2020

Living with Multiple Sclerosis

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This is to certify that the doctoral dissertation by

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has been found to be complete and satisfactory in all respects,
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2020

Abstract

Experiences of Multiple Sclerosis Patients with Continuity of Care:

A Phenomenological Study

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Dissertation Submitted in Partial Fulfillment
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Doctor of Philosophy
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Abstract

Multiple sclerosis (MS) is a potentially debilitating and degenerative chronic disease that affects the nervous system by disrupting the myelin sheath that covers and protects nerve cells. While there is a plethora of research examining the experiences of MS patients with participation in physical activities, diagnosis, and treatment options, little research has been carried out to examine their experiences with continuity of care. Therefore, the purpose of this phenomenological study was to examine the continuity of care provided to MS patients through a critical examination of their lived experiences following hospitalization for an exacerbation. Reid, McKendry, and Haggerty (2002) dimensions of continuity of care provided the conceptual framework to guide this study. Using purposive sampling techniques, respondents satisfying the inclusion criteria were recruited until the point data saturation was reached. The data were collected using semi-structured interviews and were audio-recorded, transcribed, and coded into themes. The findings of this research indicated that trusted relationships with a small number of healthcare providers are preferred for tailored and easy access to care. Informational continuity was essential although deficient as health care providers failed to provide the participants with adequate information regarding their condition. Regarding managerial continuity, the participants felt that care delivered to them was not well connected and they had to assume the responsibility of coordinating their own care. The implications for positive social change are that that the findings of this research have revealed the experiences of MS patients with continuity following hospitalization and this knowledge can be used to enhance quality of care and patient satisfaction.

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Dedication

This dissertation is dedicated to all people living with MS and their caregivers. The research is also dedicated to all organizations such as the National Multiple Sclerosis Society working tirelessly to find cure for MS and to improve the wellbeing of people living with this disease.

Acknowledgment

I would like to acknowledge all the people who helped and supported me in one way or another. Thank you Dr. Harold Ray Griffin for your support and guidance throughout this process. My sincere appreciation also goes to committee member Dr. Kimberly Dixon-Lawson, Dr. Nazarene Tubman, and the late Dr. Ernest Ekong.

I would also like to thank my family, including my mother, for teaching me what I needed to know about life and not giving up.

My sincere appreciation goes to the interviewees for their willingness to spend time with me and share their stories regarding continuity of care for MS. I learned a lot from you and I will forever be grateful.

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Chapter 1: Introduction to the Study

Introduction

In this phenomenological study, I explored the experiences of multiple sclerosis (MS) patients with continuity of care. Previous research has shown that provision of care to MS patients is usually a challenge for general practitioners, considering that the disease requires a specific approach and treatment that is best planned at the specialist level (Methley, Chew-Graham, Cheraghi-Sohi, & Campbell, 2016; Soundy et al., 2016). Patients with MS often have a host of physical and mental health challenges, suggesting that they require regular monitoring and support from a multidisciplinary team (Feinstein et al., 2014; Strober et al., 2014).

Continuity has been regarded as a crucial aspect of quality care (Beadles et al., 2014). According to Reid, McKendry, and Haggerty (2002), there are three discernable categories of continuity of care: relational, managerial, and informational. These elements are equally important but ensuring that there is continuity of care as patients move between hospitals and receive care from multiple providers is a challenge (Easley et al., 2016). For instance, patients may receive contradictory advice from different providers because the nurse or the general practitioner has not received all the essential information (Masoudi et al., 2015). Information on medical records may not be up to date or accurate, making provision of care consistent with the patient’s needs an uphill task. Developing and sustaining relationships between patients and providers; ascertaining that care is planned to meet needs; and information flow present substantial challenges

(Gardner et al., 2014). As a result, contrary to what may be anticipated, continuity of care tends to be weak (Soundy et al., 2016).

The research has the potential to initiate positive social change by supporting better overall care for hospitalized MS patients. Specifically, the findings of this study revealed issues affecting continuity of care, which if addressed, would lead to improved standards of care, along with more adequate and effective consultation for both the physician and the patient. This, in turn, can benefit patients and providers through improved efficiency of the health care system (Beadles et al., 2014; Sudhakar-Krishnan, 2007).

In this chapter, I present the background information related to MS and the experiences of patients with health care services. The concept of continuity will be discussed, as well as its relevance to MS care. The problem statement will demonstrate the need for investigating the experiences of MS patients with continuity of care. There is also a brief discussion of the research phenomenon as well as the conceptual framework that will be employed to examine the experiences of MS patients with continuity of care following hospitalization. This is followed by research questions which will be used to explore how MS patients experience the various elements of continuity of care. I will also provide the rationale for selection of a qualitative research design in the nature of the study section. Next, I will provide key operational definitions followed by the scope and delimitations related to transferability of the findings to other settings. I will also identify potential biases and mitigation strategies in the limitations section.

Background

Multiple sclerosis

Multiple sclerosis (MS) is a debilitating neurological condition that currently has no cure (Annibali et al., 2015). Though there has been some progress in immune-modulating therapy, MS remains the main cause of neurologic disability among individuals between the ages of 20 and 50 years (Helland, Holmoy, & Gulbrandsen, 2015). About 2.3 million people are afflicted by MS, of whom 400,000 live in the United States (Fraser et al., 2013; National Multiple Sclerosis Society, 2015).

Multiple sclerosis results in lost productivity and increased costs of pharmaceutical treatments and health services. The disorder has been found to impose economic, physical, and psychosocial burden to patients and their families (Ernstsson et al., 2016). A study by Casado et al. (2016) found that around 54% of MS patients had to give up their jobs and this disorder lowered the living standards of 37% of patients and their families.

The costs of disease modifying agents approved for treatment of MS have increased sharply over the past two decades (Hartung et al., 2015). For instance, the average yearly cost of disease modifying therapy (DMT) per person was $16,050 in 2004, accounting for 50% of all direct medical costs of people living with MS. First generation was costing between $8,000 and $11,000 in the early 2000s and is currently costing about $60,000 annually (Hartung et al., 2015). The high cost of drugs is a hallmark of specialty pharmaceutical classes (Torabipour et al., 2014). The high cost of MS treatment has been confirmed by a systematic review carried out by Adelman, Rane, and Villa (2013). The review found that the aggregate annual cost of MS ranged between $8,528 and $54,244 per patient annually, including direct and indirect costs. The disease ranks second only to congestive heart failure in terms of direct and indirect costs in comparison to other health conditions (Pretorius & Joubert, 2014).

Patients with MS make greater use of health care services compared to those without chronic diseases. For instance, a newly diagnosed patient will visit the general practitioner an average of eight times per year, which is around three times more compared to an individual without a chronic health condition (Owens, 2016). It is also essential to note that the frequency with which MS patients require health care usually intensifies with disease progression, adding to the considerable treatment cost that rises with time (Pozniak, Hadden, Rhodes, & Minden, 2014). These statistics about MS indicate that it is a substantial public health issue and is, therefore, a research area that is worth exploring.

Although the exact cause of MS is not known, numerous studies have been carried out to explore possible causes (Bäärnhielm, 2016; Dendrou, Fugger, & Friese, 2015). Biological, genetic, and environmental factors have been associated with the development of MS (Annibali et al., 2015). There is also a theory that environmental triggers such as low levels of Vitamin D can facilitate the development of MS in individuals with a genetic predisposition (Dendrou, Fugger, & Friese, 2015).

The symptoms of people with MS can vary significantly from one person to another. They can be present in different areas of the body, and the magnitude of severity of symptoms varies from one person to another (Davies et al., 2015). Some of the most common symptoms include sensory disturbances, walking ataxia, limb weakness, and diplopia (double vision) (Pretorius & Joubert, 2014). People with MS may also report bowel, bladder, and sexual dysfunction (Helland, Holmøy, & Gulbrandsen, 2015; Kister et al., 2013). These symptoms have not only been identified among MS patients but have also been described as the most distressing of this condition (Kister et al., 2013). Other common symptoms that might not be readily noticed by an outside observer but are equally impairing are depression, sleep disturbance, fatigue, and chronic pain (Horng & Fabian, 2017).

Living with MS

Multiple sclerosis (MS) has been shown to have a significant effect on the daily lives of patients (Pretorius & Joubert, 2014). Olsson, Skär, and Söderberg (2011) reported that people living with MS were met and treated differently due to their imperfectly functioning bodies. Boland et al. (2018) investigated the stigma associated with MS in social relations and found that MS patients felt misunderstood by others. Multiple sclerosis patients have described the time of diagnosis as a period of distress, where they not only experienced a lack of trustworthiness from others but were also dismissed by health care providers as hypochondriacs (Olsson, Skär, & Söderberg, 2011).

Multiple sclerosis patients have described their experiences of not being listened to and having to fight the disease alone (Edmonds et al., 2007). Methley, Chew-Graham, Campbell, and Cheraghi-Sohi (2015) have shown that since MS daily life varies significantly, patients experience a lack of advice and information in contacts with healthcare providers, as well as having their emotional responses taken for granted.

Soundy et al. (2016) found that MS patients are being met with insufficient knowledge about their personal needs, as well as not been given opportunities to express their concerns and vulnerabilities when meeting health care providers. These findings suggest a need for improvements in communication between patients and health care providers.

Schneider and Young (2010) report that health care practitioners experience difficulties in assisting MS patients requiring long-term management of their condition. Schneider and Young (2010) attributed the difficulties to the unpredictability of MS symptoms and lack of homogeneity in disease progression. Multiple sclerosis patients experience many setbacks and improvements as well along their way, and there is a need for an in-depth understanding of their experiences with the healthcare system (Methley et al., 2015; Schneider, & Young, 2010). Individuals living with MS in most cases seek advice from healthcare practitioners about managing their condition; thus, it is essential for providers to appreciate lived experiences and scope of MS on all aspects of their patients' lives (Schneider & Young, 2010). However, most of the research examining the lived experiences of MS patients with the healthcare system has focused solely on diagnosis and palliative care with little or no investigation of continuing care experiences (Methley et al., 2015).

Gap in Research Knowledge

Although much research has been done on diagnosis, treatment options, and participation in physical activities (Adelman, Rane, & Villa, 2013; Castro-Borrero et al., 2013; Helland, Holmøy, & Gulbrandsen, 2015; Poser et al., 2014; Schneider & Young, 2010), little research has focused on continuing care experiences of people with MS

(Methley et al., 2015). Experiences of MS patients with continuing care are currently understudied, particularly through in-depth methods such as qualitative approaches (Soundy et al., 2016). This is despite the significance of continuity of care in improving patient satisfaction and the quality of life of patients with chronic diseases (Sudhakar-Krishnan, 2007).

Problem Statement

Multiple sclerosis (MS) has been shown to have a significant effect on the daily lives of patients (Pretorius & Joubert, 2014). Olsson, Skär, and Söderberg (2011) report that people living with MS are being met and treated differently due to their imperfectly functioning bodies. Boland et al. (2018) investigated the stigma associated with MS in social relations and found that MS patients felt not understood by others. Multiple sclerosis patients have described the time of MS diagnosis as a period of distress, when they not only experienced a lack of trustworthiness from others but were also dismissed by health care providers as hypochondriacs (Olsson, Skär, & Söderberg, 2011). Multiple sclerosis patients have also described their experiences of not having been listened to and having to fight the disease alone (Edmonds et al., 2007). Methley, Chew-Graham, Campbell, and Cheraghi-Sohi (2015) have shown that since MS daily life varies significantly, patients experience a lack of advice and information in contacts with healthcare providers, as well as having their emotional responses taken for granted. Abma et al. (2015) found that MS patients are being met with insufficient knowledge about their personal needs, as well as not being given opportunities to express their concerns, including vulnerabilities, when meeting health care providers.

Schneider and Young (2010) report that healthcare practitioners experience difficulties in assisting MS patients requiring long-term management of their condition. Schneider and Young attributed the difficulties to the unpredictability of MS symptoms and lack of homogeneity in disease progression. Multiple sclerosis patients encounter numerous setbacks and improvements as well along their way, and there is a need for an in-depth understanding of their experiences with the healthcare system so that care can be provided in the context of their daily lives (Methley et al., 2015; Schneider & Young, 2010). Individuals living with MS in most cases seek advice from health care practitioners about managing their condition; thus, it is essential for care providers to appreciate their lived experiences and scope of MS on all aspects of their patients' lives (Schneider & Young, 2010).

Although much research has been done on the prevalence of the disease, economic burden, diagnosis, treatment options, and physical rehabilitation (Adelman, Rane, & Villa, 2013; Castro-Borrero et al., 2013; Helland, Holmøy, & Gulbrandsen, 2015; Poser et al., 2014), little research has focused on investigating continuing care experiences of MS patients (Methley et al., 2015). There are no previous studies exploring post-hospital continuing care experiences among MS patients, despite the significance of continuity of care in improving the quality of life of patients with chronic diseases. Consequently, there was little basis for scholars, health care practitioners, and policy makers to reach a conclusion on the continuing care experiences of MS patients; therefore, this study sought to fill the research gap by seeking an enhanced understanding of the experiences of continuity of care in the United States.

Purpose of the Study

The purpose of this phenomenological study was to examine the continuity of care provided to New York State residents diagnosed with MS through a critical examination of their lived experiences following hospitalization for an exacerbation. All participants included in this study include individuals who have been hospitalized following an MS exacerbation. The aim of the study is to examine the experiences of MS patients with continuity of care. Continuity of care can be defined as the process by which patients and health care providers are actively engaged in ongoing care management with the objective of cost-effective and high-quality medical care (Bayliss et al., 2015). There are three dimensions of continuity of care in the health care sector.

These dimensions are managerial continuity, relational continuity, and informational continuity. Managerial continuity refers to patient's perception of the degree to which health care services are provided coherently to improve their wellbeing. Informational continuity relates to patients perceptions of the availability and use of information to provide personalized care to patients. Relational management, on the other hand, is described as the patient's perceptions of an ongoing relationship with one or more care providers (Reid, McKendry, & Haggerty, 2002). Effective continuity of care enables care providers to gain patients’ confidence and become more effective advocates of patient-centered care (Guthrie et al., 2008).

Research Questions

RQ1: How do MS patients experience continuing engagement with care providers following hospitalization?

RQ2: How do MS patients experience provision of care services following hospitalization?

RQ3: How do MS patients experience exchange of information with care providers following hospitalization?

Conceptual Framework

The Reid, McKendry, and Haggerty (2002) aspects of continuity of care guided the process of conducting this study. The continuity of care concepts of Reid, McKendry, and Haggerty (2002) are based on an extensive multidisciplinary review of the literature and expert opinion. The authors defined continuity of care as “how one patient experiences care over time as coherent and linked” (Reid, McKendry, & Haggerty, 2002, p. 2). The definition was modified to "the degree to which a series of discrete healthcare events are experienced as coherent and connected and consistent with the patient's medical needs and personal context" (Haggerty et al., 2003, p. 1219). In essence, continuity of care is how an individual patient experiences coordination of services among care providers. According to Van Servellen, Fongwa, and Mockus D’Errico (2006), continuity leads to provision of quality health services, adequate flow of information, and good coordination of care among providers.

There are three dimensions that form the general framework for continuity of care in the health care sector. These dimensions are managerial continuity, relational continuity, and informational continuity (Reid, McKendry, & Haggerty, 2002). Managerial continuity refers to the extent to which services provided by different practitioners are connected and coherent as experienced by the patient (Gardner et al., 2014). Ideally, managerial continuity should integrate patient's preferences and the changing needs in the development of care plan (Beadles et al., 2014). Without proper managerial continuity, patients are likely to experience disorganized care plans from different practitioners, resulting in poor outcomes and low satisfaction.

Informational continuity refers to perception of the availability and use of information to provide personalized care to patients. It requires an organized collection of patient data and depends on adequate health records indicating the nature of illness, management and follow up, as well as referral and feedback from other practitioners (Gardner et al., 2014). In the absence of effective informational continuity, care for chronic health conditions is likely to be duplicative and improvident (Gardner et al., 2014).

Relational continuity, on the other hand, is described as the patient's perceptions and experiences of ongoing relationship with one or more care providers (Reid, McKendry, & Haggerty, 2002). In the absence of relational continuity, a positive therapeutic relationship is less likely to develop due to lack of familiarity and trust between the patient and the practitioner. The three aspects of continuity are not mutually exclusive but intertwined, thus representing processes that connect events involved in the provision of patient care (Beadles et al., 2014). This study focused on the three elements of continuity of care from the perspective of the patient.

These three dimensions of continuity of care have been summarized in Figure 1. The dotted lines in this figure depict the relationships between the elements of continuity, considering that one aspect can influence or build on another. Managerial and relational continuity are boosted by high-level informational continuity (Beadles et al., 2014). For instance, a thorough understanding of the patient’s condition enhances relational continuity by promoting practitioner-patient rapport and trust. Likewise, a thorough understanding of the patient’s condition due to effective informational continuity enhances care coordination and resolution of dissonant care plans; hence, bolstering management continuity. On the other hand, informational continuity may be enhanced if a multidisciplinary team uses an integrated health electronic system or communicates directly with one another to ensure consistency.

Though there is a likelihood of a positive relationship between relational and managerial continuity, patients might experience excellent continuity along one dimension while experiencing discontinuity along another (Jee & Cabana, 2006). For instance, managerial continuity might be optimal if all interventions provided were suitable. Nevertheless, relational continuity could be suboptimal if the patient had numerous encounters with different providers and had to keep explaining his or her condition to each one of them. Informational and managerial continuity would worsen if some providers made changes to the interventions provided or made new therapeutic decisions without informing the primary providers. In the absence of effective informational continuity, it is possible for duplication of interventions due to decisions being made in isolation (Sudhakar-Krishnan, 2007).

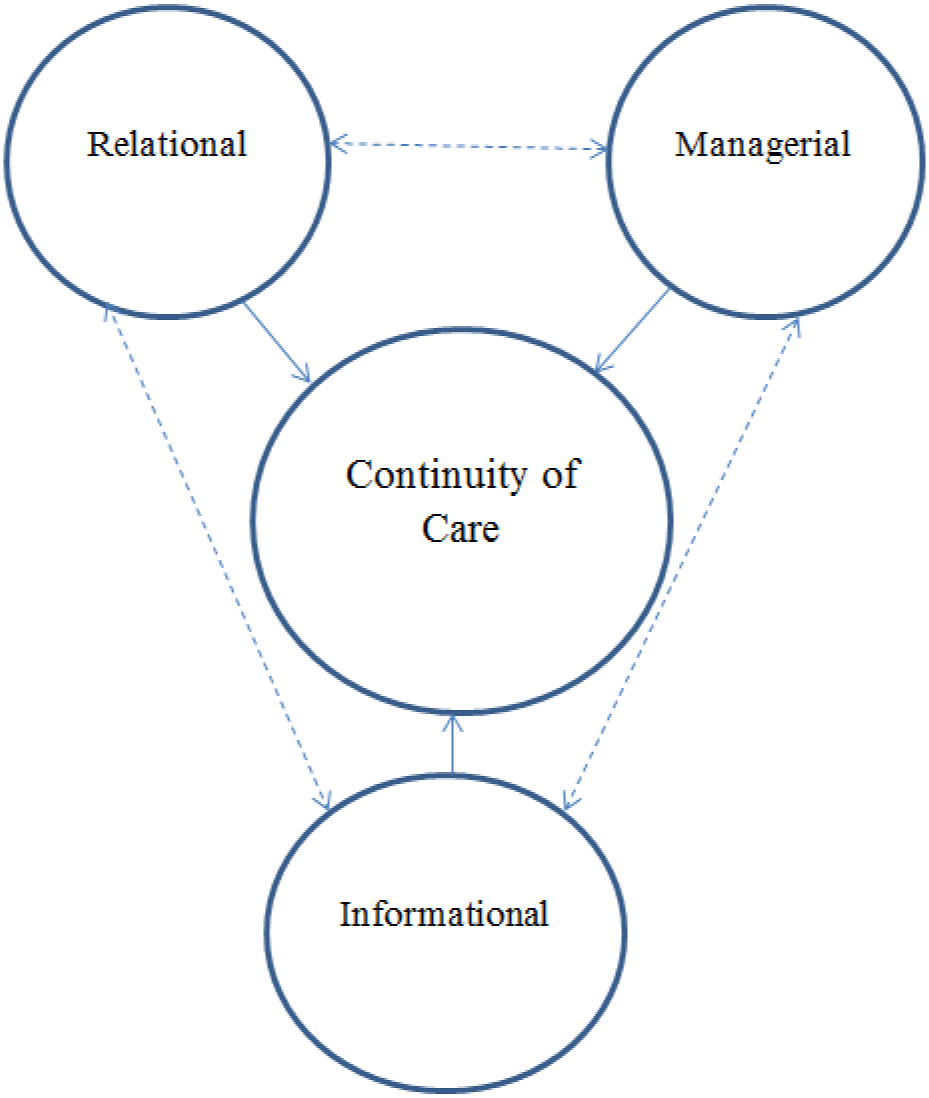

Figure 1: Conceptual model of continuity of care

The Reid, McKendry, and Haggerty (2002) dimensions of continuity of care have been used in a number of qualitative studies exploring the perceptions and experiences of chronic disease patients with continuity of care (Easley et al., 2016; Naithani, Gulliford, & Morgan, 2006; Suija et al., 2013). Prior to the Reid and colleagues report, the concept of continuity of care was poorly understood and was defined in a “myriad of ways,” despite its position as a key element in the provision of quality health care (Reid, McKendry, & Haggerty, 2002, p. 4).

Freeman et al. (2001) suggested five dimensions of continuity of care: cross-boundary and team continuity, flexible continuity, longitudinal continuity, and relational or personal continuity. Reid, McKendry, and Haggerty (2002) provided a simpler framework composed of the three dimensions and was later acknowledged by Freeman et al. (2007) as a suitable framework for the description of continuity of care. The Reid, McKendry, and Haggerty conceptual framework fits this study as it provides insights into the main elements that should be taken into account to understand the experiences of MS patients with continuity of care. The three dimensions also directed the development of research questions for this study. A further discussion of how the conceptual framework relates to the study approach will be provided in chapter two.

Nature of the Study

Situated in the field of healthcare, this study applied a phenomenological approach to explore the experiences of MS patients with continuity of care following hospitalization. This is an approach that emphasizes creating an in-depth understanding of lived experiences of the individual, with a special focus on attitudes, views, and insights of a concept or phenomenon (Creswell, 2013). The approach involves the use of rich descriptive interviews and a deep exploration of lived experiences to understand how individuals perceive a phenomenon (Van Manen, 2015). According to Creswell (2013), the overarching purpose of phenomenological research is to reduce experiences of individuals with a phenomenon to a description of universal essence. The study focused on collecting data from people with MS who have experienced the phenomenon (continuity of care) and developed combined descriptions of the essence of their experiences. This was the best approach to use in data collection process because it permitted the researcher to explore how MS patients experience the three elements of continuity of care.

In phenomenological research, the investigator analyzes the data and provides a combined explanation of themes describing the phenomenon. The main aim here is not to produce generalizable findings, as this is not possible in qualitative research designs. There are different approaches to phenomenology, based on the different perspectives of what phenomenology is: largely grouped into descriptive (Edmund Husserl) and interpretive (Martin Heidegger) phenomenology (Sloan & Bowe, 2014). In the descriptive approach, the focus is on the overall meaning of a phenomenon, and this is achieved by putting aside the investigator's experience or knowledge about the experience under exploration and approaching the data with no assertions about the phenomenon (bracketing) (Chan, Fung, & Chien, 2013).

Interpretative phenomenological research materialized from the hermeneutic philosophers who highlighted the need for the interpretation of the lived experiences by the researcher (Finlay, 2014). This approach is concerned with the individual’s viewpoint of the phenomenon, and it involves a detailed exploration of the individual’s experiences (Padilla-Díaz, 2015). The investigator attempts to identify the participant's point of view while assessing deeper meaning to what the participant overtly expresses (Padilla-Díaz, 2015). Every researcher has some background knowledge that cannot be done away with merely by the practice of bracketing as advocated in the descriptive phenomenological approach (Finlay, 2014). This is particularly relevant to this research considering that the researcher is a multiple sclerosis patient. Negating the previous experience with the provision of MS care in the U.S. is not a feasible option considering that it had the potential to shape understanding and interpretation of the findings. An interpretive approach enabled the investigator to acquire a deeper understanding of the patients' perspectives, while leveraging the value that prior experiences with MS care could bring to this research.

Participants were informed that they could provide supporting documents though this was not be a requirement for their participation. The investigator wrote field notes to record the observations made in the course of the research. All the data regardless of the source were categorized and coded as discussed in chapter 3. All the tapes, field notes, and transcriptions were crosschecked to look for recurrent concepts, at the same time ensuring the accuracy of the data. Phenomenology was the most suitable approach in that it shed light on how MS patients experience continuity of care, an area that was under-researched. In addition, the findings of the study will improve the health care provider's understanding of this phenomenon and perhaps adopt strategies to improve continuity of care.

Definitions

Continuity of care: The degree to which a series of discrete healthcare events are experienced as coherent and connected and consistent with the patient's medical needs and personal context (Jackson, MacKean, Cooke, & Lahtinen, 2017).

Exacerbation: According to the National Multiple Sclerosis Society (NMSS, 2017), an exacerbation leads to new symptoms or worsens the existing ones. It can also be called a relapse, an attack, or a flare-up and the symptoms have to last at least 24 hours for it to qualify as an exacerbation.

Multiple sclerosis: A long-term autoimmune condition that is often a disabling disease that attacks the central nervous system affecting bodily function, sensation, and movement (National Multiple Sclerosis Society, 2015).

Assumptions

All research should be replicable; thus, it is essential for future researchers to comprehend the fundamental assumptions used in the planning and execution of this qualitative study. A decision to employ certain research methods involves assumptions relating to the nature of reality (ontology) and views and nature of knowledge (epistemology) and the process of developing knowledge (methodology) (Willig, 2013).

The first assumption is that the views and experiences of MS patients with continuity of care do not exist as objective realities but are outcomes of the subjective meanings that the participants have developed from their interactions with the healthcare system. The assumption is in accord with a social constructivist worldview that is commonly used in qualitative research (Creswell, 2013). The assumption is of importance in order to understand the context and past events shaping the experiences of MS patients in a better way. Another assumption is that the researcher and the participants are mutually interactive and interdependent (Willig, 2013). This assumption is essential for the study so as to grasp the very nature of experiences of MS patients with continuity of care. The final assumption is that the phenomenon under investigation would not be detached from me as the investigator. This is an assumption that is in line with the interpretive paradigm that holds that knowledge is best obtained through the process of immersion into the phenomenon, having a firsthand experience and documenting the perspectives of those involved (Smith, 2015).

Scope and Delimitations

The problem under investigation is the lack of empirical evidence examining the continuity of care for MS clients. The exact aspects of the research problem addressed in this study included the experiences and views of MS patients with relational, managerial, and informational continuity of care. Delimitations of this study are that participants were individuals officially diagnosed with MS who had been admitted to a hospital following a relapse. The participants had to be at least 40 years old and able to read and write in English. Participants aged 40 and above were likely to have had experiences with continuity of care post-hospitalization and could perhaps share how their perceptions changed with time. The interviews were held in English language hence the participants had to express themselves in this language to be eligible. No one was excluded on the basis of race, ethnicity, gender, and type of MS. Participants without a history of hospitalization following an MS relapse and those unable to express themselves in English were disqualified due to the nature of the interviews.

The participants were required to complete a written informed consent form, and only those who offered consent were involved in the research. Participants were required to have access to email and a phone number in service. I provided rich and thick descriptions in terms of the context of the research methods and selection of participants to allow readers to make decisions regarding transferability of the findings. The scope of this research involved an examination of the post-hospitalization experiences of MS patients with three dimensions of continuity of care. The inclusion criteria allowed for a diverse sample; thus, it was expected that the findings would be transferable to other MS clients living in other states besides New York.

Although initially considered, I did not use the socio-ecological model. The model emanated from Bronfenbrenner’s (1979) viewpoint that human behavior is affected by numerous factors. Bronfenbrenner provided four levels to explaining interrelationships: micro-, meso-, exo-, and macro-systems. The micro-system involves individual’s direct relationship and experiences; macro-system focuses on cultural and political factors; meso-system focuses on the relationship within micro-systems, while exo-system involves the factors that affect the micro-systems (Sallis, Owen, & Fisher, 2015). Although the socio-ecological model assists researchers account for factors within and outside the control of individual patients, its application and exploration of the macro-system and meso-system, for instance, would have distracted the study from its core purpose of examining the experiences of individual patients with continuity of care.

Another theory that was considered to provide the theoretical foundation was the theory of candidacy. This theory describes the various ways eligibility of people for health care is jointly negotiated between patients and health services (Dixon-Woods et al., 2006). The concept of candidacy emerged from a critical review of literature on access and utilization of health care services (Dixon-Woods et al., 2006). In the health care sector, candidacy is a dynamic concept that captures individuals’ views who are candidates for certain diseases or health conditions, and the associated interventions and services (Koehn, 2009). Though the theory has been found useful in exploring the experiences of MS patients with the health care system (Methley, Chew-Graham, Campbell, & Cheraghi-Sohi, 2016), it was not chosen because it did not integrate the three elements of continuity of care, making it difficult to assess how the theory would have applied to the current study.

Limitations

There are various limitations in this study which are related to the research design and characteristics of participants. A major limitation is that the participants were selected through homogenous purposive sampling, a type of non-probability sampling technique where participants are selected based on their shared characteristics. The use of this sampling technique may introduce selection bias. There is a high likelihood that selecting participants with similar characteristics (diagnosis of MS and a history of hospitalization) would lead to a sample size with similar views and experiences (Etikan, Musa, & Alkassim, 2016). In addition, all the participants were members of NMSS thus there is a possibility of selection bias considering there was a high likelihood of involving active members of the society and a less likelihood of involving passive members of the society. To limit selection bias, the inclusion and exclusion criteria for this study were stated clearly.

The phenomenological research design can lead to limitations that are specific to the validity and the interpretation of the findings. Contrary to quantitative surveys where participants commonly check a box anonymously, qualitative interview protocols provide greater openings for the researcher to affect the responses of the participants (Bernard, 2017). Considering that the researcher was the one conducting the interviews, there was a possibility that the participants may have answered the questions in a manner to be viewed favorably or is consistent with societal expectations (Green & Thorogood, 2013; Ormston et al., 2014). Therefore, the respondents may have introduced social desirability response bias into the study. As the researcher, I designed, reviewed, and impartially administered the interview questions and assured the participants of their rights to anonymity and confidentiality to encourage the participants to provide sincere responses (Althubaiti, 2016).

With the focus of this qualitative study on examining the experiences of MS patients with continuity of care, it should be noted that as the researcher, I also had a previous encounter with the U.S. health care system and my previous experiences might in one way or another influenced how the data were interpreted. Researchers might have opinions that distort the outcomes of a study due to the unintentional influence from individual and professional experiences (Bernard, 2017). To avoid introducing the issue of researcher bias, I kept a reflexive journal, where I logged the details of how my prior experiences might have affected the findings of the study. According to Noble and Smith (2015), a reflexive diary sensitizes the researcher of his or her own preconceptions and partialities, while more fully informing the study of the effect of these influences on the trustworthiness of the findings. Moreover, the reflexive journal enables the reader of the final research report to evaluate any concerns regarding the credibility and interpretation of the interview findings (Berger, 2015).

Techniques employed in this research to ensure the credibility of the findings included prolonged engagement and persistent observation in the field while building rapport with the respondents and checking for misinformation that may originate from my previous experiences (Creswell, 2017). Another technique was peer debriefing to provide an external check of the research process. I also kept a reflexive journal to clarify my previous experiences and potential bias for the reader to be in a position to determine how my positionality may have affected the findings (Noble & Smith, 2015).

Significance of the Study

This study uniquely addressed the need to understand the experiences of MS patients with managerial, informational, and relational continuity of care. This study may help inform health care providers about the unmet needs of MS patients by filling the identified research gap. A number of previous studies have shown that effective continuity of care not only improves satisfaction of patients but also allows doctors to accumulate essential knowledge that saves time, influences the use of medical tests, and allows for timely management of patients with chronic diseases such as MS (Methley et al., 2015; Sudhakar-Krishnan, 2007). Patients being treated for MS experience the disease differently and require highly personalized treatment plans. This research revealed issues affecting continuity of care which, if addressed, can lead to quality of care improvement, positively impacting MS patients and thus their economic productivity, benefiting society at large.

Barriers to continuity of care can be related to physicians, patients, or health care organizations (Bellomo, 2018). By examining the continuity of care through the lived experiences of MS patients following hospitalization, health organizations and practitioners may be able to develop tactical strategies to overcome the identified barriers and possibly introduce positive practice changes such as the elimination of duplication in the collection of medical information. Lastly, this study may help lay the foundation for future research and studies in regard to continuity of care for MS patients in the United States and other countries.

Summary

The experiences of MS patients with diagnosis, participation in physical activities, and treatment have been well documented in existing scholarly literature. A major deficit in the current body of knowledge is the shortage of research on experiences of MS patients with relational, informational, and managerial continuity of care. This is despite the significance of continuity of care in improving patient satisfaction and the quality of life of patients with chronic diseases. Patients with MS usually have a broad range of mental and physical health needs, meaning that they require regular care and monitoring by different health providers at the various levels of the health system which makes continuity of care difficult to ascertain. The continuity of care conceptual framework of Reid, McKendry, and Haggerty (2002) was used to guide this study.

A phenomenological research design was applied to explore the experiences of MS patients with continuity of care. Semi-structured interviews were used to collect qualitative data from eight participants. Probing questions were asked, depending on the responses provided by the participants so as to allow the participants to fully express their ideas and provide as much information as desired. A tape recorder was used during the face to face semi-structured interviews. The researcher asked for permission from the participants to audio record the interviews for accuracy purposes. The actual names of the participants have not been used; the participants were assigned numerical codes to uphold their privacy. Data were analyzed using thematic analysis method. The findings of this research aim to promote positive social change by revealing the experiences of MS patients with continuity following hospitalization, which can be used to improve quality of care and patient satisfaction.

In chapter two, I will provide a synthesis of qualitative and quantitative research literature related to experiences of MS patients with the health care system. Through a critical review of the previous study of experiences of MS patients with the health care system, it will become clear how this work is distinctive from past research. I will also review previous publications relating to continuity of care so as to provide the conceptual framework.

Chapter 2: Literature Review

Introduction

The diagnosis and management of people with multiple sclerosis (MS) is often a challenge for primary care (Methley et al., 2015). Management of patients with MS requires a specific approach that is arranged at the specialist level (Soundy et al., 2016). Nevertheless, MS patients usually have a broad range of mental and physical health needs; they require regular care and monitoring by different providers at various levels of the healthcare system (Methley, Chew-Graham, Cheraghi-Sohi, & Campbell, 2016). As a result, MS care is ideally provided by a multi-disciplinary team with the objective of managing and preventing relapses through an approved disease-modifying agent (Methley et al., 2015).

A crucial aspect of the provision of care to individuals with MS is continuity (Soundy et al., 2016). According to Reid, McKendry, and Haggerty (2002), there are three types of continuity of care: managerial, relational, and informational. All these three elements of continuity of care are relevant, although achieving continuity of care when patients move between hospital and home and while receiving care among general practitioners, neurologists, and nurses, is often a challenge (Suija et al., 2013). Consequently, continuity of care for chronic diseases tends to be weak (Soundy et al., 2016).

The key position in MS care should be occupied by the patient (Soundy et al., 2016). Continuity of care should be viewed from the perspective of the patient. A qualitative research design has been found to be particularly useful in evaluating the experiences and needs of people living with chronic conditions (Suija et al., 2013). Until now, little qualitative research has been conducted with regards to experiences of MS patients with continuity of care (Methley et al., 2015). This is despite the significance of continuity of care in improving patient satisfaction and the quality of life of patients with chronic diseases (Davies et al., 2015). Therefore, the purpose of this phenomenological study was to explore the lived experiences of MS patients with continuity of care.

This chapter provides a synthesis of qualitative and quantitative research literature related to the experiences of MS patients with the health care system. This chapter begins with a description of the literature search strategy, including search terms, and electronic databases searched, followed by inclusion and exclusion criteria to enhance reproducibility. Previous publications relating to continuity of care will be reviewed, so as to provide a conceptual framework. The chapter also includes a literature review of the existing research on experiences of MS patients with the health care system and a brief discussion on the themes of this study. The main aim of the literature review is to demonstrate a legitimate research gap with regard to existing research on experiences of MS patients with the health care system. This chapter has been organized around various subsections, including search strategy, conceptual framework, and literature review related to key concepts and research topic.

Literature Search Strategy

A literature search was conducted through various electronic databases, including but not limited to Medline, PubMed, Google Scholar, EMBASE, EBSCO, ProQuest, and the MS Society library (Appendix A). The search was carried out to identify peer-reviewed journals to support this research. Key search terms used in the process include continuity of care, experiences, multiple sclerosis, and health care system. The searches were carried out using one key search term with at least one additional secondary term, as depicted in Table 1.

Table 1: Literature Search Themes

Key search Terms	Search Terms
Continuity of care	Informational continuity, relational continuity, managerial continuity, coordination of care, information provision, patient-provider relationship
Health care system	Care provision, care services, MS patients, health care providers, health care facilities
Multiple sclerosis	Diagnosis, screening, types, symptoms, treatment
Experiences	Perceptions, views, opinions, perspectives, need, satisfaction

A total of 136 studies were included and most of them (91%) were published between 2012 and 2017. There was no restriction on the publication date of studies pertaining to the conceptual framework underpinning the study. The purpose of this was to include original articles discussing the concepts of continuity of care. Only studies available in English were reviewed due to lack of translation capacity. Medical Subject Headings (MeSH) and Boolean terms were used to narrow and focus the search in line with the key words in each database. Other techniques used in the literature search process were footnote chasing and citation searching.

Articles eligible for inclusion included those that were available in full text, studies published in peer-reviewed journals, and those that investigated the experiences, views, or perceptions of patients with regard to the health care system. In addition, publications analyzing various MS concerns—etiology, prevalence, and management, as well as those providing essential information on concepts related to the conceptual framework—were included. The focus of the review was the experiences of adult patients; hence, eligible studies included adults diagnosed with MS. There are variations in adult and pediatric health care for MS patients; hence, the need to specify the population of interest (Methley, Chew-Graham, Cheraghi-Sohi, & Campbell, 2016). Narrative, editorial, and newspaper opinion pieces that merely discussed the provision of care to MS patients were ineligible. The focus of the literature search was identifying peer-reviewed journal articles to be used in the literature review.

Summary of the Literature Search Findings

All the searches were carried out using the keywords identified in Table 1. Depending on the combination or isolation of the search terms used, the total results for each search generated between 9 to 30 eligible articles. Searches combining the term experiences, health care system, and multiple sclerosis were the most fruitful and helped in retrieving 63 peer-reviewed journal articles. Similarly, no useful articles were retrieved when the term multiple sclerosis was combined with continuity of care.

The literature search process identified 136 journal articles related to the continuity of care framework, experiences of patients with continuity of care, and history and types of MS. The reference section of the eligible articles was used to identify additional sources. Studies included in this review were peer-reviewed journal articles published within the past five years. However, seminal work or landmark studies published before 2012 were included because they influence the scholarly community way of thinking and ultimately, the existing body of knowledge. Literature relating to continuity of care for MS patients is extremely scanty, highlighting the need for research on this topic. As a result, I had to examine sources that investigated the experiences of MS patients with the various aspects of the healthcare system such as diagnosis, management, and palliative care. Reasons for exclusion included not a peer-reviewed journal article, not available in full-text, studies involving pediatric population, and those not focusing on MS patients.

I carried out an additional search using Google search engine. This search led to unmanageable articles, and this may be partly due to the fact that Google search engines did not allow for advanced searching, making it difficult to limit the search in terms of publication dates or relevance to the topic (Appendix B). Consequently, I carried out an additional search using Google Scholar yielding 51,230 articles (Appendix B). Upon identifying and removing duplicated articles, 11 additional search articles were found to be eligible for this review.

Conceptual Framework

This section discusses key aspects of continuity of care that will inform and guide the process of conducting this study. The section addresses the origin of the conceptual framework and the changes it has gone through since its inception. The previous primary writings by key theorists and philosophers related to the concept of continuity of care are reviewed in this section. Moreover, previous studies that have applied this framework have been reviewed. It has been made clear how the framework will guide the study.

Two research studies, one carried out in England (Freeman et al., 2001) and the other in Canada (Reid, McKendry, and Haggerty, 2002) were undertaken with the primary objective of advancing the understanding of the concept of continuity of care. The concept of continuity of care was poorly understood prior to these reviews (Haggerty et al., 2003) and was viewed and measured in myriad ways (Reid, McKendry, & Haggerty, 2002; Freeman et al., 2007), in spite of its importance as a key feature of quality health care. Reid, McKendry, and Haggerty (2002) and Freeman et al. (2002) conceptualized the concept of continuity of care and came up with three and five dimensions, respectively. The three dimensions by Reid, McKendry, and Haggerty (2002) include managerial, relational, and informational continuity of care.

The Freeman et al. (2001) five dimensions of continuity of care include cross-boundary and team continuity, flexible continuity, longitudinal continuity, and relational or personal continuity. Reid, McKendry, and Haggerty (2002) provided a simpler theoretical framework composed of the three dimensions and was later acknowledged by Freeman et al. (2007) as a suitable framework for the description of continuity of care.

The Reid, McKendry, and Haggerty (2002) aspects of continuity of care will guide the process of conducting this study. The continuity of care concept of Reid, McKendry, and Haggerty (2002) is based on an extensive multidisciplinary review of the literature and expert opinion. The authors defined continuity of care as “how one patient experiences care over time as coherent and linked” (Reid, McKendry, & Haggerty, 2002, p. 2). The definition was modified to “the degree to which a series of discrete healthcare events is experienced as coherent, connected and consistent with the patient’s medical needs and personal context” (Haggerty et al., 2003, p. 1,219). In essence, continuity of care is how an individual patient experiences coordination of services among care providers.

Managerial continuity refers to patients’ perception of the degree to which health care services are provided in a coherent manner to improve patients’ wellbeing. Informational continuity refers to patients’ perceptions of availability and use of information to provide personalized care to patients. Relational continuity, on the other hand, is described as the patient’s perceptions and experiences of ongoing therapeutic relationship with one or more care providers (Reid, McKendry, & Haggerty, 2002). The three aspects of continuity of care are not mutually exclusive but intertwined, thus representing processes that connect events involved in the provision of patient care. This study focused on the three elements of continuity of care from the point of view of the patient.

Managerial Continuity

The managerial dimension of continuity of care is the unifying one: a prerequisite of the informational and relational dimensions (Östman, Jakobsson, & Falk 2015). The managerial aspect of continuity of care in hospital and home health care settings is conceptualized as planning and coordination of care and resources that are essential for the provision of care (Haggerty et al., 2013). The managerial aspect can be viewed as a "backstage continuity"; that is, it facilitates continuity of care at the front stage (Gjevjon, 2014). For instance, there have to be computers for information to be obtained and shared with health care providers. Competent staff members have to be present for the tasks to be accomplished appropriately. In this case, shift and care plans have to be present so as to ensure coordination of care services and minimize duplication of services. These arguments are in line with Schiøtz, Høst, and Frølich (2016) who view managing care (backstage) and the direct provision of care (front stage) as two essential elements of continuity of care in health care settings.

Currently, care models are commonly used in the health care sector to promote continuity of care (Veras et al., 2014). The responsibility of taking care of the patient is assigned to health care providers, including nurses and physicians, and enables the provider to follow-up on the patient. The team-model approach is commonly used; it places the responsibility of following up the patient on teams rather than one named health care provider (Klarare et al., 2017). The use of care models demonstrates the steps taken in the managerial dimension to expedite continuity within the informational and relational dimension: a few providers have a responsibility to ensure that there is sufficient information about the patient so as to connect present and future care. Nevertheless, the processes designed to ensure continuity of care, such as organizing care with medical teams, do not always result in continuity (Veras et al., 2014). Treatment of MS requires a specific approach and patients living with the disease require monitoring by different healthcare providers at various points in time (Soundy et al., 2016). Hill and Freeman (2011) assert that continuity of care cannot be realized until it is experienced by the patient, a perspective that recognizes the importance of patient opinions.

Though less evident from a patient's perspective, communication, planning, and coordination of service delivery influence the experiences of patients with the health care system. For instance, poor working conditions, disintegration of care provision, and reduced doctor-patient time have all been associated with poor patient experiences with continuity of care (Alazri et al., 2008; Haggerty et al., 2013). Dale and Hvalvik (2013) reported that patients had poor experiences with continuity of care due to lack of resources, shortage of staff, and breaks in the exchange of information. Likewise, many providers in the Herder et al. (2016) study lacked a collaborative attitude that is required for focusing on patient needs. As a result, many patients and caregivers expressed that they did not find sufficient support for their needs. There is evidence that patients value consistency in care provision, so that they are able to plan their day and experience predictability (Herder et al., 2016; Waibel et al., 2011). Receiving care from multiple providers who do not know the patient may lead to uncertainties and lack of trust in service provision (Hill & Freeman, 2011).

Informational Continuity

This dimension of continuity involves the use of information on prior events and personal circumstances (hospital visits and laboratory results) of the patient to make care appropriate for his or her condition. Information is one of the essential threads that link care from one practitioner to another. Dissemination and use of information refer to the transfer of information from one provider to another in an attempt to link different elements of care over time (Haggerty et al., 2003; Reid, McKendry, & Haggerty, 2002). Transferring information may become a challenge as patients move from seeing one physician over time to seeing multiple members of the same team, to receiving care from professionals working in different organizations (Easley et al., 2016).

The health care literature emphasizes transfer of information as critical, especially when providing inpatient care. Patient care is frequently handed off from one provider to another and between hospitals and other settings. Communication is essential so as to ensure that the needs of the patient are taken into account during this process (Gjevjon et al., 2013; Jeffers & Baker, 2016). In primary care settings, the concept of information transfer is often entrenched in emphasis on receiving care from the same provider over time, so as to facilitate the availability of relevant documented information during hospital visits, allowing amassing of essential contextual knowledge (Freeman & Hughes, 2010).

Accumulated knowledge is another component of the informational continuity dimension, referring to patient perceptions of the provider's knowledge, support mechanisms, and preferences to ensure that services are responsive to patient needs.

Textual documentation tends to focus on biomedical or disease-related details, with little focus on patient perceptions, values, and preferences (Reid, McKendry, & Haggerty, 2002). Research evidence shows that non-medical patient details, such as personal impression or values, are least likely to be transferred from one provider to another (Olsen, Hellzén, Skotnes, & Enmarker, 2014; Reid, McKendry, & Haggerty, 2002).

It is important to highlight that knowledge of the patient as an individual is equally important in ensuring that services provided are responsive to patient needs. According to Reid, McKendry, and Haggerty (2002), knowledge of the patient's values, social circumstances, and predilections related to health care, is essential in developing appropriate care plans, and has been associated with high rates of satisfaction. A steady practitioner-patient relationship enables practitioners to know more about the patient than what would be written in patient medical records. For instance, in the primary nursing approach, a nurse is responsible for developing the care plan and coordinating the provision of care during the patient's stay in the hospital. The nurse's knowledge of the patient as an individual is likely to lead to more effective and personalized care.

To address this element of continuity of care, this study explored both the positive and negative experiences of MS patients with the provision of information following hospitalization. It is important for care providers to be well informed of the patient circumstances and conditions so that they may not have to keep repeating their stories with each provider (Soundy et al., 2016). This study focused on how well practitioners were informed about patient condition, records, and how providers communicated with each other regarding patient condition.

Relational Continuity

Relational continuity is described as the ongoing therapeutic relationship between a patient and one or more health care providers (Freeman & Hughes, 2010). It not only ties present and past care, but also provides a link to future care. A continuing patient-provider relationship is particularly valued in primary care settings, where it translates into an implicit contract of patient loyalty to the provider and ongoing provider responsibility to the patient. Even where there is less likelihood of developing relationships with providers, such as in in-hospital care and home care centers, committed providers can give patients a sense of coherence and predictability in care (Rhodes, Sanders, & Campbell, 2014; Stange, Burge, & Haggerty, 2014).

Interactions on a one-to-one basis represent a high degree of relational continuity, while many-to-one interactions represent a low degree or lack of relational continuity (Freeman & Hughes, 2010). This is consistent with the notion that continuous provider-patient relationships are ideal (Brand & Pollock, 2017). Having one primary care provider might be beneficial by offsetting the possible disadvantages of receiving care from different providers (Stange, Burge, & Haggerty, 2014). Receiving care from one or a few providers, given a stable group of personnel, provides an opportunity where providers may better understand the patient's condition.

Relational continuity through one-to-one interactions between providers and the patient cements the relationship which, in turn, is presumed to enhance outcomes for the recipients of care (Grose, Freeman, & Skirton, 2012). Waibel et al. (2011) found that patients with chronic diseases value being able to build a relationship with their health care provider, who is not only aware of their medical history and treatment plans without having to be reminded, but also treats them as individuals who may have other needs as well. To address this dimension of continuity, this research focuses on both positive and negative experiences of having or not having close relationships with health care providers and seeing them on a regular basis.

Relationships between the Dimensions

The three dimensions of continuity of care have been summarized in Figure 1. The dotted lines in this figure depict the relationships between the elements of continuity, considering that one aspect can influence or build on another. Managerial and relational continuity are boosted by high-level informational continuity (Beadles et al., 2014). For instance, a thorough understanding of the patient's condition enhances relational continuity by promoting practitioner-patient rapport and trust. Likewise, a thorough understanding of the patient's condition due to effective informational continuity enhances care coordination and resolution of dissonant care plans; hence, bolstering managerial continuity. On the other hand, informational continuity may be enhanced if a multidisciplinary team uses an integrated health electronic information system to communicate directly with one another to ensure consistency.

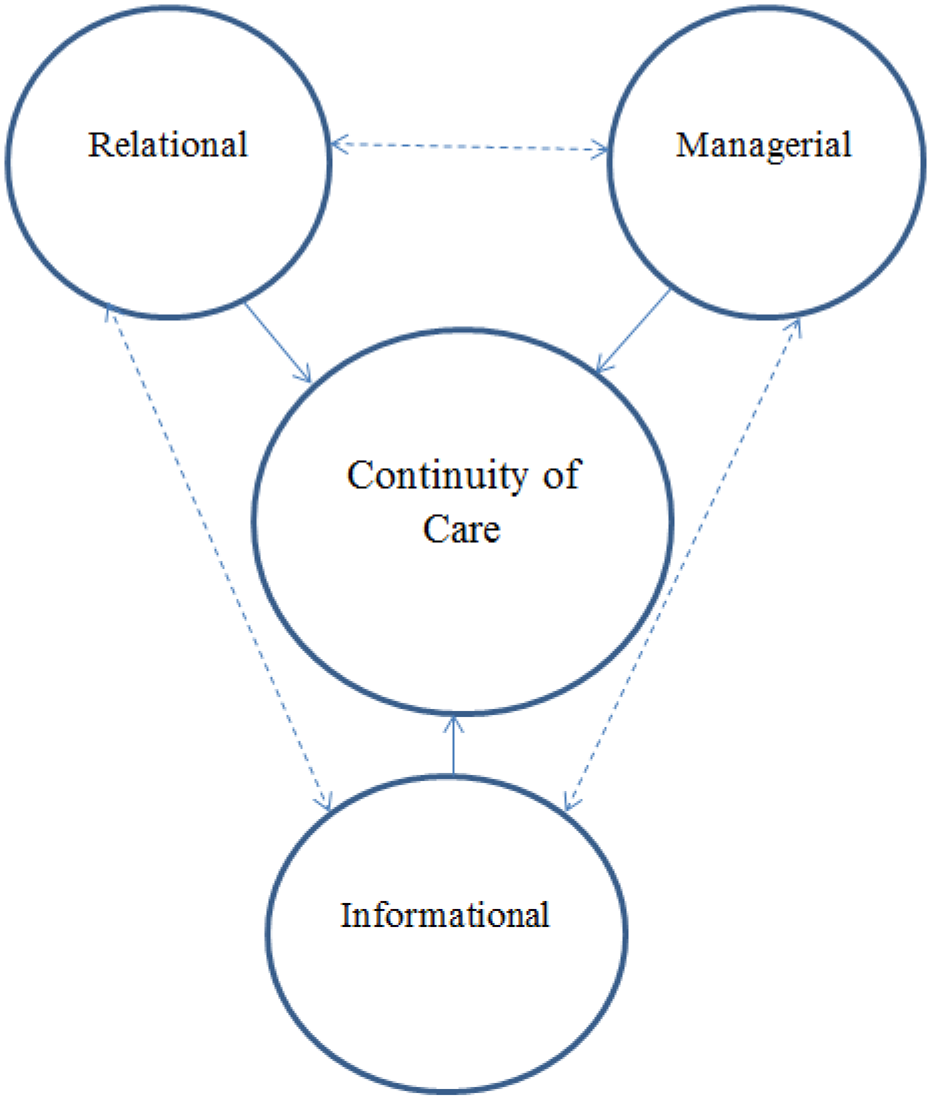

Figure 1: Conceptual model of continuity of care

Though there is a likelihood of a positive relationship between relational and managerial continuity, patients might experience excellent continuity along one dimension while experiencing discontinuity along another (Haggerty et al., 2013). For instance, managerial continuity might be optimal if all interventions provided were suitable. Nevertheless, relational continuity could be suboptimal if the patient has numerous encounters with different providers and has to keep explaining his or her condition to each one of them. Informational and managerial continuity would worsen if some providers made changes to the interventions provided or made new therapeutic decisions without informing the primary provider. In the absence of effective informational continuity, it is possible for duplication of interventions due to decisions being made in isolation (Gray, Sidaway-Lee, White, & Evans, 2015).

A literature review on the applications of the Reid, McKendry, and Haggerty (2002) framework failed to identify any study pertaining to the experiences of MS patients with continuity of care. Nevertheless, the framework has been used in a number of qualitative studies exploring the perceptions and experiences of patients with other chronic diseases (Easley et al., 2016; Herder-van et al., 2017; Suija et al., 2013). Easley et al. (2016) explored the experiences of cancer patients with continuity of care. The specific goal of this qualitative study was to explore patients' perspectives on and experiences with continuity of cancer care in Canada. Participants in this study highly valued access to timely and tailored information which was an outcome of good patient health care provider relations.

The Suija et al. (2013) qualitative study explored the lived experiences of cancer patients with continuity of care. This phenomenological study made use of semi-structured interviews to collect data from 10 cancer patients. All participants in this study expressed that provision of information was necessary, though they felt that they had not received all essential information from healthcare providers and had to look to other sources, including books on cancer. Consistent findings were reported by the Herder-van et al. (2017) study exploring experiences of patients with continuity of care in five

European countries. The study found that patients valued therapeutic relationships with a small number of key providers because they were able to receive tailored care and were easily accessible. Nevertheless, poor relational continuity was often experienced, and patients had to reiterate their histories numerous times: Informational continuity was often lacking at the point of care provision, especially in hospital settings where numerous healthcare providers were involved. With regard to managerial continuity, most of the respondents felt that care provided was fragmented. As a result, problems were poorly addressed, remained unidentified, or were discovered too late.

While the literature review failed to yield applications of the Reid, McKendry, and Haggerty (2002) framework in studies pertaining to people living with MS, the framework was selected for the current study because it offers theoretical concepts making it possible to understand the phenomenon under investigation. The conceptual framework fits this study as it provides insights into the main elements that should be taken into account to understand experiences of MS patients with continuity of care. The three dimensions also directed the development of research questions for this study. The concept of relational continuity aligns with RQ1, which seeks to explore how MS patients experience continuing engagement with care providers following hospitalization. The concept of managerial continuity aligns with RQ2, which seeks to explain how MS patients experience provision of healthcare services upon hospitalization. The concept of informational continuity is aligned with RQ3, which seeks to explore how patients experience informational exchange with care providers following hospitalization.

Table 2: Relationship between conceptual framework and research questions

Domain	Key concepts	Research questions
Informational continuity	Perceptions of information transfer between providers	RQ 3
Managerial continuity	Perceptions of coordination between providers	RQ2
Relational continuity	Perceptions of interpersonal relationship between providers and the patients	RQ1

Pathology of Multiple Sclerosis

Multiple sclerosis is a potentially debilitating and degenerative chronic disease that affects the nervous system by disrupting the myelin sheath that covers and protects nerve cells (neurons) (Pretorius & Joubert, 2014). This negatively affects the transmission of signals from the brain to the rest of the body. Eventually, this may lead to deterioration of the nerves themselves, a process that is traditionally believed to be irreversible (Horng & Fabian, 2017). In MS, because of the damage caused to the myelin sheath, the protective covering surrounding the brain and spinal nerves (Lublin et al., 2014), causes disruption of nerve signals, leading to loss of balance and coordination, as well as other functions, which may become irreversible with time (Davies et al., 2015).

Epidemiology of MS

Multiple sclerosis mainly affects young adults, mostly occurring in people aged between 20 and 40 years (Davies et al., 2015; Holland, Schneider, Rapp, & Kalb, 2011), which is a younger age of onset than many other chronic conditions (Kingwell et al., 2013). A higher proportion of females is diagnosed with the disease, with a gender ratio of 4:1 (Methley et al., 2015). MS is currently the leading cause of neurological disability in young adults living in North America and Western Europe (Leray, Moreau, Fromont, & Edan, 2016), with the U.S. having about 400,000 people living with the disease (Multiple Sclerosis Foundation, 2015). There are about 200 new cases of MS in the U.S. on a weekly basis, with the rate being twice that in the northern states, at 110 to 140 cases per 100,000 people (Multiple Sclerosis Foundation, 2015).

There are large geographical variations in terms of the occurrence of the disease, although recent research suggests that the prevalence of MS has been increasing across the globe (Koch-Henriksen & Sorensen, 2011). Nevertheless, Kingwell et al. (2013) argue that this is as a result of increased incidence rate, with an insignificant increase in prevalence due to improved diagnostic testing. North America and Europe have a higher prevalence (>100 per 100,000 people) compared to Eastern Asia and sub-Saharan Africa (2 per 100,000 people) (Leray, Moreau, Fromont, & Edan, 2016).

Although the exact cause of MS is currently unknown, numerous researchers have conducted studies with an objective of unearthing the exact cause (Dobos, Healy, & Houtchens, 2015; Schneider & Young, 2010). It has been reported that the risk of developing the disease varies with race/ethnicity, with individuals of Caucasian and African-American race in the U.S. more likely to develop MS compared to the Hispanics and Asian people (Langer-Gould et al., 2013). Gene-environment interactions have been identified as another common pathway to development of the disease (Horng & Fabian, 2017), potentially interacting with vitamin D deficiency to raise the likelihood of developing MS (Sellner et al., 2011). The presence of DR2150IBI (the human lymphocyte antigen allele) has been associated with increased likelihood of developing MS (Horng & Fabian, 2017).

Epidemiological research studies have established a positive relationship between latitudinal gradient and the prevalence of MS (Pretorius & Joubert, 2014). Alla et al. (2016) reported a threefold increase in MS prevalence with increasing latitude from Northern (37.9°S) to Southern (45.8°S) regions in New Zealand. A systematic review by

Simpson et al. (2013) found a statistically significant positive relationship between age-standardized prevalence ($p<0.001$) and changing latitude. The findings confirm a statistically significant positive relationship between MS prevalence and latitude, with the most possible reason for the variation being ultraviolet radiation.

Lifestyle factors including smoking, alcohol, and obesity have been also identified as possible risk factors (Hedström et al., 2014; Marck et al., 2016; Olsson, Barcellos, & Alfredsson, 2017). Nevertheless, in spite of the presence of various theories trying to shed light on the cause of MS, there lacks conclusive evidence regarding the etiology of the disease. On the other hand, lifestyle factors including smoking, alcohol, and obesity have been identified as possible risk factors (Hedström et al., 2014; Marck et al., 2016; Olsson, Barcellos, & Alfredsson, 2017). Nevertheless, in spite of the presence of various theories trying to shed light on the cause of MS, there lacks conclusive evidence regarding the etiology of the disease.

Types of MS

MS has been placed into four or five categories, relapsing-remitting (RRMS), secondary progressive (SPMS), primary progressive (PPMS) and progressive relapsing (PRMS). The fifth, sometimes overlooked, type is benign MS.

Relapsing-remitting MS

RRMS is the most common form of MS, contributing to about 85% of cases diagnosed (Poser et al., 2014). Individuals affected by this subtype experience symptom exacerbations called relapses which later remit, but may leave catastrophic damage, especially if left untreated. A relapse refers to a period of neurological impairment with new symptoms or exacerbation of previously-developed symptoms (Horng & Fabian, 2017). In this form of relapse, symptoms usually progress quickly over a matter of hours or days but remain for a period of weeks. The effect of the relapse varies from one individual to another, and while it can be treated at home by trained providers, severe forms in most cases necessitate hospital admission (Milo & Miller, 2014; Pretorius & Joubert, 2014).

At present, the cause of relapse in RRMS is unclear; nevertheless, there is an established link to increased risk in the first three months post-partum, particularly in women with high disease activity prior to and after childbirth. Upper respiratory tract diseases, as well as urinary tract infections, have been suggested to worsen relapses (Comi, 2013). Although anecdotally, stress has been reported as a cause of relapses, though the existing evidence base remains to a large extent inconclusive (Briones-Buixassa et al., 2015).

Primary progressive MS

Primary progressive MS is characterized by exacerbating neurological functioning (disability) from the onset of signs and symptoms without early remissions or relapses (Ontaneda & Fox, 2015). It occurs in around 10 to 15% of all MS cases and affects an almost equal number of men and women and is commonly diagnosed at a later age, 40 to 50 years (Horng & Fabian, 2017).

Secondary-progressive MS

Secondary-progressive MS develops after a period of relapsing-remitting MS (65% of people with RRMS will transition to SPMS within 15 years following diagnosis)

(Scalfari et al., 2013). For a diagnosis of SPMS type to be made, disability has to be evident within the past six months. The changes may progress at a slower pace, and it may be extended for a period of time before a diagnosis can be confirmed. A major characteristic of this subtype is continuous development of medical neurological damage with relapses and short periods of remissions (Pretorius & Joubert, 2014).

Progressive-relapsing MS

Progressive-relapsing MS (PRMS) is a rare form of MS contributing around 5% of cases and is characterized by a steadily worsening disease state from the beginning, with acute relapses but no remissions (Mahad, Trapp, & Lassmann, 2015). Signs and symptoms vary from one patient to another depending on which areas of the spinal cord or the brain are damaged by the disease. Symptoms may include double vision, sensitivity to heat, numbness, bowel problems, fatigue, and sexual dysfunction among others (Sellebjerg et al., 2017).

Benign multiple sclerosis

Benign MS, a fifth, less-recognized, form of MS, is a mild course of MS, seen in 5-10% of MS patients. In people affected by benign MS, there is no worsening of functional ability even after 15 years of diagnosis. Currently, there is no way of predicting this form of MS at the time of diagnosis.

MS Symptoms

MS symptoms vary significantly from one patient to another. They can present in different areas of the body; the severity of the symptoms varies from one patient to another depending on which part of the CNS is affected (Davies et al., 2015). Persons with MS can present sensory disturbance, walking ataxia, optic neuritis, limb-weakness, clumsiness, and diplopia (double-vision) (Helland, Holmøy, & Gulbrandsen, 2015; Kister et al., 2013). They are also likely to report sexual and bowel dysfunction problems. The symptoms have not only been reported in individuals with MS but have also been identified as the most distressing symptoms of this debilitating and degenerative neurological condition (Scaglia, Haggqvist, Lindholm, & Capobianco, 2017).

People living with the disease have reported that symptoms worsen with an increase in environmental temperature (Sumowski & Leavitt, 2014). Examples of aggravated signs and symptoms include visual dysfunction, muscle weakness, and abnormal reflexes (Horng & Fabian, 2017; Pretorius & Joubert, 2014). There is empirical evidence that the core body temperature of people with MS is more sensitive to physical activities and environmental heat (Filingeri et al., 2017). Higher body temperatures are likely to result in increased heat sensitivity leading to symptomatic fatigue, though the mechanism is not well understood (Sumowski & Leavitt, 2014). Pretorius and Joubert (2014) claim that around 78% of people living with MS experience fatigue on a daily basis. Fatigue can be a substantial problem for people with MS considering that it can limit the amount of time they spend on daily activities, such as exercise and recreational pursuits (Thomas et al., 2015). These activities provide opportunities for health benefit and enjoyment, which may be missed as a result of fatigue.

Diagnosis and Management

Considering the variety of subtypes and symptoms, MS is in most cases a complex condition to manage. The etiology of MS remains unclear, making it a daunting task to predict progression and outcomes in an individual patient (Horng & Fabian, 2017), though growing disability is a common phenomenon (Kister et al., 2013). Limited knowledge on prognoses may lead to difficulties in managing the disease for both MS patients and health care providers. Lack of information regarding future levels of disability may detract from implementation of long- term treatment and rehabilitation plans (Methley et al., 2015).

Due to the complexity of disease symptoms, the diagnosis of MS may be an intricate process. Most people with MS present their primary care provider with initial sensory symptoms such as optic neuritis or loss of mobility (Davies et al., 2015; Helland, Holmøy, & Gulbrandsen, 2015). The physician then collects data on the patient's medical history and performs a complete neurological examination. If the physician recognizes the symptoms as suggestive of MS, he or she makes an initial referral to specialist care, where diagnostic services are coordinated by a neurologist (Bielekova et al., 2017).

A number of tests are carried out for a diagnosis of MS. These include cerebrospinal fluid (CSF) examination and a magnetic resonance imaging (MRI) scan of the brain. An MRI scan showing demyelination in the white matter of CNS neurons is, by far, the most important finding in MS. Given that MRI historically had a long-time lag, while others tests may provide inconclusive results, there may be a lengthy wait between the onset of symptoms and the confirmation of diagnosis (Methley et al., 2015). However, the diagnostic criteria introduced in 2005 and updated in 2010 and improvements in diagnostic technology have been credited with improvements in turnaround time and accuracy of diagnosis (Poser et al., 2014).

Once a diagnosis of MS has been confirmed, a variety of treatments may be recommended by a specialist neurologist, for both the treatment of symptom exacerbations and the daily management of chronic symptoms, such as pain and bladder dysfunction. Disease modifying therapy has been found to be effective in reducing the incidence of relapses, possibly preventing disability from taking place (Ontaneda & Fox, 2015).

Given that the treatment for MS might not be successful or readily available, symptom management is key to long-term management of MS patients (Horng & Fabian, 2017). Primary care settings act as the gateway to health services, with most patients receiving care in these settings (Easley et al., 2016). It is likely that general practitioners in primary care settings will provide the first point-of-contact for people with neurological symptoms of MS, and will coordinate diagnoses and referral services. MS patients are entitled to specialist neurology services and are in most cases treated by a neurologist. Symptom management may involve frequent contact with both specialist and primary care services and self-management for some patients.

Effects of MS

People with MS face a host of health challenges that are directly or indirectly associated with the disease. The challenges extend to almost all areas of personal and social life. The stress associated with these conditions as well as the high degree of dependence on significant others may lead to maladaptive situations that are manifested by deterioration of their physical, mental, and social wellbeing (Jelinek et al., 2016).

Degenerative diseases such as MS cause changes in the lives of the affected. Lifestyle has to change as issues such as hot weather become challenges that must be addressed. For instance, the warmer the weather, the more challenging it is for a person with MS to acquire, remember, or even process information (Leavitt, Sumowski, Chiaravalloti, & DeLuca, 2012). As a result, a person who had enjoyed outdoor events in warm and sunny weather may have to adapt to a new lifestyle that prohibits staying outside during summer.

As stated earlier, MS occurs when the myelin sheath, a protective coverage of brain and spinal cord nerve cells, is damaged. The damage is suspected by to take place when the body's immune system cells attack the nervous system located in the spinal cord, optic nerves, and the brain (Horng & Fabian, 2017). The damage causes an interruption of the nerve signals which consequently leads to the loss of body coordination and cognitive ability as well as other functions, and these intermittent losses may become permanent (Horng & Fabian, 2017; Sellner et al., 2011).

Disabilities can have long-standing effects on the affected persons. Kamran et al. (2016) reported that disability due to MS led to low quality of life. Since MS is an autoimmune disease affecting central nervous system (CNS) commands, the body fails to respond to signals from the brain and the ability to move freely is negatively affected (Kamran et al., 2016). The opportunity to be mobile again can be achieved through other means such as motorized scooters and walkers.

The emotional stress as a result of the illness may be more severe than the physical effects. The way the family faces the challenge of the disease has a huge effect not only on the health, but also to adaption of the patient to the disease, especially when one is dependent on relatives (Olsson, Skär, & Söderberg, 2011). As a result, disturbing mental effects of MS occur at various stages of the disease. Personal doubt, confusion, and frustration are some of the problems that present to people with MS (Ferriero & Franchignoni, 2014). This has been associated with the development of anxiety, depression, memory loss, and cognitive impairment.

It has been reported that about 50% of people living with MS develop clinical depression at some point during their illness compared to only between 10 and 15% in the general population (Jones et al., 2014). Some scholars believe that the depression is as a result of damage to the CNS, while others attribute the mental health condition to medication adverse effects (Feinstein et al., 2014). Anxiety has also been reported as a rampant health condition that affects the lives of people with MS, and it results from fear of pain or the unknown due to the unpredictability of the disease (Alsaadi et al., 2015). Cognitive impairment characterized by deficits in memory, information processing speed, and attention are common features, affecting about 40 to 60% of MS patients at some point in their disease stage (Strober et al., 2014).

Living with Multiple Sclerosis

Individuals living with MS experience numerous challenges. The Malcomson, Lowe-Strong, and Dunwoody (2008) qualitative study explored the experiences of MS patients in Ireland and reported that the experiences of living with this disease begin even before diagnosis. Physical changes, including sensory disturbances, prompt people to go to see their doctors and this is commonly the way the MS diagnosis journey begins. The diagnosis process was generally filled with anxiety, uncertainty, and fear.

People living with MS have expressed that it becomes increasingly challenging to sustain their social lives as their MS symptoms progress because they have to take into account other challenges, such as ambulation and bladder and bowel dysfunction (Olsson, Skär, & Söderberg, 2011). Fatigue is the most commonly experienced symptom and has been linked to communication problems, such as speech difficulties: slurring; slower information-processing; as well as word-retrieval difficulties (Nagaraj et al., 2013; Pretorius & Joubert, 2014).

People with MS also experience challenges in their personal lives. For instance, women living with MS face the challenge of deciding how many children to have, particularly when taking into account their capability to take care of them. The challenges are also related to finances, fatigue, limited support, societal beliefs, and the possibility of passing the genetic predisposition to a child (Coyle, 2016). Another aspect of this multi-dimensional experience of MS is stress relating to the possibility of an exacerbation which may necessitate the individual moving from their residences, as stairs become difficult to climb. Often, people living with MS experience psychological distress with anxiety, low self-esteem, and depression (Feinstein et al., 2014; Strober et al., 2014).

The burden of caring for MS patients also extends to medical personnel (Strickland, Worth, & Kennedy, 2015). For instance, nurses spend at least 10% more time looking after the health issues of MS patients than they averagely spend with patients suffering from other autoimmune diseases (Strickland, Worth, & Kennedy, 2015).

Whether it is assisting them to move around, or simply keeping them company, MS patients' needs are on average more widely defined than those of other patients. In a study done by Coenen et al. (2011), researchers established that impaired functioning of patients with MS is the main culprit in the heightened level of attention that they demand. This is more so for those who develop severe complications, such as blindness. For such patients, support to relearn new lifestyles is necessary.

With no comprehensive treatment ascertained to totally eradicate symptoms, MS has a far-reaching impact on patients' lives (Cross, Cross, & Piccio, 2012). Most patients experience relapses, as well as steady disability progression. In the event where the patient is not properly supported by caregivers and/or medical personnel, he or she faces a higher mortality risk than the general population (Cross, Cross, & Piccio, 2012). Development of disability affects overall economic productivity and the social life of the patient. Progress is being made in the treatment of MS, as more medical research continues to be conducted (Curtin, & Hartung, 2014). Currently, immunomodulators are being leveraged to treat MS; with researchers looking forward to the development of neuroprotective drugs that have the ability to slow or even reverse demyelination.

The experiences that patients go through permeate even their sexual lives. To a great extent, multiple sclerosis adversely affects both men and women (Esmail et al., 2011). While men tend to assume the new sexual lifestyle precipitated by the disease, women take more time to subscribe to the new lifestyle (Esmail et al., 2011). Pretorius and Joubert (2014) also appraised the impact of MS on couples. The three investigators established that the disease mainly affects young persons, and its effects on marriage are prominent. Some of the experiences that couples go through, once MS hits one of the spouses include role reversal and relationship break-up.

Experiences of MS Patients with the Health Care System

Both quantitative and qualitative studies have explored the experiences of MS patients with various aspects of the healthcare system. Studies employing a quantitative research design made use of structured questionnaires to explore the experiences of MS patients with the healthcare system (Mattarozzi et al., 2017; Matti, McCarl, Klaer, Keane, & Chen, 2013; McCabe, Ebacioni, Simmons, McDonald, & Melton, 2015; Peters, Fitzpatrick, Doll, Playford, & Jenkinson, 2013; Ponzio et al., 2015; Tintoré et al., 2017). Most of the themes addressed in these quantitative studies have been mirrored in qualitative studies carried out on the topic. However, the deductive nature of quantitative research studies has limited the depth to which issues related to the experiences of MS patients can be examined.

Experiences with Preventative Care

Existing literature indicates that patients with progressed forms of MS, similar to other individuals living with disabilities, have experienced significant challenges in gaining access to various forms of preventive care, including exercise, disease prevention, self-management, and screening (Edmonds et al., 2007; Ghafari et al. 2014; Schneider & Young, 2010). It is a well-established fact that individuals with various forms of disabilities are more likely to experience poor health outcomes and increased morbidity in comparison to people without disabilities (Edmonds et al., 2007). Among MS patients, the main barriers to preventative care include inadequate time, fatigue, and physical impairment (Ghafari et al. 2014). These barriers are particularly compounded by various disease comorbidities such as cancer, diabetes, and cardiovascular disease suggesting an imperative role of primary health care providers in providing quality care to MS patients (Marrie et al., 2015).

Experiences of Information Provision

There are a number of studies that have explored how MS patients receive and understand healthcare information from healthcare providers. Generally, the existing literature indicates that MS care is characterized by poor provision of advice and information to patients. Inadequate provision of information to MS patients and difficulties in accessing information during diagnosis have been reported (Davies et al., 2015; Edmonds et al., 2007; Edwards, Barlow, & Turner, 2008; Johnson, 2003; Methley, Chew-Graham, Cheraghi-Sohi, & Campbell, 2016).

Participants in the Edmonds et al. (2007) study reported not being provided with information relating to diagnosis and management of the disease and had to find their own ways of learning self-management in the context of fragmented care. Consistent findings were reported by the Abolhassani, Yazdannik, Taleghani, and Zamani (2015) study, which found that participants were not provided with adequate information at time of diagnosis. A major problem was that the diagnosis was concealed by the physician; while, for others, the diagnosis was raised in an ambiguous manner that led to fear and anxiety due to the lack of essential knowledge. Participants in this study expected health care providers to provide them with vital information about the course of the disease; and treatment trends to dampen unrealistic expectations.

Mixed findings were reported in Davies et al. (2015), where some participants were happy with the information and support provided, while others were frustrated by inadequate communication with specialists, including neurologists. The Edwards, Barlow, and Turner (2008) study also had mixed findings, where some participants were provided with adequate information and were contended, while most reported the reverse. The poor experiences of MS patients at diagnosis were, in most cases, attributed to poor provision of information, and consequent lack of understanding (Edmonds et al., 2007; Edwards, Barlow, & Turner, 2008).

Provision of information also emerged as a theme in the Grose, Freeman, and Skirton (2012) phenomenological study. Participants expressed frustration at having to repeat their story with every provider during diagnosis, and how they were unable to have all their concerns addressed. Participants reported that healthcare providers were uncomfortable handling topics related to sexual wellbeing.

The inadequate provision of information was a major cause of fear and anxiety to the whole process of diagnosis in the Laidlaw and Henwood (2003) qualitative study. Participants also expressed frustration with their encounters with providers, particularly primary care providers, who were not willing to provide adequate information due to a lack of time. The main strength of the above qualitative studies is that they provide a detailed explanation of the experiences of MS patients with the provision of information. In addition, the findings of these qualitative studies are in accord with those of quantitative studies exploring experiences of MS patients with the healthcare system. Matti, McCarl, Klaer, Keane, and Chen (2013) investigated the current sources of information for newly-diagnosed patients. The main sources of information included the MS Society, nurses, neurologists, and other physicians. The study found a deficit between the amount of information patients are currently receiving and the amount they actually want from the various sources. A major finding is that symptom identification and management of relapses were not adequately addressed at diagnosis.

Needs of MS patients

There are various studies that report aspects that demonstrated the expectations of MS patients with care. Existing literature indicates that patients want more information to be provided before and at diagnosis; they would like to know what the diagnosis means, as well as receive information about symptoms and self-management practices (Abolhassani, Yazdannik, Taleghani, & Zamani, 2015; Davies et al., 2015; Deibel, Edwards, & Edwards, 2013; Holland, Schneider, Rapp, & Kalb, 2011; Lorefice et al., 2013). In addition, people with MS expect to be provided with information on MS exacerbations; and information relating to the health care system, including the availability of support services (Davies et al., 2015).

Information relating to treatment procedures and the desire to know if there is a medical cure were other crucial concepts that MS patients expressed a desire to understand (Abolhassani, Yazdannik, Taleghani, & Zamani, 2015). The respondents in the Abolhassani, Yazdannik, Taleghani, and Zamani (2015) study expected provision of education on the disease to their family members to improve the family members' understanding of common patient problems. Participants expressed the need for financial support due to the impact of their disability on income and the added cost of healthcare. They also were concerned about social stigma and discrimination.

Consistent findings were reported by the Deibel, Edwards, and Edwards (2013) qualitative study that identified a lack of service provision to support MS patients to practice self-management. The respondents felt that addressing both psychosocial and physical challenges posed by MS required the provision of information tailored specifically for MS patients. They also expressed a need for a strong relationship with healthcare providers to complement self-management. A community-based cross-sectional survey carried out by Ponzio, Tacchino, Zaratin, Vaccaro and Battaglia (2015) explored the unmet health and social care needs of people living with MS. In this survey, unmet psychological support was the most prevalent need and was mostly expressed by recently-diagnosed patients or those with a high disease disability level. Other unmet needs included access to technical aids and temporary admission to rehabilitation and nursing homes.

Mental health needs were also found unmet in the McCabe, Ebacioni, Simmons, McDonald, and Melton (2015) cross-sectional study. This quantitative study was carried out with an objective of examining the satisfaction of MS patients with the way their health needs were being addressed. Participants, particularly those from rural settings, complained of a shortage of mental healthcare providers and were, to a large extent, dissatisfied with the quality of care. Rural residents with MS also had less likelihood of receiving the recommended combination of interventions for management of depression.

Other areas of unmet needs included provision of information, financial assistance, and transportation services for people most severely affected by the disease.

The findings are in accord with those reported by the Lorefice et al. (2013) cross-sectional survey exploring the perceptions of patients and caregivers about MS management. A survey was administered to 497 patients and 206 caregivers and the findings showed that around 60% of the participants were satisfied with the medical staff, but there was a need for greater provision of information. Caregivers and patients required psychological support particularly at the time of diagnosis. Participants also expressed a need for greater involvement in the choice of medical and rehabilitation treatment.

A conference on the unmet needs of MS patients identified the need for targeted information about progressive and relapsing forms of MS, including treatment strategies and support services that are available to people living with the disease (Holland, Schneider, Rapp, & Kalb, 2011). Other themes that emerged included provision of education to patients, management of mental health, improving quality of life, and addressing family and caregiver challenges. Participants in this conference included MS specialists, caregivers, and people with MS (Holland, Schneider, Rapp, & Kalb, 2011).

Likewise, participants in the Galushko et al. (2014) study expressed a need for further information before a diagnosis was made; the meaning of diagnosis; and information regarding the symptoms and what to expect. Golla, Galushko, Pfaff, and Voltz (2014) findings supported the need for more information, with participants expressing a strong need to understand their chances of getting worse. They also expressed a need for information relating to governmental support and regulations of the healthcare system. This included information about the type of services available free of charge, agencies providing the services, and the kind of support available in case of disease progress. Information regarding treatment, and wanting to know about the possibility of a cure, were identified as key concepts that patients sought to understand (Golla, Galushko, Pfaff, & Voltz, 2014). In addition, information relating to self-management was identified as a need in the quantitative study carried out by Ploughman et al. (2014).

Experiences of patients following diagnosis

Edwards, Barlow, and Turner (2008) and Malcomson, Lowe-Strong, and Dunwoody (2008) reported unacceptable professional support from care providers. Participants in the first study reported that some care providers lacked sufficient empathy. Similarly, in the latter study, participants complained of providers who lacked sympathy and understanding. Multiple sclerosis patients have described the time of MS diagnosis as a period of distress, when they not only experienced a lack of trustworthiness from others, but were also dismissed by health care providers as hypochondriacs (Olsson, Skär, & Söderberg, 2011).

Negative experiences with diagnosis also emerged as a theme in the Schneider and Young (2010) qualitative study. Participants in this study found the diagnosis of MS a complete shock. They expressed that, upon receiving this diagnosis, their doctors failed to provide a detailed treatment plan, other than an outline of medications prescribed. Regarding self-management, participants complained of a lack of information at a time when they needed it most. They needed education on how to manage their condition on a daily basis. Further, they felt ‘left in the dark,’ not knowing what to do, suggesting a need for more support at this juncture in their lives.

Consistent findings were reported by the Davies et al. (2015) qualitative study exploring the experiences of patients and caregivers with the transition to secondary progressive MS. Though some patients were content with the process of gradual realization of the full implications of their disease, some expressed frustration that the conversations were not commenced by neurologists, in particular those with a singular sub-specialization in MS. In some instances, health care providers brought up the topic of possible transition to secondary progressive MS accidentally, while other patients only discovered this by chance, through overheard conversations. The news of progression often came as a surprise for people with MS; the confusion was heightened by a lack of understanding of how the diagnosis was made.

Significant challenges in assessing care by MS patients were identified in the process of seeking care following diagnosis. Care provided to patients seems to be more concerned with their physical needs, while excluding emotional/psychological support. Mixed findings were reported in the Edwards, Barlow, and Turner (2008) study, where a paltry number of participants were satisfied with the care provided following diagnosis; with a large majority receiving little information relating to treatment. Most of the participants experienced delays in diagnosis and treatment, especially social and psychological support.

Multiple sclerosis patients also expressed fear, uncertainty, and distress at the time of diagnosis in the Malcomson, Lowe-Strong, and Dunwoody (2008) study. Half of participants felt that the period of investigation toward diagnosis was particularly distressing, a time of uncertainty. This phase was characterized by fear of the unknown; a time of marked anxiety. Similarly, in the Edwards, Barlow, and Turner (2008) study, many participants waited an inordinate length-of-time to diagnosis (up to 25 years). Seven participants viewed healthcare providers as unsupportive as they revealed diagnosis in conversations that lacked 'sensitivity' and 'understanding.'

The findings are in accord with those of a qualitative study by Sixsmith et al. (2014), which found that patients with long-term neurological conditions experienced longer periods of time between diagnosis and referral to a neurologist. Participants emoted about how their physician diagnosed the condition but was unwilling to refer the patient to specialized medical care until they developed more severe symptoms. Nevertheless, Sixsmith et al. (2014) involved participants with different neurological conditions, making it difficult to identify the experiences specific to people with MS.

Negative experiences with the diagnosis of MS have also been identified in quantitative studies. In a survey involving a total of 2,563 participants with neurological conditions (40% being MS patients), a third of the participants expressed having to wait for *more than a year* for specialist care (Peters, Fitzpatrick, Doll, Playford, & Jenkinson, 2013). Not receiving all the essential information and not being informed of the diagnosis in a sympathetic and appropriate manner were identified as the most common problems experienced during the diagnosis period.

Fallahi-Khoshknab, Ghafari, Nourozi, and Mohammadi (2014) explored experiences of patients in confronting MS diagnosis. Emotional reactions experienced by the participants during diagnosis included fear, shock, denial, anger or some combination of these. Participants experienced trepidation at the prospect of losing their jobs, hiding their diagnosis as a result. However, some participants expressed relief following diagnosis of the disease. Likewise, participants in the Ploughman et al. (2012) study recounted their emotional reactions at the time of diagnosis. The period of diagnosis was stressful and the most worrying in their lives. This was escalated by the fear, uncertainty, and the lack of information from providers. Revealing the diagnosis even to family members was a challenge and participants recalled denying the diagnosis, despite having evident movement challenges, such as falls.

Multiple sclerosis patients have expressed disappointments with the healthcare system. Participants in the Golla, Galushko, Pfaff, and Voltz (2015) qualitative study, carried out in Germany, criticized the lack of knowledge by general practitioners about MS. They expressed that clear and early diagnosis would have built confidence in their providers. Recognizing and defining early symptoms such as diplopia, ataxia, or incontinence would have helped deal with the illness. Nursing care services were appreciated, although participants viewed them as inadequate, and wishing for more specialized nursing services.

Patients also experienced disparaging remarks and were dismissed by healthcare providers as misinformed or imagining experiences. Some patients expressed that they experienced remarks and comments suggesting that they were imagining experiences

(Olsson, Skär, & Söderberg, 2011). In some instances, patients had suspected that they had MS, but healthcare providers stated that this diagnosis was incorrect or stated that self-diagnosis was unacceptable. In other incidences, some patients expressed being treated or being given information on the basis of their physical appearance, instead of their experiences, thus constituting a form of discrimination in healthcare settings (Soundy, Roskell, Elder, Collett, & Dawes, 2016).

Patients have described feeling powerless and their opinions not being valued. Patients expressed feelings of powerlessness with the paternalistic approach to care. Examples of this include being unconcerned with the experiences of patients and belittling their experiences, which make them feel like a burden to society (Soundy et al., 2016). Other negative experiences included assuming that the patient had a low level of understanding, and that being told what to do without consultation was inappropriate (Thorne et al., 2014**)**. Such negative experiences in healthcare settings make patients desperate, and in some cases leads to development of depressive symptoms.

Multiple sclerosis patients have discussed receiving care that lacks sympathy and respect (Alroughani, 2015). Patients have expressed experiences of inadequate care and lack of satisfaction with service provision (Heeschen, 2014; Mattarozzi et al., 2017). Nevertheless, participants in the Tintoré et al. (2017) survey expressed satisfaction with the services provided by neurologists. Patients in this study were satisfied because they were involved in the decision-making process. Lack of satisfaction in the Heeschen (2014) and Mattarozzi et al. (2017) studies developed when providers showed less interest in the condition of the patient. Patients have expressed frustration with being treated like an object and receiving care that lacked compassion and empathy. For instance, one patient in the Ghafari, Fallahi-Khoshknab, Norouzi, and Mohamadi (2014) study stated, “When the doctor came, he did not even look at me. I wanted him to listen to me or talk to me, but unfortunately he just explained the future of my disease so negatively.”

Other challenges reported by patients when receiving care in acute settings included lack of emotional and psychosocial support and limited time for provider-patient interaction. Patients expect emotional and psychosocial support, and this form of support was identified as especially critical by patients living alone, or who were elderly (Ghafari et al., 2014). Patients valued their time with healthcare providers. Specific qualities they look for include sensitivity to social and emotional needs and being taken seriously and feeling valued by the provider (Ghafari et al., 2014).

Palliative care

The Embrey (2009) study is one of the studies identified through the literature search that examined experiences of MS patients with end-of-life care services. The research design was phenomenological, which is an appropriate research design for understanding the experiences of patients with provision of care services. It is reported that people with progressed forms of MS have unique, unmet needs. Palliative care improves symptoms, provides patients with opportunities to socialize and have fun, distracting patients from their illness; and providing opportunities for health promotion through a healthy lifestyle.

End-of-life issues emerged as a theme in the Golla, Galushko, Pfaff, and Voltz (2015) qualitative study. This study reports that caregivers appreciate information on symptoms and changes that occur as the disease progresses; this helps them be prepared for what may follow. Information on the final stages is essential, so as to provide quality palliative care. Issues relating to end-of-life care appear to be poorly addressed for severely affected MS patients who took part in the Borreani et al. (2014) qualitative study. Unfortunately, patients and caregivers gave little thought to end-of-life care or decisions.

Rehabilitation services

Several qualitative studies have explored the experiences of MS patients with rehabilitation services. Participants in the Borreani et al. (2014) study found that health and social care services were scarce and challenging to access. The few rehabilitation services available were not fit to meet the needs of people with severe forms of MS. Patient aids, as well as assistive devices, are crucial to help MS patients cope with mobility issues.

Healthcare Barriers Experienced by MS Patients

Stigma is an important hurdle for MS patients who have been discharged from hospital (Abolhassani et al. 2015). Abolhassani et al. (2015) studied stigmatization among Iranian patients suffering from MS, and established that patients are usually stigmatized by community members who do not understand their condition. As such, increasing awareness among community members about MS would be an effective way of reducing the stigmatization faced by MS patients.

Securing a suitable caregiver is also a major challenge for the MS patient leaving the hospital (Akkus, 2011). Family members and friends of the patient are hesitant at taking up the burden. Caregivers are sometimes forced to leave their jobs, and at times get stigmatized, together with the patient they are taking care of. As such, many people are not ready to bear this burden, leaving the MS patient with few good options following hospital release.

Depression is a major challenge that many MS patients experience during the post-hospitalization period (Alschuler, Ehde, & Jensen, 2013). A large percentage of patients are unable to access medication; their financial welfare declines; and sometimes he or she is unable to find an ideal caregiver (Alschuler, Ehde, & Jensen, 2013). As a result, the patient may become depressed, which may prove insurmountable.

While Anthony (2005) does not deny the fact that multiple sclerosis negatively affects the livelihood of patients, he is categorical that with the right attitude, and support, patients can slow disease progression. In many cases, the disease progresses rapidly due to comorbidities (Anthony, 2005). For instance, once a patient becomes depressed, the odds of developing cardiovascular disease increases. In a qualitative study done by Barker et al. (2015), researchers found that the very self-respect of MS patients is harmed. The social identity of the patient suffers progressively during their period of hospitalization, even up until discharge.

Wenneberg and Isaksson (2014) liken living with MS to “fighting a losing battle.” The patient fights on to keep his or her ‘head above water,’ while he/she well knows that his/her health is declining by the day. The patient is even more aware of loss in the post-hospitalization period. It is during this period that the disease is at its advanced stage and its progression rapid (Wenneberg, & Isaksson, 2014).

Symptoms may be classified as visible and invisible (White, White, & Russell, 2008). The visible signs are physical, such as blurred vision, while the invisible signs are emotional. In the period after a patient has been discharged from hospital, the invisible symptoms take toll on the patient more than the visible ones (White & Russell, 2008). While the visible signs occur once, and a patient gets adjusted to their manifestation, the invisible signs are recurring.

The psychological impact of the unpredictability of MS is also an aspect that forms an important dimension in the experience of patients (Wilkinson & das Nair, 2013). Patients affected by the disease live in fear that their children or relatives are at risk of getting the disease. Noticeably, MS is precipitated both by environmental and genetic causes. Thus, the fear that one’s relative will develop the disease, when one family member has developed it, is not wholly unfounded (Wilkinson & das Nair, 2013). The fear that one’s relatives will get the disease adds weight to the psychological burden that MS patients carry in the period after they are discharged from hospital.

Niino (2016) is emphatic that apart from the psychological burden conceived from the environment, there is a neuropsychological aspect of MS. That is, the destruction of neurons in the body as the disease continues to progress affects both the physiological as well as the psychological wellness of the patient. Neurological health—the health of neurons—correlates with psychological health.

Apart from healthcare barriers that the individual patient experiences, the MS patient may feel that he or she is a burden to society, both when is admitted to hospital and during the period following discharge (WHO, 2008). MS strains the health care resources available to the public and denies the community labor previously provided by the patient. The more MS affects a significant percentage of the population within a given localized area, the more it leads to a drop in the productivity of the region.

Rehabilitation poses a major barrier that MS patients encounter in the period after they are discharged from hospital (Ghafari et al., 2014). Many patients are not willing to live in rehabilitation centers. The patient remains at home against best medical advice. Rehabilitation centers are markedly more effective in realigning the MS patient to his new reality than what is typically available at home.

What is more, MS prevents affected individuals from actively taking part in physical activities. The patient living with the disease experiences fatigue, and general weakness (Kayes et al., 2011). Therefore, he or she is unable to recreate, or take part in manual economic activities. The inability to recreate may cause the patient to develop cardiovascular complications, while the inability to engage in economic activities worsens the financial woes of the patient.

Mulligan et al. (2013) looks at integrating self-help and professional assistance in overcoming the barriers to physical activity in MS patients. As the researchers observe, professional assistance is superior to self-help in overcoming the barriers when a patient has inadequate information about multiple sclerosis. However, when the MS patient has adequate information about the disease, including ways of managing it, self-help is better than professional assistance (Mulligan et al., 2013). With self-help, a patient is able to move at a pace that is suitable for him or her. Additionally, the patient incurs fewer expenses with self-help than when he or she seeks professional help.

Pfleger, Flachs, and Koch-Henriksen (2010) seek to uncover the social implications of multiple sclerosis. Their findings are in agreement with Barker (2014). That is, multiple sclerosis disconnects a patient from the rest of the community. In addition, as aforementioned, the disease lowers the self-concept of the patient, isolating him or her socially and economically.

Practice administrators identify disillusionment portrayed by MS patients as one of the most important roadblocks that they encounter when dealing with patients (Pharr & Chino, 2013). For many patients, recovery is not expected. They therefore ignore much of the advice given by medical personnel. This leads to quicker disability progression. Pharr and Chino (2013) advocate counseling of patients before their treatment begins. The MS patient needs to understand that, although their disease cannot be cured altogether, expert medical care helps slow disease progression.

Van Manen (2015) advocates patient education in a bid to overcome the challenges that he or she faces after hospital discharge. The patient also needs to be enlightened on the benefit of maintaining a positive outlook on life in the period after they are discharged from the hospital (Van Manen, 2015). The patient needs to understand that there is a correlation between cardiovascular health, and the level of distress that they subject themselves to.

As Brown, Kitchen, and Nicoll (2012) observe, physical activity is important in maintenance of the health of the MS patient, just as it is for the general population. *Aquafitness* is one physical activity that may help a patient maintain a healthy lifestyle. However, a number of MS patients face challenges as far as maintenance of *aquafitness* is concerned, especially in the period after they have been discharged from the hospital. Some of the barriers that the patient faces in the quest to attain *aquafitness* include inadequate transportation, fear associated with taking part in *aquafitness* programs, and environmental unreachability.

As noted earlier on, people with MS often complain of fatigue, which at times is accompanied by pain (Calsius et al. 2015). Participating in some physical activities, such as mountain climbing, not only assists the patient in avoiding total absorption in the disease, but harmonizes mind, body, and soul. Calsius et al. (2015) also observe that, by having MS patients participate in physical activities such as trekking, the afflicted individual can "experience their bodies as [their own]," and see it as a source of power, happiness, and meaningfulness.

Patients suffering from MS identify loss of independence in performing some routine life functions. This is a major hindrance towards self-acclimatization in the period after they are discharged from the hospital (Coenen et al., 2011). For instance, for the patient with advanced forms of MS, he or she may lose eyesight, causing loss of the ability to perform routine house chores, or studying.

Noorda et al. (2012) identify some losses experienced by the patient suffering from mitochondrial disease, but which can be applied to MS patients as well. The losses include loss of energy, independence, social participation, and social identity (Noorda et al. 2012). For many patients living with MS, they experience these losses. These losses become more real in advanced post-hospital stages of the disease.

Adhering to the specific therapeutic prescription outlined by the physician is an important barrier for the MS patient trying to settle down after hospital discharge (Menzin et al. 2013). Additionally, the MS patient may experience other stressful life events, which are unrelated to multiple sclerosis (Briones-Buixassa et al., 2015). The interaction between these remote stressful events, and those precipitated by MS, may make the patient's life miserable.

Mozo-Dutton, Simpson, and Boot (2012) analyze the impact of MS on the patient's self-image. According to the researchers, the disease lowers the self-image of the patient. Lack of supportive caregivers is also a barrier that MS patients have to grapple with in their endeavor to transition from hospital life to home environment (Mullan, Acheson, & Coates, 2011). The individual living with MS must make the personal decision to liberate himself or herself from thoughts of low self-concept (Murray et al. 2014), coping with home life (Nielsen-Prohl et al., 2013).

The MS patient who has been discharged from healthcare facilities often experiences the barrier of immobility, which severely constrains independence, by limiting freedom of movement (Normann et al., 2013). When an MS patient is assisted to regain his or her mobility, the enhanced flexibility works to promote the patient's sense of ownership, independence, and optimism. Depressive symptoms are commonplace among people living with MS and are regularly aggravated by physical and psychological pain (Nsamenang et al., 2016). In this study, researchers show that spiritual well-being may facilitate coping with such pain and becoming depressed. Such depression may go hand-in-hand with dampened social life and solitude (Patti & Villa, 2014).

Privacy concerns encountered by MS patients

MS patients are at times not left to interact with their environment in a free manner (Golden & Earp, 2012). In their study, Golden and Earp (2012) establish that the interaction between patients and their environments improves the overall outcome for the patient. There is need for patients who wish to interact with their environment in a private manner to be left to do so peacefully without the intrusion of uninvited parties. This is a privacy concern which practitioners must respect (Golden & Earp, 2012).

Harrison et al. (2015) did research on the pain that MS patients experience. As the researchers established, some patients experience pain in which they feel as if their feet are being hammered. Pain represents one of the commonest symptoms that MS patients encounter and one of the most private, as is the economic toll of MS (Hartung et al., 2015).

Serving God is a path that many MS patients choose to follow in their day-to-day lives (Harville, 2013). Those MS patients who have a healthier spiritual life tend to be less stressed. Religion and spiritual health may give a patient a positive outlook towards life, enabling him or her to have his or her head ‘remain above water.’ In effect, serving God is a strategy that patients use to vent frustrations brought about by multiple sclerosis, and find privacy during the storm around them.

As Hayter et al. (2016) observe, patients who disclose their anxiety receive better medical attention than those sick individuals who remain silent about their experiences. As such, it is usually critical for caregivers to have the patient appreciate the importance of sharing his or her anxiety. Equally, if patients who are bothered by a specific symptom open up in this regard, they motivate their caregivers to look for treatment options that alleviate the identified symptoms (Hayter et al., 2016). Even after informing them of the importance of opening up about their condition, privacy must be respected.

Heesen et al. (2009), in their study, "Evaluation of a patient information leaflet," appraised the significance of information to a patient. According to the researchers, the quantity and quality of information that MS patients have about the disease directly correlates with their level of privacy concerns. The more quality information they are given about the disease, the less secretive they are about their experiences with the disease (Heesen et al., 2009).

Privacy concerns among MS patients may be looked at from the dimension of the patients' gender. Males tend to be more confidential, and uncommunicative about their disease (Hughes, 2016). They may also fail to seek medical attention, in the fear that they will be stigmatized. Females tend to be more open with their condition and are more willing to seek medical care once they develop the disease. The anomaly in privacy concerns across the gender divide is quite advantageous in that, females are more likely to develop the disease, but are more open about it, and more readily seek medical attention (Hughes, 2016). On the other hand, males, who are more secretive and unwilling to seek medical attention, are spared receiving the diagnosis altogether (Hughes, 2016).

The profession of a patient is often an indicator of level of privacy concerns (Hunt, Nikopoulou-Smyrni, & Reynolds, 2014). Patients who belong to professions that require mastery of people skills, such as art and music, are less reserved than those in professions that do not necessarily require mastery of people skills. The justification for the aforementioned statement is the fact that those belonging to professions that require mastery of people skills are quite outgoing, and extroverted people who keep few secrets. On the other hand, MS patients belonging to professions that do not require mastery of people skills are usually introverted, keeping their affairs secret.

MS patients who develop disabilities at a quicker pace have higher privacy concerns than those whose progression to disability is slower (Jezzoni, 2011). Jezzoni (2011) hypothesizes that the more rapid pace at which MS leads to disability traumatizes them. On the converse, where the pace at which disabilities develop is slow, patients tend to be less psychologically damaged, willing to talk about their experiences. It is important for medical professionals to continually counsel patients to minimize psychological trauma as much as possible.

When patients are not supported to readjust to their new lifestyle brought about by the disease, they tend to be more reserved than in cases where they receive support from the people around them (Irvine et al., 2009). Lack of support makes the patient feel as if he or she is a burden to society, which may cause him or her to become withdrawn. On the other hand, when patients receive support from the people around them, they appreciate that they are still important and worthy of concern. Indeed, as Irvine et al. (2009) note, the level of social support a patient receives correlates with psychological wellbeing.

The patient experiencing chronic sorrow has an inferior quality of life, and increased privacy concerns compared to those with intermediate sorrowful incidences (Isaksson, 2007). Sorrow is a product of corrupted psychological fabric. The corruption may be brought about by aspects such as lack of social support, poor spiritual health, and fast pace of disability development. Sorrow lowers the self-concept of the patient, causing him or her to become more reserved. Conversely, happier patients tend to have an optimistic outlook on life, are more open, and are more willing to seek medical attention.

As it is the case with pain, fatigue is an important symptom affecting MS patients. At least 90% of patients suffering from multiple sclerosis experience fatigue (Nagaraj et al., 2013). Patients with frequent bouts of fatigue carry a higher level of trauma and are more reserved. For patients with less frequent bouts of the symptoms their trauma level is lower, and they have less privacy concerns. Provision of information about multiple sclerosis assists to lower the level of trauma that patients pass through, and hence their privacy concerns. Social support is also an important aspect, which reduces the trauma levels of patients (Aghaei et al., 2016).

Coping with MS

According to Kroll et al. (2006), persons with physical disabilities have lesser odds of making use of primary preventive medical care than members of the general population. Despite the lesser likelihood to use primary preventive healthcare, they are more likely to acquire secondary conditions, and take part in risky behavior just like the rest of community members. Since a significant percent of MS patients develop physical disabilities, such as impaired eyesight and walking impairment, they make use of preventive primary care as one of the strategies to cope with the condition. However, the uptake of primary preventive methods among physically disabled MS patients is quite low. Hence continuity of care buttresses the use of primary preventive methods.

In a study conducted by Schneider and Young (2010), the researchers established that self-management, treatments, and individual attitude are the three main strategies that female patients living with MS use to cope with the condition. Self- management refers to containment of the disease through refrainment from extreme physical effort, and by taking advantage of the social support offered by members of family and friends. Issues found under self-management are: lack of guidance from medical professionals, individual responsibility, and social support (Schneider, & Young, 2010).

The lack of guidance from medical professionals attending to their condition forces MS patients to take up self-management as a strategy of managing their condition (Schneider, & Young, 2010). Noticeably, medical specialists mainly prescribe medication, without giving MS patients a comprehensive treatment plan for their condition. As such, patients are left in the dark when it comes to the management of their condition. Often individuals are thus compelled to take up self-management to contain their condition.

Another technique included under self-management is individual responsibility. Schneider and Young (2010) delineate personal responsibility as balancing between advantageous amounts of activity, and extreme physical activity. MS patients have to prudently take part in physical activities to avoid experiencing relapses.

Another strategic move employed by MS patients under the self-management technique is capitalizing on social support. Whether it is their husbands, wives, blood relatives, or friends, patients living with multiple sclerosis count on people around them to help them manage their condition (Schneider, & Young, 2010). People around the patient offer both emotional support and physical support.

The second strategy that Schneider and Young (2010) identify as being central to management of multiple sclerosis is treatment. Basically, there are three treatment options available to MS patients: allopathic medicine, complementary and alternative medicine, as well as self-help, including nutrition and physical activity. Allopathic therapies are effective treatment regimens that improve many of the symptoms of the disease. There is currently a plethora of disease modifying anti-MS drugs which reduce the frequency of exacerbations and slow progression of the disease (Horng & Fabian, 2017).

Finally, Schneider, and Young (2010) outline that individual attitude maintained by patients is an important strategy that patients employ to help them manage their condition. Two variables under individual attitude are positive outlook and determination. Positive outlook speaks to acceptance of disease by patients, and maintenance of feelings of appreciation, and thankfulness. Determination refers to a resolve among patients to lead “normal lives,” in which they maintain their autonomy.

Another collaborative study that adds weight to the findings of Schneider and Young (2010) is that done by Goretti et al. (2009). According to Goretti et al. (2009), psychological coping, which Schneider & Young (2010) refer to as individual attitude, is indispensable as far as coping with MS is concerned. Goretti et al. (2009) explains that psychological coping is pivotal in enabling patients to accustom to the adaptive demands of the disease. Patients suffering from MS tend to have an increased psychoticism compared to members of general population and are at a higher risk of developing major depression. As such, patients may need to develop superior psychological coping strategies.

Bishop et al. (2009) cite the search for information as an effective strategic coping tool that MS patients employ to manage their condition. As the investigators explain, health care facilities do not provide MS patients with sufficient information needed in the management of multiple sclerosis. Therefore, patients are left to search for information on their own, either through studying literature that has information about the disease or arranging for consultation with their physician (Bishop et al. 2009). Information may be quite costly; for example, visiting a physician if uninsured; but many sources of information are either free or nearly so. Bishop et al. (2009) assertions are in agreement with the argument of Schneider & Young (2010), to the effect that MS patients encounter massive bottlenecks in getting information needed to better guide their treatment plans.

In general, the gap between the information expectations of patients, and the actual quantity and quality of information that sick individuals obtain exposes a major void that needs to be filled through provision of “continuity of care.” Continuity of care would see patients obtain the information that they need to guide their treatment plan. Entrenchment of information provision within the health care system will see the ’overhead costs’ that MS patients bear in seeking information reduced, or even totally eliminated.

Caregivers attending to MS patients also employ a number of strategies to help patients (Bowen, MacLehose, & Beaumont, 2011). One of the strategies that caregivers use is readjustment of their schedules. Since taking care of MS patients requires caregivers to be physically involved, caregivers have to reduce the amount of time they apportion for their own activities. For example, working husbands whose wives develop MS are at times compelled to stop working over the weekends, and to stop working overtime, so as to dedicate more time to spend with their ailing wives. Although Schneider and Young (2010) did not expressively refer to caregivers in their research outcomes, their finding on social support provided by relatives and friends corresponds to the Bowen et al. (2011) findings on caregivers. In essence, both the Bowen et al. (2011) and the Schneider and Young (2010) studies underscore the important role played by caregivers in supporting MS patients.

Older adults and middle-aged persons living with multiple sclerosis encounter many barriers in their effort to engage in physical activities and other healthy behaviors (Plow, Cho, Finlayson, 2010). To overcome these barriers, old and middle-aged MS patients often make use of health promotion services as a strategy of maintaining an active lifestyle. For example, it is during health promotion services that patients engage in physical activities.

MS patients may experience either infrequent bouts of major depression or chronic depression. Other patients grapple with stress and other psychosocial issues (Rintell, 2012). As Rintell (2012) points out, spiritual nourishment is an effective tactic that MS patients employ to preserve their self-worth; maintain a positive attitude towards challenging conditions in their lives; and avoid the disease from overwhelming them. In addition, patients endeavor to maintain active social lives, at least in the period before disease progression leads to debilitating conditions such as blindness and confinement to a wheelchair. Taking part in social activities helps patients receive the much needed physical and emotional support from the people around them (Rintell, 2012; Schneider & Young, 2010).

Summary

This critical review of the literature highlights the emotional experiences of MS patients with care services, especially during the peri-diagnostic phase. This review indicates that there is a broad range of factors that may contribute to the positive and negative experiences of MS patients. The main issues leading to dissatisfaction with care provision relate to untimely diagnosis and inadequate provision of healthcare-related information to patients.

The review suggests that enhancing communication between care providers and patients is essential in improving the lives of patients living with MS. Most of the studies reviewed examined the experiences of MS patients in relation to diagnosis and palliative care, with no investigations of experiences with continuity outside acute care settings. Overall, the available body of literature omits aspects of MS care with continuity, and only covers the beginning and the end the health care pathway. The current study aimed at addressing the identified research gap by examining the experiences of MS patients with continuity of care following hospitalization. The methodology of carrying out the study is discussed in the next chapter. This will include a discussion on the study design, sampling, data collection, data analysis, and ethical considerations.

Chapter 3: Research Method

Introduction

The purpose of this phenomenological study was to examine the continuity of care provided to New York State residents diagnosed with MS through a critical examination of their lived experiences following hospitalization for a relapse. In this chapter, the research design and the methodology of the study are discussed. The rationale for selecting a particular research design as well as the role of the researcher regarding personal and professional relationships with the participants will be discussed. Techniques for selection of participants and data collection will be explored. An analysis of the steps taken to ensure that this study is compliant with the current ethical principles guiding research involving human research subjects is presented. Tools to be used for data analysis will also be identified followed by an explanation of how they were developed. This will be followed by a discussion of the data analysis processes and ethical considerations in the context of this research. Approaches to ensure rigor such as credibility, dependability, transferability, and confirmability will also be presented.

Research Design and Rationale

The following research questions guided this study:

RQ1: How do MS patients experience continuing engagement with care providers following hospitalization?

RQ2: How do MS patients experience provision of care services following hospitalization?

RQ3: How do MS patients experience exchange of information with care providers following hospitalization?

Upon carrying out extensive reading on research designs, I determined that the above research questions would be most efficiently explored through the use of a qualitative phenomenological approach. The central phenomenon examined in this study was continuity of care for MS patients. The phenomenon is made up of three dimensions, including managerial, informational, and relational continuity of care. The aim of this study was to investigate the experiences of MS patients with continuity of care following hospitalization. Considering that little research has been conducted about the experiences of MS patients with continuity of care (Methley et al., 2015), the interpretive tradition was selected to explore the phenomenon.

According to Creswell (2017), the qualitative approach is appropriate to developing an in-depth understanding of the views and experiences of human beings with a particular phenomenon. The overarching aim of this study was to explore how MS patients experience continuity of care. Therefore, a qualitative approach was particularly suited to ascertain experiences of MS patients with continuity of care. A quantitative survey approach is not suitable when the researcher aims at obtaining an in-depth understanding of the experiences and views of the respondents. This is because results are limited in that the quantitative approach offers numerical descriptions instead of detailed narratives and accounts of human perception (Smith, 2015).

Qualitative research is limited by its dependence on the skills of the researcher making it easy for the personal partialities and idiosyncrasies of the investigator to affect the outcomes (Bryman, 2017). Moreover, issues of confidentiality can also present challenges when analyzing and reporting the findings. To avoid introducing personal assumptions into the study, an audit track containing a record of all activities involved in carrying out this research was kept. This process was aimed at recognizing personal opinions and experiences that may have impacted the investigation. The audit trail involved a persistent review of the raw data, personal diaries, and recordings. This is consistent with the Pope and Mays (2013) recommendation that the researcher should try to be objective and carry out the research with the goal of unveiling the true reality regardless of his or her personality, experiences, or social position.

Internal confidentiality or deductive disclosure occurs when third parties are able to identify the participants based on their traits or experiences (Saunders & Kitzinger, 2015). Participants’ responses were described in the final report; however, I took all possible precautions to hide their identity so that readers of the final report would not be able to link the participants' responses with the identity of the respondent. Identifying characteristics of the respondents such as their occupation, names, home address, location, and ethnic background were removed to create a clean data set. It was likely that some participants had faced some unique events in the process of care that may have led to their identification. I did take into consideration whether the quotations used to support the themes could lead to the identification of the participants through deductive disclosure. In case of a risk of identification, non-essential information such as occupation was modified to uphold confidentiality.

Creswell (2017) asserts that there are five main approaches to qualitative research, including phenomenology, case study, grounded theory, ethnography, and narrative research. The phenomenological approach involves the use of rich descriptive interviews and an in-depth exploration of lived experiences to understand how individuals perceive a phenomenon (Van Manen, 2015). According to Creswell (2013, p. 76), the overarching purpose of phenomenological research is to reduce experiences of individuals with a phenomenon "to a description of universal essence." This study focused on collecting data from people with MS who had experienced the phenomenon (continuity of care) and developed combined descriptions of the essence of their experiences. This was the best approach to be used in data collection because it permitted the researcher to explore how MS patients experience the three elements of continuity of care.

Two main approaches can be used in phenomenological research: descriptive and interpretive. In the descriptive approach, the focus is on the overall meaning of a phenomenon, and this is achieved by putting aside the investigator's experience or knowledge about the experience under exploration and approaching the data with no assertions about the phenomenon (bracketing) (Sloan & Bowe, 2014). Interpretative phenomenological research materialized from the hermeneutic philosophers who highlighted the need for the interpretation of the lived experiences by the researcher. This approach is concerned with the individual's viewpoint of the phenomenon, and it involves a detailed exploration of the individual's experiences (VanScoy & Evenstad, 2015). The investigator attempts to identify the participant's point of view while assessing deeper meaning to what the participant overtly expresses (Chan, Fung, & Chien, 2013).

Finlay (2014) argues that every researcher has some background knowledge that cannot be done away with merely by the practice of bracketing as advocated in the descriptive phenomenological approach. This was particularly relevant to this research considering that the investigator is living with MS. An interpretive approach would enable the researcher to acquire a deeper understanding of the patients' perspectives while leveraging the value that my prior experiences with MS care could bring to this research.

A case study approach did not fit the purpose of this research. Case study seeks to explore one or more cases into details (Hyett, Kenny, & Dickson-Swift, 2014). However, the goal of the research was to illustrate the meanings MS patients attribute to their shared experiences regarding continuity of care rather than seeking an in-depth investigation of individual cases. Another technique is grounded theory, and it seeks to discover or develop a theory grounded in theory collected from the field. The use of this approach would lead to the development of categories of data resulting in the construction of a theory (Marshall & Rossman, 2014). While this research led to the creation of categories of data about the experiences of MS patients, the development of a theory was beyond the purpose of this study. Instead of using the data to generate a theory, this study made use of the data collected during face to face interviews to provide an in-depth understanding of the lived experiences of the respondents.

Ethnographic research approach was beyond the scope of this study (Denzin & Lincoln, 2013). Though there are similarities between phenomenology and ethnographic research methods in that the two approaches seek to understand the experiences of research participants, ethnography extends towards understanding shared viewpoints from a cultural perspective. This study explored the experiences of MS patients with continuity of care, with no particular emphasis on their cultural point of views.

Role of the Researcher

There were no participant that I knew personally or had instructional relationships that gave me power over them. I have been an active member of the MS Society in New York, but my contacts with the members of this organization have been once in a year during the walks designed to increase awareness about this condition. Considering that there were no professional or personal relationships with the respondents, there were no mechanisms for undue influence of MS patients to take part in this study. To keep with the general requirements of the respect for autonomy ethical principle, I sought consent in circumstances that provided all the prospective respondents with a chance to consider participation and avoid undue influence. To accomplish the goal of this research, I explored and developed topic guides for the interview, carried out a literature review to demonstrate the need for this study, and identified the most suitable methodology for examining the research questions.

As an observer-participant, my personal experiences and first-hand knowledge of day to day management of MS was valuable in developing a harmonious environment in which both the investigator and the respondents felt at ease. As an observer, I documented the experiences of all respondents by first developing a rapport and observing the non-verbal cues of the respondents (Denzin & Lincoln, 2013). I took note of the core elements and most important issues discussed by the participants so as to be in a position to comprehend their views and experiences. As a participant, I took part in active conversation, while looking for opportunities to pose meaningful questions based on the circumstances and experiences of the respondent.

Methodology

Population

It is estimated that around 400,000 people are living with MS in the U.S. (National Multiple Sclerosis Society, 2015). It is predicted that there are between 110 and 140 cases of MS per 100,000 people in the northern part of the United States (The Statistics Portal, 2016). The MS rates in the Northern States are twice as that of southern parts of the United States. There are around 200 new cases of MS in the United States every week (The Statistics Portal, 2016). With regards to New York State, the New York State MS Consortium reports that there are more than 9,000 individuals with a clinical diagnosis of MS (New York State Multiple Sclerosis Consortium, 2017). The population provided a robust dataset to select participants for this study.

Sampling and Sampling Procedures

I selected the participants using purposive sampling technique (also referred to as subjective, judgmental, or selective sampling). This is a sampling method in which the researcher uses his or her own judgment to choose members of the population to take part in the study (Tyrer & Heyman, 2016). It involves identifying and choosing individuals or groups that are especially knowledgeable and experienced with the phenomenon of interest (Etikan, Musa, & Alkassim, 2016). Besides having the required experiences and knowledge, Palinkas et al. (2015) highlight the need for willingness to take part in the study as well as the ability of the respondents to communicate their own experiences and opinions in a coherent, revealing, and reflective manner.

Pietkiewicz and Smith (2014) assert that a sample size ranging from six to eight participants is suitable for a phenomenological study. On the other hand, Marshall, Cardon, Poddar, and Fontenot (2013) argue that most of the data saturation will occur by 12 interviews. The recruitment plan will involve various groups including patients with different kinds of MS, males, and females and it is likely that diverse views will emerge; hence, a larger sample may be needed. It was therefore determined that the actual sample size would be ascertained upon reaching the point of data saturation (Fusch & Ness, 2015).

While the sample size required for this research may not be huge compared to that of quantitative surveys, inadequate enrollment of respondents was an issue that was taken into consideration. It was indispensable to have a contingency plan to ascertain a sufficient sample size. With the assistance of the MS Society, I recruited participants from different support groups so as to ensure an adequate sample. I employed a range of recruitment techniques to recruit participants from the various MS support groups.

Selection Criteria

The sample of participants was obtained from National Multiple Sclerosis Society-sponsored MS support groups in the state of New York. The inclusion criteria included people with an official diagnosis of MS and a history of hospitalization in the past. They should have been able to express themselves in English (due to the nature of interviews) and be residing in the state of New York. The individuals had to be at least 40 years and willing to sign the consent form for to be allowed to take part. The exclusion criteria included people without a diagnosis of MS, individuals without a history of hospitalization, and those not able to express themselves in English.

Multiple sclerosis may affect the speech of a person especially during a relapse, making it hard for them to be understood (Renauld, Mohamed-Saïd, & Macoir, 2016). If this became an issue during the interview, the respondent was not disqualified. I planned to accommodate such issues by allowing for additional time while breaking the interviews into smaller segments to allow the participants to respond at their own pace. I also paid special attention to slurred speech and allowed the respondents more time to respond to the interview questions.

Individuals were not involved in this study if they satisfied the exclusion criteria. Since the focus of this study was on how MS patients experienced coordination of care following hospitalization, individuals without a past history of hospitalization following an exacerbation were not included in the study. This population would not be in a capacity to shed light on the experiences of MS patients with continuity of care. No individual was excluded on the basis of race, sex; type of MS, frequency of hospitalization, and duration with the health condition. It was assumed that a diverse sample with regards to duration of MS, age, gender, and type of MS was advantageous by providing a broad perspective regarding continuity of care. As the sampling process continued until the point of data saturation was reached, it was expected that the inclusion criteria may be modified as data collection processes proceeds.

Recruitment Procedures

To achieve a desirable sample size, a recruitment flyer was used in the recruitment of the participants (Appendix C). Each participant who was screened for participation received a unique study identifier. The identifier did not have a link that could be used to identify the respondent. The study identifiers referred solely to the numbers that were assigned chronologically to the participants during the screening process. The purpose of the identifiers was to indicate the status of all respondents (e.g., signed consent form, withdraw from the study, or screen failure).

The protocol was that potential respondents were contacted through phone calls to confirm that that they had met the inclusion criteria. Potential participants who did not satisfy the inclusion criteria were advised about this requirement and how it supports the objectives of the research. They were asked if they have any questions and thanked afterward for their willingness to participate and requested to refer colleagues who may have met the inclusion criteria. Individuals deemed as eligible for participation were scheduled for an interview. The interviews were scheduled for dates and places deemed as convenient to the researcher and participants.

Instrumentation

The main instrument used in data collection was semi-structured interviews with open-ended questions to explore the experiences of MS patients with continuity of care following hospitalization. Semi-structured qualitative interviews are types of comprehensive open face to face interviews that employ a topic guide that facilitates an open conversation about the phenomenon under investigation (DiCicco-Bloom &

Crabtree, 2006). This type of interviewing makes it easy for the investigator to switch from one topic to another while collecting relevant data with regards to research objectives (Green, & Thorogood, 2013).

However, they require some form of control to keep on the right track, but it should not be too rigid to the extent that the interview session turns to be a question-answer session where the participants are not given a chance to clearly explain their opinions. The role of the investigator is to listen keenly and probe if deemed appropriate but should avoid revealing their perceptions or assumptions (Pope & Mays, 2013). Therefore, the approach allowed for follow-up and probing questions regarding the experiences and views of MS patients.

Smith (2015) describes topic guides as expansive and flexible areas that outline key concepts that may be covered when carrying out an interview. Likewise, Creswell and Poth (2018) assert that the guides facilitate consistency across interviews, while providing the flexibility needed to face a smooth conversation. Prior to developing the interview guide, I read the various interview protocols used by other scholars exploring the experiences of patients with continuity of care. As I read about the types of concepts that were essential to gather data from the structured interviews, I created open-ended questions that would facilitate in-depth conversation with the respondents (Appendix D).

I designed the semi-structured interviews with caution to avoid excessive structure on the interviews, because this could interfere with the quality of the qualitative study. All the questions asked were within the phenomenon under investigation, and the participants were required to answer the questions on the basis of their experience. The various responses and experiences given in the course of research were compared with other responses to facilitate the emergence of new themes. Notes were taken during the interviews. The field notes included observation and documentation of the non-verbal reactions of the respondents during the interview.

The topic guides focused on the experiences of MS patients with the three aspects of continuity of care. Areas of the topic guide included patients' meanings and understanding of their interactions with health care providers, including nurses, neurologists, and other physicians (relational continuity). Another area that was explored was information sharing with and between health care providers to address informational continuity. On the other hand, managerial continuity was explored by having questions on the experiences of MS patients with coordination with or between care providers and the extent to which they shared a common understanding of a plan to meet the needs of the respondents (Appendix D). However, the term continuity was not asked about directly, nor was it defined. I made use of open-ended questions to allow the respondents to share their personal experiences with the three dimensions of continuity of care.

Other data collection instruments used included the demographic form questionnaire, informed consent form, recruitment flyers, and audio tapes. The demographic form was used to gather data on the gender, educational level and number of years with MS among other details that can be used to describe the characteristics of the participants (Appendix E). The consent form included information regarding ethical issues in research such as participation on a voluntary basis and how the confidentiality principle was respected during the interviews. The consent form also highlighted the right of the respondents to withdraw from the study at any time (Appendix F). The document contained a separate checkbox where the respondents were supposed to tick to indicate their agreement to be recorded. Taking into account the importance of capturing information discussed during the interviews, the need for the respondents to be recorded was essential. A recruitment flyer was used in the recruitment of the participants. It provided basic information such as the purpose of the study and provided my contact details. Interviews were audio recorded and transcribed into written form for purposes of data analysis.

Data Collection

Upon obtaining the Institutional Review Board approval from the university, I immediately started the process of recruiting participants for this study. All of them were required to complete a written informed consent form before the commencement of the interviews. All the interviews were tape recorded. The main technique used in the data collection phase was semi-structured in-depth interviews containing open-ended questions. The interviews were held during face to face meetings with the respondents. A major benefit of using a face to face approach was enabling the researcher to capture verbal and non-verbal cues which acted as additional sources of data.

An interview guide was organized around a set of predetermined questions. Nevertheless, flexibility was upheld to give an opportunity to pursue other questions that emerged during the interviews (DiCicco-Bloom & Crabtree, 2006; Mason, 2012). While the semi-structured interviews were used to allow the respondents to lead the researcher to their most important experiences of relevance to the research questions, the main questions were designed to ensure that I obtained adequate information for answering the research questions.

To determine the content validity of the main interview questions for the interview guide, I employed a panel of research consultants expert in MS. Lynn (1986, as cited in Polit & Beck, 2006) recommends a minimum of three experts and a maximum of ten. The goal for this part of the study was five panelists. Hence, the number of experts involved here was within the recommended range.

The work of the content experts, in this case, was to observe grammar, word choice, and relevance of the interview questions in line with the various constructs of continuity of care (Zamanzadeh et al., 2015). Each panelist was sent an individual email containing the interview questions. The panelist were provided with a questionnaire using a Likert scale and requested to analyze the construct and content of each research question on a scale of 1 to 4, with 1 representing no relevance, 2 low relevance, 3 moderate relevance, and 4 for strong relevance. A four-point scale was used to avoid having neutral or ambivalent midpoints (Polit & Beck, 2006). The number of those judging the items clear or applicable was computed and content validity ratio (CVR) calculated to establish the scope of content validity in each question before conducting the actual interviews with MS patients. The content validity ratio was calculated using Lawshe (1975) formula devised as:

$$\mathrm{CVR} = \frac{Ne - N/z}{N/z}$$

In this formula, Ne refers to the number of panelists that rate the question as essential and N is the total number of panelists. Questions were not eliminated if they had at least a CVR of at least .05. This is the point at which the agreement of the panelists would not have been considered to have taken place by chance at an alpha level of .05. The CVR exceeded .05 for all the questions except for two questions which were subsequently removed. The average content validity ratios for all questions was calculated to establish the CVI of the entire interview instrument. The calculated content validity index upon review by the panelists was 0.893.

Upon establishing the content validity of the interview guides, the next step was recruiting the participants. Invitation letters detailing the objectives and procedures of this study were sent electronically and via post office to all potential participants (Appendix G). The letter outlined the purpose of this research and asked people with a history of MS to respond through email or phone if interested in taking part. I made follow-up calls within one to two weeks following the distribution of the invitation letters. It is during these follow-up calls that it was determined if the respondents satisfied the inclusion criteria and confirmed their willingness to take part.

Based on the number of questions developed, I anticipated that each interview would take around 45 to 60 minutes, followed by further contact for clarification purposes if need be. All the interviews were recorded using a tape recorder. The timing of the interviews was flexible to give the respondents time to attend personal needs such as restroom breaks. At the end of the interviews, I gave the respondents an opportunity to make additional comments and seek clarification if need be. Discussions seeking clarification on various issues took place in person and were recorded so that I could have an opportunity to go back over the material for analysis.

The recordings were transcribed within 48 hours of completion, and the transcripts only contained the number the respondents assigned upon nomination to this research. The study numbers did not contain any links that could be used to identify the respondents so as to maintain confidentiality of the data. While some documents such as consent forms may entail subject identification, no personally identifiable details were used in the publication of the final product. Besides, I was the only one having access to the respondent's source documents linking them with data that could be used to identify them. All the study records were kept in a locked cabinet at my office and will be destroyed after five years.

Data Analysis Plans

The most commonly used data analysis strategies in qualitative research include preparing, organizing (text data in transcripts), reducing the data to themes through coding, counting the frequency of codes, relating the categories, and displaying the findings (Miles, Huberman, & Saldana, 2013; Smith, 2015). Nevertheless, there are variations in these approaches depending on the type of inquiry. Steps involved in phenomenological data analysis include a description of personal experiences with the phenomenon, identifying significant statements, placing the statements into groups, synthesizing themes, and lastly developing a composite explanation of the phenomenon under investigation (Creswell & Poth, 2018). The focus of the analysis was on developing a deep understanding of the meaning of the accounts provided by the respondents. The data were analyzed for emerging themes and were presented through a discussion. Creswell and Poth (2018) assert that qualitative findings can be presented in form of figures, tabular layout, or through discussion.

All the processes involved in data analysis were documented clearly to make it possible for future researchers to follow the steps and verify the emerging themes. The process for data analysis was clearly documented to improve the ability of subsequent researchers to follow my decisions and verify the results. I began by transcribing the interviews and transferring them to MS Word text files. As explained in the data collection section, the respondents were tape recorded and the data transcribed at the end of the interview. The transcriptions contained literal statements and appropriate non-verbal cues (Miles, Huberman, & Saldana, 2013). I composed the notes and documented all non-verbal communications in the field notebook. Data analysis involved reading and rereading the texts as well as listening to the recorded interviews more than two times to ensure the accuracy of the data (Ritchie, Lewis, Nicholls, & Ormston, 2013). The focus of the analysis was to comprehend the meanings of the accounts provided by the participants.

The next step involved immersing myself in the data by reading the transcripts several times and familiarizing myself thoroughly with the content (Graneheim & Lundman, 2004). During this phase, I reviewed the content of the data to get a sense of the data as a whole. I wrote short notes on the margins of the transcripts or field notes to assist in the process of getting a holistic view of the interviews. At this stage, I disregarded the predetermined interview questions so as to understand what the respondents were trying to convey (Creswell, 2013). The possibility of researcher bias influencing the findings was kept minimal through the practice of bracketing. The audit trail were used to assess possible bias relating to my previous experiences with the health care system.

Upon reviewing the relevance of the content, the next step in the data analysis process was the identification of keywords, phrases, and paragraphs that are connected to each other and with comparable meanings (Creswell, 2017). Basic meaning units were identified and labeled with codes to facilitate interpretation of large bits of information. Determining how these meanings have been linked leads to the development of new categories. Once the themes have been developed, a coding sort will be used to gather related coded texts (Graneheim & Lundman, 2004). The final step was synthesizing the data to explain how the different codes fit together and determine the meaning of the responses provided by the respondents. This is in line with the Creswell (2007) argument that the basic purpose of phenomenological research is to reduce individual experiences with a phenomenon to a description of universal essence.

Issues of Trustworthiness

Rigor is essential in establishing the trust and worth of research findings irrespective of the approach taken (Morse, 2015). The trustworthiness of qualitative research findings is often questioned by positivists who assert that their concepts of validity and reliability cannot be addressed in the same manner as in naturalistic work. However, several scholars have demonstrated how qualitative research can incorporate various measures to deal with these issues (Creswell, 2017; Graneheim & Lundman, 2004; Lincoln, & Guba, 1985). While there seem to be differences between naturalistic and positivist research philosophies, the two approaches use similar measures to establish the quality of standards (Morse, 2015).

Most naturalistic scholars, however, prefer to use different terms to discuss rigor so as to distance themselves from the positivist paradigm. One of such authors is Guba and Lincoln who propose four criteria for evaluating rigor in qualitative research (Lincoln & Guba, 1985). By addressing similar issues, Lincoln and Guba's four-point criteria corresponds with that of positivist scholars. The criteria include credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity).

Credibility

One of the core criteria used by a positivist scholar is that of ensuring internal validity, in which he or she seeks to ascertain that his or her tests measure what is actually intended (Lincoln & Guba, 1985). An equivalent concept in qualitative research is credibility, and it is used to determine the congruence between the findings and the reality (Graneheim & Lundman, 2004). Lincoln and Guba (1985) maintain that ascertaining credibility is one of the most significant factors in determining trustworthiness. Various provisions may be made to promote confidence that the investigators have accurately described the phenomenon of interest.

To improve confidence in the credibility of the interview data, I made use of techniques such as saturation, whereby the respondents were recruited till no new insights emerged (Graneheim & Lundman, 2004). According to Fusch and Nessm (2015), data saturation in qualitative research is reached when the ability to gain new additional information has been reached and when development of further categories is not feasible. Failure to reach data saturation negatively affects the quality and content validity of the research (Morse, Lowery, & Steury, 2014; O'reilly, M., & Parker, 2013).

Another technique that was used is negative case analysis, as recommended by Lincoln and Guba (1985). It requires the investigator to refine the hypothesis till it takes into account all cases within the data. On completing the development of the categories, I reexamined the data to ensure that the constructs indeed addressed all cases of the phenomenon involved. The process involved reviewing negative or disconfirming cases to come up with alternative explanations leading to the development of an in-depth understanding of the phenomenon.

Lincoln and Guba (1985) consider member checking as the single most critical technique that can be used to bolster the credibility of qualitative research. Checks relating to the accurateness of the data can take place during or after data collection (Shenton, 2004). The technique mostly involves taking back the data and the interpretations to the participants and asking them to establish the credibility of the information and narrative account (Lincoln & Guba, 1985). In line with this technique, I took my preliminary analyses to the respondents so that they could establish the accuracy of the accounts. This is in accord with the Stake (2010) recommendation that participants in qualitative research should play an active role in directing as well as acting in the study.

Another strategy for ensuring credibility in qualitative research is prolonged engagement and observation in the field. This enables the investigator to build trust with the respondents, becoming familiar with their culture and checking for misinformation stemming from distortions by the researcher (Creswell, 2017). I was already familiar with the culture of the respondents having lived with MS for more than 20 years. I spent adequate time with the respondents to build trust and develop a rapport with them in a bid to be in a position to understand their experiences.

To improve intra-rater reliability, I scrutinized the referential materials, including the transcripts and tape recordings to substantiate the subsequent interpretations. Exhaustive respondent quotes were used to authenticate the analyses further. According to Shenton (2004), researchers should seek peer scrutiny of their projects to give an opportunity for fresh perspectives. I requested an independent researcher to use the data analysis procedures and make comparison of the codes to calculate the inter-rater reliability. The review and feedback provided enabled me as the investigator to strengthen my research.

Another technique that was used to ensure the credibility of the data collected is triangulation. The technique involves the use of different data collection techniques to cross examine findings in qualitative research (Denzin & Lincoln, 2013; Creswell, 2017). Triangulation can also be achieved through data sources by involving a broad range of participants. This makes it possible for the opinions and experiences of the informants to be compared and verified against others. Eventually, a rich and detailed understanding of the experiences, behavior, or views of the respondents is constructed (Van Manen, 2015).

To ensure triangulation, I exploited opportunities to check out bits of information across respondents. I recruited a broad range of informants in terms of MS type, gender, age, and frequency of hospitalization and corroborated their accounts by comparing the information provided during the interviews. I also compared data collected through different sources including field notes, transcripts, and documents.

Where applicable, site triangulation can be achieved by having participants from different organizations in a bid to decrease the effect of the research of particular local factors (Shenton, 2004). The findings may have greater credibility in the eyes of the reader if they are similar (Shenton, 2004). In line with these arguments, I followed the concept of circling reality. The concept of circling reality advocates for obtaining different viewpoints for one to have a detailed and a better view of reality based on a broad range of observations (Dervin, 1983).

Various qualitative methodologists have recommended other techniques to ascertain honesty and integrity of data collection processes. One of these techniques is ensuring that participants are given a genuine opportunity to decide whether to take part in the research or not, so as to ensure that only those who are genuinely interested take part (Shenton, 2004). In line with this requirement, I emphasized that participation is on a voluntary basis and that the respondents could withdraw at any time without disclosing any explanations. Another strategy in ensuring honesty in the respondents is encouraging them to be frank from the outset of each interview (Leung, 2015). As a result, I endeavored to develop a rapport with each participant and encouraged them to be sincere with their responses.

The use of probes and iterative questioning has been recommended as a suitable technique for ensuring the integrity of the data collected (Shenton, 2004). I made use of probing questions to seek an in-depth explanation of ambiguous issues. I also made use of iterative questioning techniques including rephrasing the questions to elucidate a possible discrepancy in the responses provided by the respondents.

Reflexivity, which is the process of scrutinizing oneself as the investigator and the relationship with research, is another practice for ensuring credibility in qualitative research (Lincoln & Guba, 1985). It is the practice of self-searching that involves reflecting on one’s assumptions and preconceptions and how they might impact the decisions made during research (Berger, 2015). My main assumption during this research was that the views and experiences of MS patients with continuity of care do not exist as objective realities but are outcomes of the subjective meanings that the participants have developed from their day to day interactions with the healthcare system. The assumption is in accord with a social constructivist worldview that is commonly used in qualitative research (Creswell, 2011). I also kept a journal to describe my experiences during the research and how my values and beliefs influenced the data collection and analysis practices.

Transferability

The focus of most, if not all, qualitative studies is to explore particular phenomena or issues of a given population in a specific context (Houghton, Casey, Shaw, & Murphy, 2013). Therefore, generalizability of qualitative research findings is usually not an expected attribute. It is also not the interest of any qualitative study to generate generalizable findings. Nevertheless, with the increasing emphasis on rigor and the growing trend of meta-synthesis of qualitative findings, approaches for ensuring transferability have become essential (Leung, 2015).

A pragmatic approach to ensuring transferability of qualitative findings is providing rich and thick descriptions to allow the readers make decisions regarding how the findings apply to other contexts (Creswell, 2017; Morse, 2015). Therefore, in line with the interpretative philosophy, I have provided a thick and detailed description of the research methods and characteristics of the research participants to allow the reader to determine the extent to which he or she can transfer the findings to his/her own context. The thorough descriptions of the research methods provide the reader with sufficient information to establish if the findings of this study apply to their situation (Creswell, 2017).

In line with the naturalistic paradigm, the findings of any qualitative study should be understood within the context of the particular characteristics of the organization or the locality in which the data were collected (Barnes et al., 2005). To determine the scope to which the findings may be relevant to people in other circumstances, similar projects utilizing the same techniques but carried out in different contexts are imperative (Shenton, 2004). Gaining an in-depth understanding of a phenomenon is rarely obtained simply by carrying out a single study. Nevertheless, the issue can be addressed by conducting complementary work to allow for a more comprehensive picture to be obtained (Shenton, 2004).

Even when different studies produce inconsistent findings, it does not necessarily mean that one approach is untrustworthy; it may be simply demonstrating multiple realities (Shenton, 2004). With regards to the current research, the phenomena related to experiences of MS patients with continuity of care occur in multiple settings and different geographical areas; thus, this study sought to provide baseline understanding with which the findings of consequent research should be compared.

Dependability

In addressing the issue of reliability, the positivist paradigm is concerned with measures to ensure that if the work were repeated in the same context, methods, and participants, similar results would be obtained (Anney, 2014). Nevertheless, as Marshall and Rossman (2014) note, the changing nature of the social phenomena explored through qualitative methods renders such requirements problematic considering that even identical respondents may provide different responses at a later date. To address the issue of dependability in qualitative research, Shenton (2004) asserts that all the processes involved in the study should be described in detail, thereby making it possible for a future investigator to replicate the work, and if possible obtain similar results. Such in-depth explanation enables the reader to determine if the researcher had followed appropriate research practices (Graneheim & Lundman, 2004). Thus, in an attempt to enable readers to develop a detailed understanding of the research procedures and their effectiveness; I have provided a rich description of the research method to allow for possible replication of this study.

According to Barnes et al. (2005), the more consistent the investigator has been in the research process, the more dependable are the results. To further ensure dependability, I developed a protocol comprising of the interview guides and the main questions, to unswervingly obtain appropriate data to address the research questions. Such an approach makes it possible for another researcher to replicate the data collection processes used (Shenton, 2004). The application of rigor also calls for an accurate and detailed description of the research participants (Anney, 2014). As a result, I have been devoted to providing a detailed description of the research participants, including the inclusion and exclusion criteria. I also offered a detailed description of the demographic details upon completion of this research.

Shenton (2004) maintains that to provide a comprehensive understanding of the research methods, researchers should be devoted to providing explanations about the study design and the operational details regarding data collection and all other processes involved in the field. In line with this recommendation, I have explained the research design and the data collection plans. I also kept an audit trail detailing all steps involved in data collection and analysis processes. The audit was reviewed to determine the extent to which the activities for meeting dependability have been followed. This technique has been supported by Shenton (2004) who maintains that the dependability of qualitative research is diminished if the researcher fails to keep an audit trail.

Confirmability

The concept of confirmability in qualitative research is equivalent to that of objectivity in quantitative studies. Measures must be taken to ascertain that the findings are consistent with the experiences and ideas of the respondents, instead of the partialities and characteristics of the investigator (Shenton, 2004). Lincoln and Guba (1985) consider a key criterion to confirmability as the extent to which the investigators acknowledge their own predilections. To this end, the researcher ought to acknowledge the beliefs and views that underpinned the decisions made and the techniques employed as well as the reasons for favoring one approach over another (Krefting, 1991). To ensure confirmability in line with the above sentiments, I provided a reflective commentary on various areas of the research. I have already disclosed my personal beliefs and experiences that led to the selection of the research topic.

Comprehensive methodological description allows readers to establish the extent to which concepts emerging from the data are acceptable (Shenton, 2004). An essential strategy to ensuring this is keeping an audit trail to enable the reader to trace the course of the research through the described procedures and decisions reached (Denzin & Lincoln, 2013; Krefting, 1991). I have clearly documented all the procedures and provided justification for the decisions made. The approach shows how the data resulting in the findings were gathered and analyzed during this research.

Though distance between the participants and the investigator is viewed as a sign of objectivity in quantitative studies, qualitative researchers seek ways to decrease the distance to ensure that the findings reflect the true account of the experiences and views of the respondents (Denzin & Lincoln, 2013). In line with the naturalistic paradigm, I prolonged engagement with the respondents to build trust and rapport with them. I also stayed in the field until I reached a point where more sampling and more data did not lead to the development of new categories related to the research questions. After all, the goal of this research is to ensure objectivity of the collected data and not essentially impartiality (Lincoln & Guba, 1985).

Ethical Procedures

Taking into account the ethics compliance requirements at the University, this study can be said to be of general low risk. This study aimed at exploring the experiences of MS patients with continuity of care following hospitalization. Pertaining to the data collection procedures, there was minimal risk or danger that the respondents could be exposed to as a result of their participation in this research. However, it was essential for a researcher to comply with the ethical requirements when carrying out research involving human participants, even though there may not be foreseeable risks (Ritchie, Lewis, Nicholls, & Ormston, 2013). Prior to data collection, I sought IRB approval from the Walden University Research Ethics Committee. Research materials sent for IRB review included the research proposal and supporting documents including the consent forms and the data collection tools. Approval letter was also sought from the National Multiple Sclerosis Society before recruiting the participants (Appendix H).

Upon receiving approval, individuals meeting the inclusion criteria were provided with an informed consent form to confirm their willingness to take part. The purpose of the study and the data collection processes were explained individually to each participant. I also gave each one of them an opportunity to ask questions and seek clarification if need be. Informed consent was obtained from each respondent prior to their enrollment. The participants were informed that participation in this study was absolutely on a voluntary basis and that they could terminate the interview at any time.

To uphold the principle of confidentiality, the respondents were assigned pseudonyms to safeguard their identity. Any particular information that would lead to the identification of the respondents was not be provided in the final report. The print materials were stored in a secure location and will be destroyed after five years. Electronic files (transcripts and coding) were only shared with consultants and stored in a password protected personal computer. The electronic files did not contain personal identifiers and will be destroyed at the end of five years.

Researchers should avoid doing harm to participants and should instead promote their wellbeing. In other words, the benefits of taking part in the research should outweigh potential harms (Mason, 2012). Possible risks as a result of taking part in this research included temporary discomfort as the participants may experience undesirable feelings when talking about their experiences with continuity of care. To reduce the likelihood of respondents experiencing discomforts, I prolonged my engagement and built rapport with them to make them feel comfortable during the research. I started with general questions about the lives of the respondents so as to get to know them better before the commencement of the interviews. I gave each participant $75 as compensation for his or her time and effort devoted to this study.

Summary

In this chapter, I provided an explanation of the research design and the research questions focusing on exploring the experiences of MS patients with continuity of care. A qualitative phenomenological design was used to provide detailed explanations of the experiences of the participants. I have also provided thorough descriptions of the methodology, characteristics of the participants and the data collection and analysis practices. In addition, the process of developing and reviewing the core interview questions has been provided. I have also provided a detailed discussion regarding trustworthiness issues to enable readers understand what philosophical assumptions influenced the decisions made and enhance replication of this research. In the next chapter, I will provide the thematic data analysis of the results of data collection in an attempt to address the research questions for this study.

Chapter 4: Results

Introduction

Continuity is considered a crucial aspect of quality of care (Beadles et al., 2014). Reid, McKendry, and Haggerty (2002) identify three discernable categories of continuity of care, which include informational, managerial, and relational continuity of care. The elements are equally important for all MS patients, but ascertaining that there is continuity of care as patients move between hospitals and receive care from multiple providers remains a challenge (Easley et al., 2016). Despite the importance of continuity of care in ensuring that patients receive quality care, limited research has focused on this crucial aspect of care provided to MS patients. There are no previous studies exploring post-hospital continuing care experiences among MS patients, with the problem being demonstrated in the existing body of literature (Methley et al., 2015). Taking into consideration the gap in the literature pertaining to experiences of MS patients with continuity of care, this phenomenological study was appropriate. The purpose of this qualitative study was to examine the continuity of care provided to New York State residents diagnosed with MS through a critical examination of their lived experiences following hospitalization for an exacerbation.

This study was guided by a central research question followed by a series of closely related questions that sought to explore the experiences of MS patients with various dimensions of continuity of care. The three research questions included:

RQ1: How do MS patients experience continuing engagement with care providers following hospitalization?

RQ2: How do MS patients experience the provision of care services following hospitalization?

RQ3: How do MS patients experience exchange of information with care providers following hospitalization?

In this chapter, I will describe how the study was carried out while paying special attention to how the elements of the proposed plan were performed and findings produced. Challenges of recruiting the participants and how they were overcame will be discussed. The setting, demographics of the participants, and data collection processes, including how the participants were recruited, interviewed, and data recorded and transcribed, will be explained. In addition, the data analysis processes, including the procedures for developing the codes and the synthesis of the codes into themes and categories, will be discussed. Measures that were taken to ensure that the findings were credible and trustworthy will also be presented. Finally, the actual detailed and candid descriptions of the experiences of MS patients with continuity of care while demonstrating thematic patterns in relation to the research questions will be presented.

Setting

There were no personal or organizational conditions that in any way influenced the participation of MS patients in this research. In addition, no personal or organizational factors influenced the interpretation of the findings of the interviews conducted. I recruited the participants and gathered data using methods that were approved by the Institutional Review Board (IRB) of Walden University. Participants were enrolled in this research from the IRB pre-approved site, which was the National

Multiple Sclerosis Society. The topic was of interest to the participants; thus, they readily accepted to take part in this study.

Demographics

Purposive sampling technique was used to assist in the identification of individuals who would enable development of insights into the research questions (Etikan, Musa, & Alkassim, 2016). Demographic characteristics were collected for all participants and are presented to set the context for the data and interpretation. Three men and five women with MS took part in this study. This reflects a higher prevalence of MS in women, as discussed in the second chapter. Five of the participants were working at the time of study, while the remaining three had retired by the time the interviews were been carried out. Six of the participants were disabled and were receiving Social Security and Medicare benefits. The participants were aged between 40 and 75, years, with the mean age being 56.12 years with a standard deviation of 7.62. All the participants lived with their family members who were also their main source of support. All the participants had a diagnosis of MS from a neurologist. A summary of the demographic characteristics of the participants is provided in Table 1.

Table 3:

Participant Demographics

Participant	**Gender**	**Age**	**Educational level**	**Interview location**
P01	Male	56	College degree	Home of the participant
P02	Female	61	College degree	Home of the participant
P03	Female	50	Masters degree	Home of the Participant
P04	Female	55	College degree	Office of the Researcher
P05	Male	46	Masters	Office of the participant
P06	Male	52	PhD	Public library
P07	Female	58	PhD	Public library
P08	Female	71	Masters	City garden

Data Collection

IRB approval was granted March 15, 2019. The first participant was recruited on March 15, 2019. The last participant was enrolled on June 16, 2019. The participants were continually recruited into this research until the point of data saturation was reached; that is, the point at which no more categories could be developed (Morse, Lowery, & Steury, 2014). This occurred after enrollment of eight participants. This was anticipated as the number is within the range that is common for phenomenological research design sample size of around 8-12 participants (Laureate Education, Inc, 2013).

Overall, the recruitment of participants went well, although some of the participants who agreed to take part did not show up for the interviews. The recruitment of the participants proved challenging as some potential participants failed to attend the interviews, thus extending the data collection phase for one month as I kept contacting other potential participants. There were no variations in the data collection protocols for the eight participants. Data collection procedures went on as initially planned without deviation. Prior to their participation, the participants were informed about the data collection processes that would be followed and required to sign an informed consent form. The completion of the informed consent form was also used to confirm that the participant had satisfied the inclusion criteria. I will keep the screening and the informed consent forms in a closed file cabinet in my private office.

Eight participants were interviewed in places that were convenient for them. The place of the interview needs to be selected carefully as it may impact the data collection exercise (Rashid, Hodgson, & Luig, 2019). According to McGrath, Palmgren, and Liljedahl (2019), interviews ought to be carried out at a time and place that is convenient to the participants, a place that is in a comfortable setting free from any potential disruptions. Three interviews were conducted at the homes of the participants, one in my home office, one in the office of the participant, two in a public library, and one in a city garden. All the participants who signed the consent forms completed the interviews. Four participants had promised to take part in the study but failed citing commitments to other issues while one potential participant did not provide any explanation. All the interviews went on without interruption or adverse event such as emotional breakdown of the participant.

All the participants were recorded and transcribed as had been planned in the proposal. Zoom digital recording device was used to record the interviews. I did all the transcriptions, and I listened to the recording several times while checking the transcripts to make sure all the responses were captured. It took an average of 2.1 hours to transcribe each interview with a standard deviation of 4.71. The average time spent carrying out the interviews was 40.5 minutes with a standard deviation of 5.24. The duration of the interviews ranged from 30 to 50 minutes, with longer interviews taking place with older participants who had a lot to talk about regarding their experiences as people living with MS. One participant provided comprehensive background information regarding his diagnosis with MS and his demographic profile before we began addressing the interview questions. I decided not to interrupt him or change the topic, thus respecting the principles of qualitative research. Looking back, I feel that I made the right decision as the participant at the end did address the interview questions and offered a detailed description of his experiences with care with regards to the three crucial elements of the continuity of care framework. As the interviewer, I used empathy during the interviews to create a more personal connection with the participants, and this gave even the younger participants a fair amount of experiences and perceptions to share with the interviewer.

Data Analysis

Data analysis was an ongoing process that began as soon as I prepared the first transcript. The process of the data analysis began by immersing myself into the data, reading and rereading the transcripts, and familiarizing myself with the content of the data. The preliminary reading of all the transcripts was carried out to ascertain that adequate data were obtained to address the research questions, before starting the coding process (Ritchie, Lewis, Nicholls, & Ormston, 2013). As I reviewed the transcripts, I expected to find statements relating to the main points of interest with regards to informational continuity, relational continuity, and managerial continuity.

I used the Saldana's (2016) structural coding method to analyze the data. The author stated that the original questions in a research interview could be used to structure the coding process, where the content for each question assists in labeling codes and categories so that it is possible to examine similarities and differences across all cases. For each question, I chose words and phrases that seemed to represent the focus or the intent of the statement. The identified codes were combined into categories and themes.

Evidence of Trustworthiness

Credibility

A number of techniques within the naturalistic paradigm are used to create the true value of research findings (Creswell, 2007). One way that was used to ensure trustworthiness was spending adequate time with the participants to develop a rapport. I attended the regional MS meeting and spent time with MS support groups, and people with MS viewed me as one of them and volunteered to take part in the study. The rich descriptions offered by the participants reflected the level of comfort in taking part in this study. To improve confidence in the precision of the data, a priori sample size was not established. Instead, the recruitment process went on until no new insights could be obtained from the data. When certain experiences appeared as contradicting to the emerging themes, these accounts were scrutinized further to establish whether they represented disconfirming cases (Creswell, 2007).

To improve intra-rater reliability, I scrutinized the transcripts and tape recordings several times to substantiate the interpretations. Relevant samples of the transcripts were reviewed several times to confirm the primary and secondary themes. This led to closer attention to coding segments of text when the participants discussed various concepts. The detailed quotes of the respondents were also used to substantiate the interpretations made. Campbell, Quincy, Osserman, and Pedersen (2013) recommend analyzing a sample of texts to establish the intra-rater reliability as huge volumes of data are usually collected in qualitative studies. The researchers add that it is appropriate to evaluate the intercoder reliability on a sample of the texts to be analyzed, particularly when the expenditures discourages multiple coding of each text. Nevertheless, there is limited agreement as to how large a sample of text should be, with some recommending 10% of the set documents (Hodson, 1999). On the other hand, Campbell et al. (2013) assert that investigators should continue with sampling of transcripts and refining the code scheme till they are contented with the scope of intercoder reliability. Thus, in keeping with Campbell et al. (2013) guidelines for inter-rater reliability, I carried out the three-stage process for semi-structured interviews. Upon reviewing all the transcripts, I generated a total of 80 codes. The transcripts were then given to another investigator and another review was carried out with overlapping codes being combined. The numbers of codes were decreased while sorting the codes in line with the research questions.

Two reviewers were involved in the coding process. The independent investigator provided the coded transcripts, and the codes were compared and contrasted using Campbell, Quincy, Osserman, and Pedersen (2013). Of the codes compared, five were in agreement, yielding an initial discriminant capability of 75%. This was an acceptable level of agreement in qualitative research, considering that most studies report an intercoder reliability level between 40% and 60% (Campbell et al., 2013). To resolve the differences, I reviewed the transcripts with the independent investigator using the negotiated agreement method until we reached an agreement on the remaining codes.

The disagreements, with regards to the coding outcomes, were mainly as a result of the problem of unitization. Unitization refers to the identification of proper blocks of text for a given code or codes. According Campbell et al. (2013), the unitization problem arises as different coders may unitize the same text differently. This is because they might not agree on the segments containing a particular meaning. This was anticipated, considering that open-ended questions usually lead to long and complex responses, unlike structured questionnaires, where short responses are usually provided. Respondents usually provided background information and talked about many issues when responding to the interview questions leading to one section of text where several codes could be identified (Campbell et al., 2016). While this led to various segments of the background being included in some codes, there were no differences with regards to the meaning units and the essence of how they had been labeled. In some cases, more than one code was found to represent more than the same meaning.

To further improve the credibility of the findings, triangulation was used to collect data from different sources. According to Shenton (2004), triangulation can be accomplished by taking into account perspectives or views from different sources. This makes it possible for different opinions and experiences to be compared and verified against each other, leading to a detailed understanding of the phenomenon of interest. As the investigator, I sought peer response from another researcher to obtain feedback on my interpretations of the data. I provided the colleague with the transcripts and asked for his views regarding the developed codes. It is with the input of the independent investigator that I managed to revise and identify appropriate codes for this study. As highlighted by Shenton (2004), there is no single best way to seek peer debriefing, and the most appropriate approach depends on the purpose of the study, the investigator, and the time as well as resources required for the research.

Transferability

Although generalizability of qualitative research findings is not an anticipated attribute, the increasing emphasis on rigor has raised the need for qualitative investigators to ensure that their findings are transferable to other settings (Leung, 2015). The aim of this research was providing baseline awareness of the issues related to continuity of care pertaining to MS patients. In keeping with the principles of naturalistic paradigms, the focus of this study was on depth, and not breath and generalizability of the findings to other MS patients was not an expected attribute.

To allow determinations of transferability, I have provided thick and detailed description of the research setting and characteristics of the participants to allow readers to make decisions regarding the extent to which the findings apply to their context. I have provided inclusive descriptions of the context of the study and identified the geographical location where the study was carried out to facilitate the transferability of the findings. The thorough descriptions of the research methods provide the reader with sufficient information to establish if the findings of this study apply to their situation (Creswell, 2007). Eventually, to evaluate the scope to which the findings presented in this study apply to other environments, additional research may have to be carried out as only through numerous studies can there be increased certainty of applicability of the findings to other contexts.

Dependability

To improve the dependability of the findings, the proposed methods were strictly followed as initially planned. I consistently followed the study protocols and the interview guides for each participant to address the research questions. There were no deviations from the protocol to carry out the research, and the protocol has been discussed extensively in the methodology chapter. The demographic characteristics of the participants have been discussed in details. I kept an audit trail of all research activities, including recruitment and data collection processes.

Confirmability

While an additional aim of this study was to determine the objectivity of the data, it was not the aim of this research to confirm the neutrality of the researcher. The detachment between the investigator and the respondents is often viewed as a sign of objectivity in the positivist paradigm was not germane to the current interpretive approach. Besides contributing to the credibility of the findings, the techniques of saturation and prolonged contact with the respondents also contributed to the confirmability of the results. Prolonged time in the field led to the enrollment of more participants and allowed the recruitment of the participants until the point of data saturation was reached. The development of a rapport with the respondents facilitated the openness and genuine nature of the responses; thus, ensuring that the data did not reflect my biases rather than the actual experiences of the respondents.

Comprehensive methodological description allows readers to establish to what extent the data and the concepts emerging are acceptable (Shenton, 2004). An essential strategy to ensuring this was keeping an audit trail to enable the reader to trace the course of the research through the described procedures and decisions reached (Creswell, 2007; Denzin & Lincoln, 2008; Krefting, 1991). I have documented all the procedures and justified the decisions made. The approach shows how the data resulting in the findings were collected and analyzed during this research.

Results

Informational continuity

Emerging themes are discussed herein as they relate to the research questions. All the participants expressed that having adequate information regarding MS was of paramount importance to them. Nevertheless, most of the participants taking part in the interviews expressed not been provided with adequate information regarding managing

MS during diagnosis. “At the time not that much: they said they would help me deal with problems as they arise” (Participant 01). In some cases, the participants had to search out information regarding MS through platforms such as the internet. “I was not told much about it. I was just told to expect some exacerbations, and I had to read much of the disease from the internet” (Participant 07).

The participants found it essential that health care providers were well informed about their condition as they did not want to keep repeating their histories. Understanding of their conditions by the healthcare providers also assured them that the practitioners had the right information to make decisions regarding their treatment. "If they all understood the condition of the patient, there would be better quality treatment" (Participant 02).

For all participants, informational continuity appeared to be a weak point in the provision of care. This was evident in circumstances under which different healthcare providers had been involved. During the interviews, it became evident that healthcare providers were poorly informed regarding the history of the patient, did not have regular contact with other healthcare providers or access to patient records. Adverse effects resulting from this according to the participants included the need to reiterate medical histories several times, duplication of tests, worries regarding the quality of care, and becoming agents of information transfer among healthcare providers.

“I don't think he is informed. He does not know much about me, and each time he has to check his records, and he has been in some case suggested that I need to have certain tests, and I was like I had this test done by my neurologist a few months ago” (Participant 07).

"My neurologist and primary care physician have duplicated tests for blood work like how much iron I have. I told them head-on that I do not want tests duplicated. The MRI only concerns the neurologist… never a duplicate" (P04).

Contrary to the above findings, some participants provided examples of how health care providers working closely together in form of networks were often well informed regarding the medical history of the participants as well as their individual characteristics. "They do communicate with each other… all professionals share information with others regarding my treatment" (Participant 05). A similar response was provided by Participant 02. "They are able to read notes from each other, especially now that I'm going to professionals under the NYU Langone umbrella, and that's very helpful."

Relational continuity

Participants had both positive and negative experiences regarding relationship with healthcare providers. Generally, participants had positive experiences regarding having close relationships with a small number of health care providers. These providers paid attention to the patient as an individual behind the illness and took time to respond to talk about the illness and personal lives of the participants. Trust was established when the participants were known by the health care providers, so that they could take their needs and preferences into consideration to tailor care.

"I would say that I feel quite safe receiving care from my family doctor. Our relationship has built over time, and I like the fact that he knows much about my condition, and I don't have to have explanations for all things happening as he understands my condition.

I don't have to say when certain things happened, such as when I was hospitalized or which medications I have been taking” (Participant 07).

Participants appreciated the presence of healthcare professionals responding adequately to their needs. Besides, continuing relationships with various health care providers allowed monitoring of the progress of the patient.

“I feel that it is important to have one or two doctors to care for all my medical needs. As my disease is now stabilized, my need for neurologist services is limited. Since my stem cell bone marrow transplant procedure, MRI’s ordered by the neurologist have shown no new lesions. However, there is permanent damage I live with” (Participant 01).

Nevertheless, lack of relational continuity was often experienced as well, and this meant that participants needed to spend a lot of energy in establishing new relationships, repeating their histories, and did not know what they could expect from health care providers.

“At the moment, I would say no, as I mostly receive care from my family physician, who is relatively new and has not known much about me. I have to explain about my past experiences, but he is a helpful doctor who tries to understand my situation” Participant 08.

Long-term relational continuity allows healthcare providers to know their medical histories that made them feel supported. In some cases, medical histories were intricate and transversed for a long period of time; most respondents were concerned about getting their facts correct and felt that care was more responsive when they did not have to repeat the same information at every consultation. Relational continuity of care was felt to protect against anxiety or risk of error to some extent.

"I would say that I feel quite safe receiving care from my family doctor. Our relationship has built over time, and I like the fact that he knows much about my condition, and I don't have to have explanations for all things happening as he understands my condition. I don't have to say when certain things happened, such as when I was hospitalized or which medications I have been taking" (Participant 07).

Besides not having adequate knowledge regarding the illness of the respondents and their health histories, the participants perceived healthcare providers not familiar with the condition of the patient as not able to identify or judge the progression or emergence of new symptoms. In addition, lack of relational continuity meant that healthcare providers were not aware of the personal situation of the patient; thus, not in a position to provide a holistic appraisal of a particular situation or set of symptoms.

"The physician was not aware of my condition and my symptoms and as they changed he said, you must have always been like this" (participant 03).

There were differences in terms of relational continuity identified for different professional groups that could have affected the perceived responsiveness of an identified professional. Long-term relational continuity of the general practitioner was often reported, including the period during which participants went through during which participants underwent diagnostic tests.

"I mostly receive care from the same family doctor, although I have changed neurologists in the past decade. My relationship with my care physician is good, and he cares about my condition. I just realized that my former consultant was not listening to my needs and was concerned about the time he had allocated for each patient" (Participant 07).

Poor relational continuity prohibited respondents from establishing a trusted relationship with individual neurologists and often they were not viewed as a part of respondent's regular healthcare team. Respondents reported feelings of confusion and frustrations when contact with a neurologist was sporadic without explanation. "It has been difficult to get my neurologist for no reason. I am considering changing my neurologist" (Participant 06).

Long-term relational continuity provided reassurance and ascertained easy navigation of services and improved access to care as the participants felt that they always knew there was a trusted and knowledgeable healthcare provider to go to in case of relapse or progression. "I do have a hematology doctor I feel a close relationship with. I can text her when I am concerned about a relapse" Participant 03.

On the other hand, a few participants talked about not having a given specialist and would see any available specialist when attending routine follow-ups. The participants claimed that this was frustrating particularly when the lack of relational continuity led to less responsive services viewed to ask non-essential repetitive questions. "At times it is not easy to see my preferred neurologist…. this was challenging for me as I had to keep repeating the same information with different practitioners" Participant 04.

The responses provided by the participants highlighted various opportunities for improving relational continuity. Participants talked the need to have few healthcare providers they would establish therapeutic relationships with. They wanted to have personal relationships with healthcare providers who cared about them would listen to them, and involve them in care provision processes.

"I would like to have more of a personal relationship with my doctor. I want to be involved in my care. Nowadays I feel that some doctors don't look at you as an individual. They don't seem to want to involve you. They're not telling you about your medication. I have to ask you. You're not telling me what it's for" Participant 03.

Participants highlighted the need for timely and up-to-date information that is easily accessible. They wanted healthcare providers to be routinely updated and aware of what was going on with their care. They felt that updates regarding the condition of the patient did not have to always come from the patient but could be obtained through sharing of information among providers. "Primary care doctors should share notes with and correspond with specialists rather than everyone doing his own thing" Participant 02.

Managerial continuity

Participants wanted to be viewed as individual patients with healthcare needs instead of medical subjects. This required the healthcare providers to view the participants with a holistic lens and offer multidisciplinary care to support the needs of the patient. "I wish the doctors would talk to each other. Doctors need to be trained in patient care, not just diseases" Participant 03. Provision of holistic care was highlighted by participant 07. "We have a good relationship, and he cares about my condition and views me as a patient as not as a number".

The significance of this became evident as the participants provided examples in which healthcare providers did not work in a multidisciplinary approach. Almost all the participants felt that care provided by their healthcare providers was not well connected as the providers were more concerned about their own specialties. “My neurologist and primary care physician both work independently. I do not think they collaborate. If I ask them to, they talk to each other. But, without me asking they do not collaborate. It’s basically by each physician but I wish there was more collaboration” Participant 04.

All participants described themselves as responsible for coordinating and managing their own care. They performed their roles by booking healthcare visits and acting as the source of information across healthcare providers and services. “I make my own appointments. I call for referrals, which has nothing to do with the doctors” Participant 03. There was poor coordination of care and the respondents had to repeat the same information during healthcare visits. I had to keep explaining the same information to different providers during my admission and had to pass the same information to my family doctor after discharge (Participant 08).

Generally, participants did not like the waiting times, particularly when neurologists were involved. It was challenging for most participants to see a neurologist although it was easy to make an appointment with a family doctor. “It depends. It is not that hard to have an appointment with the family doctor. But it is challenging to see a neurologist. There is a time it took me two months to see one although I had received limited support from the family doctor. It seemed like eternity waiting all that time and experiencing all the flare-ups” Participant 08. Nevertheless, some had positive experiences as waiting times for their primary care physicians and neurologists were short, meaning that they could receive care within a short duration. “I don’t have much problem waiting for my neurologist and primary care physician. I usually wait for my two main doctors for 15 minutes or less” Participant 04.

Poor managerial continuity has been marked with duplication of medical tests. “I remember having certain lab tests and x-rays repeated when I got admitted” participant 07. Participants also talked about feeling dismissed and ignored when their needs and knowledge regarding their experiences with MS were dismissed. They also spoke regarding the lack of communication and poor listening skills with healthcare providers. This led to the development of non-trusting relationships and they had to change their providers. Another challenge identified is that some providers were more concerned about the amount of time they spent with each patient rather than the quality of care provided.

“I mostly receive care from the same family doctor, although I have changed neurologists in the past decade. My relationship with my care physician is good, and he cares about my condition. I just realized that my former consultant was not listening to my needs and was concerned about the time he had allocated for each patient” (Participant 07).

I had to change my original doctor because she was withholding valuable information like from blood work. I had a high white cell count but she didn’t notify me. She had me follow up with an oncologist (Participant 03).

Summary

In this chapter, I described how the study was carried out and reported the findings of this study. The interviews identified characteristics of the participants regarding informational, managerial, and relational continuity of care. Chapter 5 will present an interpretation of the findings, including how the results compare with the existing body of literature and how the study contributes to the existing body of knowledge. The limitations that emerged following the execution of this study will be outlined and recommendations for future research identified. Implications for positive social change at the individual, family, and organizational levels will be identified before ending with a brief summary of the entire study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This qualitative study was carried to explore the experiences of MS patients with continuity of care following hospitalization for an exacerbation. Continuity of care is considered a crucial aspect of quality care, but ensuring that there is continuity of care as patients move between hospitals and receive care from multiple providers remains a challenge (Easley et al., 2016). Information on medical records may not be up to date or accurate; making provision of care consistent with the patient's needs an uphill task. Developing and sustaining relationships between patients and providers to ascertain that care is planned to meet the needs and information flow present substantial challenges (Gardner et al., 2014). As a result, contrary to what may be anticipated, continuity of care tends to be weak (Soundy et al., 2016). There are no previous studies exploring post-hospital continuing care experiences among MS patients, despite the significance of continuity of care in improving the quality of life of patients with chronic diseases. Consequently, there is little basis for scholars, health care practitioners, and policymakers to reach a conclusion on the continuing care experiences of MS patients. Therefore, this study seeks to fill the research gap by seeking an enhanced understanding of the experiences of continuity of care in the United States.

The purpose of this study is to address the gap in the literature to gain insights regarding the experiences of MS patients with continuity of care. Taking into account the early stage of this research, as well as the limited knowledge regarding appropriate variables, the qualitative phenomenological design was appropriate. The qualitative phenomenological design was also an appropriate design as it allows the respondents to provide detailed descriptions of their lived experiences (Van Manen, 2015). Semi-structured interviews were carried out with eight participants who were individuals living with MS to gain their insights regarding their experiences with continuity of care following hospitalization.

Informational continuity, relational continuity, and managerial continuity appeared prominent among all the interviews carried out. Participants found it crucial that health care providers were well informed about their conditions, as this prevented them from having to repeat their stories with each healthcare provider. Being informed about the condition of the patient made it easy for the patient to trust their healthcare provider as they had adequate information to make decisions regarding their treatment choices. Nevertheless, informational continuity was viewed as weak at the point of care provision by the participants. This was especially the case where multiple health care providers took part. It became a concern when they did not know anything about the medical history of the patient as the patients had to keep explaining themselves to each and every provider. Poor informational continuity was associated with adverse effects, including the need to repeat their medical histories all the time and at times received contradictory advice.

Participants had both positive and negative experiences with relational continuity. Having a team of health care providers made it easy for patients to develop therapeutic relationships with the professionals. The health care providers paid attention to the patient with the disease and made efforts to understand them besides their illness. Being known by a health care provider improved the trust of the patient that their needs and wishes could be taken into consideration during care provision. In addition, continuing relationships with particular health care providers allowed monitoring of the progress of the patient. On the other hand, the lack of strong relationships with certain health care providers was challenging for the patients as they had to spend a lot of time building rapport by repeating their medical histories to different health care providers.

Regarding managerial continuity, the participants wanted to receive holistic care while been viewed as individual patients instead of medical subjects. Some participants were concerned about health care providers working in a fragmented fashion and only dealing with issues pertaining to their area of specialization. As a result, some issues remained unaddressed or were identified when it was too late. Poor managerial continuity was also associated with duplication of medical tests. Participants also talked about taking the responsibility of coordinating and managing their own care. They had to perform their roles by booking healthcare visits and acting as the main source of information for health care professionals and their services.

Interpretation of the Findings

The present research exploring the experiences of MS patients with relational, informational, and managerial continuity of care is in its infancy. The shortage of research studies pertaining to the experiences of MS patients with care has been acknowledged by Methley et al. (2016) and Soundy et al. (2016). By addressing some of the gaps in the literature, the findings of this study will add to the existing body of evidence. In this section, I will describe the ways the findings confirm or disconfirm to the existing body of evidence regarding continuity of care.

Relational continuity

Regarding relational continuity, the participants found it quite essential to have trusted relationships with a small number of health care providers in order to receive care that is tailored to their needs. Relational continuity was often at stake when numerous health care providers were involved. This finding has been confirmed by Easley et al. (2016), who found that provision of care by different health care teams can easily jeopardize relational continuity. To maintain relational continuity of care, multidisciplinary collaboration can be practiced behind the scenes, but patients may only desire a small number of health care providers who understand their condition.

The participants shared both positive and negative experiences with relational continuity of care. Participants felt valued by health care providers who viewed them as individuals behind the illness and took time to understand their illness and personal lives. Consistent findings were reported by Soundy et al. (2016) who found that MS patients valued been viewed holistically and having health care providers who understood their condition and listened to their needs. Soundy et al. (2016) review involved 49 qualitative studies investigating the experiences of MS patients. In addition, long-term relational continuity allowed health care providers to learn about medical history and psychosocial context of patients, empowering them to identify new or progressing symptoms. A related finding of an early qualitative study is that close relationship with health care providers makes people with MS feel understood while improving the ability of the care providers to appraise the symptoms and progress of the patient holistically. A major finding of this research is that patients viewed the quality of relational continuity in terms of patient centeredness with an emphasis on being treated with dignity and being viewed as a person and not a case number.

This study yielded findings indicating that some patients had negative experiences with relational continuity. The absence of relational continuity meant that the participants had to spend a lot of energy in developing new relationships by repeating their histories and not knowing what to expect from health care providers. The above findings are in accord with those reported by Brand and Pollock (2018), with participants in this study, placing strong value on continuous personal relationship with the same health care provider. Lack of relational continuity was associated with feelings of frustration and anxiety, as some respondents explained having to repeatedly explain their condition to a series of new health care providers.

The qualitative design allowed the participants to explain their responses in detail. By not having adequate knowledge about the illness of the patient, the respondents viewed health care professionals not familiar with their condition as not able to identify new symptoms or judge the progression of the existing symptoms. The participants associated the absence of relational continuity by health care professionals as a contributing factor with the lack of holistic appraisal of the needs of the patient. Davies et al. (2015) also made similar observations as negative experiences with health care providers’ decreased person-centeredness and responsiveness of care. The findings highlight that the desire for holistic care is crucial to the experiences of people living with MS in facilitating satisfaction with care provided.

Some respondents were concerned about not having a particular specialist or health care provider thus, they would have to see any available specialist when attending routine follow-ups. The absence of relational continuity led to less responsive health care services. Similar findings were reported by a qualitative study conducted by Jackson, MacKean, Cooke, and Lahtinen (2017), which found that patients were concerned about being attended to by many hospitalists and specialists, which made it difficult for them to develop therapeutic relationship with a given health care professional.

Informational continuity

The notion that patients are not receiving adequate information regarding the management of their condition has emerged in past studies exploring the experiences of chronic disease patients with continuity of care. A qualitative phenomenological study by Suija et al. (2013) regarding the experiences of cancer patients reported that participants expressed lack of information regarding the disease and its treatment as a major concern. Participants in this study reported that having adequate information regarding their illness was of utmost importance to them. They talked about having to search for information from books as they did not receive information regarding what they needed from the health care provider.

All the participants in this study appreciated the importance of positive experiences with continuity of care. They talked about the need to have adequate time with health care providers to discuss their feelings and share information regarding their condition. They appreciated health care providers who were well informed about their condition as they did not want to keep repeating their histories. In some cases, the respondents were viewed as the only source of information as health care providers were poorly informed about their condition. Consequently, they had to keep repeating the same information to different professionals involved in their care. Consistent findings were reported by a qualitative study by Jackson, MacKean, Cooke, and Lahtinen (2017), which found that poor informational continuity made patients with complex health conditions keep repeating their history. The researchers found that substantial knowledge was lost when health care professionals failed to listen to the patient or their caregiver and value their contribution. The knowledge could include areas such as previous treatments and what had worked or not worked.

Further exploration of how MS patients experience informational continuity indicated that a few participants had positive experiences as health care providers worked closely together and were well informed about their medical condition. The participants appreciated that they did not have to assume the responsibility of information transfer between the health care teams. Additional findings from past studies indicated that provision of information made patients feel empowered as they perceived a partnership with health care providers (Soundy et al., 2016). This point of view made patients feel safe and have them the confidence to ask questions or express their feelings.

Managerial continuity

The findings of this study revealed that managerial continuity was a weak link in care provision. The responses provided by the respondents indicated that the health care providers generally lacked a collaborative attitude in which they could focus on the needs of the patient. Almost all the respondents felt that care delivered by their health care providers was not well connected as the professionals were concerned about their specialties. When asked about the responsibility of managing and coordinating health care services, all the participants talked about being entirely responsible for proper management and coordination of their health care. Consistent findings were reported by Jackson, MacKean, Cooke, and Lahtinen (2017), who found that patients viewed managing and coordinating health care services as a shared responsibility among health care professionals and patients.

Previous research has shown that poor coordination is one of the leading causes of poor quality care (Soundy et al., 2016). Poorly coordinated care can be detrimental to the patient and can lead to wastage of resources as a result of duplication of diagnostic tests and conflicting care plans (Easley et al., 2016; Freeman & Hughes, 2010). The findings of this study support past research showing that poor managerial continuity has been marked with duplication of tests and conflicting care plans during hospital visits. The interpretive design allowed the respondents to provide more detailed responses regarding their experiences with various aspects of managerial continuity. A number of qualitative studies have reported patients’ concerns with poor managerial continuity, including feeling ignored, dismissed, and having their expertise not taken into consideration in the decision-making process (Davies et al., 2015; Jackson, MacKean, Cooke, & Lahtinen, 2017). This was the case in the current study, as respondents expressed concerns about their needs being ignored, and their experience in managing MS not been taken into account.

Getting professional help before worsening of the health condition of the patient was crucial to the respondents. Nevertheless, waiting times were a major issue, as the participants did not like the waiting times, especially when neurologists were involved. Majority of the participants found the waiting times extremely frustrating and challenging, as they were concerned about the possibility of the condition worsening. Consistent findings were reported by Biringer et al. (2017) phenomenological study exploring the experiences of mental health patients with continuity of care. Most of the participants in Biringer et al. study reported that the waiting time was challenging and frustrating, and this led to worsening of their condition. However, not all the participants in the current study had negative experiences with waiting times. Waiting time for some neurologists was short, meaning that some were able to get help when needed.

Conceptual framework

The conceptual model used for the present study is the continuity of care framework put forward by Reid, Haggerty, and McKendry (2002). In summary, the model asserts that there are three types of continuity, including informational continuity, relational continuity, and management continuity. All the three concepts of continuity of care were found in the narratives of the participants. For instance, relational continuity is all about ongoing therapeutic relationship between a patient and one or more providers. MS patients who took part in this study acknowledged that having a team of providers made it easy for them to develop therapeutic relationships with their care providers.

Being known by the healthcare team improved trust as patients knew that their preferences and needs would be taken into consideration. Participants were concerned about poor relational continuity as it prohibited them from developing a trusted relationship with individual neurologists.

Informational continuity is about the use of information on previous events and situations to make care appropriate for the individual. The way providers use information is crucial in connecting health care events to present ones and in adapting care to meet the needs of the patient. Transferring documented patient information from one health care provider to another is a condition for coordination of care (Freeman & Hughes, 2010). In this study, the respondents reported their experiences with this aspect of continuity of care, and all of them expressed that having adequate information regarding MS was of utmost importance to them. However, majority of the participants in this study were concerned about not been provided with adequate information about managing MS.

Managerial continuity is about the provision of care over time in ways that complement each other while ensuring that the needed services are not duplicated, missed, or poorly timed (Freeman & Hughes, 2010). The participants also addressed this aspect of continuity as they talked about their experiences with waiting times, duplication of medical tests, and the need for a multidisciplinary approach to MS care.

Limitations of the Study

This study explored the lived experiences of MS patients with regard to managerial, informational, and relational continuity of care. The findings of this study are based on self-reported data from the participants who included people living with various forms of MS. Even though majority of the respondents shared experiences that were in accord with the descriptions provided in the existing body of evidence, the study was limited geographically to the state of New York, specifically involving MS patients living in New York City.

A small sample size was utilized (eight participants); thus, the findings cannot be generalized to all MS patients in New York. Nevertheless, this was a qualitative study; hence, the intent was not to generate findings that can be generalized to the entire MS population in New York. According to Carminati (2018), generalizability of findings in qualitative research is a controversial topic since this is a key aspect of the positivist tradition within social sciences. The positivist paradigm has made generalizability of findings a crucial element of rigor in quantitative research. Therefore, this qualitative research did not seek to generate findings that were generalizable to the entire state but was directed towards offering in-depth explorations and meanings of the phenomenon (continuity of care as experienced by MS patients) instead of obtaining findings that could be generalized.

Another limitation to the trustworthiness of the findings of this phenomenological study is selection of participants. The participants were selected using purposive sampling, a non-probability sampling technique. The use of a non-probability sampling technique can easily introduce bias in qualitative research (Carminati, 2018). To limit the selection bias, the inclusion and exclusion criteria were stated clearly. The recruitment process led to the identification of a variety of individuals living with MS in New York State. The trustworthiness of the findings of this study lay on the applicability of the findings of this study to other settings. As a result, a thick and rich descriptions of the study design and participants have been provided to allow the readers to determine the extent to which the findings apply to their context. While it may have been appropriate to view generalizability of the findings as a limitation, this should not be perceived as insufficiency in the conduct of this study.

Another potential limitation relating to the trustworthiness of the findings is bias in the interpretation of the findings. Peer debriefing was considered to address the potential bias in the interpretation of the responses provided (Creswell, 2007). The researcher spent great time and effort in the field to build a rapport with the participants. The investigator enlisted an independent researcher who assisted in the evaluation of the analysis. The independent investigator also carried out a separate analysis of the transcripts and led to identification of new accounts, leading to an enhanced understanding of the information provided.

Another limitation relating to the trustworthiness of the findings that arose while carrying out of the study is the lack of experience by the researcher. This was the first qualitative research that I have carried out; thus, it can be argued that I am a novice researcher, and my interview skills are still work in progress. It was challenging for me to listen to the interviewee carefully while processing the next proper question. This may have led to lost opportunities to probe further and gain new insights. This limitation can be addressed by carrying out further research in future regarding the experiences of MS patients with continuity of care.

Recommendations

Research regarding continuity of care for MS patients is still in its early stages (Methley et al., 2015). The body of evidence regarding experiences MS patients with continuity of care can be improved by addressing some of the limitations of the current research. Future studies should attempt to refine the conceptual framework to comprehend the intricate multidimensional concepts of continuity of care in a better way. The relationship between the three types of continuity of care and how the presence or absence of one influences the other for MS patients should be investigated. The current study could not establish how the presence or absence of one element of continuity of care affects the other. Future research studies should be designed to go beyond exploring the experiences of MS patients with continuity of care to exploring the link between the various elements of continuity of care. Without these connections, it will be challenging to comprehend whether the presence or absence of one aspect of care impacts the experiences of patients with another element.

The current research has provided knowledge regarding the experiences of MS patients with continuity of care. It has identified how patients experience relational, managerial, and informational elements of continuity of care. Future research should explore how health care providers perceive continuity and what they do to ascertain continuity of care for MS patients. It is also important to explore what dimensions of continuity of care they emphasize and their reasons. The research should involve health care providers working in different settings and should involve a huge sample to obtain findings that can be generalized.

Another recommendation for future research is that a new technique which can be in the form of a questionnaire can be developed to assess and evaluate continuity of care for MS patients. The measure should be applicable to all settings. The tool can guide quantitative research, which is needed to verify the findings of the present study regarding the experiences of MS patients with continuity of care. The tool would also be useful for practice as it can be used to survey service provision as part of routine quality assessments.

It is imperative to evaluate the experiences of continuity of care with other patient groups. The current study focused on experiences of continuity of care for individuals aged 40 years and above. Therefore, it cannot be established to what extent the findings of the current study apply to young people with MS. It would be essential to understand how younger MS patients experience care as coordinated as they receive various types of health care conditions.

An additional avenue to enhance the provision of care to MS patients is exploring the experiences and views of those in other states. The current research only focused on MS patients in New York State. Besides focusing on a particular geographical area, the study involved a small sample size, meaning that the findings cannot be generalized to the entire MS patient population in New York City. Future research involving a representative sample of MS patients is required to obtain findings that can be generalized. The research should involve MS patients from all over the US to obtain findings that are representative of MS population in the country.

The strength of this study lay on its design; qualitative phenomenology, which allowed the participants to provide a detailed explanation regarding their experiences with the various aspects of continuity of care. Importantly, the findings of this study confirmed those of previous studies that reported that continuity of care is most at risk at transition points leading to poor experiences of patients with continuity of care. Future research should address how well health care providers can work together and involve patients to improve their experiences with relational, informational, and managerial continuity of care elements. An additional recommendation is that future qualitative studies should attempt to employ a longitudinal component to better understand views of MS patients and health care providers regarding continuity of care.

Implications

Implications for social change

The findings of this study have potential impact for positive change at the individual, family, organizational, and societal levels. The potential social change at the individual level is that people with MS will learn from experiences of the participants who took part in this study, and know what to expect and prepare for care provision as their condition progresses. To give them insights regarding what to expect, I plan to share the findings of this study through MS publication and issuing presentations in MS functions. Knowing about the experiences of others will help MS patients be more prepared to play their role to improve continuity of care following hospitalization.

The potential for positive social change at the family level is immense. The findings of this study will provide a better understanding of the plight of MS patients by the families. The family members or caregivers may offer support to people living with MS so that they can have better experiences with continuity of care. I plan to improve the understanding of family members by sharing the findings of this project during annual MS events and discuss the various ways families can support their loved ones living with MS to play their role in improving continuity of care.

The implications of the findings of this study at the society level are immense. To begin with, there will be an increase in the knowledge base as research regarding the experiences of MS patients with continuity of care is scarce. The results of this study identified both the positive and negative experiences of MS patients with continuity of care. Challenges such as poor communication between providers as well as difficulties in arranging appointments as they had to be arranged quite a distance in the future and had long waiting times were identified.

The anticipated social change as a result of this study is the improved awareness regarding the experiences of MS patients with continuity of care. By gaining insights into experiences of MS patients with continuity of care, relevant health care policies can be developed and reviewed as required to ensure the provision of quality care. In addition, this study can serve as a blueprint for other studies on the views and experiences of MS patients with any element of continuity of care. I plan to share the findings of this research with organizations such as the National Multiple Sclerosis Society, an organization that can assist in advocating for the development of policies to improve continuity of care to MS patients.

I plan to seek publication of a summary of the findings of this research in a journal article to ensure that they are accessible to all key stakeholders, including health care providers. A major finding of this study was that the participants found it quite essential to receive care from a small group of providers who could comprehend their condition, thus eliminating the need to keep repeating their health information at each hospital visit. It is essential to make health care providers aware of the experiences of MS patients so that they can find ways of improving their experiences with continuity of care. The findings of this study may lead to the establishment of best practices in ensuring continuity of care for MS patients.

Methodological, theoretical, and empirical implications

The findings of this study add to the existing body of evidence regarding the experiences of MS patients with continuity of care. The description by the respondents offered a wealth of information regarding the experiences of MS patients with relational, informational, and managerial aspects of continuity of care. Information regarding the above elements of continuity of care fills some gaps in the literature regarding the experiences of MS patients with care provision. The findings of this study were explained under the conceptual model of continuity of care developed by Reid, McKendry, and Haggerty (2002).

The interpretative phenomenological approach allowed detailed exploration of the individual experiences with the phenomenon of interest- continuity of care. The qualitative phenomenological design allowed for casting a wide range of experiences regarding the three key aspects of continuity of care; hence, it can be used to explore the experiences of MS patients in other states. The boundaries of this study were confined to the individual experiences of the eight participants who took part in the interviews. Taking this into consideration, additional quantitative research may be carried out to obtain findings that can be generalized to the entire MS population.

Recommendations for Practice

There are a number of ways the experiences of MS patients with continuity of care can be enhanced. Forward planning of care is one of the techniques, where there are several doctors working in a clinic, individual clinic lists can be used to ensure that the MS patient receives care from the same physician all the time. This will decrease the frustrations experienced by MS patients who have to repeat their medical stories with each new professional. Such an approach will require making efforts to organize the patient lists, rather than waiting for the clinic clerks to randomly allocate patients or having physicians simply pick up notes of the next MS patient who arrives in the clinic. The clinics should ensure that there is adequate time for interaction with the patient during consultations to facilitate the development of therapeutic relationship. This qualitative phenomenological study showed that MS patients are likely to experience continuity of care if they receive care from a small number of health care providers who are readily available and collaborating with each other.

To promote the provision of best care to MS patients, health care providers should be informative, responsive, and able to identify and address the needs of the patient. To be responsive, they should comprehend the common information requirements of patients. They should tailor the information they are providing to the needs of the patient.

Effective listening and empathy are essential in their interactions with patients. There is also a need for training programs on continuity of care for health care providers, so that they can fully understand the skills required to ensure that patients receive care that is well coordinated and consistent with their needs. In addition, healthcare providers should be educated about the use of electronic health records to facilitate communication and retrieval of information. They should also be encouraged to have a proactive follow-up of MS patients following significant life events to improve management continuity.

Conclusion

Continuity of care is a critical aspect of care for MS patients. It has been found to improve satisfaction of patients with the quality of care and quality of life. According to the existing body of literature, there are three types of continuity of care, including relational, management, and informational continuity. All these aspects are of equal importance, but ensuring continuity of care as patients receive care from different practitioners remains a challenge. Therefore, contrary to what is usually anticipated, continuity of care for people with chronic diseases tends to be weak (Easley et al., 2016; Freeman & Hughes, 2010). The central position of care should be occupied by the patient. In this regard, this qualitative phenomenological study sought to explore the experiences of MS patients with the three aspects of care.

The findings of this qualitative phenomenological study identified both positive and negative experiences of MS patients with the three elements of continuity of care. Continuity of care appeared to be weak, as participants narrated how their needs were not fully met. Informational continuity is a cornerstone of high-quality MS care, although failure by health care providers to provide the respondents with adequate information regarding their condition colored their experiences with care as unsatisfactory. Participants found it quite essential to receive care from a small group of health care providers who could understand their condition and eliminate the need to keep repeating their medical histories when seeking care. However, some patients experienced poor relational continuity as they received care from multiple providers.

The anticipated social change as a result of this research is improved awareness regarding the experiences of MS patients with the various aspects of care. The study revealed challenges which if addressed, can lead to improvements in continuity of care. Some of these challenges include the poor provision of information, provision of care by multiple providers, and long waiting times for MS services, among other challenges. It is important to inform health care providers about the experiences of MS patients as well as the challenges experienced in identifying best practices to improving continuity of care. Future conversations regarding continuity of MS care should focus on how well providers and services can work together with patients to co-design a healthcare system built around patient-centered relationships.

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Appendix A: Databases Used

CINAHL Plus with Full Text

Cochrane Central Register of Controlled Trials

Cochrane Database of Systematic Reviews

Cochrane Methodology Register

MEDLINE

Embase

ERIC

PsycINFO

ProQuest

MS Society library

Appendix B: Google and Google Scholar Search Outcomes

Google

Two search terms: Health care system, Multiple sclerosis = About 19,900,000 results

Three search terms: health care system, multiple sclerosis, experiences = About 11,000,000 results

Four search terms: Health care system, multiple sclerosis, experiences, continuity of care = About 352,000 results

Google Scholar

Two search terms: Health care system, Multiple sclerosis = About 770,000 results

Three search terms: health care system, multiple sclerosis, experiences = About 103,000 results

Four search terms: Health care system, multiple sclerosis, experiences, continuity of care =About 17,000 results

Using Google Scholar (with limiters; since 2013)

Two search terms: Health care system, Multiple sclerosis = 29,200 articles

Three search terms: Health care system, multiple sclerosis, experiences= 16,900

Four search terms: Health care system, multiple sclerosis, experiences, continuity of care= 5,130 articles

Appendix C: Recruitment Flyer

Multiple Sclerosis (MS) Research Seeking Participants

The researcher is seeking to carry out a research study designed to explore the experiences of MS patients with continuity of care in the state of New York. The primary goal of this research is to gather information on these experiences and determine the needs of MS patients for continuity of care.

Participation in this study is expected to take around 45 minutes and the interviews will be audio-taped. To take part in this research, you should be at least 18 years, able to express yourself in English, have a history of hospitalisation following an MS exacerbation, and be a resident of New York State.

Participants will receive a $75 gift voucher for participating. If you are interested in taking part in this study, please contact the researcher at **(914) 502-xxx** or by email at **william.witt2@waldenu.edu**

Note: This research is for my Walden doctoral dissertation.

Appendix D: Core Interview Questions

Introduction

Thank the participant

Explain the purpose of interview

Ask the patient to talk a little bit about themselves (their career, where they live, who they live with etc)

Diagnosis and Care Trajectory

Since when were you diagnosed with MS?

How was the diagnosis?

What were you told about your illness?

What do you know about your disease now?

Where did you get the knowledge / information about your illness?

What would you like to know about your illness?

Have you been to a medical specialist or been hospitalized because of your illness? (What kind of specialist? Why was it necessary? Who sent?

Relationship continuity

What professionals have been involved in your treatment?

What do you think about your relationship with the professionals of the hospital who treat you?

How has your relationship with your primary doctor/nurse changed with time?

Who usually deals with you in a family doctor center? (One family doctor, several family doctors, sister, sisters?)

Do you have a doctor or a specialist who knows you and your illness most and who you always seek help? Explain in details (who are this person ….)

How do you feel about the presence or absence (based on the response to the above question) of such as key person? Why?

Continuity of information

How do the professional who take care of you communicate with each?

How is their care connected?

How informed is your doctor about your health/antecedents/treatment or tests done in other care levels?

Continuity of clinical management

How are hospital visits organized?

How do you like the time you have to wait?

Have tests been duplicated? Why?

Are there some services / kinds of help that have been difficult to get? Which ones? Why?

Do you think that the family doctor and the specialists who provide care to you collaborate with each other? Why?

Do you think your care providers share a plan to address your needs?

Concluding questions

If you could change anything about the care coordination process, what would it be?

Are there any other issues that you would like to comment on?

Appendix E: Demographic Questionnaire

Study: Experiences of MS Patients with Continuity of Care

Demographic Survey

Please choose the best option for each of the following:

1. What is your gender? ☐ Male ☐ Female

2. How do you identify your race/ethnicity?

☐ Caucasian or White

☐ African American or Black

☐ Asian/Pacific Islander/Native Hawaiian

☐ American Indian or Alaska Native

☐ Multiracial (please specify) _________________

☐ Some other group (please specify) _________________

3. What is your age _____?

4. What is your highest educational qualification?

5. When were you diagnosed with MS?

Appendix F: Informed Consent Form

Dear XXX,

You are invited to take part in a research study exploring the continuity of care provided to New York State residents diagnosed with MS through an examination of their lived experiences. Continuity of care refers to the process by which the patient and his/her physician care team are cooperatively involved in ongoing health care management toward the shared of high quality. The researcher is seeking to recruit people with a diagnosis of MS who have a history of hospitalization following an exacerbation, aged 40 or above, and currently residing in the state of New York. This form is part of the research process that is called “informed consent” and is meant at allowing you to understand the nature of the study before deciding whether or not to take part.

The researcher conducting this study is known as William Witt and is a public health doctoral student at Walden University.

Background Information

The purpose of this study is to explore the continuity of care provided to New York State residents diagnosed with MS through an examination of their lived experiences.

Procedures

If you accept to take part in this research study, you will be asked to take part in an interview session with the researcher. The interview will take about 45 minutes to complete and will be audio-taped.

The interview will take place at a convenient location for you and can be carried out by phone, Skype, or face to face meetings depending on your preference. The data collected will be transcribed later, and you will be requested to review it for accuracy purposes. It may take about an hour to read the transcripts sent back to you. You are free to contact the researcher to provide further information that may not have been provided during the interviews.

Voluntary Nature of the study

Participation in this study is absolutely on a voluntary basis, meaning the researcher will respect your decision of whether or not to be part of this research. If you decide to take part, you can still withdraw at any time without disclosing any explanations. If you feel fatigued during the study, you may request the interviewer to stop the interview and give you time to relax. You are free to skip those questions that you might find intrusive.

Risks and Benefits of Taking Part

There is minimal risk or danger that the respondents could be exposed to as a result of their participation in this research. A possible risk is that some of the questions may not be within your comfort level. You are free not to answer those questions that may make you uncomfortable. If discomfort or fatigue arises, you may request the interviewer to postpone the interview to a more convenient time.

You will not be identified by name through the information collected, and you will be assigned a unique number so that no demographic details could be used by third parties to identify you. No reference to any identifying personal or professional detail will be made in the study. Taking part in this study will not put your safety or wellbeing in danger.

The benefits of taking part in this research are that experiences of people with a diagnosis of MS will be added to the extant body of literature regarding continuity of care for chronic diseases. This will increase awareness about and possibly improve the lives of people with MS.

Compensation

Participants will receive gifts worth $75 as an appreciation for their time and effort devoted to the study.

Confidentiality

To uphold confidentiality, the participants will be assigned unique study numbers, and any identifying information will not be included the dissertation. The data will be stored in a password protected device kept in a private office and will not be used for any purpose outside this research study.

Contact and Questions

If you need further details about the research, you may contact the researcher via phone at (phone number) or email at william.witt2@waldenu.edu.

If you want to have a private talk about your rights as a participant, you can contact Walden University representative at +1-800-925-3368 ext. 312-1210 or irb@mail.waldenu.edu.

You will be provided with a printed copy and you are encouraged to keep it.

Statement of Consent

I……………………………………… have read and understood the information related to the study well enough to decide on participation.

By signing below, I agree to the terms described above.

Date of Consent

…………………………….

Participant Signature

…………………………….

Researcher Signature

Appendix G: Invitation Letter

Greetings (Name)

I am William Witt and I am reaching out to you today because I am working on my doctoral dissertation for doctorate in Public Health. I am carrying out this research to contribute to the body of literature on the experiences of Multiple Sclerosis patients with continuity of care as there is limited research pertaining to the various concepts of continuity of care.

I am planning to conduct face to face interviews with individuals living with Multiple Sclerosis, aged 40 and above, and with a history of hospitalization following an exacerbation. I was hoping that you would find this research interesting and find time to take part in the interviews. Participation in this study is expected to take around 45 minutes and the interviews will be audio-taped. An additional follow-up interview may be required for clarification of various issues if need be.

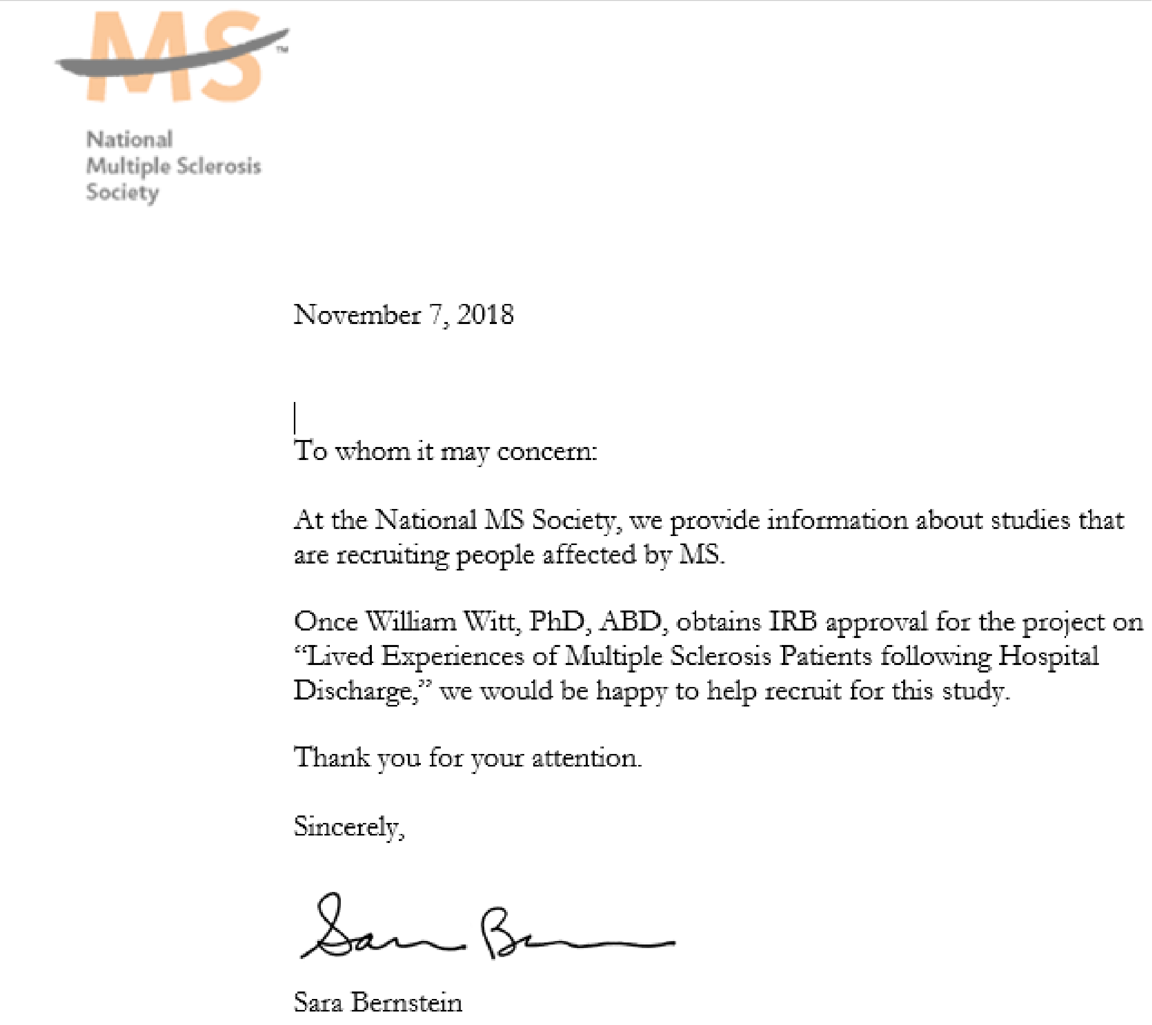
Thank you for your time and positive consideration,

Looking forward to hearing from you soon,

William Witt, MPH, Doctoral Candidate

Walden University

Appendix H: Institutional Approval



National
Multiple Sclerosis
Society

November 7, 2018

To whom it may concern:

At the National MS Society, we provide information about studies that are recruiting people affected by MS.

Once William Witt, PhD, ABD, obtains IRB approval for the project on “Lived Experiences of Multiple Sclerosis Patients following Hospital Discharge,” we would be happy to help recruit for this study.

Thank you for your attention.

Sincerely,

Sara Bernstein

Study Protocol

Schedule of Procedures

Recruitment/ invitation of participants

Inclusion and exclusion: Confirming eligibility

Consent forms

Interviews:

Introduction

Begin recording

Demographic details

Interview questions

Final comments

Thank the participant

Stop recording

Follow-up call (if need be)

Reminder script

Hello

This is a friendly reminder for you to take part in research seeking to explore lived experiences of MS patients following hospital discharge.

Participation consists of one interview lasting approximately forty minutes. A short follow-up interview may be required to clarify any questions.

For further information, please contact

William Witt (Principal investigator) at

Phone number xxxx

Thank you

CONFIDENTIALITY AGREEMENT

Name of Signer:

During the course of my activity in collecting data for this research: “Experiences of Multiple Sclerosis Patients with Continuity of Care: A Phenomenological Study” I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant’s name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I’m officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**

Qualitative Dissertation Checklist

- **The following provides guidance for reporting on qualitative studies.**
- **All items may not be relevant to your particular study; please consult with your chair for guidance.**
- **The checklist items may not necessarily be in the order that works best for your dissertation. Please consult with your committee; however, the checklist should work well in the absence of other considerations.**
- **Instructions for Students:**
  - **Indicate on the checklist the page number (use the actual document page number, not the MS Word pagination) where the appropriate indicator is located.**
  - **Respond to comments from the chair and/or URR comments in the comment history box. Do not delete previous comments—just add your response and use some means to clearly identify your remarks (different font/bold/italics/color).**
- **Instructions for the chair and/or URR**
  - **Provide specific feedback in the comment history column. Do not delete previous comments—just add your response and use some means to clearly identify your remarks (different font/bold/italics/color).**
  - **If you made detailed comments on the draft (using track changes and comments), you can make reference to the draft rather than restate everything in the checklist comment history section.**

Date: (click here and type today's date →) **4/4/20**

Student's Name: WILLIAM M. WITT
Student ID (for office use only) **– A00133498**
School: (click here and pull down to select school name →) **Walden University**

Committee Members' Names:
Chairperson Dr. Harold R. Griffin
Member Dr. Kimberly Dixon-Lawson
University Research Reviewer Dr. Nazarene Tubman

Front Matter	
Checklist Items	**Comment History**
Experiences of Multiple Sclerosis Patients with Continuity of Care A Phenomenological Study	
Most important conceptual issue investigated.	
Qualitative tradition applied.	
Participant group to which the study applies.	
Abstract	
Describe the research problem and why it is important.	
Identify the purpose of the study.	
State the theoretical foundations and/or conceptual frameworks, as appropriate.	
Summarize the key research question(s).	
Describe, concisely, the overall research design, methods, and data analysis procedures.	
Identify key results, conclusions, and recommendations that capture the heart of the research (for the final study only).	
Conclude with a statement on the implications for positive social change.	

Chapter 1		
Checklist Items	**Pg/NA**	**Comment History**
Introduction		
Describe the topic of the study, why the study needs to be conducted, and the potential social implications of the study.	1	

Preview major sections of the chapter.	2	

Background		
Briefly summarize research literature related to the scope of the study topic.	3-6	
Describe a gap in knowledge in the discipline that the study will address.	6	
End the section on why the study is needed.	6	
Problem Statement		
State the research problem.	7	
Provide evidence of consensus that the problem is current, relevant, and significant to the discipline.	7	
Frame the problem in a way that builds upon or counters previous research findings focusing primarily on research conducted in the last 5 years.	8	
Address a meaningful gap in the current research literature.	8	
Purpose of the study Provide a concise statement that serves as the connection between the problem being addressed and t		
The research paradigm.	9	
The intent of the study (such as describe, compare, explore, develop, etc).	9	
The concept/phenomenon of interest.	9	
Research question(s)		
State the research questions.	10	
Theoretical and / or Conceptual Framework for the Study (Studies must include either a theoretical foundation or a conceptual framework section (stu		
Theoretical Foundation		

Identify the theory or theories and provide the origin or source.		
State concisely the major theoretical propositions and/or major hypotheses with a reference to more detailed explanation in chapter 2.		
Explain how the theory relates to the study approach and research questions.		

Conceptual Framework This applies to qualitative and some epidemiological studies (as well as some other quantitative studies)		
Identify and define the concept/phenomenon that grounds the study.	10	
Describe concisely the conceptual framework (for qualitative studies, the contextual *lens*; for quantitative studies, description of the body of research that supports the need for the study) as derived from the literature with more detailed analysis in chapter 2.	10-14	
State the logical connections among key elements of the framework with a reference to a more thorough explanation in chapter 2.	11-13	
State how the framework relates to the study approach and key research questions as well as instrument development and data analysis where appropriate.	13-14	
	Nature of the study	
Provide a concise rationale for selection of the design/tradition.	14	

Briefly describe the key concept and / or phenomenon being investigated.	15	
Briefly summarize the methodology (from whom and how data are collected and how data will be analyzed).	15-16	

Definitions		
Provide concise definitions of key concepts or constructs.	16	
Define terms used in the study that have multiple meanings (e.g., socioeconomic status, educator, health service professional, etc.). Do not include common terms or terms that can easily be looked up in a dictionary	16	
Include citations that identify support in the professional literature for the definition or operational definition.	16	
Assumptions		
Clarify aspects of the study that are believed but cannot be demonstrated to be true. Include only those assumptions that are critical to the meaningfulness of the study	17	
Describe the reasons why the assumption(s) was/were necessary in the context of the study.	17	
Scope and Delimitations		
Describe specific aspects of the research problem that are addressed in the study and why the specific focus was chosen.	18	
Define the boundaries of the study by identifying populations included and excluded and	19-20	

theories/conceptual frameworks most related to the area of study that were not investigated.		
Address potential transferability.	19	

Limitations		
Describe limitations of the study related to design and / or methodological weaknesses (including issues related to limitations of transferability and dependability).	20	
Describe any biases that could influence study outcomes and how they are addressed.	21	
Describe reasonable measures to address limitations .	20-22	
Significance		
Identify potential contributions of the study that advance knowledge in the discipline. This is an elaboration of what the problem addresses.	22	
Identify potential contributions of the study that advance practice and/or policy (as applicable).	22	
Describe potential implications for positive social change that are consistent with and bounded by the scope of the study.	23	
Summary		
Summarize main points of the chapter.	23-24	
Provide transition to chapter 2.	24	

CHAPTER 2		
Checklist Items	**Pg /NA**	**Comment History**
Introduction		
Restate the problem and the purpose.	25	
Provide a concise synopsis of the current literature that establishes the relevance of the problem.	25	
Preview major sections of the chapter.	26	

Literature Search Strategy		
List accessed library databases and search engines used.	26	
List key search terms and combinations of search terms (with more detailed search terms located in an appendix if appropriate).	27	
Describe the iterative search process by explaining what terms were used in what database to identify germane scholarship.	27-28	
In cases where there is little current research, and few(if any) dissertations and/or conference proceedings, describe how this was handled.	27-29	
Theoretical Foundation (as appropriate)		
Name the theory or theories.		
Provide origin or source of the theory.		
Describe major theoretical propositions and/or major hypotheses, including delineation of any assumptions appropriate to the application of the theory.		
Provide a literature and research based analysis of how the theory has been applied		

previously in ways similar to the current study.		
Provide the rationale for the choice of this theory.		
Describe how and why the selected theory relates to the present study and how the research questions relate to, challenge, or build upon existing theory.		

Conceptual Framework (As appropriate)		
Identify and define the concept/phenomenon.	30	
Synthesize primary writings by key theorists, philosophers, and / or seminal researchers related to the concept or phenomenon.	30-39	
Provide key statements and definitions inherent in the framework.	31-35	
Describe how the concept or phenomenon has been applied and articulated in previous research and how the current study benefits from this framework.	37-40	
Literature Review Related to Key Variables and/or Concepts **Provide an exhaustive review of the current literature that includes the followi**		
Describe studies related to the constructs of interest and chosen methodology and methods that are consistent with the scope of the study.	42-66	
Describe ways researchers in the discipline have approached the problem and the strengths and weakness inherent in their approaches.	52-65	
Justify from the literature the rationale for selection of the variables or concepts.	66	

Review and synthesize studies related to the key concepts and/or phenomena under investigation to produce a description of what is known about them, what is controversial, and what remains to be studied.	52-82	
Review and synthesize studies related to the research questions and why the approach selected is meaningful.	52-66	

Summary and Conclusions		
Concisely summarize major themes in the literature.	82-83	
Summarize what is known as well as what is not known in the discipline related to the topic of study.	82	
Describe how the present study fills at least one of the gaps in the literature and will extend knowledge in the discipline.	82	
Provide transitional material to connect the gap in the literature to the methods described in chapter 3.	83	

CHAPTER 3		
Checklist Items	**Pg /NA**	**Comment History**
Introduction		
Restate study purpose as described in chapter 1.	84	
Preview major sections of the chapter.	84	
Research Design and Rationale		
Restate research questions exactly as described in chapter 1.	84	
State and define central concept(s) / phenomenon (a) of the study.	85	
Identify the research tradition.	85-89	
Provide rationale for the chosen tradition.	85-89	

Role of the Researcher		
Define and explain your role as observer, participant, or observer-participant.	89-90	
Reveal any personal and professional relationships researcher may have with participants, with emphasis on supervisory or instructor relationships involving power over the participants.	89	
State how any researcher biases and / or power relationships are or will be managed.	89	
Other ethical issues as applicable (these could include doing a study within one’s own work environment, conflict of interest or power differentials, and justification for use of incentives) and the plan for addressing these issues.	89	
Methodology (needs to be described in sufficient depth so that other researchers can replicat		

Participant Selection Logic		
Identify the population (if appropriate).	90	
Identify and justify the sampling strategy.	90-91	
State the criterion/a on which participant selection is based.	91-92	
Establish how participants are known to meet the criterion/a.	92	
State number of participants / cases and the rationale for that number.	91-92	
Explain specific procedures for how participants will be identified, contacted, and recruited.	93	
Describe the relationship between saturation and sample size.	91	

Instrumentation		
Identify each data collection instrument and source (observation sheet, interview protocol, focus group protocol, video-tape, audio-tape, artifacts, archived data, and other kinds of data collection instruments).	93-96	
Identify source for each data collection instrument (published or researcher produced).	93-95	
If historical or legal documents are used as a source of data, demonstrate the reputability of the sources and justify why they represent the best source of data.		
Establish sufficiency of data collection instruments to answer research questions.	94-96	
For published data collection instruments		

Who developed the instrument and what is the date of publication?		
Where and with which participant group has it been used previously?		
How appropriate is it for current study (that is, context and cultural specificity of protocols/instrumentation) and whether modifications will be or were needed?		
Describe how content validity will be or was established.		
Address any context- and culture-specific issues specific to the population while developing the instrument.		

For researcher-developed instruments		
Basis for instrument development (Literature sources, other bases (such as pilot study).	94	
Describe how content validity will be / was established.	95	
Establish sufficiency of data collection instruments to answer the research questions.	95	
Procedures For Pilot Studies (as appropriate		
Include all procedures for recruitment, participation, and data collection associated with the pilot study and the main study.		
Describe the relationship of the pilot study to the main study (e.g., what is the purpose of the pilot study?)		
Include the IRB approval number (completed dissertation).		

Procedures For Recruitment, Participation, and Data Collection (for students collecting their own data)		
For each data collection instrument and research question, provide details of data collection.	96-99	
• From where data will be collected? • Who will collect the data? • Frequency of data collection events. • Duration of data collection events. • How data will be recorded? • Follow-up plan if recruitment results in too few participants.	96-99	
Explain how participants exit the study (for example, debriefing procedures).	98	
Describe any follow-up procedures (such as requirements to return for follow-up interviews).	99	

Data Analysis Plan		
For each type of data collected identify:	99-101	
▪ Connection of data to a specific research question. ▪ Type of and procedure for coding. ▪ Any software used for analysis. ▪ Manner of treatment of discrepant cases.	99 99-101 102	
		Issues of Trustworthiness

Credibility (internal validity): Describe appropriate strategies to establish credibility, such as triangulation, prolonged contact, member checks, saturation, reflexivity, and peer review.	101-106	
Transferability (external validity): Describe appropriate strategies to establish transferability, such as thick description and variation in participant selection.	106-108	
Dependability (the qualitative counterpart to reliability): Describe appropriate strategies to establish dependability, such as audit trails and triangulation.	108-109	
Confirmability (the qualitative counterpart to objectivity): Describe appropriate strategies to establish confirmability, such as reflexivity.	109-111	
Intra- and intercoder reliability (where applicable).	104	

Ethical Procedures		
Agreements to gain access to participants or data (include actual documents in the IRB application).	111	
Describe the treatment of human participants including the following (include actual documents in the Institutional Review Board (IRB) application):	111	
• Institutional permissions, including IRB approvals that are needed (proposal) or were obtained (for the completed dissertation,	111	

include relevant IRB approval numbers).		
• Ethical concerns related to recruitment materials and processes and a plan to address them.	112	
• Ethical concerns related to data collection/intervention activities (these could include participants refusing participation or early withdrawal from the study and response to any predicable adverse events) and a plan to address them.	112	
Describe treatment of data (including archival data), including issues of:		
• Whether data are anonymous or confidential and any concerns related to each.	112	
• Protections for confidential data (data storage procedures, data dissemination, who will have access to the data, and when data will be destroyed).	111-112	
Other ethical issues as applicable (these issues could include doing a study within one's own work environment; conflict of interest or power differentials; and justification for use of incentives).	112	
Summary		
Summary of main points of the chapter.	112-113	
Transition to chapter 4.	113	

Chapter 4		
Checklist Items	**Pg /NA**	**Comment History**
Introduction		
Review briefly the purpose and research questions.	114	
Preview chapter organization.	114	
Pilot Study (If Applicable)		
Describe the conduct of the pilot study.		
Report any impact of the pilot study on the main study (for example, changes in instrumentation and /or data analysis strategies).		
Setting		
Describe any personal or organizational conditions that influenced participants or their experience at time of study that may influence interpretation of the study results (for example, changes in personnel, budget cuts, and other trauma).	115-116	
Demographics		
Present participant demographics and characteristics relevant to the study.	116-117	

Data Collection		
State number of participants from whom each type of data were collected.	117	
Describe location, frequency, and duration of data collection for each data collection instrument.	118-120	
Describe how the data were recorded.	118	
Present any variations in data collection from the plan presented in chapter 3.	119	

Present any unusual circumstances encountered in data collection.	119-120	
Data Analysis		
Report process used to move inductively from coded units to larger representations including categories and themes.	120	
Describe the specific codes, categories, and themes that emerged from the data using quotations as needed to emphasize their importance.	120	
Describe qualities of discrepant cases and how they were factored into the analysis.	120	
Evidence of Trustworthiness		
Credibility: Describe implementation of and / or adjustments to credibility strategies stated in chapter 3	120	
Transferability: Describe implementation of and / or adjustments to transferability strategies stated in chapter 3	123	
Dependability: Describe implementation of and / or adjustment to consistency strategies stated in chapter 3	124	
Confirmability: Describe implementation of and / or adjustment to consistency strategies stated in chapter 3.	124	

Results		
Address each research question (chapter may be organized by research question or patterns or themes).	125-134	
Present data to support each finding (quotes from transcripts, documents, etc.).	125-131	

Discuss discrepant cases/ nonconfirming data as applicable.	125-131	
Include tables and figures to illustrate results, as appropriate, and per the current edition of the Publication Manual of the American Psychological Association.		
Summary		
Summarize answers to research questions.	134	
Provide transition to chapter 5.		

CHAPTER 5		
Checklist Items	**Pg /NA**	**Comment History**
Introduction		
Concisely reiterate the purpose and nature of the study and why it was conducted.	135	
Concisely summarize key findings.	135-137	
Interpretation of the Findings		
Describe in what ways findings confirm, disconfirm, or extend knowledge in the discipline by comparing them with what has been found in the peer-reviewed literature described in chapter 2.	137-141	
Analyze and interpret the findings in the context of the theoretical and/or conceptual framework, as appropriate. • Ensure interpretations do not exceed the data, findings, and scope.	143-144	

Limitations of the Study		
Describe the limitations to trustworthiness that arose from execution of the study. These should be used to revise what	144-147	

was written in chapter 1 for the proposal.		
Recommendations		
Describe recommendations for further research that are grounded in the strengths and limitations of the current study as well as the literature reviewed in chapter 2. • Ensure recommendations do not exceed study boundaries.	147-149	
Implications		
Positive Social Change		
• Describe the potential impact for positive social change at the appropriate level (individual, family, organizational, and societal/policy).	149-151	
• Ensure implications for social change do not exceed the study boundaries.		
Describe methodological, theoretical, and/or empirical implications, as appropriate.	151-152	
Describe recommendations for practice, as appropriate.	152-153	
Conclusion		
Provide a strong “take home” message that captures the key essence of the study.	153	

APA Form and Style Check		
Checklist Items	**Comment History**	
Citations and Referencing		
All citations have been crosschecked to ensure that there are corresponding references (and that there are no references that do not have associated citations).		
All sources are cited correctly per APA formatting requirements (for example, studies listed in alphabetical order by first author; no first names of authors).		
Grammar, Spelling, and Syntax		
The paper has been thoroughly checked for grammar, spelling, and syntax errors.		
For the final dissertation, the dissertation has been checked for correct verb tense representing a completed study.		
Headings		
Headings are used, consistent with the Walden Dissertation Template, to make sections of thought distinct.		
Use of the Writing Center Template		
The Writing Center Dissertation Template (APA, 6th edition) was used to construct the proposal and/or dissertation so that all formatting is correct.		