observation, thick vivid description, and impactful evocative writing (Lincoln
(journal, audit trail) and data analysis for the study. I tried to write honestly from my
experience and to use wording that helped depict my life experience in struggling to
manage and understand my illness.

In summary, the criteria for rigor being applied in this study are those proposed
by LeRoux (2017), Wall (2016), and Chang (2006). Their criteria are specific to
autoethnography. In addition, several verification strategies proposed by Morse et, al.
(2002) for qualitative studies will be incorporated.

**Limitations**

A primary source of bias in my autoethnography relates to the subjective nature
inherent in writing about oneself. My writings express my personal view of my
experience. While I endeavored to recall events with accuracy and authenticity, and with
intent to represent others with fairness, a personal perspective always entails subjectivity.
In consideration of emic versus etic perspectives, my study favors the insider perspective.
I am the person experiencing my own illness episode. My perspective may lack the
objectivity and detachment of an outsider’s point of view, because it details an experience I am deeply connected to and that has happened to me directly.

Other sources of bias that may have influenced the study include my being a woman, my point of view as a registered nurse and health care provider, and my cultural heritage including my background being raised part Hispanic. As a registered nurse, I am immersed in and influenced by the values and beliefs of modern medical practice and culture. As part Hispanic, there are cultural views that influence my experience of illness. Hispanics can view physicians and males as authority figures (Thompson & Whiffen, 2018), thus, paternalism may influence my interactions with health care providers. Additionally, Hispanic cultural practices and views such as familism (Perez & Cruess, 2014; Stein et al., 2014) and fatalism (Roncancio, Ward, & Berenson, 2011) can also exert influence on my experience of illness. Familism can exert influence in my not wanting to stress my family with my illness, looking instead to the overall needs of the family over my individual personal needs. Hispanics value harmonious relationships with family and value family honor (Perez & Cruess, 2014). Family values may alter the course of a chronic disease by influencing health behaviors that may be important in managing the condition or by increasing stress levels which can result in immunocompromise (Perez & Cruess, 2014).

One of the ways I tried to understand the biases that influenced my study was to make notes in my audit journal and to reflect on the sources of bias during my data analysis. Reflexivity is a valid technique for identifying bias (Anderson, 2006; Bochner & Ellis, 2013). Reflexivity allows the researcher to examine their connection to the
research situation and their effects on it using self-conscious introspection (Anderson, 2006). Autoethnography is in a sense, a project of understanding self in context.

A limitation of this study was that it drew on the experience of only one person. As such, it is not generalizable, but may be transferable if it provided data that makes transferable judgement possible to others supported by thick rich description (Lincoln & Guba, 1985).

Another limitation was that the perspective was that of someone who is female. There may be differences in experience based on gender. This study is also limited by some of the cultural factors that define who I am, such as my Hispanic background and my orientation and ideology framed by the discipline of nursing. These factors limited my experience and defined my world view. While these may present as limitations, they may be considered a strength for an autoethnography that seeks to analyze personal biographical elements within a cultural context.

**Conclusion**

My study will used autoethnography to explore three research questions:

1. What is it like to be a registered nurse living with chronic undiagnosed illness?
2. How is the experience of chronic undiagnosed illness shaped by cultural contexts of healthcare, family, and profession?
3. What are the implications of my autoethnography for future nursing research, nursing and medical education, healthcare delivery, and patient empowerment and advocacy?
Primary sources of data included autoethnographic writing in a journal, samples of handwork, and photographs. The data analysis used narrative analysis, thematic analysis, and visual source analysis.

This study proposed addressing a gap in the literature, specifically, to understanding the experience of a registered nurse living with chronic undiagnosed illness. There are only five autoethnographies where a registered nurse has explored their own experience of diagnosed illness (Allbon, 2013; Sealy, 2012; Smith, 2015, & Peterson, 2017; White, 2003). There are no autoethnographies of a registered nurse with chronic undiagnosed illness.

Chapter 4 presents the autoethnographic writing, which incorporates and reports the data analysis. This autoethnography contributes to gaps in the literature pertaining to the experience of living with chronic undiagnosed illness. Using a patient-centered, holistic, and ethnographic approach, the meaning and context of the patient experience with undiagnosed illness were presented. The cultural contexts of healthcare, family, and profession were included in the study.

This study contributes to the illness experience literature and expands on limited knowledge on a registered nurse’s experience of illness. The systematic analysis and rigor of the study strengthens research in this area, where some of the illness experiences in the literature by registered nurses, lack formal data analysis and qualitative rigor.

This study further retrieved a body of research principles that have been marginalized. Experiences are sources for the development of knowledge, not just beginning sources. Personal knowing and the individual experience of illness are valid sources of nursing knowledge (Chinn & Kramer, 2015).
Recommendations were identified through the autoethnography on how to better support the care for those with undiagnosed conditions. The therapeutic value of narrating one’s illness experience was supported by the study findings. Recommendations for the education and training of medical and nursing providers in caring for those with chronic undiagnosed illness were identified in the study.

An autoethnography may also be a way to eventually engage the public in an issue that traditional scientific academic writing would never reach. The public is now more than ever engaged in wanting to understand their medical conditions, their illness, and management of their individual care. The study provides important implications for future research, clinical practice, and for advocacy for those living with chronic undiagnosed illness.
Chapter 4

Introduction

Chapter 4 presents the findings of my autoethnography. Findings are presented in a format that makes the study’s data sources and methods explicit.

Narrative of My Medical History

This is the “narrative” of my medical history spanning several decades beginning in 1981 to December 2019. Descriptive narrative research attached to autoethnography facilitates an interpretive outcome. Polkinghorne (1988) posited that narrative meaning evolves from one’s mental realm, drawing together human experience, actions, and relevant events that impact the writer of narrative in a meaningful way. Creating the written narrative is a linguistic practice that can “make some aspect of our lived world or lived experience reflectively understandable…(narrative) research does not merely involve writing: research is the work of writing – writing is its very essence” (van Manen, 1998, pp. 125-126).

My narrative begins with a neurological attack I experienced when I was in my mid-twenties and continues to describe many years of recurring and undulating symptoms with new symptoms emerging over time. I will present thematic analysis at the end of my medical history narrative.

I spent fourteen days hospitalized in 1981 for what would eventually be diagnosed as Atypical Guillain Barre Syndrome. I was twenty-six years old at the time. The year is important to the story, because I was diagnosed based on available knowledge of neurological diseases in that time period. MRI was not in routine use. Lumbar puncture was done at the bedside without radiologic guidance. Antibody testing for myasthenia
Gravis was not available then, although tensilon testing was done. My Harvard-educated neurologist was always frank that I might be presenting with early symptoms of another neurological disease. He was not certain that it was Guillain Barre, and also mentioned the possibility that it could be multiple sclerosis or myasthenia gravis. Those were the two diseases he felt more likely related to my symptoms. It was always understood that the original diagnosis of Guillain Barre was simply an attempt to capture what might have been occurring based on symptoms and testing results at that given point in time. I am grateful to this day for my neurologist’s candor in this regard.

I was treated with IV steroids at the time and did respond in the hospital with an improvement of my symptoms. The hospitalization was not easy. I was later told by my nursing colleagues that I had ocular paralysis. They described walking in my room and telling me my “eyes were rolling around”. I was not fully aware of all my symptoms at the time. I remember struggling with breathing for part of the time. I remember having trouble swallowing my foods. I remember feeling so very weak and barely able to walk—with shaking in my hands and arms. While both sides of my body were weak, the weakness was worse on my left side. I also had numerous paresthesias on my scalp and back—numbness and tingling all over in those areas. I improved on the medications and was finally discharged.

When I arrived back home, I was unable to lift my one-year old baby with my left arm weakness. I know my baby had some separation anxiety from my being in the hospital because when I couldn’t lift my child, she turned away from me. I read this as a rejection of me in some form. My infant child did not understand my being gone and was angry with me. The recovery was very slow. Family members came to help me. I went
back to work after eight weeks but was not recovered by any means. I had to call the physician more than once complaining that “it is not going away” and that “it is still there.” Six months after discharge, I was re-hospitalized with ongoing complaints of shortness of breath, rapid heartbeats, high blood pressure, arm and leg muscle weakness, hand tremors, fatigue, and other symptoms. Another lumbar puncture ensued and more testing. The doctor could not fully explain what was happening and again conjectured it could be an evolving neurological disease.

I have never been the same since that original attack. Many years have elapsed where I noticed I could not do things others could due to my ongoing symptoms. Fatigue, muscle weakness, and shortness of breath kept me from hiking in the mountains with family members. Many of the family members were much older than I, yet I was the one with some handicap. I would try to hike and have to turn back because I couldn’t do it.

I would experience hand tremors and arm shaking with physical activity with my arms. I suffered from some residual facial paralysis on the left side. When I am very fatigued, one eyebrow is higher than the other. It is not classic ptosis but does present as a droop at times. Eyelid spasms and twitching have been common. I do not have double vision but have complained of blurry vision in the heat when it is hot outside for years. My eyes tire easily with reading.

This illness never went away. At times, symptoms were better but never completely gone. Over time, more symptoms came into play which concerned me. In my late forties, I began to notice gastrointestinal symptoms: heartburn, and some lower gastrointestinal symptoms as well. I struggled with heavy fullness after eating and would
often try to walk after eating because food seemed to stay in my stomach forever and I felt bloated after meals. I began to have intermittent diarrhea.

I also noted increasing bladder issues in the late 1990s. One day, urine just started to trickle down my legs. I couldn’t stop it. I started to have problems with urgency and getting up in the middle of the night needing to void. At this time with the bladder symptoms, I was convinced I had multiple sclerosis.

This was further supported by beginning to notice some cognitive symptoms which I reluctantly confided to my internal medicine physician and a few physicians I worked with. The cognitive changes were subtle, but I was becoming increasingly self-aware. More neurological testing ensued: MRIs, nerve conduction, lab testing, EMG, etc. with negative results. I did have some abnormal elevation in inflammatory markers—ESR, C-Reactive protein, and chromogranin A.

I was beginning to experience fainting spells, which I one day realized were also associated with high blood pressure readings. My internist intervened swiftly adding two more blood pressure medications to try and stabilize very high blood pressure readings that proved very labile. I was referred by a gastroenterologist to a specialist in carcinoid out of state because of the abnormal Chromogranin A result, gastrointestinal symptoms, and the facial flushing which I had also noted as a new symptom. I flew out of state for testing. The specialist did not feel I had carcinoid. A consultation with a neurologist who specialized in multiple sclerosis in the city where I live did not yield any conclusions on multiple sclerosis. A muscle biopsy was done at a major university health center by a leading neuromuscular neurologist which was negative. It was not looking like a myopathy.
I was referred to the Mayo Clinic in Scottsdale in 2006 by my internist to review all my symptoms and testing. No new neurological testing was done, but cognitive testing was completed while I was there. There were some delays in finger tapping in the left hand and some findings on the executive functions which the report concluded would serve as a baseline for further cognitive testing in the future. They did find other issues unrelated to my neurological symptoms, but no conclusion was reached on any primary neurological disease.

A cardiologist there was instrumental in helping me to manage the “fainting spells” I was having several times a week before going to Mayo. Although she treated my fainting spells as cardiovascular, she managed to recommend therapy that would help me manage a symptom that would later be found to be neurologically based. She told me to avoid being out in the heat, to hydrate heavily, and to not skip meals. By following her guidance, I was able to virtually eliminate the weekly fainting spells. I could now drive without fear. By avoiding being out in the heat, I could avert the fainting spells.

I never “recovered” but continued to manage my life working full time as a nurse and continued to note any new symptoms in the hope they would point to the answer. One day around 2010, I began to feel as if someone was taking a knife and stabbing me in the right eye. I had a corneal ulcer on my right eye secondary to a herpetic infection, it was thought. Despite aggressive treatment by an ophthalmologist, it recurred, and I ended up on antivirals for two years. The physician confirmed eye dryness was contributing to the problem. Sunlight was also stinging my eyes. These eye symptoms would later be related to neurological disease.
Next, I struggled with mouth dryness, and a loss of taste. Food began to lack flavor. I would form mucoid ulcers in my mouth. I was worked up next for Sjogren’s syndrome. Lab testing and a lip biopsy indicated I did not have primary Sjogren’s, although I am convinced now I do have it as a secondary form due to neurological illness. At this time, I also had a rheumatology work up again. This was my second round on rheumatology testing. I had an abnormal ANA, but no other conclusive labwork. I did not have a rheumatologic disease.

At this point, it seemed likely that neurologic disease was the likely culprit. I returned again to my neurologist for testing for more obscure neurological diseases. I began to also believe very strongly that my family history was pertinent to what was happening. My father had struggled with some odd health and life issues. I believed he had been ill with something, but never diagnosed. I also began to discuss this possibility with physicians. I was tested for NMO (neuromyelitis optica), CIDP (chronic inflammatory deymyelinating polyneuropathy), and myasthenia antibodies were repeated. I had more MRIs: brain and spine.

I began to notice more problems on my right side. One day I couldn’t lift a glass with my right hand. I was having trouble with fine motor functions now in my right hand. I couldn’t open things. My handwriting changed a bit sometimes when I wrote. I couldn’t pick up things well. I was puzzled, as my left side had been impacted originally. Now I was having right sided symptoms. I was having trouble making fine motor movements with my right hand. I was also dropping things right and left.

I was referred to a neuromuscular specialist and repeat EMG and nerve conduction was done to rule out myasthenia gravis. I had Single Fiber EMG done at the
University of Colorado Hospital to further rule out myasthenia gravis. The conclusion was that it was highly unlikely that I had myasthenia gravis, although it was still possible it could be a genetic form.

Pulmonary testing around this time at a leading respiratory hospital showed some abnormalities on PFTs, (pulmonary function testing) but did not support a primary lung issue. My chest x-ray showed atelectasis on my left side. I was puzzled by this. I did have an abnormal echocardiogram which indicated diastolic heart failure and was referred to a cardiologist. He concluded I did not have diastolic heart failure based on further testing, but he took me off of beta blockers for my blood pressure which resulted in one of the largest improvements in my breathing in decades. This was a hint that I might be dealing with a neurological disease that was also impacting my breathing and medications had made it worse.

Around this time, a colleague at work confided that she had myasthenia gravis. She and I had common ground in having autonomic nervous system symptoms. I had begun to live with disabling diarrhea, bladder spasms, bladder urgency, bladder leakage, tachycardia, and labile severe elevated blood pressure, and shortness of breath. This colleague helped me to manage the autonomic symptoms by pushing hydration and taking an occasional salt tablet. This helped, but I still was experiencing spells of tachycardia every day or so. She referred me to another neurologist in the city who had diagnosed her illness, describing him as a real tactical diagnostician and problem solver.

I met the new neurologist as I was completing the testing for myasthenia gravis which turned out negative. He recommended a skin biopsy to look for small fiber neuropathy which he felt also tied to autonomic symptoms. A previous neurologist had
concluded I did have a small fiber neuropathy, but had not tested for it. The results came back positive. The new neurologist confirmed I did have a small fiber neuropathy which explained burning in my feet, and hands, numbness, etc. I confided more symptoms with balance and some newer cognitive symptoms. I was having trouble reading and interpreting graphs for handwork and schoolwork. I began noticing I was driving over curbs, not quite gauging distance well.

    My neurologist felt I had to do another lumbar puncture (to rule out CIDP). I had my fourth and final lumbar puncture this past year (2019). It did not show any protein elevation or indication of CIDP. It did not appear I was dealing with an inflammatory neurological disease, in particular multiple sclerosis or CIDP. At this point he decided to look in a completely different neurological direction; that of neurodegenerative disease. Looking for inflammatory neurological disease had been the pattern over many years, based on the original diagnosis of Guillain Barre. This was my turning point in seeking a more definitive diagnosis.

Analysis of My Medical Narrative

Tension Between Being a Patient and Being a Nurse

    Reflecting on the story, it’s mostly medical facts of symptoms, testing, potential diagnoses for exclusion. It reads very much as a medical chronology of symptoms and testing, similar to the medical history section of a standard history and physical. My medical story documents my observations of physical symptoms and the progression of my symptoms over time. Early symptoms from my initial attack are described and there is detail on the emerging symptoms over time such as later symptoms of cognitive issues and bladder symptoms.
My experience as a patient, however, is less prominent with fewer details. What is missing is the impact of chronic undiagnosed illness on my life. How does living with chronic undiagnosed illness affect my life? The lived experience and contexts of living with undiagnosed illness are missing in my medical story.

There are no details on the emotional aspects of my illness experience. My narration of the medical story does not capture social impacts or the emotional experience of having chronic undiagnosed illness. It rather neutrally narrates my frustrating interface with medicine through multiple encounters in an attempt to get answers.

There are only glimpses of family’s presence in this medical story narration. For example, my concern that my infant child had interpreted my absence during my hospitalization as rejection of her was further compounded when I could not lift her when I returned home from my hospitalization. She turned away from me as if hurt. Another description in this medical story relates to not being able to do physical things that other family members were able to do, even those older than I. There are only hints in the story that this chronic illness has affected my family relationships and interactions in some way. Thus, my medical narrative contains many gaps, which were explored using other data sources and are presented later in this chapter.

A thematic analysis (cite) of my medical narrative identified the following themes: 1) living with “not knowing” the diagnosis, 2) progression of symptoms observable by others to symptoms less visible to others, 3) observations offered by other nurses, and 4) researching the medical literature behind the scenes.
Living with “Not Knowing” the Diagnosis

In analyzing my medical story there is an evident continuous experience of “not knowing” what I have and a pattern of going back repeatedly—over the course of decades—for testing and answers. This medical story is a summary, and cannot capture fully all the appointments, consultations, and testing I have endured, yet even the summary attests to endless, repeated cycles of testing and physician appointments. The repeating pattern of negative testing and inconclusive reports is indicative of Frank’s (1995) chaos narrative typology.

Both the patient and the medical specialist are “not knowing” the diagnosis. This perspective is analogous to Frank’s (1995) chaos typology for illness narratives. For the patient, the not knowing contributes to an inability to order or make sense of one’s world.

From the perspective of being a nurse, however, my medical narrative describes in detail a typical process of research or inquiry, which begins with not knowing something. Medical testing, which results in obtaining findings that confirm or exclude diagnostic criteria then are used to help point to a possible diagnosis. It is a systematic working through of excluding and confirming what the illness could be, or what the symptoms could suggest. This is similar to systematic inquiry which is used in scientific method and the research process. I found this process of “systematic inquiry” also evident in my journal entries that reflect a methodological approach to analyzing my symptoms and looking for a pattern.

The influence of nursing process (Chinn & Kramer, 2015) is also evident in my medical narrative. The telling proceeds from a listing of symptoms which are part of my assessment observations, the first phase of the nursing process. The symptoms are
typically used in medicine and in nursing to formulate medical and nursing diagnosis, respectively. The challenge embedded in my medical story is that without the diagnosis, moving to the next steps in nursing process (planning and interventions) does not happen.

**Progression of Symptoms Over Time from Observable to Others to Less Visible to Others**

My initial attack in 1981 had very observable symptoms such as facial paralysis, motor challenges evidenced by my not being able to lift my child, ocular paralysis, hand tremors, and difficulty speaking. Some of the physical symptoms that emerged during the mid-point of my illness around the 1990s were less visible, such as fatigue, muscle weakness, and shortness of breath. I also noted that the later symptoms of my disease were less visible. For example, episodes of dizziness and heart racing were much less visible to others. My bladder symptoms were highly visible to me, but less visible to those around me. Cognitive symptoms which I became increasingly aware of were also more visible to me. Somehow, others were not able to discern these as easily. Journal entries further describe how I have created work arounds that help me manage slip-ups and lapses, which made some of my symptoms less visible to others.

**Considering and Reflecting on the Observations of Other Nurses**

There are also several places in the “medical story” where other nurses contribute observations that helped form a more comprehensive picture of my symptoms. During my initial attack and hospitalization, it is nursing colleagues that described some of my physical symptoms to me later. My ocular paralysis was not a symptom I was aware of; it took nursing colleagues to describe what they (and not my neurologist or family members) had observed to me. Many decades later in my story, it is a nursing colleague
who again notes some of my neurological symptoms and the details in my neurological medical history to try to help connect me to a neurologist who could help diagnose me. These colleagues observed me in work settings: in hospitals and in nursing education settings. Thus, interactions with nursing colleagues helped to describe and confirm some of my symptoms. I trusted their observations, relying on nurses to describe things that were happening when I could not self-observe: in work settings, nurses with expertise in neuro nursing offered reliable observations that matched my own awareness.

Another aspect that relates to my nursing culture, is how I have narrated the medical story. I describe my physical symptoms then relate the correlating testing that ensued, followed by the results. How I tell this part of my story follows a typical pattern for a chronological history that is influenced by the medical and nursing paradigms (Lake, 2007; Shanafelt et al., 2019) that I have been educated into.

**Researching the Medical Literature Behind the Scenes**

My “medical story” fails to capture my private, informal efforts to address “not knowing” my diagnosis. Behind the scenes, this experience of undiagnosed chronic illness contributed to my evolution as a nursing researcher. Outside of the medical appointments, I researched the literature on each of the diseases I potentially had in-depth as I sought more definitive answers. I needed research data from the literature to interpret my medical test findings and to validate or challenge medical providers’ interpretations of test findings in my search for a diagnosis.

In the early years after my diagnosis of Guillain Barre, my research database was in the form of journal articles hard-copied manually from journal volumes researched from the stacks at two university medical libraries. Computer search capabilities for
medical research evolved and resulted in my using online medical databases for my searches with articles downloaded to computers first, then subsequently to laptops. My current laptop has a medical information folder with multiple subfolders for each potential disease I have been evaluated for. The subfolders contain journal articles pertaining to each of those diseases.

**Journal Entries (2018-2019)**

By augmenting my medical narrative with other sources of data, this autoethnography could document various aspects and contexts of my experience as a nurse living with chronic undiagnosed illness. The journal entries were written from 2018-2019, and comprise another source of data. Journal entries documented and reflected on my current and earlier experiences.

**The Emergence of a Nurse Researcher**

My journal entries detail my evolution as a nurse researcher, beginning with my initial neurological attack in my mid-twenties. I describe how I would go to the medical libraries in different locations where I lived or studied and look up neurological diseases in medical journals using the early indexes that were used at the time. This habit of checking the medical and nursing literature became a dedicated habit which continues to the present time. My nursing education evolved over time to developing skills in online searches using established medical and nursing databases. My computer files archive numerous articles resulting from searches for the different diseases I have been evaluated for in different medical specialties: neurology, respiratory, rheumatology, cardiology, gastroenterology, and internal medicine. Verification and validation of evidence became a habitual approach after consultations with medical specialists.
In characterizing my research process, it is apparent that I leaned heavily toward an inductive process (Chinn & Kramer, 2015), moving from the particular (my symptoms and history) toward the general, or the underlying diagnosis or etiology for my symptoms. I am repeatedly trying to piece together the individual elements into some overall order or explanation. This may also support a personal lean toward qualitative research methodology, especially for the search for meaning in an illness experience. An example of this inductive approach is demonstrated when I decide to use a systematic approach to try and relate my individual observable symptoms. I also apply logic to analyzing my symptoms trying to ascertain what fits appropriately and what does not, based on evidence. The following journal excerpt that illustrates inductively analyzing my symptoms:

It is interesting, that at one point I decide with certainty that I knew something was wrong, aberrant with what was happening to me. At that point, since I had to deal with an empirical medical approach I decided to “follow the symptoms”- at least doctors could sometimes see those were “real”. I started with my dry eye, dry mouth, and corneal ulcers. There was no reason for me to have had the recurrent corneal ulcers in my right eye if I had perfect health. Something was underlying this– that is when I started the Sjogren’s workup. (May 26, 2019)

A systematic approach is also reflective of a nursing research approach (Polit & Beck, 2018). My medical narrative and my journal entries reflect a methodical systematic approach to inquiry. I go through one focused medical evaluation for a specific disease. As each disease is excluded, there is consideration of the next. My reasoning also reflects a systematic approach. In my journal there are entries where I use the research I have
read to validate or disconfirm the likelihood of a potential diagnosis based on the research evidence. For example, a negative lumbar puncture signals to me less likelihood of a primary inflammatory neurological disease (Dalakas, 2011; Vedeler et al., 2012).

Emergence of Nurse as Expert

As I researched more on neurological diseases, I became more of an expert on diagnostics and management for those diseases. There were times when I was able to validate information received from physicians as the most current level of research evidence. An example from my journal entries is when a neurologist told me that I didn’t have a small fiber neuropathy because my EMG did not confirm it. My research into the medical literature had informed me that it would not be possible to diagnose a small fiber neuropathy by EMG. It is worth noting that a skin biopsy conducted several months later did confirm that I had a small fiber neuropathy. As another example, another neurologist told me I couldn’t have CIDP because I had “small fiber” symptoms. My research in the medical literature, also confirmed by a second neurologist, revealed there is a small fiber variant of CIDP. I do not have CIDP, as confirmed by later testing (lumbar puncture), but again my careful reading of the medical literature allowed me to confirm or disconfirm accuracy of the medical statements by providers.

In my early years after diagnosis my pattern was to rely heavily on medical expertise. If a physician told me I didn’t have a specific diagnosis, I considered their opinion fairly absolute. Over time, when I noted inconsistencies between what I was told and what I was experiencing, I began to be more assertive in questioning some medical interpretations. When I was younger, it was easier to be convinced that stress was a
possible source of my symptoms. Later, a strong sense of logic forced me to ask why my symptoms were occurring when I was relaxed and not stressed at all.

I believe I have a high degree of respect for medical authority and for medical expertise. I spent fifteen years working at a 900-bed hospital with top caliber medical specialists in internal medicine, cardiology, pulmonology, and neurology. I believed in specialization in medical practice and respected the knowledge of physicians I worked with and those trying to diagnose my continued symptoms. I have wondered over time, if my subservience to physicians was a part of my nursing culture (Arford, 2005; Corser, 2000). The following excerpt from my nursing journal captures this:

I end up wondering if my hidden illness and secret sick self is also evolving. I am beginning to feel a sense of empowerment in taking a more active role in my illness and disease management. I can’t take delays and a lack of options anymore. I am becoming more assertive and have to also wonder why I have allowed others to dominate this conversation about my health and its impact on my life. I really am the expert on the experience and impact of this. I am also beginning to care less what others think which has in the past been a strong influence. Sometimes, I wish I hadn’t been a nurse—then I could have pushed back more and demanded better explanations. I tend to respect medical authority, yet, I know it is because I am a nurse that I have a sense of something very wrong physically with me. It does not fit a normal health pattern. (October 28, 2018)

I do believe now that I may have been acquiescing early in my illness to medical authority. Whereas, I am assertive now in seeking more definitive answers, I had been too respectful and accommodating. I may also have wanted to be the “good patient”. This
also may be reflective of my nursing culture (Arford, 2005; Corser, 2000; Leininger, 1994).

Observation

Observation is an accepted method with diverse applications in qualitative research (Creswell, 2013; Denzin & Lincoln, 2011; Flick, 2014; Patton, 2015; Polit & Beck, 2018). My journal entries describe my own observations of physical and psychological symptoms in living with my illness. The reflective comments in the journal also describe emotional and thought processes during the extended time period without a diagnosis.

Observing Physical Pattern of Symptoms

My observation and reporting of the physical pattern of my symptoms is influenced by my education on the nursing process (Chinn & Kramer, 2015, Meleis, 2018; Rodgers, 2005). Assessment, the first phase of the nursing process, is where I have been taught to start. This phase includes the description of symptoms and includes evaluation of the medical history as some of its components. I notice careful explanation in my journal entries of my symptoms. Here is how I describe fatigue in one journal entry:

Fatigue, one of my overwhelming symptoms is really hard to get physicians to understand. They think you are just getting older or feeling tired. They do not understand a kind of fatigue that robs you even of doing pleasurable things. They cannot fathom it. They also dismiss it as a minor symptom. For those with chronic neurological diseases and some autoimmune connective tissue diseases it is disabling. (May 26, 2019)
In my detail I try to capture an accurate description of the symptom, the pattern, and how it changes over time. I note that with some symptoms I try to explain the experience of having symptoms which others do not see such as fatigue and bladder symptoms. Over time, my journal documents how I am becoming more adept at describing characteristics of my symptoms. I am observing more acutely and capturing detail as I relate symptoms.

In another journal entry, I describe not only the characteristics of my bladder issues, but also their psychological impact on my life and family relationships:

I think the bladder and bowel issues have taken over my life. The other night I woke up after having a nightmare where I needed to go to the bathroom and all the toilets were filled with waste and toilet paper to the brim and wouldn’t flush. I remember the sense of panic in my dream and I end up having to go to the bathroom where others can see me going. I wake up with bladder urgency and have to go to the bathroom. Bathrooms have become a part of my life. I plan my life around them. I now am losing bladder control more easily. It coincides with the spells of weakness. If I cough, I don’t have control. Now sometimes, urine just starts running down my legs and I can’t hold it back. I am buying larger bladder leak pads. I wonder how soon it will be before I have to wear depends or something like that. I would at least like to know why this is happening. My son doesn’t know about this symptom. I know it would embarrass him and I think I embarrass him already. He wants the perfect mom. (September 26, 2018)

This quote shows how my bladder symptoms are described in a social context and how these physical symptoms impacted both social and family relationships. Despite
being a registered nurse, I found the self-disclosure of these personal symptoms difficult and embarrassing.

**Observing as a Nurse**

As I analyzed my journal entries, I found descriptions of how my nursing role and nursing education had influenced my interpretation of my symptoms and my continued inquiry. Nursing assessment is mentioned in several entries. Nursing process is an underlying conceptual that I bring into my interpretations. One journal entry captures this nursing influence:

> We are taught in nursing to do assessment— to observe what is happening and to explore the history of the patient. It is this training that is enabling my linking things. It really is an epidemiologic approach— to consider genetics and history of disease symptoms or patterns in trying to find an answer to an unknown disease.  
>  
> (April 13, 2019)

Not all nursing influences advanced my inquiry. Another influence evident from nursing and medical culture is that I often aggregated my descriptions of my medical symptoms by organ systems. However, this organization of my symptoms into discreet categories may have made it harder to note an overall pattern and to identify a primary disease which was causing multiple symptoms across varying body systems.

**Observing Variability versus Archetypes**

Nursing and medical students are taught to learn typical symptoms of a given disease which would form general overall patterns of symptoms for different diseases (Welk, 2002). Undergraduate nursing education is typically structured around organ
systems with characteristic descriptions of major diseases with aligned symptoms that then may signal the need for confirmatory diagnostic testing.

A person with chronic undiagnosed illness may not exhibit typical symptoms, making it harder to establish the underlying cause of their illness (Nettleton et al., 2005; Spillman et al., 2017). In the case of my personal illness, “atypical” has been a common identifier in my illness experience used by varying physicians involved in my care. First, my original diagnosis from my attack in 1981 was “Atypical Guillain Barre.” My presentation of illness and subsequent evolving patterns were not typical for the many diseases suspected. There were variations and distinctions in my symptoms. As I am nearing a more conclusive diagnosis, “atypical” is once again being used in my working diagnosis.

My journal entries suggest how even my own knowledge of diseases and their symptoms based on archetypes obstructed my search for a diagnosis. In the case of the many providers I sought out, disease “archetypes” also influenced their interpretations and delayed more definitive diagnosis. I relate in my journal how I have lectured on neurological diseases based on typical symptoms and focusing on “classic presentations” of illness. I taught the symptoms of Parkinson’s disease for years based on the classic motor form of the disease, visualizing a stooped older man with shuffling gait and hand tremors. After I researched further, I learned of non-motor akinetic forms of Parkinson’s and also of atypical forms of the disease. In the akinetic form of the disease, slowness of movement and balance issues may be more typical. I noted the following in my journal entry:
In nursing, we teach the archetype— with Parkinson’s a disease that old people get. Yet, that is not what research now tells us about the disease. I note the fact is correct in one nursing text, but not in another. I am humbled by the fact I have taught Med/Surg students about neurological diseases and I have taught the archetype as well. We have to teach nursing and medical students to be alert to distinctions in disease patterns. There were many missed clues in my presentation. Shortness of breath was certainly one of them. Cognitive symptoms were another. (March 3, 2019)

Early onset familial forms of Parkinson’s disease are also not familiar to most nurses and physicians, because knowledge of these emerged from more recent research.

**Observing Cultural Objects**

Autoethnography, as a form of ethnography can include observation of cultural objects including photographs, film, video, artwork, drawings, collages, among other forms of cultural expression (Glaw et al., 2017). Entries from my journal captured some of my observations related to loss of fine motor skills and cognitive abilities. As part of my autoethnographic data, I also analyzed examples of my quilting and knitting handwork captured in photographs, photographs of family members, and family letters showing handwriting. Photo elicitation (Glaw et al., 2017) yielded additional parts of my story and made them available for data analysis.

Examination of cultural objects in my study helped to visually and materially demonstrate and extend what was being described in my journal. They provided an additional source of data that informed a cultural perspective in the study. Cultural
objects were triangulated across other data sources to enhance rigor. Further, these cultural objects helped to elicit through memory other parts of my illness experience.

**Observing Changes in Handwork**

My love of handwork helped to make me more self-aware of physical and cognitive changes. Quilting was a personal hobby that I had done since my early twenties, influenced by my grandmother’s love of quilting. I became a fairly advanced quilter and could execute very fine detailed applique as one example of my quilting skills. I became more aware of decreasing motor skills, challenges with finishing projects with lack of energy, and in the past two years with difficulty laying out basic patterns which I had been able to do earlier in my life. These were not difficult patterns, but they required reading a graphical layout. I had problems executing the design.

Knitting, which I began in my late fifties, also signaled clues. Despite having advanced to an intermediate level with lessons, I found I was making repeated errors and that reading graphs for patterns in knitting was difficult for me. These graphs may require reading from left to right on one row and changing to right to left for the next row. They also require interpretation of symbols for specific stitches. I organized my projects into individual tote bags for each project. Project bags were accumulating where I had made errors and could not mentally process my way to correct the error and continue the project.

The journal entry below shows my increasing awareness regarding changes in my ability to do handwork and what it might signal:

I miss my quilting and hand sewing. My hands are changing for sure and I think it is linked to this too. I know my doctor has told me I have carpel tunnel— but I don’t
think that explains problems lifting things in both hands. Fine motor is changing somehow. Strength is also an issue. I first noticed it when I picked up a glass and it seemed heavier somehow. Then unable to open things, and dropping things. (May 5, 2018)

In my journal text, I am still focused on the body and my physical symptoms. Changes in my physical body and my physical ability to do things dominate my descriptions. Another quote captures the change in my abilities over the duration of my illness:

I once did the most beautiful hand applique; lovely floral quilt blocks with exquisitely small fine hand stitching. Right now, I can barely thread a needle. I have shifted to knitting but have to moderate that with pain in my right hand. Plus, right now the brain fog— affects my product. Two baby sweaters on hold right now because I lack the mental acuity to fix the errors in them now. I can’t even be creative with this. That is taken from me too. (May 5, 2018)

My handwork, including both the quilting and the knitting became indicators of declining physical and cognitive abilities. I first became more aware of this with the knitting where I struggled in particular with graphs that are used for lace and colorwork patterns. I was having difficulty following the patterns. Blurriness of vision also was impeding my ability to visually track written patterns. With knitting, I found myself making repeated errors in my work that required assistance from my knitting instructor. I became more aware that these were not the errors of a beginning knitter as I had progressed to immediate level skills. At first, I excused the errors as part of the process. It was only as the errors in my work accumulated and I was able to see the total number of
times this impacted my projects that I understood the pattern of errors as reflective of cognitive symptoms.

As I tried to return to quilting, I became aware of my hands not working properly. I was having problems with fine motor skills in both hands, but especially in my dominant right hand. I could not make the fine motor motion to pick up pins or to place them into layers of fabric. I knew from many years of caring for elderly patients that it was not aligned with my age or due to normal changes in aging. A more frightening awareness happened when I tried to layout a pattern for a simple quilt for my grandchild. I was at the level of an advanced quilter in my thirties. I made repeated errors in laying out the simple pattern. I could not follow the visual layout. I had to repeatedly tear out and resew the pattern. I cried the day I noted this change, as it was a stark clue to a decline in cognitive ability. As I noted this change, I also reflected back on my challenges with data that was presented in graphs in my quantitative course. Things were beginning to connect. Interpreting and following visual data was presenting challenges.

**Observing and Analyzing Handwork Photographs**

Photos of my handwork illustrate what I have described in my journal entries and reflections. The photos include samples of applique quilt blocks I made in my late twenties to early thirties. The blocks were a part of an attempt to make a Baltimore Album quilt after taking classes from experts in the technique at a large annual quilt show. The fine, evenly spaced stitches attest to a high degree of dexterity and skill in the applique technique. Photographs will also show some of the types of graphs for both quilting and for knitting that present continued challenges for me now, because of cognitive issues.
The first handwork block (Figure 1.) is an example of my needlework ability in my late twenties and thirties. This block is hand appliqued with the pattern folded and cut out with very fine applique scissors. Each edge of the fabric for the design is carefully turned under by the tip of a very fine applique needle (size 12). Stitches are 1/16\(^{th}\) of an inch apart. On the front, stitching is not visible.

**Figure 1**

*Applique Quilt Block*

The next example photograph (Figure 2) captures the back of the same block. It helps to visualize the tiny stitching and the small fine knots on the back of the white background fabric. This is considered an advanced form of applique.
In analyzing these blocks, I reflected on more recent physical abilities. With changes in my vision, including blurry vision and difficulty focusing my vision at times, there are definite changes that limit my ability to do anything this fine. It is when I reflected on my ability to handle a needle that I was convinced my fine motor skills had definitely declined. I could no longer hold a needle, even a much larger needle. When I tried to pin fabrics together, my hands moved clumsily with poor coordination and execution. I couldn’t even pick up the pins. I kept dropping them.

Graphs are used in knitting to signify which stitches should be done for each row. They are numbered and even rows are for one side of the knitting with odd rows for the opposite or wrong side. The graphs are read from right to left, then from left to right for alternate rows. A photograph of a typical easier knitting graph pattern is shown below (Figure 3) to illustrate how they are depicted and followed by a knitter.
Figure 3

Sample of Basic Knitting Graph

This sample knitting graph is a simple basic graph pattern often used to make lace knitted patterns. The graphs can become more complex and intricate for advanced knitting. I found myself making repeated errors on the simple graphs and I found it difficult to process what stitch I should do on the wrong side of the fabric. I became easily confused in trying to think through what stitch I should be doing. Row 1 is read from right to left, with Row 2 typically read from left to right. Then stitches may change depending on whether one is on the right side of the knitting fabric or the backside.

I had become aware of the challenges with the knitting, and thought at one point that I would shift to an easy quilt pattern to make a small baby quilt for my grandchild. Again, my skills in quilting and applique were at an advanced level. I would go annually to the largest quilt show in the country in Houston where, each year, I took more advanced classes and learned finer techniques. I had not only done very fine applique during that time, I learned to hand-dye fabrics and taught the technique as well to other quilters. I hand-printed my own fabrics for one quilt where I wanted an unusual artistic quilt. As I went to layout and sew the first rows of the simple quilt pattern, I was stunned.
when I kept making errors in the layout and had to take out rows and sew them again multiple times. This was a very simple layout. I asked my husband to check my layout for several rows after repeated frustration. He has an architecture degree, and had read blueprints much of his professional career in commercial estimating. He glanced at me oddly when I explained I could not mentally do the layout. I knew I had never asked him for help in any of my laying out of patterns in the past. The small quilt is shown below (Figure 4) after I had managed to sew the rows together.

**Figure 4**

*Baby Quilt*

The diagram of the layout for the quilt is shown below (Figure 5). To layout the pattern, one has to shift the pattern on the diagonal to interpret how each row is laid out. It is a basic nine patch pattern considered one of the easiest patterns to sew. The nine patch blocks are then set with solid color blocks with small diagonals in each corner. The solid color blocks have different color diagonal blocks that have to be matched to the pattern.
Figure 5

Nine Patch Layout

The photograph below (Figure 6) helps depict the multiple knitting projects which were accumulating, each in a separate tote bag, and capture my growing awareness of cognitive challenges. Each represents a mental error resulting in a handwork error that I could not fix. Five projects are shown here each with their tote bags. On the far left, in orange, peach, and yellow colors is a baby sweater, unfinished. Far right in the photo, another black, red, and grey hooded baby sweater, unfinished. In the center, an easy pattern for a linen scarf. An error was made and I cannot mentally figure out how to fix it.

Figure 6

Unfinished Projects
I counted a total of thirteen tote bags each with an unfinished knitting project due to mental errors. This total flagged for me a consistent pattern of mental errors. I knew that I had already tried to adapt to my propensity toward mental error by making sure I never tried to knit when I was very fatigued. This helped some. In other cases, I began to select simpler patterns to knit, but even this was not a fix as I would also make errors on simpler patterns. It was difficult to scale down to easier patterns as I had always liked challenging myself to do more difficult things, and love learning new things. I began to realize that working lace patterns, as much as I loved their intricacy and complexity, would likely not be suitable with my symptoms. The stack of unfinished projects in their tote bags serve as a stark reminder of something not right.

It was after these experiences that I began to notice any symptom that might flag my problem in interpreting visual data. At this same time, I had become more self-aware of problems judging distance. I was beginning to drive over curbs when I turned corners with my car. Another example, when I would go to place a glass on a coaster, I sometimes misjudged the center of the coaster. If I was not careful, the glass would tip off the edge of the coaster. I relayed the two examples of challenges interpreting visual data and making errors in judging distance with my driving to my neurologist.

In my role as a nurse educator, I was observing changes in my voice that made my voice lower, softer, and more difficult to project. I had to at times use a microphone or a lavalier to teach my classes when my symptoms were worse. If I was also fatigued, my voice would almost completely fade out and I would have to break the class to rest my voice. As I lectured, I began to notice difficulties at times in articulating words that I knew. I knew the word I wanted to say conceptually, but could not recall the specific
word. This particularly concerned me as I have been an articulate speaker in prior nursing roles. I adapted to this challenge by being very methodical in my lecture notes. If I literally became “stuck,” I would carefully look back at my notes to try to move forward.

I reflected back on some of my personal habits and wondered if they may have evolved over time to compensate for an evolving cognitive deficit. I am grateful to have inherited my mother’s categorizing mind, or perhaps her habit of being very methodical about everything she did. I recheck myself repeatedly for error. I acknowledge this may also reflect my nursing education as well. Repeatedly checking is part of how we teach nurses to administer medications safely. I make meticulous lists of tasks I need to do or complete. I am known for my sticky notes, which help cue not forgetting something. This may have helped to make my cognitive symptoms less visible to others. I, however, am more acutely aware of them.

I observed more challenges with written communication as well. I was making errors in my writing and missing them when I proofed my work. I had considered myself a careful fairly skilled writer. I was acknowledging to myself that this was also changing.

In the past year in going over old records and papers in my home, I found GMAT scores. I first took the GMAT when I started my Master’s degree at the University of Colorado in the late 1990s. My scores were adequate to qualify me for admission and I obtained my degree. Around 2006, I wanted to go to the University of Colorado for a degree in Public Affairs. This aligned with my avid interest in policy and government. The GMAT was required for admission. I prepped extensively for the exam, in particular with the mathematical prep. When I went to take the exam, I remembered not being able to recall how to do the calculations I had studied for extensively. I remember thinking it
odd. Then when my results came back and they were very low, I still could not understand it. I had never had a challenge on any form of standardized testing in my past. I still applied to the program and was not accepted. I had not connected what happened until this past year when I found both sets of scores in my paper records. This was statistical evidence of my declining cognitive ability and I had missed the clues.

As evidence of evolving and worsening neurological symptoms was mounting, and as my neurologist shifted from considering inflammatory neurological disease to the possibility I may have a neurodegenerative form of neurological disease, I began to reflect again on possible family patterns of disease and to examine photographs of family members for possible evidence. My concern regarding my father’s medical history of unexplained symptoms also prompted the careful examination for further signs. Parkinson’s disease was a possible diagnosis that was proposed, and I was being worked up for a DaTscan, and a medication trial of Parkinson’s medications was being considered.

Observing Family Photos and Handwritten Artifacts

Photo elicitation is using photographs or other visual mediums to generate discussion and to create data and knowledge. Visual methods enhance rich data collection which help in discovering additional layers of meaning. They enhance validity and trustworthiness of findings, and allow for nonverbal methods of expression (Glaw et al., 2017). Photo elicitation is both a data collection method and a form of analysis. The areas of the brain that process visual information evolved earlier than those that process verbal information, therefore, visual data may evoke non-verbal parts of consciousness, including visual memory (Harper, 2002).
I observed photographs of family members to see if I could identify any physically observable signs of illness, in particular signs of neurological symptoms. What I observed helped to define a possible pattern of illness that could have familial etiology. I observed for facial masking, for changes in body posture that could signal degenerative disease. Along with these observations, I searched my memory for potential symptoms based on my recollection of family members’ symptoms and known medical testing and illnesses. I recalled puzzling neurological symptoms that my father had exhibited in his mid to late life. I examined his handwritten letters for any content or signs related to illness and to determine if there had been visible changes in handwriting pattern.

I will list the photographs in the order in which I had identified them as relevant to my search. For each photograph, I will describe what I visually noted and also share any reflective memory that contributed to my evaluation of the photograph.

I examined these photographs after I was given a working diagnosis of Atypical Parkinson’s disease in April 2019. I felt it important to examine them after researching Parkinson’s disease and learning that, since the 1990s, there are now known familial genetic forms of the disease, with alpha synuclein discovered in 1997 (Nussbaum, 2017). Some familial forms of the disease also have earlier disease onset. Thus, when I looked at family photographs, I was looking for evidence of neurologic symptoms and neurodegenerative disease.

**Wedding Photograph 1977**

The first photograph that I observed that showed some physical signs for my father was a photograph taken during my wedding. It shows my father shaking my husband’s hand as we arrive at the head of the altar for our church ceremony. I am
standing by my father in my wedding dress. My father was just over six feet tall and a thin man most of his life. What captures my attention is his back is markedly stooped. When I reflect on his age at the time, he was in his mid-forties. He is too young when the photograph was taken to have had such a marked sloping of his upper back. I had not noted this before. In Parkinson’s disease, body posture may become stooped, there may be limb rigidity, a tendency for a shuffling gait, and lack of arm swing when walking, in addition to rest tremor (Sveinbjornsdotir, 2016).

*Photograph of Father Lifting Wood*

The next photograph I analyzed is one of my father, approximately in his fifties. He is wearing a flannel shirt and jeans, and must be in a remote area of the Southwest. There is an RV in the background and a stack of wooden logs. The photo strikes me because he is lifting a heavy wooden log. What captures my attention is the manner in which he is lifting the heavy log. I relate to it because of my own history with arm and leg weakness. I have challenges with lifting heavy objects with my arms. Occasionally nurses I worked with have glared at me as if challenging my not fully helping when lifting patients, as I try to explain I lack comparable arm strength ever since my initial neurological attack.

In the photo he is lifting the log of wood in what seems to me an atypical way for a man. Instead of putting both arms under the wood and lifting it up with arm strength, my father is holding the log overhand. His knees are bent, boots are very close together, and I see his abdomen straining (as mine has) as he tries to pull it up with an overhand hold up the length of his body. As I view the photograph, I understand he has lost arm strength and is compensating. His upper arms likely lack strength to lift any other way. I
remember and reflect on the muscle wasting I witnessed on his upper arms and legs in the later years of his life. I begin to understand how a man who was physically very active in his youth (tennis, hunting, fishing), who in his mid-life, long before he was an older man, began to limit physical activity and physical exertion. He lacked physical capacity, and I compare and relate to my own physical symptoms and experience in this regard.

Research on Parkinson’s disease has shown that there may be systemic effects outside the central and peripheral nervous systems, including impairment of peripheral mitochondrial function in platelets, lymphocytes, and on skeletal muscle (Savica et al., 2010). Kim and Jeon (2013) found that musculoskeletal problems are common in Parkinson’s disease, contribute to poor quality of life, and are often under evaluated and under treated. Musculoskeletal problems (45%) were the most prevalent comorbid disorder in a survey on comorbidities on health-related quality of life in Parkinson’s disease (Andreadou et al., 2011).

Photograph of Father’s Facial Expression

The next photograph I flag for analysis is one of my father in his mid-sixties, in 1990. I make a mental note of his facial expression which I would describe as angry. I would not describe my father as having a masked expression as typical of Parkinson’s patients, however: I would note that he seldom smiled, and that his facial expression as he became older could often be described as grim or angry, even though he was not overtly angry all the time. I know when I took this photograph that he was not angry at anyone at the time. It just captures his typical facial expression.

I continued to have an underlying concern that my father may have lived most of his life with some form of an underlying illness that began in his late twenties and
worsened during his lifetime. As I examined photographs, I reflected on some of the neurologically related symptoms he had over his life that remain unexplained: physical weakness, choking spells, problems with his balance when he walked, occasional seizures, vision issues, sensitivity including light sensitivity, and digestive issues such as diarrhea. Around his forties, he also began to exhibit mental symptoms include paranoia, delusions, and cognitive issues. I have always questioned whether my neurological symptoms may have some familial connection. As a nurse, I also began to wonder if this was inherited, would it exhibit an autosomal dominant or autosomal recessive pattern? If my father had it and I had it, that could reflect a higher degree or penetrance, or perhaps a trait that was dominantly inherited.

Photographs of Paternal Grandfather

As I began this analysis of family photographs, I began to think about my father’s parents. I had never considered looking at my paternal grandparents’ photographs or reflecting on my memories with them to signal a connection to my own medical history. I did this only after there was consideration of my having a neurodegenerative disease in the last year.

I begin by looking at a photograph of my father’s biological father. I remember he was very tall, about six-foot-three, as I look at one of the photographs of him in his seventies sitting on a swing with me in my grandmother’s back yard. I flash back to a memory of him walking each day with his cane. His steps, I now recollect, were definitely short shuffling steps. He also has a slight stoop to his back, but not as obvious as my father’s. What I do note in this photograph, is a masked facial expression. I remember observing when he spoke that his facial expression changed very little and his
voice had a monotone, even pattern to it. He would smile, but his smile was more restrained as in a barely formed grin. I reflect also on whether he may have had cognitive signs as well, remembering how he stuck his hand under the running lawnmower one day when he was trying to cut the grass. I spent the afternoon with him in a medical clinic, where they sutured his two amputated finger stubs.

Memory flags another incident. My fiancée takes my grandfather for a drive in his prize possession: a Chevy Camaro. My grandfather sits in the passenger’s side for the drive. After the drive, my husband goes to close the car door after helping him out of the car and sticks his hand into the groove of the arm handle inside the car to close the car door shut. He pulls his hand out in disgust as sticky dark brown wet “snuff” drops off from his hand. My grandfather having left his “spittoon” behind had decided the arm groove was where to spit out. Could this suggest cognitive issues? I know he had to move in with his sister (my grandmother) in later life because it was deemed he could not live alone.

*Photograph of Grandmother (Paternal Aunt)*

My father’s mother is really his aunt. His biological mother died of influenza shortly after his birth and he was raised by his aunt. My biological grandfather at the time had several small children to raise already and he was a farmer. My grandmother, a nurse, took her nephew in and raised him as her own. This explanation is necessary because of what I will relate next. The next family photograph I examine is a photograph of my grandmother on her driver’s license. She is in her eighties. The photograph makes me sit perplexed for a few minutes. I am confused because I am suddenly aware of something that has been right before me for as long as I can remember her. She has the classic
masked face of a Parkinson’s patient that we teach in medicine and nursing courses.

Bradykinesia in Parkinson’s disease contributes to the expressionless face (hypomimia) often characteristic of Parkinson’s (Sveinbjornsdottir, 2016). The photo I observe triggers my memory of that facial expression which rarely changed. Seldom smiling, although immensely caring, her voice is something that I reflect on from memory. Her voice was very soft, almost like a hoarse whisper. You almost had to strain your ears to hear her. I sometimes thought she spoke so softly to capture your attention. She also shared my grandfather’s slow shuffling gait, barely lifting her legs as she moved forward.

I wonder about whether she may have had gastrointestinal or urinary issues as I remember her keeping a commode by her bed. She stated she often needed to go in a hurry and didn’t want to get locked out of the bathroom by my grandfather or house guests. I slept in the next room by her with just a curtain divider and would hear her get up multiple times during the night.

I connect the photograph with an entry from my journal which describes the details elicited from the photograph:

My grandmother on my father’s side was my father’s aunt who raised him (and a nurse). I have her driver’s license photograph. She has the classic Parkinson’s masked expression and rarely smiled. She did not walk with a shuffling gait but she walked very slowly, very definitively lifting up heavy legs and plopping them down slowly. I know she rested often on her bed when we visited her. I think she also may have had my autonomic GI and bladder issues because she kept a bedside commode by her bed, often using it during the night. She would wake me sleeping in the next room when she got up. I also remember her being very physically
inactive and wonder if her blood clots related to that. This is speculative, but could point to a possible autosomal dominant pattern of inheritance and an unknown disease. (April 13, 2019)

When I began to rationalize how it is possible that both of them could have some Parkinson’s symptoms when both were not my father’s biological parents, it suddenly became apparent. They are biologically related to each other as brother and sister. They could share genetic predispositions to illness and inheritance patterns. It is at this point that I began to map out family members that had symptoms and began to observe a possible dominant pattern to the symptomatology. No family member in my father’s immediate family had ever been diagnosed with Parkinson’s disease.

I began keeping a file of the photographs and other “artifacts” which I carried to my appointments with my neurologists. I began examining and collecting photographs and artifacts pertaining to family history in April 2019, shortly after my neurologist introduced the possibility that I could have a form of neurodegenerative disease and suggested testing in that area. I later shared my family history symptom diagram with a specialist in motor disorders at a major university research center. It was copied for my file. With my primary neurologist, I carried the photos and artifacts to appointments three times. He declined to view them until the third time, when I insisted they were relevant to our ongoing discussions on confirming a possible diagnosis: familial Parkinson’s versus atypical Parkinson’s versus other forms of neurodegenerative disease.

**Observing Handwritten Artifacts**

After completing nursing school in the late 1970s I moved out of state away from my family, and didn’t return to live in the same state until after my father had died.
During that time frame, my father would periodically send handwritten letters. During the last few years of his life the letters increased in frequency. I saved those letters in remembrance, but it was in the course of this dissertation and the evolving concern regarding neurodegenerative disease that I began to consider them a form of data that could be analyzed.

In Parkinson’s disease, changes in handwriting have been noted in the research literature, in particular micrographia where amplitudes of handwriting become smaller (Sveinbjornsdottir, 2016). In an earlier study (Oliviera et al., 1997) hypometric handwriting movements were also confirmed, but it was also noted that letter size increased significantly between visual targets and amplitude of the writing increased when required to write between parallel lines. Some of my father’s late letters were written on ruled notepads.

Observations of my father’s letters reveal changes in the pattern of his handwriting, problems with spelling words, and some delusional statements. One handwritten letter, written in 1983, is written in cursive. I note several spelling errors, which seems unusual for someone who taught high school English and was a passionate, avid reader. He made an occasional spelling error at times, but this was not a general pattern. During the last decade of his life in the late 1980s -1990s, his handwritten letters are no longer in cursive writing. Instead he is block printing each letter in capital letters. In letters with no ruled lines, his printing slopes to the right downward where it used to be level. On ruled stationary his letters are printed between the lines. In the sets of letters, I highlight any misspellings and note that he is making repeated spelling errors on words that are fairly common to spell. For example, he spells reserve as “researve”, security as
“secrrity”, impaired as “impared”, shoulder as “sholdier”, and interest as “enterest”. For each letter there are multiple misspellings. This was not reflecting his normal level of writing ability.

As I compare to my own handwriting, I do not exhibit micrographia, but am beginning to struggle with cursive writing where I am making errors forming cursive letters at times when I try to write a word. It is happening frequently enough that I can evaluate it as a beginning change. It is as if my brain is moving slower than my hand sometimes, so the letter comes out wrong in its cursive form. I note now that it also worsens during periods where my medication for Parkinson’s is wearing off, or I am late taking a dose of my anti-Parkinson’s medication.

**Thematic Analysis of Family, Professional and Cultural Contexts**

Sullivan (2010) described this kind of examination of artifacts as process and product of *artistic knowing*, in which the artist is both the researcher and the object of the study. In his words, “If a primary purpose of the research is to increase awareness of ourselves and the world we live in, then it seems plausible to argue that understanding is a viable outcome of inquiry….Individual and social transformation is a worthy human enterprise, for to *know* means to be able to think and act and to thereby change things” (p.97). His ideas resonate with my methods for this autoethnography.

After analyzing the above artifacts, journal entries were re-examined to identify themes relating to family, professional and cultural context. Themes on context that were identified from the journal entries were 1) not being believed, 2) hidden secret self, 3) diminished self-identity, and 4) diminished family and professional roles.
Family Context

My journal entries reflect ongoing concern regarding family members’ disbelief in the legitimacy of my undiagnosed illness. As years passed without a new confirming diagnosis after my initial diagnosis of Atypical Guillain Barre, my journal entries evoke emotions regarding lack of credibility and not being believed.

Whereas my spouse was more supportive, my children struggled to understand and empathize with symptoms they could not see. One of my children was only one year old during the severe attack in my late twenties. My other child had not been born yet, arriving as part of our family four years after the attack. They did not observe the highly visible symptoms of the initial attack. The following quote from my journal reflects this:

I quickly send a short text to my children that the test results were negative and that I knew this would not be easy to pin down. I don’t hear back from them. I know they don’t understand what I have been experiencing and that at times they do not believe me. This is one of the crosses I find hard to bear. I don’t care as much what others think of me, but it is different with my children. That really matters. I don’t want them to see me as some kind of flake. (May 21, 2018)

My son is very embarrassed by all this…I have some mystery disease that makes it hard for our house to look like all his friend’s houses…I can’t do it all. I have let him down in some way. (September 3, 2018)

Other relatives similarly struggled to accept that I have an undiagnosed but real illness. Another journal entry notes:
I was talking with a family relative who asked me how I was feeling. When I answered her honestly, she gave a little humph sound. It was a disbelieving humph. I finally said, “I realize my medical problems and symptoms are hard for people without a health background to understand.” I finally have decided she doesn’t believe I am ill and I will not talk with her about it. Back to being secret Fran. I used to get upset that she never asked me how I was feeling and now I want her to stop. It is not supportive. I want her to say “I am sorry you are feeling bad right now,” instead I get “Humph.” I know what that means. No interpreter is needed.

(September 26, 2018)

Relatives’ expressions of doubt that I have a legitimate (if undiagnosed) illness contributed to my withdrawal from family and sometimes their withdrawal from me. This is illustrated in a journal entry:

One relative calls and I catch up on family news. I explain my next medical journey and sense an immediate locking down, not wanting to hear anything about it. I am alone in this. It has taken too long for answers, robbing me of credibility. Robbing me of even a semblance of concern from others. I feel like I live a secret life I can’t share with others. I am different. (July 6, 2018)

In this experience of a “hidden secret self,” I would not tell others how I was feeling and respond with general platitudes like “I am fine,” when I was not.

This theme of hiding my self extended to my role as a nursing scholar and researcher. Despite many years of researching medical literature during the course of my illness, I would not disclose my medical literature research into different diseases to others, including my providers. It is only since I have entered the PhD program that I
cautiously began to share my knowledge of the literature with providers. I also kept my passion for investigation and research more discreet until the last five years. It is now part of my identity as a nurse. I have been able to share that passion teaching research to nursing students.

Living with chronic undiagnosed illness also affected my function and role as a family member. I was not able to participate fully in normal family activities because of symptoms that limited me. I noted this first with hikes in my thirties extending late in life. I had noted that others far older than me could participate hiking up on family reunions in the mountains. I was plagued with muscle weakness in my legs and shortness of breath. When syncopal episodes and rapid heart rate symptoms ensued, I had to avoid events that required being out in the heat or I could pass out. Going to venues that hosted large crowds such as concerts and sporting events were the next thing I had to give up. Missing sporting events particularly isolated me as our family loves sports. Another missed family activity is captured in this journal excerpt:

I remember one time one of my adult children asked me if I would go the St. Patrick’s Day parade in our city with a friend and the friend’s mother. I declined explaining that I couldn’t take the walking and the heat. A comment was then made about how I couldn’t do things that the friend’s mother could do and I felt terrible. Yet it is true. When I worked with the nurses’ association they participated in that parade each year and I had to decline then, too. I can’t do it physically with the crowds, the heat, and having to park in the boonies (July 28, 2018).

The experience of hiding my illness extended to how I sometimes declined to share information on my family medical history. There were times during the course of
my medical evaluations that some providers would ask if stress could explain my symptoms; however, I was hesitant to disclose some symptoms that could be labeled psychiatric. For example, I have at times had symptoms of anxiety and depression. I tended not to disclose these because I believed they would be mistakenly taken for a primary source for my illness, versus a secondary symptom in addition to other clear physical symptoms. This is apparent in my descriptions of family symptoms in my journal where I had excluded considering my father’s severe nightmares and history of anxiety. This is also evident in my willingness to describe physical symptoms, but my hesitancy to identify psychological symptoms more openly.

**Nursing Context**

In analyzing my journal entries, the theme of hidden secret self is repeated in entries about my professional role as a nurse educator. However, in contrast to the family context, journal entries focused on my nursing context demonstrate that my interactions with other registered nurses reflected both positive and negative experiences. Some nurses tried to help me understand my symptoms and were careful listeners; some colleagues shared their descriptions of my early physical symptoms when I was hospitalized. Later, over the years as a diagnosis was more elusive, other nurses voiced critical comments implying a lack of acceptance of my undiagnosed illness.

Journal entries also describe missed professional events due to physical fatigue and lack of stamina. When I could not participate fully in my professional role and its expectations, my identity as a nurse was diminished. Even after a tentative diagnosis, this lack of self-confidence in my professional role is reflected in a journal entry:
My sense of self and confidence in myself has taken such a beating, and knowing I now may have Atypical Parkinson’s has not made me more confident. I am more confident in managing some of my symptoms and life, but not in my capacity to succeed with this. I lack a sense of belief in my future right now. It is as if – I now stop here. This is the most I can do professionally – or I perceive it as such. Do I dare envision myself in a new job or a new direction in the future after graduation? Is it realistic? I know what it takes now for me to do a lot of intense mental tasks – learning new systems, etc. It takes me more to do that than others. I now realize that. But I also know I have determination and do find the motivation to make myself do the hard things. Is it enough to make a difference? (June 9, 2019)

Whereas some of my family and professional colleagues could not believe my undiagnosed illness was real, I struggled to believe in myself and my future as a nurse.

**Hispanic Identity**

In journal entries I wondered whether my Hispanic background may have contributed to a subservience to medical authority and a reluctance to question medical authority figures. Could I have been influenced by a form of fatalism influenced by my Hispanic background; a sort of “que sera, sera?” Did I fail in some of the years I was seeking diagnosis to assert myself fully, acquiescing and accepting whatever I was told?

As I analyzed my journal entries and discussed them with my dissertation chair, an already familiar theme emerged with respect to my Hispanic heritage. Similar to how I was treating my illness as a secret part of my life, I was also treating my Hispanic background as secret. One excerpt illustrates:
Last week had a good session talking with my dissertation chair about some articles on immunology and anthropology. As we explored some ideas about living a hidden life with my illness, she commented about my Hispanic background. In our discussion, I realized this is another aspect of my self-identity that is also a form of hidden self. I explain to her that it is hard for me to talk about my Hispanic background because of some of the elements of my mother’s family ties to wealth and politics in Mexico (October 28, 2018).

Another journal entry reflects an emerging realization that even how I relate my story of my Hispanic background may include elements that serve to self-protect me. Thus, the theme of hidden secret self applies to my cultural identity. I seek to keep this hidden and limit self-disclosure. The following entry from my journal depicts this critical self-reflection:

Do I sometimes use the story of Mom’s wealthy family as a way of saying I am different from other Mexicans? I am not poor (although I am at times) … is this a way of getting “accepted” by others who would view Mexicans as poor, uneducated, or even “criminal”? I don’t tell many about this, but does it serve some hidden purpose? Am I more acceptable as a “Mexican” if my background is different… Or do I use it to exclude myself from the brotherhood? (October 28, 2018).

These interpretations of data from my journal help inform how my experience with chronic undiagnosed illness is shaped by and shaped within family, cultural and professional contexts.
Chapter 5

Introduction

This study is one of the first known to examine a registered nurse’s experience living with chronic undiagnosed illness using autoethnography. Ethnographic approaches, and particularly autoethnographic approaches, have been less utilized in nursing compared to phenomenology and grounded theory (Robinson, 2013). Autoethnography which incorporates biography with ethnography has been used very limitedly by registered nurses in examining their own illness (Allbon, 2012; & Colter, 2017; Etorre, 2006; Peterson, 2017; Sealy, 2012; White, 2003). In this chapter, the major findings of the study will be discussed. The discussion of the findings will be followed by clinical, research, and policy implications ending with the study conclusion.

Summary of Study Findings

Research Question 1

Research question 1 asks: What is it like to be a registered nurse living with chronic undiagnosed illness? The study found that the medical history narrative presented as a chronological sequence of symptoms, reading similar to a standard history and physical. Absent from the medical history narrative was any reference to the cultural, familial, and professional experience of living with chronic undiagnosed illness. Three major themes related to living with chronic undiagnosed illness were identified. These themes include not knowing, loss, and hidden secret self.

Research Question 2

Research question 2 asks: How is the experience of chronic undiagnosed illness shaped by cultural context of health care, family, and profession? Findings for this
Research question include: themes related to family context were not being believed, hidden secret self, diminished self-identity, and diminished family role. Social context themes were hidden secret self, diminished social role, and hidden Hispanic identity. Professional context themes were hidden secret self and impact on professional role.

**Research Question 3**

Research question 3 asks: What are the implications of my autoethnography for future nursing research, nursing and medical education, health care delivery, and patient empowerment and advocacy? Findings for this research question include clinical, research, and policy implications. Clinical implications relate to identifying nursing’s role in caring for patients with undiagnosed illness; identifying the interventions for patients with chronic undiagnosed illness; and including content for education in chronic undiagnosed illness, the experience of illness, and more focus on teaching about atypical presentations of disease instead of archetypes. Research implications include the need for future qualitative and quantitative studies that consider the real-life practice settings and cultural context of patient’s experience. Policy implications include the need for policy analysis on how the lack of a diagnoses affects access to federal and state benefits and protections; the need for research funding; and exploration of nursing’s role in supporting patients with chronic undiagnosed illness through care coordination, navigation, case management, and advocacy.

**Discussion**

**Being a Nurse with Chronic Undiagnosed Illness: An Inquiry in Two Parts**

Beginning with the early decades of my illness up to my first years in the PhD program, the first part of my inquiry was informal and focused on my physical
symptoms. During this phase, there was collection of the available information on
different diseases, consultation with medical experts, diagnostic testing, interpretation of
results, epidemiologic inquiry, and some kinship research on my father’s medical history.
The physical symptoms, emerging new symptoms, and history of my illness were the
central focus. I did reflect on the social-cultural aspects of my life at times, but that
related more to family relations and was secondary to my physical experience of illness. I
was a nurse during all of this time, but had reflected little on how being a nurse informed
or shaped my illness experience. I was using informal, literature-based “research” as my
method of inquiry. I sought a diagnosis for my illness symptoms by seeking medical
knowledge using skills I had learned in the nursing profession to search the medical
literature. This lengthy phase was heavily influenced by the medical and nursing
paradigms which are part of my socialization to a nursing role. I sought a diagnosis and
relied on medical explanatory models to confirm my illness.

**Inquiry Extends to Autoethnography**

The second phase of my inquiry started in 2018 as I began to gather sources of
data for my dissertation about my illness experience. I began to reflect on my experience
by recording a journal across the course of nearly two years. I then wrote a narrative of
my symptoms and medical history. I made observations of artifacts, including my
handwork, family photographs and family letters. I also conducted these observations in
order to elicit memories. These different sources of data completed my autoethnographic
database.

Autoethnography, as a form of ethnography, represented a qualitative research
method that would allow analysis of my data sources and provide a systematic
framework to more fully describe and examine my illness experience. I identified the tools that would comprise my ethnographic toolbox to generate and analyze my data. I would use narrative writing in the form of my journal as one component. My toolbox, which I originally imagined would only contain a narrative of my illness, expanded to incorporate different types of data and this allowed me to begin to see aspects of experience that couldn’t be seen in a clinic setting or based on my medical history narrative alone.

Whereas reflexivity is important to all qualitative work, for an autoethnography it becomes a major part of data analysis and even the development of data sources (Hokkanen, 2017). My journal included written observations and reflections on my daily experience of living with chronic undiagnosed illness. It detailed visits to providers, medical testing and results during the time period of the journaling, family, professional, and social interactions as relevant to my illness, and also related some of my early dialogues with my dissertation chair on my illness experience.

In the data analysis phase, I contrasted and compared the findings across different sources of data. It was the systematic analysis of these core sources of data that resulted in an integrated holistic understanding of my illness experience. Discussions with my dissertation chair, feedback from committee members, and analyzing my journal for themes and then again for contexts helped me to see the ideas and assumptions I brought to the study but was not aware of.
Becoming a Bricoleur

Making sense of being a registered nurse living with chronic undiagnosed illness involved becoming a bricoleur. This term, first applied in anthropology, has also been discussed in the qualitative research literature.

French anthropologist Levi-Strauss (1966) was the first to use the term bricolage, to describe a type of thinking or symbolization (Anthrobase, 2020). The bricoleur is a “jack of all trades” who uses whatever is at hand to observe and interpret the world and create a meaningful narrative about the world. Levi-Strauss contrasted the bricoleur to the engineer who creates scientific explanations more based on modern Western mechanical science (Mambrol, 2016). In early anthropology the term was used to help explain the mythology of indigenous societies and how these narratives functioned to order and guide behavior, identity and experience.

Bricolage was a concept later applied to qualitative research by Denzin and Lincoln (1994) who described the qualitative researcher as a “bricoleur” who “produces a bricolage which is a set of pieced-together, close-knit practices that provide solutions to a problem in a concrete situation” (Denzin & Lincoln, 1994, p. 2). Denzin also compares a bricoleur to a maker of quilts. The intellectual bricoleur however, does not work with his hands, but instead with signifiers, signs, and precepts (Gobbi, 2005). This interlinking, interweaving of one activity with another is also characteristic of nursing practice (Benner, 1986; Welk, 2002).

The etymologic roots of the term come from a French expression which creatively use leftover materials from other projects to construct new artifacts (Rogers, 2012). A bricoleur uses materials at hand. When the term is used in reference to qualitative
research it refers to methodologic practices rooted in emergent design, which involves flexibility and plurality. A bricoleur may also use “bits and pieces,” concepts and approaches, from different disciplines such as nursing, philosophy, psychology, education, sociology and anthropology to examine a phenomenon (Gobbi, 2005).

My study is a form of qualitative bricolage. Different sources of data were gathered from different “things at hand”—my journal, my quilts, my family photos and letters—that were used to investigate the research questions. Memories are part of my autoethnographic record that are documented in the journal and the medical narrative, and evoked when viewing the quilts, photographs, and letters. The different data sources were individually analyzed and then related to each other.

Similar to Gobbi’s (2005) description for bricolage as identifying precepts and signifiers, I have systematically identified common signs and signifiers across the data. This pulling together of themes incorporated from the different data sources used bricolage (linked practices) to develop a qualitative autoethnographic study of the experience of living as a registered nurse with chronic undiagnosed illness. Bricolage can be seen in the medical history narrative, which incorporated objective diagnostic findings obtained over decades and included the evidence-based research I examined to identify disease patterns and symptoms in the medical literature.

The Study’s Key Themes:

Dimensions of Experience of an RN Living with Chronic Undiagnosed Illness

As the findings were compared across the data sources three themes were identified that define my experience of being a registered nurse living with chronic
undiagnosed illness. The three themes were: a) not knowing, b) loss, and c) hidden secret self.

**Not Knowing**

The theme of “not knowing” propelled a decades-long inquiry into a possible diagnosis for my recurring mystery illness. There was a component of “not knowing” the diagnosis. There was also the unpredictability of “not knowing” the potential progression of the disease, and its impact on my future. There were the unknown factors that could relate to hereditary disease. The “not knowing” contributed to emotional and mental stress, fear and anxiety during the course of my illness experience.

This finding that “not knowing” is a feature of living with chronic undiagnosed illness is also evident in the chronic illness literature. Wideman-Johnston (2016) in a dissertation on the experience of living with a chronic illness identified fear of chronic illness as a subtheme. Hermanns’ (2008) dissertation on the illness experience of living with Parkinson’s disease identified three subthemes: uncertainty, unknown, and worsening. The unknown in Hermann’s study is congruent with the theme of “not knowing” in this study of living with chronic undiagnosed illness.

This theme of “not knowing” contributes to the limited research on the experience of living with chronic undiagnosed illness by identifying that the psychological experience can be as relevant and impactful as the physical symptoms and disabilities of a disease. When a patient experiences chronic undiagnosed illness with a protracted course, the experience of “not knowing” is indefinite. Patients with chronic illness may have uncertainty regarding the progression of their disease. However, in my study, the patient without a diagnosis experiences a pervasive and constant not knowing what their
symptoms “mean” or why they are happening: an experience that was a continuous underlying presence for my illness experience. Yet, medical providers did not inquire into that aspect of my illness. As a health care provider, my frame of reference to disease is rooted in a diagnosis. During my years in providing care as a registered nurse, I observed and assisted patients all around me in getting answers for their complex conditions. There was dissonance in my not being able to obtain a diagnosis in my own professional field of health care– living with “not knowing” while helping others to “know”.

Even as “not knowing” was an impetus and a recurring theme in this study, I came to appreciate the fact that every scientific inquiry begins with not knowing about some problem. It is the initial presentation of something unknown that compels a systematic inquiry, analysis and problem-solving process to develop knowledge of what it is not known.

**Loss**

The second theme of “loss” was evident in journal entries and in the handwork artifacts examined in the analysis. Detailed in journal entries was the loss of physical abilities such as ability to walk for normal distances without experiencing shortness of breath and muscle fatigue. The loss of fine motor abilities was noted in journal entries and evident in the diminished ability to execute fine handwork. Loss of cognitive ability was described in journal notes and in the observation of handwork. Photographs capture projects that were unfinished and journal notes detail challenges in interpreting visual data such as graphs.

The loss experience extended beyond the physical to include lost experiences in social contexts, including being unable to participate fully as a family member, and to
engage in numerous social activities with others. The theme of loss was also evident my professional role, limiting my ability to fully engage in professional nursing activities.

Research has documented loss as a major source of stress for those living with chronic illness (Ahlstrom, 2007; Boss & Couden; 2002; Charmaz, 1983; Golub, Gamarel, & Rendina, 2013). More recently, self-loss has been identified as a critical construct in understanding adaptation to chronic illness where identity processes may influence symptom perception and health outcomes beyond traditional measures of health status (Golub, Gamarel, & Rendina, 2014). There is a gap in the literature on loss in undiagnosed illness compared to chronic illness. Little is known about whether the loss(es) experienced by patients with undiagnosed chronic illness are similar or not to losses experienced by those with diagnosed chronic illness, or what the impact of loss is on health and quality of life in undiagnosed illness.

**Hidden Secret Self**

“Hidden secret self” was the third key theme identified in this study. Hidden secret self emerged across all contexts of my illness experience including family, professional, and social contexts. This propensity to live my life harboring my secret illness and to carefully guard self-disclosure even extended to keeping my Hispanic identity hidden from others.

The theme of “hidden secret self” identified in my autoethnography was evident in all the contexts of my life. It pervaded my family, professional, and social contexts, impacting relationships and altering my role and identity within each of those contexts. The pattern of hiding self contributed to profound isolation experienced in all of the contexts explored in the study. This theme of “hidden secret self” is related to loss of self
and diminished self-identity which are identified in the chronic illness research literature (Charmaz, 1983, 1985; Golub, Gamarel, & Rendina; 2014). People with chronic illness try to minimize others’ knowledge of their symptoms (Strauss & Glaser, 1975; Swoboda, 2006).

As a part of this hidden secret self, my illness experience describes a sense of self-blame and shame associated with my illness experience. This is seen across all the cultural contexts in this study. It is seen in my family and gender roles where I am embarrassed at not being like “other mothers” or able to participate in family life fully. This sense of personal shame begins to pervade my cultural identity, and supports that living with chronic undiagnosed illness also is associated with stigma (Frank, 1995; Goffman, 1963).

**Family, Social, and Professional Context**

The findings for family, social, and professional contexts were presented in Chapter 4. The themes identified for the family context were a) not being believed, b) hidden secret self, c) diminished self-identity, and d) diminished family role. The themes identified for social context were a) hidden secret self, b) diminished social role, and c) hidden Hispanic identity. The themes identified for professional context were a) hidden secret self and b) impact on professional role. Significantly, the theme of hidden secret self occurred in all three contexts being evaluated.

In looking across all three contexts of my illness experience two other themes come forward in the analysis: a) isolation and b) feeling of being different or not normal. If one were to look at my illness experience strictly from a biomedical model all of these critical aspects of experience would be missing. These contextual themes affirm the value
of nurses and health care providers engaging in understanding the “hidden” dimensions of an undiagnosed illness event or experience.

Examining my illness experience with an (auto) ethnographic lens forced me into a dual role: that of insider versus outsider. When I examine my illness experience from my professional “lens” I am observing myself as a patient through my professional nursing paradigm. Yet the emic (insider) perspective of my illness is laden with the chaotic emotional experience of not knowing what I had or how my illness would progress and evolve.

This also affirms that reflexivity in ethnographic qualitative research is not just about identifying biases, but about the need to engage the many dynamic domains of an individual’s experience with illness in order for hidden aspects—aspects hidden in the literature and aspects hidden to the researcher—to become known. Originally reflection on bias was intended to manage the self in order not to contaminate data (Edvardsson & Street, 2007). This was influenced by Cartesian dualism where there needed to be separation of mind from body, promoting the objectivity of science.

Emerging approaches to ethnography advocate for the nurse as “embodied” ethnographer, using a scholarship that combines the analytical with the “sensate”. This study has shown that using multiple methods and multiple data sources can help elicit memory and description of embodied experience. Embodiment theory deals with how we as embodied beings are situated in, experience, and understand the world through our body (Edvardsson & Street, 2007). An autoethnography is one way to explore the embodied experience of illness which is often missing in research on nursing practice.
Pattern Recognition

This study demonstrates how one nurse thinks about and looks for pattern in her symptoms, functioning, relationships, and ways of coping with chronic undiagnosed illness. Pattern recognition is a recognized approach to generating knowledge for both nursing and medicine. In this study, linkage of individual themes across the data sources was established through a systematic data analysis process supported by an inductive approach. There was meticulous review of data and observations to identify linkages and recognize patterns in the data. Recognition of patterns also informs development of knowledge in ethnography, in nursing theory and nursing research, and in medicine.

Ethnographic methods help facilitate observing behavior, seeing cultural patterns, and understanding their meaning within different contexts (Robinson, 2013; Wolcott, 1999). Robinson (2013) explains the critical role of the researcher in recognizing patterns and determining their relevance and argues for ethnography’s role in nursing research. Van Manen (1990) explained that the illumination of patterns is accomplished through description, interpretation, and critical analysis and is important to researching lived experience.

Madeleine Leininger’s (1988) theory of culture care diversity is based on the premise that caring is essential to nursing practice and that discovering patterns of caring contributes to new knowledge in nursing (Robinson, 2013). Leininger (2007) argued that observing patterns in human behavior could inform nursing actions to maximize health.

Margaret Newman’s (1994) Theory of Health as Expanding Consciousness proposes pattern as a central concept to revealing nursing knowledge. Newman described nursing situations as often ambiguous and uncertain, requiring a method to capture the
essence of nurse-client encounters. Newman argues for focusing on a unitary pattern of
the whole and maintains that praxis research focused on pattern recognition reveals the
nature of nursing practice (2002). In order to identify a person’s pattern within the nurse-
client relationship, Newman emphasized dialogue that engaged in understanding
meaningfulness of events in a client’s life. These meanings informed a pattern that
possessed meaning. Per Newman (2002), as meaning was discovered pattern became
apparent and insight into the client’s evolving pattern occurred.

Another advocate for recognition of pattern as central to nursing knowledge is
Patricia Benner (1986) in her work on expert nursing practice. According to Benner,
expert practice is learned through experience and characterized by practical reasoning,
pattern recognition, embodied know-how, skill of involvement with patients, ability to
manage technology and ability to work with patients (Oberle & Allen, 2001). Pattern
recognition is one of the essential aspects of expert nursing. My use of autoethnography
to study my own illness experience also aligns with Benner’s characteristic of embodied
know-how. My autoethnography is an embodied form of research because it examines
my lived experience with chronic undiagnosed illness as situated in the world, affected by
social and cultural forces.

Conceptually, nursing process can be interpreted as a form of pattern recognition
using inductive process. The assessment phase of nursing entails the gathering of
particular singular data elements of the patient’s symptoms to inform a diagnosis
(nursing). Pattern recognition is one of the processes that nurses rely on to identify
related symptoms. Newman (2002) argues that even the Nursing Diagnosis NANDA
classification system represents a form of pattern recognition. Pattern recognition is also
used in medical and nursing education to enhance the diagnostic reasoning process (Welk, 2002), where students are expected to identify characteristic pieces of data fitting together to inform the medical diagnosis (Fonteyn, 1998). Identifying patterns also has application to epidemiology, where patterns of disease occurrence elucidate the burden of disease occurring in communities (Gordis, 2014).

The findings in this study were based on patterns observed in the data, including patterns of symptoms, patterns observed in family, social, and professional contexts, patterns noted in execution of handwork as my disease progressed, patterns in handwriting, and patterns in physical postures and facial expressions observed in family photographs. Robinson (2013) argues that ethnography provides the best means of understanding how people assign meaning to health experiences. Ethnography provides a systematic process for recognizing behavioral patterns and understanding their meaning in different contexts. The different values and beliefs that inform cultural perspective can lead to different individual and group conceptualizations of both wellness and disease, thus the nursing view of health, according to Robinson (2013), depends on an embodied, holistic understanding culture. Observing pattern was necessary to interpreting and analyzing the data of my experience with undiagnosed illness.

**Reflexivity**

Reflexivity was what enabled me to see the overall patterns in my data. Reflexivity, often utilized in qualitative research is a critical component of an autoethnography (Anderson, 2006; Coffey, 1999; Ellis, 2004; Madison, 2012). It refers to the use of reflexive practice and self-critique to examine the assumptions on which knowledge is based (May & Perry, 2014). Analytic reflexivity involves understanding of
self, and examination of one’s actions and perceptions in reference to others while maintaining awareness of the researcher’s connection to the research. (Anderson, 2006). Reflexivity methods are important tools for capturing the hidden meanings of illness experience (Anderson, 2006; Hokkanen, 2017). Coffey (1999) describes reflexivity as having an ongoing conversation about experience while at the same time living in the moment. Autoethnography moves beyond description of experience to include constructive interpretation (Chang, 2008). Reflexivity is the process that enables interpretation.

Whereas reflexivity in ethnography has traditionally involved consideration of the researcher’s positionality, Lichterman (2017) argues for going beyond positionality in reflexivity to achieve an interpretive reflexivity. Interpretive reflexivity shows how interpretations evolve and converge to contribute to the findings. Madison (2012) reminds that one must move beyond one’s individual objective self to understand how our subjectivity in relation to others is informed by our interactions with others to inform a form of critical ethnography. We are subjects in dialogue with others. In analyzing the cultural contexts of my experience, I extend beyond my own individual perspective to interpret experience with others, also supported by validation with others (dissertation chair, committee members). Patton (2010) also speaks to the use of ethnographic approaches to understanding the “other” where autoethnography represents the use of creative narratives based on the writer’s experience within a culture. Reflexivity enables the researcher to demonstrate a visible self, accountable for developing findings about other in relationship to self.
Reflexivity for this autoethnography required maintaining an awareness of the influence of a medical paradigm on the experience of illness. Cheek (2000) describes the emergence of the idea of “the clinic” was based on a disease model of care, influenced by the writings of Foucault who referred to the medical “gaze”. The medical “gaze” is an act of viewing illness and disease and even the body based on scientific medical discourse. The clinical body becomes a docile body under the authority of medical discourse. Even the ways in which nurses portray themselves can be influenced by their close relationship to scientific and medical discourse (Cheek, 2000). This relationship is evident from journal entries in my autoethnography.

In my data analysis, I demonstrated self-reflection and self-critique by describing my thought processes, sharing underlying assumptions, explaining my interpretation of data to find meaning of my experience, looking for different threads in my own perspective, and looking for evidence of missing information or cues. Descriptive writing in the journal incorporates use of rich voice to both document and enhance reflexivity. Ethnographers focus on rich points or differences they note to capture a dynamic and more holistic perspective (Agar, 2004).

**My Illness Narrative and Frank’s Typologies**

Frank (1996), in his classic work, characterizes illness narratives as one of three types: chaos, quest, and restitution narratives. A chaos narrative is evident in my journal entries as I detailed struggles with worsening of my symptoms and a frustration with failure to obtain a diagnosis. Chaos was seen in my journal entries describing increased anxiety regarding test results, withdrawal from others, and fluctuating patterns of
physical symptoms that disrupted my social and professional life and sometimes caused providers to start over and rethink their ideas about my symptoms.

Chaos narratives often show lack of control in one’s life and a story that lacks coherence and structure. Without a diagnosis, my illness story lacked an endpoint. Chaos stories demonstrate vulnerability, futility, and impotence. My medical narrative also has elements of chaos with no definitive final diagnosis, but is also reflective of a quest story per Frank’s (1996) typologies. The continued researching into different illnesses and many diagnostic tests and procedures align with a quest for a diagnosis. Frank’s restitution typology is less evident in my illness narrative, largely because for my illness restitution in the form of any symptom relief was contingent on a diagnosis which was elusive.

Frank’s (1996) typologies imply a singular linear process to the illness experience with restitution or cure being the endpoint of the experience. My experience with chronic undiagnosed illness did not follow a linear pattern: my narrative was more circular, alternating between periods of chaos and quest. Frank’s typologies categories may be limited in classifying narratives of living with chronic undiagnosed illness. In addition, family, professional, and social aspects of my illness experience are not well described by the typologies.

When I first began writing my medical history narrative and began my journal entries on living with my illness, I believed that my study would primarily focus on my narrative about my illness. As the research developed, the centrality of the narrative changed. The narrative was an important source of data, but the study’s findings stemmed from the analysis of the narrative and the other sources of data. The medical narrative of
my illness was a starting point that pointed to gaps or missing domains of experience, to be examined through other data sources. The narrative became one part of the overall research.

**Implications**

The implications from this autoethnography for clinical practice, for research, and for policy are presented here.

**Clinical Implications**

The first and most important clinical implication of this study is the need to identify and develop nursing’s role in caring for patients living with chronic undiagnosed illness. Nursing’s presence is needed to support patients dealing with chronic undiagnosed illness. The research literature is ample on nursing care and interventions for those with different types of chronic illness, but it does not address nursing care and interventions for those living with undiagnosed illness. Many patients living with chronic undiagnosed illness intersect the health care system more often in outpatient settings, where they may encounter only physicians and supporting technical staff.

The advent of the Affordable Care Act signaled a critical role for registered nurses in care coordination. The American Academy of Nursing, in its white paper on care coordination, identifies patient centered care coordination as a core professional standard and competency for all nursing practice (Camicia et al., 2013). One area identified for redesign of the healthcare system is the development of an evidence-based model of care coordination and transition management to work with chronically ill patients in ambulatory settings (Haas & Swan, 2014). The care coordination role for registered nurses and advanced practice nurses could serve as an effective care delivery
model for working with patients with chronic undiagnosed illness. Nursing as a profession needs to explore professional opportunities to identify and engage with and care for patients struggling to obtain a diagnosis in both inpatient and outpatient settings.

More recent efforts such as the Undiagnosed Diseases Network (Spillman et al., 2017; Undiagnosed Diseases Network, 2019) which tries to diagnose patients with undiagnosed illness are laudable, however their limited ability to reach a broad population with undiagnosed illness, and their primary focus on diagnosis and treatment, leave many who have undiagnosed illness with limited recourse. Their “quest” for a diagnosis does not address the psychosocial experience of living with undiagnosed illness, including how to manage or adapt to an unknown disease in the context of daily life. As a nurse living with undiagnosed illness, I would have welcomed any opportunity to just connect with someone else with a similar experience. Support groups are needed for patients with undiagnosed illness, to facilitate coping with the isolation and the experience of hidden, secret self.

A second clinical practice implication of this study is the need for patient centered care and holistic approaches to caring for individuals with chronic undiagnosed illness. Patient-centered care is a concept that has been promoted as an essential part of quality health care and is embraced by the medical and nursing professions (Institute of Medicine, 2001). It emphasizes the consideration of a patient’s desires, values, and concerns and places the patient as the central core around which care and treatment revolve. It is antithetical to a disease centered approach and aims to involve patients more centrally in their plan of care. It is conceptualized as an approach that includes exploration of a patient’s objective disease but that also incorporates their subjective
experience of illness (Liberati et al., 2015). This study affirms that providing patient-centered care and holistic care have to include the patient’s perceived subjective experience of illness.

There are many implications for nursing and medical education from this study. The topic of caring for those with chronic undiagnosed illness needs to be a content area covered at all levels of nursing education. It is relevant to pre-licensure nursing education, to advanced practice nursing, for master’s level curriculum, and for doctoral education. Currently, much of nursing pre-licensure education is organized around body systems and interventions specific to diseases. Chronic illness is sometimes included but undiagnosed illness, specifically, is not.

It is vital that nursing and medical education incorporate teaching about the experience of illness, not just teaching the biophysical aspects of illness. Patient narratives about illness can help to describe the patient experience for medical and nursing students, and could help to develop empathy in health professions students. Wear (2000), a professor of medicine, critiques knowledge generated by traditional scientific approaches, noting that students are often confused trying to apply what they know about function without knowing about the human experience of health and illness. She advocates for students being invited to create meaning within their learning in order to better understand lived complexities of life and health.

Robert Nussbaum (2017) is one of the pivotal physician-researchers that helped to identify alpha-synuclein as the first Parkinson’s disease gene in 1997. Hereditary forms of Parkinson’s disease are considered rarer forms of the disease. The application of knowledge on genetic forms of Parkinson’s have contributed to specific knowledge and
new therapies regarding Parkinson’s disease and illustrate how research on rarer forms of a disease can contribute to broader understanding of more general forms of a disease.

Nussbaum (2017) reminds that in 1657, William Harvey wrote:

> Nature is nowhere accustomed more openly to display her secret mysteries than in cases where she shows traces of her workings apart from the beaten path; nor is there any better way to advance the proper practice of medicine than to give our minds to the discovery of the usual law of Nature by careful investigation of cases of rarer forms of disease.

Thus, nursing education needs to exercise caution in reliance on archetypes for disease symptoms as a teaching approach. Nursing education needs to balance instruction on archetypes with correlating instruction on atypical presentation of disease symptoms, using (yet to be developed) case studies of patients with undiagnosed illness. While archetypes and teaching patterns in symptoms have had value in nursing and medical education in helping students associate symptom patterns with specific diseases (Welk, 2002), it is critical to also educate that atypical presentations of disease occur and may be more common in patients with chronic undiagnosed illness. Thus, nursing textbooks need to reflect the most recent medical research. Atypical Parkinson’s syndromes, which have been identified in more recent research, are seldom taught in nursing education (Levin et al., 2016; Marras & Lang, 2017). When archetypes are ingrained, they may exclude recognition of other signs that could signal a potential diagnosis and may reflect outdated knowledge.

Further, archetypes may not capture symptoms that are not easily “visualized.”

An ethnography by Hermanns (2013) explored what it meant to individuals with
Parkinson’s disease (PD) to have PD. An important distinction was noted between visible and invisible symptoms of disease, both of which can be stigmatizing. Findings identified with invisible stigmatization included changing self, self with PD, and a form of disability, contributing to further self-isolation. Uncertainty and fear of the unknown were noted to occur in invisible stigmatization. The study noted that people with invisible disabilities are often stigmatized because they can’t perform actions normal people can, yet they may appear to be capable to doing those actions (Hermanns, 2013). They can be misinterpreted as noncompliant.

Neurological diseases pose inherent challenges in that many neurological diseases have symptoms that are less visible. An example of another neurological disease with less visible symptoms is multiple sclerosis, with sensory symptoms that others may not see such as numbness, blurry vision, weakness, and paresthesias. Parkinson’s disease patients often have equal challenges with non-motor symptoms that are not visible to others, including autonomic nervous system symptoms, cognitive symptoms, and fatigue.

Another implication of this study is the need for intervention in the absence of a diagnosis in patients with chronic undiagnosed illness. Those living with chronic undiagnosed illness may require more time with health care providers, and questions posed during medical inquiries should focus on not only physical but also mental health concerns, including social isolation. Often, a diagnosis is what initiates both medical and nursing interventions for a patient. Symptom management was a major challenge in my life, yet the predominant focus of my medical appointments was targeted toward diagnosing my illness. Any interventions that could have targeted managing my symptoms such as bladder and gastrointestinal issues, autonomic nervous system
symptoms, and fatigue as examples, would have greatly improved quality of life in the absence of a diagnosis. As noted, nursing interventions for those with chronic undiagnosed illness should also target their psychosocial and cultural experience with illness.

**Research Implications**

This autoethnography lays the foundation for a future nursing research agenda for patients with chronic undiagnosed illness. Further research, using both quantitative and qualitative approaches, is needed to inform effective care for those living with chronic undiagnosed illness.

Research on chronic undiagnosed illness is relevant to several of the topic areas identified in the National Institute of Nursing Research’s (NINR, 2016) current strategic plan. Core to NINR’s mission are the goals of:

- Enhancing wellness by understanding the physical, behavioral, cultural, and environmental influences on health status and developing culturally tailored interventions to prevent illness and promote health; and
- Helping individuals with chronic health conditions better understand and manage these conditions by engaging individuals as active participants in managing their own health.

This autoethnography of a registered nurse living with chronic undiagnosed illness aligns with both these topic areas. Symptom science research has also been identified as a topic area under NINR’s strategic plan (NINR Strategic Plan, 2016), and is directly relevant to improving care for those with chronic undiagnosed illness.
A major conclusion from this autoethnography is that there is limited nursing and medical research on caring for patients with undiagnosed illness. Research studies utilizing both quantitative and qualitative approaches are needed. The epidemiology of chronic undiagnosed illness can be studied using quantitative methods including surveillance data, trends in population data, community level data, and to evaluate morbidity, mortality, and other measures for disease impact with undiagnosed illness (Gordis, 2014). Quantitative nursing surveys could be used to identify barriers to care in patients with chronic undiagnosed illness and to evaluate quality of life based on quantitative instruments. Quantitative nursing intervention studies could identify nursing interventions and test their effectiveness in managing patients with chronic undiagnosed illness.

Further qualitative research on patients with chronic undiagnosed illness is imperative to analyzing the experience of their illness. Autoethnography as an approach in this study has demonstrated value in identifying cultural influences and the relevance of context to the illness experience. Ethnographic research involving interviews with individuals with chronic undiagnosed illness could be used to further develop knowledge about living with chronic undiagnosed illness. Ethnographic interviews with patients and their families are needed; ethnographers need to follow patients through their diagnostic experiences, and could include observations of interactions with providers, family members and work settings. Just as there is little formal research on living with chronic undiagnosed illness, there is a need to understand the family experience of living with someone who has chronic undiagnosed illness, which has not been formally researched.
Studies are needed to document how cultural life and identity are impacted by chronic undiagnosed illness.

Other qualitative approaches are equally suited to explore the experience of living with chronic undiagnosed illness, including grounded theory and phenomenology. Case studies focusing on one individual’s experience with chronic undiagnosed illness would contribute to understanding individual experience of illness. Nursing research has incorporated the use of focus groups, which can be used to evaluate patient experience. Self-management of undiagnosed illness can be researched with both quantitative and qualitative approaches, including to understand the use of holistic or complementary forms of self-care.

According to the NINR (2016), “nursing science transcends the boundaries of disease and research disciplines to better understand the experiences of individuals and families living with illness and to develop personalized approaches that maximize health and well-being for individuals at all stages of life, across diverse populations, and settings” (p. 6). Personalized approaches to care need to be informed by qualitative nursing science focused on the patient’s individual experience.

Future research must also utilize a health equity lens in examining how health disparities can further characterize and affect the experience of living with chronic undiagnosed illness. Communities of color and communities of lower socioeconomic status have greater challenges in accessing health care services and diagnostic testing which make obtaining a diagnosis more challenging with chronic undiagnosed illness (LaViest & Isaac, 2013).
Context Critical to Studying Illness Experience

A major research implication derived from my autoethnography is that analyzing the patient’s social context is a critical part of researching a patient’s experience with illness. In this study, examining the family, social, and professional contexts demonstrated that I did not just have an illness with physical symptoms, but my experience and perspective was shaped by the cultural values, beliefs, and assumptions of others in these different contexts. My study also demonstrates that a nurse living with undiagnosed chronic illness has a dual perspective. Karen O’Reilly is a sociologist and ethnographer who developed the idea of practice stories:

Practice stories should reveal the complexity of people’s lives, should try to understand cultural differences, and challenge stereotypes and typifications. But structures are both internal and external, so agent’s perceptions can never be divorced from structural contexts (Patton, 2015, p. 131).

With the current emphasis on patient centered care, identifying appropriate research approaches that capture the complex social realities of health care experiences becomes imperative. Current research in patient centered care does not adequately capture the practices, relationships and perspectives that make up the patient experience within health care contexts (Liberati et al., 2015). Ethnography and reflexivity are methodologies these authors propose to move the tacit knowledge of everyday practice into actionable knowledge. Further, the authors suggest that health care providers’ and patients’ first-hand experiences within care contexts can inform the concept of patient centered care (Liberati et al., 2015). This form of knowledge is marginalized in biomedical science.
Leeman and Sandelowski (2012) cite the need for the inclusion of evidence about the experiences and practices of health care providers in real world practice settings. They relate that most research evidence has been produced in a way that systematically excludes practice-based evidence or evidence on perceptions, practices, clinical observation, or clinical experience.

**Autoethnographic and Ethnographic Research on Illness Experience**

The approach used in this autoethnography derived from the analytic approach defined by Anderson (2006). Analytic reflexivity and theoretical analysis of autoethnography data are essential characteristics. For Anderson, analytic autoethnography requires dialogue across multiple sources of data to strengthen the qualitative rigor of the study. Findings in one data source were compared or confirmed in other sources of data. Wall (2016), a nurse, autoethnographer, and qualitative methodologist critiques the quality of autoethnographies for their lack of careful analysis and explains they should include observation and participation in a context in addition to multiple sources of data. Anderson (2006) argues for the use of both material and visual sources of data in an analytic autoethnography which this study included. This autoethnography met the standards for analytic autoethnography (Anderson, 2006) and for Wall’s (2016) criteria.

In beginning this study, I had ongoing concern that not emphasizing the evocative aspect of my illness experience would limit understanding of the experience on a personal level. One of the insights from using the analytic autoethnographic approach is that using a systematic approach still captured the emotion or feeling of the experience, but provided a more comprehensive description and narration of the experience of
undiagnosed illness including the social and professional contexts. Without the analytic approach, the study would have been a basic narrative analysis relating to the symptoms rather than the experience of my undiagnosed illness. The use of the analytic approach enabled understanding the social and cultural dimensions of illness as experienced by a nursing professional.

This has implications for nursing researchers trying to decide on which autoethnographic approach to utilize for their research. The analytic approach was congruent with qualitative research standards, using narrative and thematic analysis and yielded findings which were consistent across the study’s data sources. Other nursing researchers could also use analytic autoethnography to approach other research topics with some assurance that the method is both scientific (analytic) and rigorous, while still caring about and examining evocative aspects of illness experience.

My analytic approach to autoethnography includes a person-centered approach to ethnographic research. Robert LeVine is an anthropologist who created a subfield of psychological anthropology and advocated for an approach known as person-centered ethnography (Gaines, 2015). This approach argues that when a discipline tries to study culture by applying the abstract concept of culture “onto” individuals, the discipline then can inadvertently and falsely prove their own conception of culture and not allow for the meaningful aspects of the lived cultural world of an individual to emerge (Hollan, 2001). In using a person-centered approach, one starts with the individual and asks them to think about their own culture. Robert Levy, an anthropologist and psychiatrist, first coined the term “person centered ethnography” to describe an ethnographic approach which is concerned with how individuals relate to their experience and understand topics including
the experience of self, morality, body, illness and healing, emotions, and family experiences in larger sociocultural contexts (Levy & Hollan, 1998).

In starting with my illness experience and then subsequently analyzing the cultural context, I have applied a person-centered ethnographic approach. The study of undiagnosed illness as evidenced from this autoethnography, benefits from an inductive approach that begins with individual experience and proceeds to then understand cultural contexts. Illness experience needs to be examined holistically with patient-centered approaches (Liberati et al., 2015) that use LeVine and Levy’s (1998) method.

A final research implication is that nurses need to describe and analyze their own personal experiences with illness. Compared to the extensive research and personal accounts of physicians in the “narrative medicine” literature, nursing has largely refrained from documenting and examining nurses’ personal illness experience as a way to inform practice. Autoethnography has only been used by a few nurses as cited in this study to explore their illness experience. A potential future study could be a meta-analysis of multiple autoethnographies that relate to people living with chronic illness in a world that does not understand them.

There is a need for research that examines registered nurses’ own experiences with illness and how the dual experience of being both a patient and a nurse influences their nursing and their lives. The nurse who is also a patient is both an insider (a patient) and an outsider (a nursing professional) to their experience of illness. This autoethnography has helped to describe that being a registered nurse with undiagnosed illness may impose greater psychosocial stress imposed by being a nurse “not knowing”
their diagnosis and that the experience of being a registered nurse living with chronic undiagnosed illness is also influenced by the norms within the nursing profession.

**Policy Implications**

Nurses can play a critical role in advocacy for those living with chronic undiagnosed illness not only in advocating for broader social policies to help those with chronic undiagnosed illness but also in advocating at the individual, family, community and population level of care. Advancing policy that benefits those with chronic undiagnosed illness aligns with Nursing’s Social Policy Statement (American Nurses Association, 2010) with its emphasis on the profession’s contract with society to advocate for social concerns in healthcare. The ANA statement calls to expand nursing and health care knowledge grounded in the belief that healthcare includes cultural perspectives, values and beliefs of individuals receiving care. Nursing can help to bring forward awareness of a patient population group that is largely absent in the nursing research literature and that has unmet needs for care.

Policy research and analysis are needed to evaluate whether and in what ways, for those debilitated by undiagnosed chronic illness, the absence of a diagnosis may be a barrier to accessing federal and state disability benefits and legal protections. Policy reforms need to be identified relevant to individuals with chronic undiagnosed illness. Disability rights organizations need to be involved in future policy analysis along with the nursing profession on this issue. Nursing policy analysts need to develop partnerships with other organizations to advance a policy agenda that benefits those living with chronic undiagnosed illness.
Nursing can advocate for public and private funding of research focused on those with chronic undiagnosed illness at local, national, and international levels. Nurses advocating federally for health care research priorities should include patients living with chronic undiagnosed illness as a population group that deserves focus.

At an individual level, nursing advocacy is needed for those living with chronic undiagnosed illness. This can be demonstrated in one on one care with an individual, or through support groups where nurses are engaged in facilitating care. At points of care coordination, case management, and navigation, nurses can provide that holistic patient-centered care for those with chronic undiagnosed illness by focusing on the patient’s overall experience with illness.

**Limitations**

A primary limitation of the study is that it draws on the experience of only one person (n=1). As such, the study is not generalizable but may be transferable if it provides data that makes transferable judgments possible to others (Lincoln & Guba, 1985). While the study seeks to generate knowledge regarding the experience of chronic undiagnosed illness, future research on chronic undiagnosed illness must incorporate additional, diverse accounts in order to build a strong layer of evidence. The limitation of only one research participant in this study did yield a deeper analysis of an illness experience revealing themes which could be confirmed or extended in future studies. Other sources of possible bias include gender bias since I am a woman, my bias as a registered nurse, and influences from my cultural heritage, including being raised part Hispanic.
Summary and Conclusions

This study used an analytical approach to autoethnography to examine the experience of a registered nurse living with chronic undiagnosed illness. Key themes of the study related to the impacts of not knowing the diagnosis, experiences of loss, not being believed by others, and hidden secret self.

This study demonstrates the value of using diverse ethnographic research methods to research an illness experience. Autoethnography began in this study with a biographical narrative of my illness experience. Additional sources of data (artifacts, photographs, handwork) were gathered and analyzed in combination with the medical history narrative to inform a comprehensive, critical, and rigorous study of my illness experience.

Madeleine Leininger (1988), who was formally trained in anthropology and nursing, saw common ground in the two disciplines, arguing that the study of cultural meanings, values, and beliefs could be used to help patients and communities by promoting health, healing, and quality of life. The ethnonursing research method she developed provided a means of gathering data within a theoretical framework of culture care (Leininger, 2007). Not only has ethnography been utilized in the past, but focused ethnographies are being used by nurses more to study specific health practices with specific health populations (Roper & Shapira, 2000). In examining the cultural influences and context of my own illness experience, I am extending the ethnographic approach which has been utilized by nursing scholars to include autoethnography.

Autoethnography can represent a form of embodied research that incorporates the sensate experience with that of analytic logic (Edvardsson & Street, 2007). The sensate
includes the experience through the senses, active reflections on the experience, and even the possible interpretations of the experience. Embodied research grants access to lived experiences that are often taken for granted and which can contribute to opening up nursing practice to phenomenologic description (Benner, 1994).

Using autoethnography as method for this study enabled an examination of the physical experience of my illness in relation to the familial, social, and professional contexts of my life. It is the ethnographic emphasis on being embedded in an experience or context and embodying multiple perspectives (such as patient and nurse) that informed this study. Like autoethnography, ethnography is both cognitive and emotional, conveying the affect and internal dimensions of lived experience (Coffey, 1999).

Autoethnographic research studies can lay a foundation for future qualitative research on undiagnosed illness. This study demonstrates that autoethnography, similar to an ethnographic approach to studying illness experiences, can enable understanding of human experiences from the perspective of the person, including the person’s family experience and broader community experience (Robinson, 2013). Autoethnography has been used limitedly in nursing research, despite its acceptability (often based on its innovative findings) in other research disciplines such anthropology, psychology, and sociology. Its combination of biographical with cultural analysis makes it a suitable nursing research approach to study illness experience. In this study, the use of analytic autoethnography methods for data analysis contributed to a systematic and rigorous approach that could be applied to personal experience with other illnesses, including further research on undiagnosed illness. Thus, autoethnography can provide an effective
research approach for systematically documenting, describing and analyzing illness experience.

This study demonstrated that the reflexivity methods inherent in ethnographic and autoethnographic studies are an important tool for capturing the more hidden meanings of illness experience (Anderson, 2006; Hokkanen, 2017). Reflexivity methods should be taught at every level of nursing education not just as a research method but as part of a nursing approach and a method for analyzing nurses’ and patients’ experiences in healthcare.

The implications of this study highlight the need for future research on chronic undiagnosed illness in order to provide holistic patient centered care. Central to this care is the knowledge that the cultural context of illness is a dynamic part of individual experience. The study supports the need for reforms in nursing curriculum and education to include content on chronic undiagnosed illness and patient care; the need for further research on chronic undiagnosed illness including the development of evidence based interventions for care; the need for research approaches that advance patients’ perspectives on their illness experience and care; the need for policy analysis at state and federal levels; and advocacy for those with chronic undiagnosed illness at the individual, family, community, and population level of care. In conclusion, an analytic approach helps situate autoethnography as a viable form of ethnography for future nursing research.
APPENDIX

Human Research Protections Program

May 1, 2020

Dorinda Wolfe
DWelle@salud.unm.edu

Dear Dorinda Wolfe:

On 5/1/2020, the HRRC reviewed the following submission:

Type of Review: Initial Study
Title of Study: Autoethnography of a Registered Nurse Living with Undiagnosed Chronic Illness
Investigator: Dorinda Wolfe
Study ID: 20-215
Funding: No Affiliated Company
Grant ID: None
IND, IDE, or HDE: None
Documents Reviewed: • CITI Ricker
                     • ERA COI Ricker
                     • RN UNDIAGNOSED CHRONIC ILLNESS NHSP
                     • HSC COI Ricker
                     • COI Ricker

The HRRC determined that the proposed activity is not research involving human subjects. HRRC review and approval is not required.

This determination applies only to the activities described in the submission and does not apply should any changes be made to these documents. If changes are being considered and there are questions about whether HRRC review is required, please contact the HRPO for guidance.

Sincerely,

[Signature]

Thomas F. Byrd, MD
HRRC Executive Chair
References

Agar, M. (2004). We have met the other and we’re all nonlinear: Ethnography as a nonlinear dynamic system. *Complexity, 10*(2), 16-24.


Berger, R. (2015). Now I see it, now I don’t: researcher’s position and reflexivity in qualitative research. *Qualitative Research, 15*(2), 219-234.


Centers for Disease Control. National Center for Chronic Disease and Health Promotion. (2019). *Chronic disease*. [https://www.cdc.gov/chronicdisease/resources](https://www.cdc.gov/chronicdisease/resources)


https://doi.org/10.1067/mno.2000.109154


Flick, U. (2014). *The SAGE handbook of qualitative data analysis*. SAGE.


Goodall, H.L., Jr. (2000). *Writing the new ethnography*. AltaMira Press.


Groundbreaking documentary on undiagnosed diseases seeks $150K in crowdfunding to change the future of medicine. (2014, June 3). *Business Wire*.


International Rare Disease Consortium. (2019). IRDiRC Report. Retrieved from: [www.eurordis.org/content/irdirc](http://www.eurordis.org/content/irdirc)


https://literariness.org/2016/03/21/claude-levi-strauss-concept-of-bricolage/


200


Wear, D. (2000). Toward qualitative understandings of health phenomena or a pedagogical epiphany from a long-time medical humanities professor who thought she was on the right track. *Qualitative Health Research, 10*, 227-283.


