

## ABSTRACT

### THE LIVED EXPERIENCE OF YOUNG ADULTS WITH CHRONIC ILLNESS

By Sonya Gilson

Young adulthood is traditionally a time of self-discovery, career establishment, and developing relationships and family. It is this time in life that some specific chronic and debilitating illnesses are diagnosed. Autoimmune disorders such as multiple sclerosis (MS), rheumatoid arthritis (RA), psoriatic arthritis (PsA), and systemic lupus erythematosus (SLE) are most commonly diagnosed between the ages of 20 and 40. Though treatments are advancing, there is no cure for these diseases. A discussion of treatment of these illnesses as well as the future of those affected by them is imperative. People are generally fearful of the unknown and the ability to converse openly with healthcare providers about illness can be empowering and comforting for young adults with unknown futures.

The purpose of this study was to describe the lived experience of young adults who have been diagnosed with a chronic illness. The research question was: What is the lived experience of young adults with chronic illness? Parse's Theory of Human Becoming was used as a theoretical framework for the study, as it provided a foundation for investigating the lived experience.

A qualitative, descriptive, phenomenological approach was used to study the lived experience of young adults with chronic illness. The five participants for the sample were selected using a convenience and snowball sampling method. The population for the study was young adults (between the ages of 20 and 40) with a chronic illness, living in a Midwestern state. After process consent was obtained and demographic data were collected, a tape-recorded interview took place. The tape-recorded interview was transcribed verbatim and analyzed using Spiegelberg's method of analysis. The goal of analysis was to find common categories and themes in young adults with chronic illness.

Analysis of the data led to the identification of the overwhelming hope and optimism experienced by young adults with a chronic illness. Three themes were identified to describe this experience: (a) what happened? (past); (b) what now? (present); and (c) what next? (future). Additionally, nine subthemes were identified. After initial feelings of denial and disbelief at the thought of chronic illness diagnosis prior to age 40, acceptance and perseverance caused the participants to press on and reach for goals that may have been set prior to the disease onset. Some participants made accommodations or adjustments regarding activities and lifestyle. The optimism caused acceptance of the need for lifelong medication use. Participants also accepted responsibility for their health and future.

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by

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I would like to thank my husband, Mike. Thank you for your support and strength.

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## TABLE OF CONTENTS

|   | Page |
|---|------|
| LIST OF FIGURES.....  | vi   |
| CHAPTER I – INTRODUCTION.....                                 | 1    |
| Significance to Primary Health Care Nursing .....             | 3    |
| Statement of the Problem .....                                | 4    |
| Purpose of the Study .....                                    | 5    |
| Research Question .....                                       | 5    |
| Definitions of Terms.....                                     | 5    |
| Conceptual Definitions .....                                  | 5    |
| Operational Definitions.....                                  | 6    |
| Assumptions.....  | 6    |
| Summary .....   | 7    |
| CHAPTER II – THEORETICAL FRAMEWORK AND LITERATURE REVIEW..... | 8    |
| Introduction.....   | 8    |
| Theoretical Framework .....                                   | 8    |
| Concepts of the Theory of Human Becoming .....                | 9    |
| Meaning and Principle One.....                                | 9    |
| Rhythmicity and Principle Two .....                           | 10   |
| Transcendence and Principle Three .....                       | 12   |
| Case Study.....   | 13   |
| Review of the Literature .....                                | 15   |
| Quality of Life .....   | 15   |
| Satisfaction With Health .....                                | 17   |
| Social Experience.....  | 17   |
| Coping.....   | 18   |
| Adaptation .....  | 20   |
| Summary .....   | 21   |
| CHAPTER III – METHODOLOGY .....                               | 22   |
| Introduction.....   | 22   |
| Research Design and Sample .....                              | 22   |
| Population .....  | 22   |
| Data Collection Instruments.....                              | 23   |
| Data Collection Procedures .....                              | 24   |
| Data Analysis Procedures.....                                 | 24   |
| Limitations .....   | 25   |
| Summary .....   | 25   |

## TABLE OF CONTENTS (Continued)

|   | Page |
|---|------|
| CHAPTER IV – RESULTS OF THE STUDY .....                   | 27   |
| Introduction.....   | 27   |
| Demographic Data.....                                     | 27   |
| The Interview Process .....                               | 28   |
| Results .....   | 28   |
| Themes .....  | 30   |
| What Happened? (Past) .....                               | 30   |
| Denial/Disbelief.....                                     | 30   |
| Am I Going Crazy? .....                                   | 32   |
| Mourning.....   | 33   |
| What Now? (Present) .....                                 | 34   |
| Acceptance/Perseverance .....                             | 34   |
| Accommodations/Adjustments.....                           | 35   |
| Frustration .....   | 38   |
| Support.....  | 40   |
| What Next? (Future).....                                  | 42   |
| Hope/Optimism.....  | 42   |
| Lifelong Medication Use.....                              | 43   |
| Discussion of Results .....                               | 44   |
| Summary .....   | 50   |
| CHAPTER V – SUMMARY, CONCLUSIONS AND RECOMMENDATIONS..... | 51   |
| Introduction.....   | 51   |
| Summary .....   | 51   |
| Conclusions.....  | 56   |
| Implications.....   | 57   |
| Nursing Practice .....                                    | 57   |
| Nursing Education .....                                   | 58   |
| Nursing Research.....                                     | 58   |
| Chapter Summary.....                                      | 59   |
| APPENDIXES  |      |
| Appendix A: Demographic Questionnaire .....               | 60   |
| Appendix B: UW Oshkosh IRB Approval Letter.....           | 62   |
| Appendix C: Informed Consent.....                         | 64   |
| BIBLIOGRAPHY .....  | 66   |

## LIST OF FIGURES

|                                      | Page |
|--------------------------------------|------|
| Figure 1. Themes and Subthemes ..... | 29   |

## CHAPTER I

### INTRODUCTION

The purpose of this study was to investigate and describe the lived experience of young adults who have been diagnosed with a chronic illness. Young adulthood is traditionally a time of self-discovery, career establishment, and developing relationships and family. Young adults often have a sense that they are invincible. It is this time in life, that some specific chronic and debilitating illnesses are diagnosed. Although chronic illnesses are generally thought to be challenges in the later years of life, many young adults are forced to struggle with diagnoses that will affect them for a lifetime. Autoimmune disorders such as multiple sclerosis (MS), rheumatoid arthritis (RA), psoriatic arthritis (PsA), and systemic lupus erythematosus (SLE) are most commonly diagnosed between the ages 20 to 40. Though treatments are advancing, there is no cure for any of these diseases. With improved technology, the quality of life and length of life in those with chronic illnesses may also improve.

Many ailing young adults do not appear ill. They do not have obvious deformities and are able to go about their daily routines with minimal difficulty. They may have a medicine cabinet full of medications meant to keep their disease from worsening, or to minimize the discomfort. This outward appearance of health can be frustrating if chronic pain or fatigue is present. Young adults may hesitate to use services meant for chronically ill people because they appear healthy to others. Those who are affected with these illnesses commonly experience pain or a variation of sensation, something most young adults do not have to endure. Another problem these young adults encounter is looking into the future. They know that the decline of their health condition



is imminent, and likely will decline at a much faster pace than their healthy counterparts. Advancing treatments are effective, but are known to have serious side effects that are also bothersome.

There is a relationship between increasing age and increasing work disability. Persons affected with a chronic illness are likely to have some inability to perform their regular jobs earlier in life than those who are healthy as young adults. The most common reasons for work disability in the U.S. are chronic health conditions. Arthritis is the third most common diagnosis causing activity limitations. Multiple sclerosis is second on a list entitled, *Top 10 Most Frequently Limiting Conditions* (Stoddard, Jans, Ripple, & Kraus, 1998, p. 2).

Chronic illness frequently causes physical impairment, but can also cause social, mental, and financial impairment (Jolly, 2005). Impairment ranges from mild to severe and is experienced and perceived differently by each individual. Charmaz (1995) defines adaptation to chronic illness and impairment as "altering life and self to accommodate to physical losses and to reunify body and self accordingly"

(p. 657). She goes on to describe three distinct stages in adapting to impairment.

1. Experiencing an altered body...Bodily appearance affects social identifications and self-definitions.
2. Assessing one's altered body; appearance to self and others, and the context of life results in changing one's future identity accordingly.
3. Surrendering to the sick body means the end of the quest for control over illness (p. 659).

Unfortunately, not every ill young adult adapts; some remain in a state of denial for years until symptoms inevitably worsen and can no longer be ignored.

Many researchers have measured quality of life in various chronic illnesses and have made comparisons concerning the conditions. Jolly (2005) compares quality of life in patients with SLE to those with other chronic illnesses such as hypertension, congestive heart failure, adult onset diabetes mellitus, myocardial infarction, and depression. Typically, all of the aforementioned illnesses occur in older adulthood with the exception of depression. Research indicated consistently lower ratings of quality of life in patients with SLE at younger ages than those with the other common chronic diseases (Jolly).

A neglected area of research is with young adults suffering from chronic illnesses. By the age of 40, some of these adults are severely affected by their chronic conditions. More information is needed regarding this population. Qualitative, descriptive research used in this study allows a rich depiction of the lived experience of these young adults with chronic illness.

#### Significance to Primary Health Care Nursing

As chronic illnesses are treated more aggressively and successfully, young and aging adults will be able to live full lives just as their healthy counterparts. Advanced practice nurses (APNs) will see young adults with chronic illnesses in specialty settings, primary care settings, as well as urgent care settings. In order to provide the best care for these clients, it is necessary for these nurse practitioners (NPs) to be educated regarding the various experiences of these young adults and their families. It is the

health care provider's duty to keep lines of communication open in order to facilitate the medical and nursing needs of these patients.

Advanced practice nurses can assist clients with chronic health problems by talking with them and educating them about any resources available in the community, including any new and advancing treatments. Another way APNs can provide optimal care is to ask questions about symptoms and provide any treatment or referrals needed for optimal care. Patients trust that health care providers will care for them in a compassionate and effective manner. As there is still no cure for these chronic illnesses that affect patients in the prime of their lives, it is best that health care providers approach each patient with an open mind in order to individualize and optimize care.

A discussion of the treatment of chronic illnesses as well as the future of those affected by them is imperative. People are generally afraid of the unknown; therefore the ability to talk openly to health care providers about their illness can be empowering and comforting for young adults with unknown futures. Although not approached in this study, these discussions can benefit patients with illnesses such as diabetes as well. Diabetes (type 2) is being diagnosed in progressively younger patients, which means that complications of poor control will be seen earlier in the next decades. Health care providers must be able to prescribe proper treatment as well as explain why compliance is so important. Proper compliance may allow patients to enjoy longer lives with fewer complications.

### Statement of the Problem

The lived experience of young adults with chronic illness is largely unexplored. Various studies have been completed relating to quality of life, satisfaction with health,

social experience, coping, and adaptation of adults with chronic illness. Often young adults have attitudes of invincibility and are surprised by a diagnosis that will be present for a lifetime. Advanced practice nurses need to understand the individual nature of chronic illness, and also that emotional as well as physical support is needed, even if it is not being requested by patients. An enhanced understanding of the lived experience of young adults with chronic illness will give health care professionals an opportunity to provide more holistic, comprehensive care to these patients.

### Purpose of the Study

The purpose of this study was to investigate and describe the lived experience of young adults who have been diagnosed with a chronic illness.

### Research Question

What is the lived experience of young adults with chronic illness?

### Definitions of Terms

#### *Conceptual Definitions*

*Lived experience*: "The sum total of the things that have happened to an individual and of his or her past thoughts and feelings" (*Encarta® World English Dictionary*).

*Young adult*: A person who has reached legal adulthood, at least 18 years old.

*Chronic illness*: A medical condition that is of long duration and causes changes in the body.

### *Operational Definitions*

*Lived experience*: "The sum total of the things that have happened to an individual and of his or her past thoughts and feelings" (*Encarta® World English Dictionary*) as stated by participants in this study. For this study, the subjective articulations of the experience of young adults who have been diagnosed with chronic illness as recounted in the participant's own terminology.

*Young adult*: Any male or female between the ages of 20 and 40 at the time of diagnosis with chronic illness.

*Chronic illness*: "A state of bad health" (*Encarta® World English Dictionary*) that lasts for an extended period of time. In this study, the examples include MS, RA, PsA, and SLE.

### *Assumptions*

1. Participants would answer questions honestly.
2. The lived experience of young adults with chronic illness is different from the lived experience of healthy young adults.
3. The lived experience of young adults with chronic illness is different from the lived experience of older adults with chronic illness.
4. Health is ever changing and is perceived differently by each individual.
5. Participating young adults could read, understand, and speak English.
6. Humans freely choose significance in situations; by choosing such implications for these things, humans give up the alternative significance and must bear the accountability of such choices.

## Summary

In this chapter an introduction to the problem under investigation, its significance to nursing, and the purpose of the study were presented. The research question to be explored was: What is the lived experience of young adults with chronic illness? Conceptual and operational definitions to key terms were also included as well as assumptions of the study. Chapter II includes the theoretical framework for the study as well as a review of the literature related to the research question.

## CHAPTER II

### THEORETICAL FRAMEWORK AND LITERATURE REVIEW

#### Introduction

The purpose of this study was to investigate and describe the lived experience of young adults diagnosed with a chronic illness. The theoretical framework utilized in this study is discussed in this chapter. An overview of the Theory of Human Becoming is explained as well as its relevance to this particular study. Additionally, a review of literature will follow, providing a background for the current study.

#### Theoretical Framework

Parse's Theory of Human Becoming (1998) is a school of thought rooted in human sciences. It is a culmination of work based on Parse's dissatisfaction with commonly used nursing theories. Her goal was "uncovering the meaning of phenomena as humanly experienced" (p. 9). Parse states that each person should be considered as a whole rather than a collection of individual parts. Each person individually relates to the environment (or universe), always connecting with and separating from it, continuously co-creating health. She postulates that just as the universe affects the human, the human affects the universe and the two must co-exist based on choices made by the human. The objective of research directed by the Theory of Human Becoming is to understand the meaning of each person's lived experience and how it affects his or her life.

The Theory of Human Becoming examines the various aspects of the human's coexistence in the universe. "Man-environment relationships are such that a continuity

of what was and what will be unfolds in the now." (Chinn & Kramer, 2004, p. 237) Man is able to choose his response and the meaning given to situations and must take responsibility for those choices.

### *Concepts of the Theory of Human Becoming*

There are three assumptions of human becoming which have been created from nine original philosophical assumptions:

1. Human becoming is freely choosing personal meaning in situations in the intersubjective process of living value priorities.
2. Human becoming is co-creating rhythmical patterns of relating in mutual process with the universe.
3. Human becoming is co-transcending multidimensionally with emerging possibles (Parse, 1998, p. 29).

These assumptions are the foundation for the Human Becoming theory. Human becoming, as a construct, involves quality of life and health as constantly evolving factors in life with one always affecting the other. Health is to be defined not as good or poor, but as a process, ever changing and interpreted by self and others. "Disease from the human becoming perspective is not something a person contracts, but, rather, a pattern of the human-universe mutual process" (Parse, 1998, p. 33).

The three major themes of these philosophical assumptions are meaning, rhythmicity, and transcendence. A key principle is derived from each theme. An explanation of the themes and key principles follows.

#### *Meaning and Principle One*

The implication of the word "meaning" in this context is that of a fluid word referring to an objective in life and grasping the consequences and worth of each



change that takes place in the universe. Meaning refers to, not only the happenings of everyday life, but also the greater purpose and significance of life. It is vibrant and constantly transforming. Principle one is derived from the concept of meaning.

Principle one is defined as, "Structuring meaning multidimensionally is co-creating reality through the languaging of valuing and imaging" (Parse, 1998, p. 35). Each moment in life is experienced and interpreted uniquely by each individual. The meaning individuals give to encounters provide reference for future interpretation and future decision-making. Structure meaning multidimensionally is based on the concepts of imaging, valuing, and languaging. Imaging is individual and unstructured interpretation, according to each person's worldview, and consists of visualizing meanings from previous actual experiences as well as perceived possible outcomes. The second concept is valuing, which is defined as a person selecting, treasuring, and working on the things that are significant and important in life. Values are constantly reviewed and altered according to meaning taken from experiences. Finally, languaging is the conveying of experiences including images and values with others, through verbal and non-verbal communication. Communication can effectively take place through verbal or written word, as well as gestures and the lack of communication, or being silent and motionless.

#### *Rhythmicity and Principle Two*

Rhythmicity is "the cadent, paradoxical patterning of the human-universe mutual process...a flowing process as cadences change with new experiences arising with diversity" (Parse, 1998, p. 30). It is ever changing and difficult to predict, though a pattern can sometimes be determined. Rhythmicity is an important factor in principle two: "Co-creating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating" (Parse, p. 42).

The paradoxical relationships are the focus; they are rhythmic, patterned, and ever-present. Specifically, the paradoxical relationships are revealing-concealing, enabling-limiting, and connecting-separating.

Revealing-concealing deals with the possibility of putting an outward appearance of one emotion, and feeling an imminence of the opposite emotion. It is "disclosing-not disclosing all-at-once" (Parse, 1998, p. 43). An example of this is voicing disappointment at the end of a vacation, yet feeling relief with the imminent end of a chaotic trip and a return to normalcy and routine of work and family life.

Parse (1998) explains, "Enabling-limiting is living the opportunities-restrictions present in all choosings all-at-once" (p. 44). Choosing a certain opportunity will cause restriction in other areas. Human becoming stresses the acceptance of both the access to opportunity in the desired area, and the restriction of certain additional possibilities in other areas. Humans are continuously making choices; this is a part of the unlimited universe.

Connecting-separating is the third dynamic relationship in principle two. This concept is defined as the simultaneous "being with and apart from others, ideas, objects, and situations" (Parse, 1998, p. 45). As one is involved with one person, one is away from others. This relationship deals with disconnection from one person or thing while associating with another. These two processes occur at the same time and are ever-changing. As humans we are continually making new connections in our lives while other parts are ending as we are separated from them, whether on purpose or as a result of the newer associations.

### *Transcendence and Principle Three*

Finally transcendence deals with the idea that humans can strive to that which seems impossible. The human-universe dyad provides endless possibilities that cannot be discovered unless they are explored. Principle three states, "Co-transcending with the possibles is powering unique ways of originating in the process of transformation" (Parse, 1998, p. 46). In other words, human becoming is in motion with aspirations while the paradox of pushing-resisting creates fresh ways of looking at both the familiar and unfamiliar. Every choice humans make affects the future in some way; the choices cause some limitations and some new possibilities. Each human is affected by, and will affect each choice made. The interpretations of a situation are unique to each individual and are based on previous experience and inexperience. The specific concepts of Principle 3 are powering, originating, and transforming.

Parse (1998) explains, "Powering is the pushing-resisting process of affirming-not affirming being in light of non-being" (p. 47). Non-being refers to the unknown future and the impending risk of losing something treasured. Risk refers to any unexpected or expected occurrence, whether misinterpretation, condemnation, or even death. Powering deals with intensions and actions of self and others in a continuously fluid process.

Originating is formulating new ways of "conforming-not conforming in the certainty-uncertainty of living" (Parse, 1998, p. 49). Originating can be finding and exerting uniqueness in life's choices; it can also be striving for consistency with the norm of the universe. The general societal pull is for conformity; however, the choice for distinctiveness is ever-present. Although conformity is comfortable and safe, it cannot be the only way of being.

"Transforming is shifting the view of the familiar-unfamiliar, the changing of change in co-constituting anew in a deliberate way" (Parse, 1998, p. 51). Humans are continuously interacting with the universe; mutual emergence occurs as the human affects and is affected by change. Each human attaches unique meaning to each situation and occurrence. Inevitably, humans' circumstances change, and therefore, so must the humans. As the universe changes, the human undergoes transformation in finding meaning and value in the new environment.

The three concepts and principles related to each have been discussed in this summary of the Theory of Human Becoming (Parse, 1998). A case study exemplifying this theory's framework follows.

### *Case Study*

JR is a 28-year-old White male who was diagnosed with multiple sclerosis 2 years ago. JR lives in an apartment building with his wife and a pet cat. JR had experienced transient symptoms including numbness in extremities and visual disturbances for one year prior to his diagnosis. He spent the year following diagnosis feeling angry and disappointed. He and his wife decided not to have children as the progression of the disease is yet unknown. He has suffered progressive weakness and is no longer able to exercise, as he would like to. He transitioned to working from home and is able to rest frequently during the day. He is more active in his church than previous to his diagnosis and frequently counsels teens about life and their hopes and dreams. He is involved in physical and occupational therapy; these therapies help him care for himself as long as possible. JR has a positive outlook and is impressed by the support of family and friends. He remains sad, at times, due to the active life he will never have again.

As principle one of the Theory of Human Becoming states, it is up to each individual to interpret and give meaning to moments in life. JR feels sad at times, but, though his body cannot do all that he would like, he is able to utilize his mind to help the youth of his church and continue working from home. He appreciates the effort his family and friends make rather than assuming they are being nice because they feel sorry for him. In these ways, JR shows imaging, valuing, and languaging as discussed previously.

Rhythmicity is the key to principle two; JR acknowledges the ever-changing universe and accepts that new experiences will occur, usually without an apparent pattern. He is able to both enjoy his life the way it is and mourn the life that he would have without the multiple sclerosis.

Principle three is based on transcendence. JR will continue to plan for his future with his wife, despite an unknown time period before he may be bed-ridden. He accepts new opportunities as well as limitations as they come, accepting that he will not be able to do everything physically that he would like, but he will remain active and independent as long as he can.

In summary, the objective of research directed by the Theory of Human Becoming is to understand the meaning of each person's lived experience and how it affects his or her life. The researcher must be an impartial observer during the interview, interjecting questions only to clarify information obtained. The Theory of Human Becoming described health not as a continuum of healthy to ill, but rather the day-to-day living and ways of being. The theorist seeks to find the individual's way of living, including experiences, interpretations, and meaning given to experiences. It is in this way that the Theory of Human Becoming is appropriate for the purpose of this study.

## Review of the Literature

Multiple research studies have been completed on individuals who have been diagnosed with chronic illness. Autoimmune diseases have been compared to each other and to other, more common, chronic illnesses in terms of physical and psychological effects. Most of the studies involve an average population age of 40 years and older. The following review relates to studies completed involving adults with chronic illnesses. These studies include qualitative and quantitative inquiry and various study designs. The categories of the literature cited include quality of life, satisfaction with health, social experience, coping, and adaptation.

### *Quality of Life*

Quality of life is a common area of study in health care. Several researchers have assessed the situations and needs of people with chronic illnesses. Comparisons have been made regarding patients' perceptions of the severity of their disease and how it affects day-to-day life.

A research study completed by Sokoll and Helliwell (2001) compared quality of life in patients with psoriatic arthritis to those with rheumatoid arthritis. This study tested a null hypothesis: "disability and quality of life are similar in patients with rheumatoid arthritis and psoriatic arthritis providing the disease has been present for a similar period of time" (p. 1845). The sample comprised 47 participants with mean ages of 45 (PsA) and 51 (RA). The participants were matched for duration of disease, but not age or gender. Health assessment forms, laboratory studies, and radiographic studies were completed on participants and compared. The results included a higher rate of joint damage and higher number of medications in the group with RA, but an overall equality in the general function and quality of life scores in both groups. The researchers

postulated that the effects of psoriatic skin lesions in those with PsA were a significant factor in the equality of function and quality of life scores despite less joint damage.

Another research study completed by Jolly (2005), compared quality of life of those with SLE with those diagnosed with other chronic illnesses (including hypertension, congestive heart failure, adult onset diabetes mellitus, myocardial infarction, and depression). Jolly used the Medical Outcomes Study Short Form-36 to evaluate measures relating to quality of life. The results indicated general quality of life was lower in participants with SLE. General health was rated the worst and pain was rated highest in those with SLE. Other factors such as mental health and social functioning were rated lowest in those with SLE and, understandably, depression. A lack of matching and controlling of variables limited the results of this study; no definitive conclusions could be made. There was a comparison of SLE to prevalent chronic diseases, though not to other autoimmune diseases. The mean age of participants was 40.5 years, with the SLE population being younger in general. It is significant that the generally younger participants with SLE had a lower rating of quality of life than the older group with more common chronic illnesses.

A study by Bishop, Shepard, and Stenhoff (2007) sought to increase the understanding of the relationship between multiple sclerosis, quality of life, and psychosocial adaptation. The authors used four different scales to gather information from 98 individuals with an average age of 48.7. The average age at disease onset in this group was 35.9. The researchers found a statistically significant positive correlation between scores on a self-management scale and perceived control and quality of life.

Quality of life has been investigated recently in several quantitative studies in relation to chronic illness (Bishop et al., 2007; Jolly, 2005; Sokoll & Helliwell, 2001).

These studies tended to compare less prevalent diseases with each other or with other more common chronic diseases. The population included a group of males and females with average ages of 40 to 51 years (Bishop et al.; Jolly, 2005; and Sokoll & Helliwell, 2001). The usage of questionnaires or surveys enabled the researchers to statistically analyze responses and determine rankings of participants' quality of life. Numerical data provided quality data regarding those with illness; however, a true description of their experiences cannot be obtained through surveys and questionnaires.

#### *Satisfaction With Health*

Long, Husted, Gladman and Farewell (2000) studied a group of 169 people with PsA with the purpose of assessing their satisfaction with health and measures of function and disease status. Through the use of tools such as questionnaires, medication lists, and physiological assessments, the researchers found, "patient satisfaction with health is relatively independent of traditional clinical measures of function" (p. 963). They suggest more research in the area of patient satisfaction with health in order to gain a better understanding of the determinants and consequences of health. The authors also recommended looking at patient satisfaction with health as a process, "and study its relationship with treatment side effects, comorbidity, and other possible influences such as satisfaction with care" (p. 965). It seems that factors such as support received, attitude and outlook can be important determinants of satisfaction with health, and not necessarily functionality as is sometimes assumed.

#### *Social Experience*

Fong, Finlayson and Peacock (2006) completed a study exploring a group of older adults (mean age of 62) with MS. Utilizing qualitative interviews and a quantitative assessment tool, the authors investigated the social changes and potential social needs



unique to individuals aging with a chronic disease. Key concepts from the data analysis included concerns for future and progressive disability, emotional health related to role transitioning, and a strong desire to be understood by others. Participants verbalized a need to be supported, but not smothered with care and concern, as basic functioning can decline as a result of overprotective caregivers. "From the findings, a supportive environment was one that promoted personal control, self-management of the disease, and provided opportunities for the enhancement of relationships" (Fong et al., p. 704).

### *Coping*

Coping has been studied in different ways in the last 10 years. Researchers have sought information on how people with chronic illnesses manage their diagnoses emotionally, physically, spiritually, and socially. Baker and Wigintin (1997); Curtis, Groarke, Coughlan, and Gsel (2004); and Narayanasamy (2003) used either qualitative interviews and/or quantitative measures such as various scales related to stress, coping style, and support to measure how people with chronic illness coped with the diagnosis and ongoing treatment. Narayanasamy (2003) focused on spiritual coping in chronically ill patients. She interviewed 15 people with an age range of 23 to 80. Her findings included a large number of participants turning to God and/or religion in order to find meaning or purpose in illness. Many patients, however, hide this spirituality from nursing staff and health care providers due to a feeling of embarrassment. Narayanasamy concluded that nursing and medical staff could better care for patients by assessing and supporting their spiritual needs as well as physical and psychological needs.

Baker and Wigintin (1997) completed a qualitative study in order to determine the perceptions of women with lupus about their disease, as well as its impact on self-management and coping. The mean age of the group studied was 45. The researchers

found that in many cases, the diagnosis itself was a relief as the women had suffered from perplexing symptoms. Other results reported included,

Few relationships between characteristics of women with lupus and their perceptions of the disease, few assumptions can be made about the ability of women living with lupus to cope based on length of time since diagnosis, age, number of symptoms experienced, or number of information sources accessed (Baker & Wiginton, p. 134).

These findings suggest that each person with lupus should be treated as an individual, as expressions of the disease and needs of the individual are unique.

A final research study was completed by Curtis, Groarke, Coughlan, and Gsel (2004). The purpose of this study was to examine the function and influence of disease states, psychological stress, social support, and coping on adjustment in women with RA in a particular yearlong period of time. They used several questionnaires evaluating stress, coping styles, social support, adjustment to disease, and impact of disease on physical, social, and psychological functioning. The researchers used various ratings and lab tests to measure the disease states. The study took place in Ireland with a 52-member group of participants and a mean age of 60. Pertinent findings indicated that disease severity was an accurate predictor of the illness related to areas of physical functioning and pain. Furthermore, disease severity was not an accurate predictor of variation in social or psychological adjustment.

Results of studies regarding coping in individuals with chronic disease did not indicate that severity of disease was correlated with poor coping skills or lack of social or psychological attitude. Social support and attitude do seem to affect the ability of an individual to cope with chronic illness effectively.

### *Adaptation*

The concept of adaptation was discussed in the introduction. A study completed by Charmaz (1995) discussed methods of adaptation to impairment in chronic illness. Gordon, Feldman, and Crose (2001) used Charmaz's stages of adaptation as a basis for research regarding the meaning women attach to the concepts of disability and illness. Gordon et al. interviewed 40 women between the ages of 28 and 79. The emerging themes based on qualitative analysis included difficulty with labels such as disability, personal perception of societal views, attitude changes toward others with disability, and identification of implications for counselors. The participants verbalized a feeling of negative judgment from others based on intermittent symptoms or non-obvious signs of illness. Those who had been living with chronic illness reported a changed view of how they perceived illness in others, including more compassion and understanding. Implications for counselors included taking the previously discussed themes into account and acknowledging the unique experience of every individual with chronic illness.

The research studies identified in this review of the literature included a range of qualitative and quantitative methods and various important topics related to the experience of living with a chronic illness. Little is known, however, about younger adults (less than 40 years) who may be at the beginning of their journey with the diagnosis of a chronic illness. These young adults face years of treatment and may have to endure progressive disability, pain and fatigue as the years progress. All adults face more medical difficulties as they age, but being diagnosed with a chronic illness in early adulthood hastens this process. Health care professionals would benefit from the reported lived experience of young adults with chronic illness by giving them an

increased appreciation and understanding of the varied psychological, social, physical, and spiritual needs of these individuals.

### Summary

The Theory of Human Becoming states that each person should be considered and treated as a whole, rather than a group of parts. Each person is able to make decisions for himself or herself, but must maintain responsibility for those choices and their consequences. Each person is able to attach meaning to life events as he or she wishes. Individuals with chronic illness have been studied extensively in the areas of quality of life, satisfaction with health, social experience, coping, and adaptation. Most of this research however, involved populations age 40 and over, leaving a window of needed research in the less than 40-years-old age range. Gaining a true understanding and appreciation for the lived experience of young adults with chronic illness would be helpful for health care professionals by increasing knowledge of the variations in psychological, social, physical, and spiritual needs of these individuals.

Chapter III discusses aspects of this research study including the study design, population, data collection instruments and procedures as well as data analysis and limitations of the study.

## CHAPTER III

### METHODOLOGY

#### Introduction

The purpose of this study was to investigate and describe the lived experience of young adults diagnosed with a chronic illness. In this chapter the research design, population, sample, setting, procedures for data collection and data analysis, and limitations of the study are discussed.

#### Research Design and Sample

This research study used a phenomenological, descriptive design. The phenomenologic approach is inductive and descriptive; its goal is to "describe lived experience" (Speziale & Carpenter, 2007, p. 77). Speziale and Carpenter also state, "It is this lived experience that gives meaning to each individual's perception of a particular phenomenon and is influenced by everything internal and external to the individual" (p. 77). This design allowed the researcher to explore the phenomena of the lived experience of young adults with chronic illnesses in order to gain a more in-depth understanding of this lived experience.

#### Population

The population studied was young adults in Wisconsin with chronic illnesses. Inclusion criteria were: (a) age range of 20 to 40 at the time of diagnosis; (b) age 21 to 45 at time of participation in the study; (c) diagnosis of a chronic illness for more than

1 year prior to interview with researcher; (d) the ability to read, write, and communicate in English; and (e) residence in the state of Wisconsin. Exclusion criteria included: (a) ages outside of set range, (b) unclear or unspecific diagnosis, and (c) unwillingness or inability to answer questions honestly.

The sample included five participants. They were selected from a neurology clinic setting as well as by personal referral. Participants were asked to give the study information to others with known chronic illnesses to see if they were interested in participating.

#### Data Collection Instruments

Two instruments were used for data collection—a demographic questionnaire and an open-ended interview. The demographic questionnaire (Appendix A) included, but was not limited to participant's age at interview, participant's age at diagnosis with chronic illness, diagnosis, gender, education, salary range, living arrangement and marital status.

The primary question was, "Tell me about your experience with your chronic illness." Probing questions were asked as the interview proceeded according to what was offered by the participant. Specific probing questions included: Tell me about the time directly before and after you were diagnosed with a chronic illness. Tell me about any life adaptations you have made because of your chronic illness. What else would you want me to know or think I should know?

### Data Collection Procedures

Prior to data collection, approval was sought from the University of Wisconsin, Oshkosh Institutional Review Board (Appendix B). The risks to the participants were minimal and were related to emotional issues that might be discovered during the interview. Process consents were discussed with and obtained from each participant prior to any interview questioning. The process consent gave the researcher permission to ask questions as planned and could be re-visited during the interview if topics arose that were not anticipated. A pilot study was conducted with the first participant; the researcher evaluated the interview process after analysis of the transcribed data. Probing questions were modified in order to get the most complete description of the lived experience of young adults with a chronic illness.

The interviews took place in the homes of the participants. Informed consent for the interview and tape recording was obtained from each participant prior to data collection (Appendix C). The researcher planned for an approximate interview length of 60 minutes. Consent to call participants on the phone was also obtained to clarify any missing or unclear data after the interview had been completed. Interviews were tape recorded and transcribed verbatim for analysis.

### Data Analysis Procedures

Data were analyzed according to Spiegelberg's method of analysis, which included intuiting, analyzing, and describing. This process took place in order to provide rich description of the data collected (Speziale & Carpenter, 2007). The researcher identified the key essence of the data after thorough examination. After data collection, the researcher became immersed in the data known as intuiting. Next, the researcher

identified the essence of the investigated phenomenon. Finally, the researcher described the phenomenon using terminology from the interviews in order to fully communicate the themes and subcategories and to describe the most accurate interpretation of the phenomenon in question (Speziale & Carpenter).

The trustworthiness of the data was preserved through telephone communication with participants after interviews and analysis to verify the interpretations and categories. Data, including audiotapes, the demographic data and transcribed data were kept in the researcher's home in a locked box in order to preserve confidentiality. Participants' names were not on any documentation and were only identified by code.

### Limitations

The researcher anticipated limitations of the methodology to be the small sample size, a limited geographical area, and potential response bias. The small sample size limits the generalizability of the results. The geographical area also limited generalizability, as the residents of the state of Wisconsin cannot represent all young adults with chronic illness in the U.S. or elsewhere. A response bias may have occurred, as participants might not have honestly and completely answered questions.

### Summary

In Chapter III, the study design, sample, population, data collection instruments and procedure, data analysis, and limitations were discussed. A qualitative, descriptive approach was used to study the lived experience of young adults with chronic illness. After process consent was obtained, and demographic data were collected and a tape-recorded interview took place. The tape-recorded interviews were transcribed and



analyzed in order to find common themes, which described the experience of young adults with chronic illness.

## CHAPTER IV

### RESULTS OF THE STUDY

#### Introduction

The purpose of this study was to investigate and describe the lived experience of young adults who have been diagnosed with chronic illness. The results of the study are presented and discussed in relation to Parse's (1998) Theory of Human Becoming and to relevant literature.

#### Demographic Data

The participants for this study were residents of a mid-western state, selected from a neurology clinic setting as well as by personal referral. Young adults with chronic illnesses were selected and screened for inclusion and exclusion data. The ages of the participants ranged from 27 to 40, with a mean age of 33. Two participants had been diagnosed with MS, two had been diagnosed with RA and one had been diagnosed with PsA. The sample consisted of three females and one male; four were married and one was single. The household income varied greatly from less than \$15,000 to more than \$75,000 a year. Four participants were residing in a private residence with their spouse. The only unmarried participant was living at home with her teenage son. The highest education level attained by the participants varied and included: one high school graduate, one college student, one college graduate, and two currently enrolled in graduate school programs. Employment also varied greatly, including: one unemployed

full time student; one unemployed part time student; one unemployed, on disability compensation; one full time work; and one part time work.

### The Interview Process

Potential participants were selected according to specified criteria. They were contacted by health care providers at the neurology clinic who requested permission for the researcher to contact them by telephone. When contacted, the participant and researcher set up a mutually convenient time and location for the interview. Informed consent for the interview and tape recording was obtained from each participant prior to data collection. Interviews lasted approximately 30 to 60 minutes. All interviews were transcribed verbatim and themes identified according to Spiegelberg's method of analysis. The interviews elicited emotional memories as well as strong feelings regarding the experience of life with a chronic illness. Information of how to contact the researcher was shared with the participants. The participants were also encouraged to contact the researcher if additional information was needed or if they desired to withdraw from the study.

### Results

Thorough analysis of the data collected revealed that the young adults experienced diverse feelings regarding their diagnoses. The themes of these experiences are categorized in as: (a) what happened?"(past); (b) what now?(present); and (c) what next? (future) (Figure 1). These themes as well as nine subthemes are identified below and discussed in detail in the following pages.

## THEMES

### ***What Happened?***

1. Denial/disbelief: "And it was just kind of weird because no one in my family has, like anywhere, has any kind of autoimmune disease."
2. Am I going crazy? "When I thought about telling doctors about this I thought, "They're going to think I'm totally making this up'."
3. Mourning: "I can't do everything that I love anymore."

### ***What Now?***

4. Acceptance/perseverance: "What are you going to do? I roll with it."
5. Accommodations/adjustments: "I can pretty much do everything except for walking long distances. My legs start getting stiff."
6. Frustration: "But I mean, it was just, I mean I've never been in the hospital, never been sick and now all this crap has been happening."
7. Support: "My husband, we were dating when I was diagnosed and he's been with me through everything. He's actually been a really good support."

### ***What Next?***

8. Hope/optimism: "I'm still mobile, I can still do stuff, so just focus on the positive."
9. Lifelong medication use: "Well, I guess basically knowing that I have to be the one responsible to take medication, to make sure that I'm going what I can do to stop my disease state."

*Figure 1. Themes and subthemes.*

## Themes

### *What Happened? (Past)*

The participants' recollections of the time directly before and after diagnosis of a chronic illness varied from experiencing a solitary symptom and having an immediate diagnosis, to several symptoms and a year or more before definitive diagnosis. There was a sense of disbelief, and, at times, a question of personal sanity. Additionally, a mourning process of the loss of youth and health occurred in some of the participants.

#### *Denial/Disbelief*

This subtheme captures one stage in the disease process in which young and previously healthy adults are faced with a life altering diagnosis. It is challenging to face life in which physical deterioration is more imminent than in healthy counterparts. The fear of the unknown can cause denial of certain change. Although denial is strongest at the time of diagnosis, participants verbalize having feelings of disbelief and denial in all phases of the disease process, not just with initial diagnosis.

One participant with RA stated, "And it was just kind of weird because no one in my family has, like anywhere, has any kind of autoimmune disease." Another participant, who was in nursing school at the time of her diagnosis, explained her meeting with the neurologist for diagnosis:

And then I didn't like the neurologist, cause she just came in and said matter of factly, no emotion or anything, 'Well you have MS, multiple sclerosis.' Well, I was in nursing school at that time and I was taking care of a patient with MS in a nursing home at that time, so as soon as she said that, guess what popped into my head... This paralyzed old lady who's all contractured and had a supra pubic

catheter and you know, that just popped into my head. It was like the floor just dropped out from under me. It was bad; it was just horrible at first.

Another participant was diagnosed with MS after a tortuous process of testing. Initially, she did not appreciate the seriousness of her symptoms and even after the possibility was discussed, she did not fully grasp the idea:

I thought it was something that would pass, I didn't know. I just casually mentioned it in the annual doctor's appointment about my face being numb all the time...I didn't even read that report fully where it said at the end that it could be possibly MS or a tumor... until my mom read it over and brought it to my attention. Shocking.

Even after diagnosis and prescription of medication for MS, another participant decided on her own she could not have MS and did not use any medication until 5 years later. The consequence was a partial vision loss. She stated:

And then of course as a nursing student, you go and look up everything, and it says, well, in order to be diagnosed you had to have 2 clinical symptoms; well I didn't have two symptoms...so I was in denial. I can say that now looking back, I was in denial...and at that time all the MS medications were fairly new, so the one she wanted to put me on...she said we're going to put you on Avonox, or Avonex or whatever it is and we don't know if insurance will cover it. So, ah, guess what, I didn't get it filled.

One participant initially isolated herself, feeling as if she would be a burden if those she was close to had to help her with certain things or hear about her illness.

I don't feel like acknowledging it, or being around it. You know I just want to live my life and whatever happens to me I deal with it.

### *Am I Going Crazy?*

This subtheme encompasses both the participants' thought processes while going through diagnostic procedures and the responses from healthcare professionals that misinterpreted their symptoms or complaints. Because signs and symptoms of autoimmune disorders can be difficult to describe and assess, diagnosis of these diseases can be challenging. The symptoms may come and go and change to different locations prior to a visit to a primary care provider. Once the participants presented for care they verbalized a sense of apprehension, as if their complaints were so peculiar they would not be taken seriously.

I thought I was losing my mind. Honestly, it sounded...when I thought about telling doctors about this I thought, they're going to think I'm totally making this up, cause it sounds so absurd, that I wake up and have pain in different areas.

Conversely, one participant sought care for generalized numbness of her skin. She was sent home with antidepressants as the provider interpreted her numbness as a psychological lack of feeling, when in fact her skin was unable to perceive anything but aggressive pressure.

It kind of felt like everything was asleep, it didn't come back... So we went to one physician and they gave me this depression handout, or screening thing. And I'm like, okay, do I answer this truthfully? You know cause I know what they're thinking... So he diagnosed me with depression and sent me out with antidepressants. So I tried the antidepressants for a few days, well probably a day or 2, and I just slept, cause I don't like those things. And I finally I'm like this is not up here, I'm not psychosomatically numb, or... There's something wrong with me!

Another participant verbalized a fear that her symptoms would not be taken seriously by health care professionals:

I always had a fear that doctors would say, "Oh, you're just being a hypochondriac, there's nothing really wrong with you, you just want attention." You know I always had that fear, and I still do to a certain extent, even there is actually something physically wrong with me, there are tests to prove that there is something physically wrong with me.

### *Mourning*

The participants articulated a sense of mourning. They felt as though their "normal" and healthy self was gone and replaced by a defective body. These imperfect bodies were not expected, and certainly not welcome. The transition from perfectly healthy to requiring daily or weekly medications was less than smooth in most cases. One participant described the change that had taken place since her diagnosis with rheumatoid arthritis:

So the big thing for me is going from completely healthy and having no health problems, to now all of a sudden having this chronic condition that I have to take medication for every and day and have to take shots once a week. Just waking up and not feeling like I can do everything I used to do. I used to do triathlons and it just...it's more cramping my lifestyle more than anything. And knowing that it's something that's not going to go away.

Although one participant reported having a good outlook, she still had a difficult time with the active, independent self she used to be.



Like I said, just if I have to walk distances, or if I get too hot, or too cold. I don't like the cold to begin with before I got this. But I like to, you know, walk and like I said, be outdoors. I can't do everything that I love anymore.

I just kind of put it out. But every once in a while, like in the summer when it's nice out, or when I want to run. I can't run anymore, so then it's like, this sucks, type of thing. You grieve a little each time maybe. But like I said, my thing is it always could be worse. This is what I got dealt with and I just have to live with it.

#### *What Now? (Present)*

In discussing the present state of illness or health, and despite all of the participants taking disease-slowing medications regularly, they voiced a sense of perseverance and acceptance. These attributes allowed them to continue with life and reach for goals. Accommodations and adjustments were made as needed, basically, a compromise between what participants wanted to do and were realistically able to do. A sense of frustration was verbalized due to living with a chronic illness, and also to a lack of specific knowledge from health care professionals about medications or the disease process.

#### *Acceptance/Perseverance*

Though acceptance and denial seemed to oscillate throughout illness; clearly, acceptance dominated. A desire to continue living an unencumbered life and inner strength seemed to be pivotal in the acceptance and perseverance sub-theme. When asked how they thought their lives might be different from the lives of their healthier counterparts, responses were overwhelmingly of acceptance. Recognition of the lifelong and daily effects were verbalized with such statements as, "What are you going to do? I roll with it" and, "It's something I'm going to be dealing with for the rest of my life." One

participant eloquently and stoically stated how life with a chronic illness differed from that without:

Probably no different than living a normal life other than you know you are living with a chronic illness and there are some days that are better than others when your deficits affect you and you get kind of down, but my mentality is I'm not going to let this thing beat me, so, I just think, you know, things could always be worse. I could be in a wheelchair, I could be dead, you know.

Of the side effects of a specific injectable medication one participant verbalized, "I have big spots on me...which I don't like, but whatcha going to do? And I don't know if I'm going to be self conscious about them this year or not." She advises of life in general, "The key is just acceptance, you have to accept it and do what you can do. I never roll over."

#### *Accommodations/Adjustments*

Part of life with a chronic illness involves making the best of what one has. Participants verbalized the ability and necessity of making accommodations and adjustments in special circumstances and everyday life in order to make the best of things. Life adjustments came in the form of an increased awareness of potential injury and the need for more activity or a warm-up in the morning in order for the day to go more smoothly. One participant expressed an increased degree of body awareness:

I would say now that I've had treatment, no, I don't think I live my life any differently, I guess, I mean...I shouldn't say that, I am a lot more careful about injuries since. Like, um, physicians have told me that when you break something, that's when you're more likely to get arthritis in those joints. And they also told me that psoriatic arthritis can affect the spine, so I am more careful

about day to day lifting stuff, I don't want to injure my back in any way. I'm not as reckless with my body, I'm also 33, so that's probably, might be why I'm not as reckless. But, I don't want to cause any injury to myself to further increase the arthritis, so, yeah.

Another participant daily accommodated for her severe stiffness in the morning: I wake up early in the morning so that I can actually walk on the treadmill for 10 to 15 minutes to try to get loosened up... I was doing an ET tube intubation and after doing it about three times my hand had gotten so like, stiff and cramped up I needed to like stop. That's been frustrating, cause I want to work in ER or work in surgery, and that was kind of an OK, if doing this for 15 minutes has made my hand so numb, and I can't do anything with them is this going to affect which direction I go in school now?

Exercise can be limiting when joints are painful and sore. Activities were sought that would be strengthening as well as minimally painful. Additionally, some activities were avoided.

It does because now it's like the only physical activity I can actually do that my body doesn't hurt is swimming. And my schedule is limited, and trying to find a time when the pool is open that I can get there. It's just, I can tell things that I used to all my patients to do, cause I worked in a childhood obesity clinic, like park farther away so you can take more steps, I find myself trying to find the closest spot, so that I don't have to walk extra in the grocery store because I know my feet are going to go numb, stuff like that.

One participant had lived in a second floor apartment and stated, "I live downstairs. We lived upstairs for a while and now we live downstairs. Cause going up and downstairs can really kill your knees."

Some adjustments were easier to accept than others. One participant has chronic foot pain from rheumatoid arthritis. She knew wearing the typical shoes for her wedding would cause agony, so she wore bejeweled tennis shoes,

The only other thing I had to do was I had to wear tennis shoes on my wedding day. I got married in December and I just knew that I would not be able to make it if I were wearing any kind of heel or flat, so I actually wore tennis shoes to my wedding, which was fine cause we got sparkly tennis shoes and everything, but...Who really wants to wear tennis shoes on their wedding day?

One participant with MS did not feel like her illness was particularly limiting. She stated, "I can pretty much do everything except for walking long distances. My legs start getting stiff." Other participants' adjustments had to do with life-long medications and the possibility of side effects or limits on child bearing. A participant with rheumatoid arthritis stated that starting a family sooner rather than later might give her a more active role in raising children, and maybe not. She verbalized her concerns about the potential accommodations needed when raising children.

Things that were important to me in my life, like having a family and having kids, just become more of an issue of, am I going to be able to go to the park and play with my kids? Am I going to feel good enough to do the things that I wanted to do?

*Frustration*

All of the participants verbalized a sense of frustration. The frustration developed due to the transition from overall health to chronic illness and from relationships with healthcare providers and others. Each of the participants saw a specialist regularly, but verbalized a desire for more knowledge and holistic information from primary providers. When chronic illness set in, the patients wanted answers to important questions and, unfortunately, primary care providers were not as prepared to answer those questions as the study participants had hoped. For instance:

My regular doctor doesn't have a great understanding of what RA is and anytime there is a question, she deflects all the time to the Rheumatologist, which I mean, I guess it's just that you have to find someone to specialize with.

Unfortunately, sometimes the specialists also did not have answers for pressing questions. A gap in knowledge or an unwillingness to answer some of the tough questions existed. One participant expressed:

One of my big concerns is what are these medications doing to like, my fertility. Like if I want to have kids, am I doing something that would make that more difficult because of the medication that I'm taking? But my primary doctor, who I ask questions to like that, has no idea. It's just like, ask your rheumatologist. So I ask the rheumatologist and she doesn't know cause she doesn't specialize in that. So it's kind of like there's a gap in that area.

Another stated:

Right, it's just you should ask the rheumatologist, or you should ask your primary doctor, or when you get to that and you want to have kids you'll just have to work with a specialized OB/GYN...People have enough of a hard time getting

pregnant some times and I don't want to wait forever, I mean I'm not really to be pregnant now, but if it's going to be difficult I don't want to wait till I'm 35 to start.

One participant had less than a therapeutic relationship with her initial neurologist. In the first year after her MS diagnosis, she had many questions and concerns, which she wanted to talk about with her provider. The provider however, made her feel as if her questions and concerns were insignificant and not worth his time. She explained her frustration:

The [first] neurologist that I had was a whack, he wasn't very good. I would go in with questions, because they say that should be your number one doctor, you can you know go to them anytime and ask questions when I make an appointment. I'd make an appointment and ask questions, and he'd get mad, like you know there's other patients that I have and you come in with just those? So, um, that was really upsetting, for sure.

Another participant was in nursing school when she was diagnosed with MS. Her symptoms were severe enough that she missed a few days of clinical. Her clinical instructor was unsympathetic when the situation was discussed. The instructor's response irritated the participant, but also motivated her to press on and not be influenced by that response.

When I was in nursing school, and I was going through (oh that was a horrible time in my life) and one of my nursing instructors actually looked at me when I told her, when I finally decided to tell her why I missed pediatric clinical at UW Pediatric Children's Health for like 3 weeks, you know what I can't feel anything, I'm not going to like pick up a kid. And she actually looked at me and said, 'I

think you need to find a different profession'... and that's where I turned around and I got really tough.

Finally, a participant was frustrated with her disease itself and the toll it was taking on her body. As a previously healthy young woman, she verbalized her struggle to find effective and safe medication. "But I mean, it was just, I mean I've never been in the hospital, never been sick and now all this crap has been happening." She was frustrated by her very circumstances. Luckily, all the participants verbalized the importance of support systems and the presence of supportive people in their lives. Support systems were pivotal in getting through the frustrating times.

### *Support*

Participants verbalized the importance of support from family, friends, and health care providers throughout the process of diagnosis and management of their chronic illness. They articulated the need for a good listener and for someone who would be supportive throughout various life changes. When asked about their support systems during the time of initial diagnosis, participant's responses were positive. "...my husband, we were dating when I was diagnosed and he's been with me through everything. He's actually been a really good support." And "Everybody's awesome; they're very good, very understanding, supportive. My parents were feeling guilty at first, like there's something they may have done." Also, "I'm lucky enough to have a good support group, supportive husband, family, friends." One participant had good family support, "...my mom and dad are a big support that I talk to." However, she was not comfortable being in typical social situations due to her illness and its manifestations:

I think I reserve myself a lot. Like I said, I don't feel like burdening anybody, I don't get out and really make friends. Just cause I don't know where to go really. I've gone to a couple of support groups that I really like.

For her the fear and discomfort in social situations has impeded her ability to seek out relationships and has reinforced her unhappiness with not having a relationship with a person of the opposite sex. She expressed a fear of not finding a mate as similar to the fear of going out and meeting new people, "My scary thing is being alone. It's a big scary thing. But it's also, you know, involving myself in a relationship and how do you go about doing that?"

Some participants were able to articulate what a provider could do to be more helpful. The answers were simple, "Just being supportive...my [neurology] nurse practitioner is awesome, Kathy. She just takes time to sit down and see how everything is going." And, "Just a provider that is just in tune with you, supportive, sit down and talk with you." Finally, "just listen to patients." This advice seems simple enough, but, unfortunately, not all providers were able to be as supportive as desired. In discussing a provider with whom she was not able to make the desired bond. One participant said, "I wanted someone more to connect with the MS I think."

Another participant spoke of learning to rock climb after several years with MS and having an issue with walking and foot drop, "And though I might not walk very well, the people we go rock climbing with, they say, they're very supportive, they say, 'you climb better than you walk!'"



### *What Next? (Future)*

#### *Hope/Optimism*

The participants were a bit reserved when asked about the future. There was some uncertainty, however an overwhelming sense of hope and optimism was apparent. Overcoming the diagnosis and continuing on with life was a common goal. Participants spoke of their futures, not based on illness, but on finding the best in their situation and looking on the bright side of life. The participants also voiced an acceptance with the need for life-long medications. These illnesses are not curable, but medications are available to slow the progression and physical damage. Participants verbalized an understanding of the importance of the medications, even if the side effects were uncomfortable.

After living with MS for several years, this participant explained that focusing on her limitations is futile; focusing on the positive was imperative. She stated;

You know, so it's just...you find what you are good at and what you can do and kind of put your energy into that. You just don't dwell. Otherwise you just get all teary-eyed...and what does that get you? Nowhere! It doesn't get you anywhere. You just have to accept it and work on the positive stuff cause it could always be worse. I could be in a wheelchair, and so I can't run, but I can walk, sometimes not very good, but I can walk.

This participant refused to let her illness limit her potential. Since her diagnosis with MS, she has completed both an undergraduate and graduate nursing program. Her perseverance was impressive. She explained;

I'm not going to sit down and feel bad about it, you know. So OK, I have this but, you're not going to tell me that I can't do something. So I got very stubborn, I

guess. I don't know if I accepted it and was still in denial at the same time...

Nobody's going to tell me that you should find a different profession,

After her diagnosis, another participant explained what it was like to finally have time to take care of herself after many years of focusing on raising a son. She described, "I started going crazy and discovering myself, cause it was the first time that I really had time to focus on myself, since being a mom." Once diagnosed with a chronic illness, her focus remained on her son until the disease process worsened. Then she was forced to take care of herself. She verbalized a sense of peace in her increased self-awareness and is now able to give her son the support he needs as well as caring for herself.

As a parting comment, this participant wanted the readers to know that MS was not her life, only a small part of it. She does not feel limited and looks forward to each new day. She articulates, "I'm still mobile, I can still do stuff, so just focus on the positive."

#### *Lifelong Medication Use*

One participant stated his pain was almost completely relieved with his current medication. Although his symptoms were controlled, he verbalized apprehension, as there is no way to predict how long the medication will be effective, or how long he will tolerate it. He stated,

So I guess post medicine living with this chronic illness isn't an issue at all, other than the small inconvenience of taking a few shots here and there. Um, but there is always the thought in the back of your head, how long is the medicine going to last?... The doctors said keep using it until it doesn't work.

Some of the injectable medications used to treat MS have side effects including flu-like symptoms, therefore taking medication to control the side effects was common. "I take a shot every other day, I have to take ibuprofen with it; otherwise I get sick." This side effect was manageable, just inconvenient and unpleasant. Medication and treatment was the way one participant took ownership of her illness, "Well, I guess basically knowing that I have to be the one responsible to take medication, to make sure that I'm doing what I can do to stop my disease state."

### Discussion of Results

Parse's Theory of Human Becoming (1998) is a school of thought rooted in human sciences. It is a culmination of work based on Parse's dissatisfaction with commonly used nursing theories. Her goal was "uncovering the meaning of phenomena as humanly experienced" (p. 9). Parse states that each person should be considered as a whole rather than a collection of individual parts. Each person individually relates to the environment (or universe), always connecting with and separating from it, continuously co-creating health. She postulates that just as the universe affects the human, the human affects the universe, and the two must co-exist based on choices made by the human. The objective of research directed by the Theory of Human Becoming is to understand the meaning of each person's lived experience and how it affects his or her existence.

These research results support the concepts of Parse's theory. For example, each participant had an idea of how their life would be without health problems. Each was then forced to reconsider these views upon diagnosis with MS, RA, PsA, or SLE. Each life experience is individual and is based on previous experiences and life lessons.

adults with chronic illness can be explained by a need for a close support system; yet feeling isolated and not understood at times due to the process of illness.

The third Principle of Parse's Theory of Human Becoming (1998) involves transcendence. Transcendence deals with the idea that humans can strive to that which seems impossible. Every choice made affects the future in some way; the choices cause both limitations and new possibilities. Interpretation of each situation is based on the experience or inexperience in a certain situation. Additionally, transcendence is based on powering, originating, and transforming. Powering relates to aspirations and hesitations about the future. One participant verbalized a comfort in knowing his medications were working now, but was hesitant that they may not work forever to control his joint deterioration. Originating is choosing conformity or uniqueness. This can be related to whether or not participants are willing to disclose their illness and admit their uniqueness, or attempt to conform by concealing any symptoms. As the universe changes, the human undergoes transformation in finding meaning and value in the new environment. Transforming is the final piece of transcendence. Each human attaches unique meaning to individual situations and occurrences.

All three principles of Parse's Theory of Human Becoming (1998) provided guidance in describing the experiences of young adults who had been diagnosed with chronic illness. Each participant's lived experience was analyzed according to how it affected his or her life. The process of health was discussed, with the concepts of adaptation and optimism predominating.

Past research studies about chronic illness and autoimmune disorders were characterized according to their focus, including: quality of life, satisfaction with health, social experience, coping, and adaptation (Baker & Wigintin, 1997; Bishop et al., 2007;

Charmaz, 1995; Curtis et al., 2004; Fong et al., 2006; Gordon et al., 2001; Jolly, 2005; Long et al., 2000; Narayanasamy, 2003; Sokoll & Helliwell, 2001). These were topics that were discussed by some of the participants of this study. Some likenesses were noted, however, the demographic data of these participants varied from that of previous research. The themes categorized in previous research will be discussed in relation to the findings of the current study. Bishop et al., Jolly , and Sokoll and Helliwell, studied quality of life. These researchers found that factors affecting quality of life most often included pain and self-management. The current study found that pain certainly affected daily life, and control of that pain was a focus to some of the participants. Additionally, the idea of self management was discussed both by a participant who was afraid of becoming a burden on her family and friends, and another participant who took ownership of her illness and knew she was the only one responsible for taking her medications as scheduled in order to limit the progression.

Satisfaction with health was based on factors including support received, attitude, and outlook (Long et al., 2000). These factors are similar to the findings discussed in the current research. The Long, et al. research found that functionality itself is not a major factor in satisfaction with health. The participants in the current research also voiced the importance of support from family, friends, and the healthcare team, an upbeat attitude, and a positive outlook in coping with their chronic illness.

Research conducted by Fong et al. (2006) looked at older adults with MS. Key concepts from the analysis of their data included concerns for future and progressive disability, emotional health related to role transitioning, and a strong desire to be understood by others. Participants verbalized a need to be supported, but not smothered with care and concern as basic functioning can decline as a result of

overprotective caregivers. Similarly, the participants in the current study verbalized a desire to be both independent and supported by family, friends, and healthcare providers.

Baker and Wigintin (1997), Curtis et al. (2004), and Narayanasamy (2003) studied the concept of coping in relation to chronic illness. Narayanasamy concluded that nursing and medical staff could better care for patients by assessing and supporting their spiritual needs as well as physical and psychological needs. This mirrors the subtheme of support in the current research. Baker and Wigintin found that in many cases, the diagnosis itself was a relief as the women had suffered from perplexing symptoms. These results relate to the subtheme of "Am I going crazy?" As discussed previously, the symptoms involved in autoimmune disorders can be transient and confusing. The reassurance that there is a real problem associated with them, although frightening, is also comforting in some ways. Curtis et al. (2004) used questionnaires to evaluate stress, coping styles, social support, adjustment to disease, and impact of disease on physical, social, and psychological functioning. Their research indicated that disease severity was not an accurate predictor of variation in social or psychological adjustment. Correspondingly, the participants in the current study were able to use optimism and perseverance in order to adapt to their diagnosis with chronic illness.

Finally, Charmaz (1995) discussed the concept of adaptation in relation to impairment and chronic illness. The participants in the current research verbalized adapting in various ways including learning which physical activities could be done with the least pain and the need to take medication regularly in order to slow disease progression. Conversely, research conducted by Gordon et al. (2001) used qualitative analysis to find the following themes related to chronic illness: difficulty with labels such

as disability, personal perception of societal views, and attitude changes toward others with disability. These themes did not emerge from the current research. Perhaps due to the young age of the participants, they did not verbalize any issues with labeling or the public's perception of disability.

In summary, the concepts of hope and optimism were overriding in the analysis of interviews performed with young adults with chronic illness. After initial feelings of denial and disbelief at the thought of chronic illness diagnosis prior to age 40, participants were relieved that their sanity was intact due to the confusing symptoms of autoimmune diseases. Additionally, a period of mourning took place while the participants transitioned from being overwhelmingly healthy, to chronically ill. Later in the disease process, acceptance and perseverance caused the participants to press on and reach for goals that may have been set prior to the disease onset. Some participants made accommodations or adjustments regarding activities and lifestyle including looking at those things that were possible, rather than the things that were not. A sense of frustration occurred with both acceptance of illness and with communication with health care professionals. Providers were not always able to answer all of the questions participants asked. The general emotional support from family, friends, and health care providers was paramount in the lived experience of these young adults. As stated previously, hope and optimism were the dominant subthemes in the research. This optimism caused acceptance of the need for lifelong medication use. The participants were willing to be responsible for their own care and followed the advice and instructions from healthcare providers in order to maintain optimum health.

### Summary

In this chapter, the results from the study and discussion pertinent to relevant literature were presented. Three themes were identified to describe the lived experience of young adults with chronic illness: (a) what happened?; (b) what now?; and (c) what next?. Nine subthemes were identified and further explained these themes.

Additionally, this chapter includes a discussion of how the themes related to Parse's (1998) Theory of Human Becoming and how the results of the current study related to current literature.



## CHAPTER V

### SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

#### Introduction

The purpose of this study was to investigate and describe the lived experience of young adults who have been diagnosed with a chronic illness. In this chapter a summary of this lived experience is discussed. Additionally, conclusions and implications for nursing practice, education and research are presented.

#### Summary

The design for this study was qualitative descriptive and was based on the tradition of phenomenology. The phenomenologic approach is inductive and its goal is to "describe lived experience" (Speziale & Carpenter, 2007, p. 77). Phenomenology attempts to describe the perceptions of human experiences as they are occurring without interjecting the bias of the researcher. Speziale and Carpenter state, "It is this lived experience that gives meaning to each individual's perception of a particular phenomenon and is influenced by everything internal and external to the individual" (p. 77). Thus, the description of life as experienced by young adults with chronic illness is an appropriate topic for this research approach.

The participants for this study were residents of a mid-western state, selected from a neurology clinic setting and also by personal referral. Data were collected through audiotaped interviews. The participants were asked to describe their experiences of living with a chronic illness. The audiotapes were transcribed verbatim and themes identified according to Spiegelberg's method of analysis. This method of

analysis includes intuiting, analyzing, and describing. These steps were undertaken to provide rich description of the data (Speziale & Carpenter, 2007). The interviews elicited emotional memories as well as strong feelings regarding the experience of life with a chronic illness.

The experiences of adults with chronic illness have been studied in terms of quality of life, satisfaction with health, social experience, coping, and adaptation (Baker & Wigintin, 1997; Bishop et al., 2007; Charmaz, 1995; Curtis et al., 2004; Fong et al., 2006; Gordon et al., 2001; Jolly, 2005; Long et al., 2000; Narayanasamy, 2003; Sokoll & Helliwell, 2001). A review of the current literature revealed, however, a gap in research involving descriptive data concerning the younger population with chronic illness. The current study examined the distinctive experiences of those adults who may be considered in the prime of their life, but are afflicted with a chronic illness. Probing questions were asked in order to obtain information about the time period directly before and after diagnosis and regarding adaptations that had been made in order to live the fullest life possible. Participants' lived experiences were analyzed according to how chronic illness affected their lives. The process of health was discussed and the concepts of adaptation and optimism predominated. According to Parse (1998), health is to be defined not as good or poor, but as a process, ever changing and interpreted by one's self and others.

Parse's Theory of Human Becoming (1998) is a school of thought rooted in human sciences. Parse states that each person should be considered as a whole rather than a collection of individual parts. Each person individually relates to his/her environment, always connecting with and separating from it, continuously co-creating health. She postulates that just as the universe affects the human, the human affects the universe,

and the two must co-exist based on choices made by the human. The objective of research directed by the Theory of Human Becoming is to understand the meaning of each person's lived experience and how it affects his or her existence. All three Principles of Parse's Theory of Human Becoming (1998) provided guidance in describing the experiences of young adults who had been diagnosed with chronic illness. Parse's three principles include: meaning, rhythmicity, and transcendence. Principle one of Parse's theory is based on meaning. Meaning can refer to every day occurrences as well as the greater purpose and significance of life; it is constantly transforming. Each participant was able to verbalize the meaning of chronic illness in their life as well as the value they put on current and sustained abilities, rather than on lack of ability. Principle two is rhythmicity, which involves paradoxical relationships. Some participants struggled initially whether to tell others or to conceal the diagnosis. Also, the outward appearance of the participants was one of complete health, despite the internal autoimmune process. The participants strived for a normal, pain free life, when in fact; many were in pain each day. The participants were able to live a potentially more fulfilled life due to their attitudes; however, the disease states limited each person in some way. The final paradoxical relationship can be explained by a need for a close support system, yet feeling isolated and not understood at times due to the process of illness. The third principle of Parse's Theory of Human Becoming involves transcendence. Transcendence deals with the idea that humans can strive to that which seems impossible. Every choice made affects the future in some way; the choices cause both limitations and new possibilities. Interpretation of each situation is based on the experience or inexperience in a certain situation. When adults are diagnosed with a chronic illness, initially, there is a process in which some degree of

acceptance seems important in deciding whether the future will be limited or vast. Transcendence is based on powering, originating, and transforming. Powering relates to aspirations and hesitations about the future. One participant verbalized a comfort in knowing his medications were working now, but was hesitant that they may not work forever to control his joint deterioration. As the universe changes, for instance with the unanticipated diagnosis of an incurable chronic illness, the human undergoes transformation in finding meaning and value in the new environment. Each human attaches unique meaning to individual situations and occurrences. In the current study, the participants were able to verbalize their interpretation of the experiences of living with a chronic illness.

These experiences were analyzed and the researcher identified the essence of the investigated phenomenon. The researcher described the phenomenon in question using terminology from the interviews. This was done in order to accurately communicate and describe the themes and subcategories of the phenomenon in question (Speziale & Carpenter, 2007). The themes related to the past, present, and future experiences as discussed by the participants. Initially, most participants verbalized a sense of disbelief and wondered if the diagnosis was accurate. Although experiencing symptoms, they wondered if healthcare providers would take their complaints seriously as symptoms can be transient and difficult to describe. The participants also articulated a sense of mourning. They felt as though their "normal" and healthy self was gone and replaced by a defective body. These imperfect bodies were not expected, and certainly not welcome. After the shock of diagnosis subsided, the participants verbalized an acceptance of the chronic disease state and were able to make adjustments in daily life to accommodate for joint stiffness, balance problems, or

decreased endurance. There was a definite impression of perseverance. Acceptance and perseverance allowed the participants to continue with life and reach for goals. A sense of frustration was verbalized, however, not only due to living life with a chronic illness, but also due a lack of specific information about the medications or the disease process from primary health care professionals. Each participant regularly saw a specialist for disease specific care. The frustration came about when primary providers were not knowledgeable about their specific chronic disease process and when communication was lacking. One challenge was deciding which question to ask which health care provider, the primary provider or the specialist. Some participants continue to have this type of frustration, while others have developed a collaborative healthcare team in which all members are aware of the status of medications as well as testing and monitoring. Participants verbalized the importance of support from family, friends, and health care providers throughout the process of diagnosis and management of their chronic illness. They articulated the need for a good listener and for someone who would be supportive throughout various life changes. Finally, the participants discussed the future in broad terms. No one knows the speed or severity in which chronic illness will progress, but a sense of hope and optimism was obvious in the interviews. Overcoming the diagnosis and continuing on with life was a common goal. Participants spoke of their futures, not based on illness, but on finding the best in their situation and looking on the bright side of life. The participants also voiced an acceptance with the need for life-long medications. These illnesses are not curable, but medications are used to slow the progression and physical damage. Participants verbalized an understanding of the importance of taking these medications.

When discussing the lived experience of chronic illness, each participant verbalized genuine optimism. Despite initial disbelief and occasional frustrations, the interviews revealed overwhelming acceptance and perseverance.

### Conclusions

The results of this study indicate these young adults had inner strength and the desire to overcome adversity in dealing with their chronic illness. The following conclusions were made about the study results:

1. The experience of these young adults with chronic illness is inspiring. Accepting a few limitations and having the perseverance to work toward personal fulfillment is not unlike the lives of young people without chronic illness.
2. Being diagnosed with a chronic illness at a young age causes feelings of denial and raises a question of sanity at times. Additionally, these young people felt a sense of mourning as they transitioned from a young and healthy adult to one with a chronic illness.
3. Support networks including family, friends, and health care providers are imperative to these young adults. Frustrations occur and it is crucial that support systems are available when patients need them.
4. In an otherwise optimistic group of people, the unknown future can be a tense topic. Young adults with chronic illness question the need for medication over the lifetime as well as the possibility that medications may not be useful for the entire course of the disease.

5. The young adults have an overwhelming sentiment of optimism and hope. They will not let their disease state hold them back in terms of any goal they hope to reach.

### Implications

#### *Nursing Practice*

Discussing the lived experience of those young adults with chronic illness has provided an increased understanding of their educational and emotional needs. Advanced practice nurses have the responsibility and privilege of providing primary care to all individuals, including those who have been diagnosed with a chronic illness at a young age. It is important that practitioners take the time to educate themselves about the implications of these illnesses in order to build trusting relationships with their patients. Patients look to primary care providers to coordinate care and to provide care services in a knowledgeable and caring manner. Life with chronic illness comes with many stressors; it is helpful for patients to know that teamwork between primary care providers and specialists is taking place so that the best interests of the patient are being met.

These young adults with chronic illness also verbalized a desire for healthcare providers to be a part of their support system. They needed health care providers to listen to what they had to say and support them in their lives. Encouragement and facilitation can occur by APNs providing holistic care. Patients may benefit from therapy, or may be looking for a support group. Advanced practice nurses can provide better care by being knowledgeable about the various disease processes, adding complementary therapies as needed, and by being a caring and supportive listener who

guides patients through the journey of living with a chronic illness. Nurses need to provide support, holistic healthcare and active listening to each patient, especially those with special circumstances.

### *Nursing Education*

Educators can incorporate the importance of treating each person as an individual into nursing curricula. Young adults have hopes and dreams for the future, as well as families to support and care for, whether they are living with a chronic illness or not. Young adulthood is a time of self-discovery, career establishment, and developing relationships and family. Nurses should be taught how to therapeutically communicate with patients so that the needs of each person are being met.

Primary care APNs can play a pivotal role in the lives of young adults with chronic illness. Advanced practice nurses should be instructed that these patients are the same as other young adults and have similar problems and concerns. Therefore, each person deserves thorough care and respect. Additionally, these patients are looking for collaboration between primary and specialty providers who will work together to coordinate care.

### *Nursing Research*

The results of this study have imparted some understanding of the lived experience of young adults with chronic illness. Recommendations for further research include:

1. Further qualitative research studies with a larger, more diverse sample in other geographical areas.
2. Further qualitative research with a broader range of chronic illnesses.
3. Using qualitative or quantitative research in a longitudinal design on a group



of patients beginning directly after diagnosis and following them through several years or even decades of illness management.

4. Quantitative research on young adults with chronic illness in areas of quality of life, perceived health and satisfaction with health.

### Chapter Summary

This chapter provided a summary of the current study. Conclusions that were drawn from the study were discussed. Implications for nursing practice, education and research were presented in relation to the lived experience of young adults with chronic illness.

APPENDIX A  
Demographic Questionnaire

## Demographic Data

Age \_\_\_\_\_

Diagnosis (circle one):                      Multiple Sclerosis                      Rheumatoid Arthritis  
   Psoriatic Arthritis                      Systemic Lupus Erythematosus

At what age were you diagnosed with this illness? \_\_\_\_\_

Gender (circle one):                      Male                      Female

Marital Status (circle one): Single      Married      Separated      Divorced  
Widowed      Living with significant other

Household Income (circle one):

|                  |                  |               |
|------------------|------------------|---------------|
| less than 15,000 | 15,000-24,999    | 25,000-34,999 |
| 35,000-44,999    | 45,000-54,999    | 55,000-64,999 |
| 65,000-74,999    | More than 75,000 |               |

Living Arrangement (circle one): Live alone  
Live with spouse, friend, family, or significant other  
Assisted Living

Education Level (circle one):    Less than high school                  High school or equivalent  
    Some college                      College graduate  
    Graduate school                  Post graduate school

Employment status (circle one): Full time                      Part time

Homemaker

| Self-employed (Full time)                   | Self-employed (Part time) |
|---|---------------------------|
| Unemployed, on disability compensation      |                           |
| Unemployed, without disability compensation |                           |
| Other                                       |                           |

APPENDIX B

UW Oshkosh IRB Approval Letter



Ms. Sonya Gilson  
E2709 Rockledge Rd.  
Casco, WI 54205

Dear Ms. Gilson:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: The Lived Experience of Young Adults with Chronic Illness.

Your research has been categorized as NON-EXEMPT, which means it is subject to compliance with federal regulations and University policy regarding the use of human participants as described in the IRB application material. Your protocol is approved for a period of 12 months from the date of this letter. A new application must be submitted to continue this research beyond the period of approval. In addition, you must retain all records relating to this research for at least three years after the project's completion.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail: [rauscher@uwosh.edu](mailto:rauscher@uwosh.edu)).

Sincerely,

Dr. Frances Rauscher  
IRB Chair

cc: Vicki Moss  
1263

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APPENDIX C  
Informed Consent

### Informed Consent: The Lived Experience of Young Adults With Chronic Illness

I give Sonya Gilson, a University of Wisconsin Oshkosh graduate nursing student permission to include me as a participant in her research study. I understand that she will audiotape an interview concerning the *Lived Experience of Young Adults With Chronic Illness*. I understand that I may stop the study at any time and may refuse to answer any questions that I choose. I understand that the information will remain confidential and will not have any impact on the health care I receive. I understand that there is no anticipated medical or social risk to me, other than the inconvenience of the time required for the interview. Benefits of this study include increasing the knowledge and understanding of healthcare professionals caring for young adults who have been diagnosed with a chronic illness.

If I have any questions regarding the study, I can contact Sonya or her research advisor, Dr. Vicki Moss, College of Nursing, UW Oshkosh, Oshkosh, WI 54901 (920) 424-2124. If I have any complaints about my treatment as a participant in this study, I can write or call:

Chair, Institutional Review Board  
For Protection of Human Participants  
C/o Grants Office  
UW Oshkosh  
Oshkosh, WI 54901  
920-424-1415

Although the chairperson may ask for your name, all complaints are kept in confidence.

I have received an explanation of the study and agree to participate. I understand that my participation in this study is strictly voluntary. If I do not wish to sign my name for confidentiality reasons, consent will be assumed through my voluntary participation in this study.

I agree to participate in the study: \_\_\_\_\_  
(name) (date)

I agree to be audio taped during the interview: \_\_\_\_\_  
(name) (date)

Thank you for your willingness to participate in this study.

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