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STRUGGLING WHILE MANAGING CHRONIC ILLNESS

A Thesis Submitted in
Partial Fulfillment of the Requirements
for the Degree of
Master of Science in Nursing
at Minnesota State University, Mankato

by
Amy M. Perkins, B.S.N.

May, 2011

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Amy M. Perkins, BSN

Struggling While Managing Chronic Illness

Amy M. Perkins, BSN

This thesis has been examined and approved by the following members of the thesis committee.

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TO: Vivian, Maxwell, and Eric

For Vivian, whose delightful smile and melodic giggles remind me of life's true meaning, and whose eyes hold promise of all that is yet to come.

For Maxwell, who first taught me the joy of motherhood, and whose loyal, honest, big-hearted, curious disposition inspires me to be worthy of his adoration.

For Eric, who encourages me to persevere and thrive, while profoundly touching me with his thoughtfulness, friendship, wit, and love.

With special thanks to my thesis advisor, Norma, for her advice and assistance.

Abstract

Although research documenting the struggling response to chronic illness would assist nurses in understanding their patients and potentially in the assessment and support of struggling patients, such research is only in the infancy stage. The purpose of this research study was to address the rarity of literature describing and defining the concept of families struggling while managing chronic illness. Using Strauss and Corbin's paradigm model and grounded theory methodology, the researcher analyzed interviews with nine rural families managing chronic illness. The analysis revealed that families managing chronic illness struggled with everyday living, to obtain a diagnosis, with spiritual beliefs, and with cognitive and existential thoughts, encompassing mind, body and spirit struggles. Struggling occurred within and between individuals and groups. A thought process, more specifically, an awareness, interpretation, deciphering of meaning, or perception was a strong component of the struggling experience. The core phenomenon identified was struggling, which was preceded by the causal conditions perceiving uncertainty and/or vulnerability and ascribing negative meaning to illness management. Struggling occurred within the context of managing chronic illness. Intervening conditions for struggling were ineffective adapting and adapting. Action/interaction strategies for struggling were denying, emphasizing loss, fostering independence, strengthening relationships, and turning to faith. Consequences of the action/interaction strategies were stagnating and reintegrating. In light of this study's findings, struggling while managing chronic illness is defined as the perception of a difficult process (e.g., a battle, conflict, strenuous effort, or task) while managing chronic illness. The perception of great difficulty is often preceded by perception of vulnerability

or uncertainty and/or ascribing negative meaning to chronic illness management. The difficult process can occur within the body, mind, or spirit of a person or group of persons. The understanding of struggling as a perception makes it relatable to other literature exploring perceptions, representations, and ascribed meanings of not only illness experiences, but also other experiences, such as pain and treatments. Nurses can help those managing chronic illness identify its associated perceptions and representations, which in some cases is struggling.

TABLE OF CONTENTS

	Page
LIST OF TABLES	vi
LIST OF FIGURES	vii
CHAPTER	
I. INTRODUCTION	1
Background	1
Significance of the Study	2
Problem Statement	3
Purpose of the Study	4
Research Questions	5
Operational Definitions	5
Assumptions of the Study	6
Limitations of the Study	6
Conclusion	6
II. REVIEW OF THE LITERATURE	8
Introduction	8
Intrapersonal Struggling	9
Physical Intrapersonal Struggling	9
Cognitive Intrapersonal Struggling	10
Spiritual Intrapersonal Struggling	14
Existential Struggling	16
Family Struggling	18
Sociocultural Struggling	19
Summary	20
Conclusion	23
III. RESEARCH METHODS AND DESIGN	
Introduction	24
Research Study Design	24
Original Study	25
Population Sample and Setting	26
Procedures for Original Study	26
Scientific Rigor of Original Study	29
Research Study from Archived Data	29
Data Analysis	30

Scientific Rigor	30
Summary	31
IV. STUDY FINDINGS.....	32
Introduction.....	32
Findings.....	32
The Paradigm Model.....	32
Causal Conditions	33
Perceiving Uncertainty and/or vulnerability	33
Ascribing Negative Meaning to Managing Chronic Illness	34
Phenomenon.....	38
Struggling With Everyday Living.....	38
Struggling to Obtain a Diagnosis	40
Spiritual Struggling.....	41
Cognitive and Existential Struggling	42
Context.....	42
Intervening Conditions.....	43
Ineffective Adapting	43
Adapting.....	44
Action/ Interaction Strategies	45
Denying.....	45
Emphasizing Loss	45
Fostering Independence	46
Strengthening Relationships	46
Turning to Faith	47
Consequences.....	47
Stagnating	47
Reintegrating.....	48
Conclusion	48
V. DISCUSSION	49
Introduction.....	49
How Families Struggle While Managing Chronic Illness	49
A Definition of Struggling While Managing Chronic Illness	50
Comparison of Study Findings to Other Research	51
Implications for Nursing Practice	54
Future Research Directions.....	55
Conclusion	56
REFERENCES	58

LIST OF TABLES

Table	Page
1. Review of Literature	67

LIST OF FIGURES

Figure	Page
1. Struggling While Managing Chronic Illness	81

What counts in life is not the victory, but the struggle.

Pierre de Coubertin (Julliard, 2008)

Chapter I: Introduction

This chapter provides the background, significance of the study, problem statement, purpose of the study, research questions, operational definitions, assumptions, and limitations of the study.

Background

Depictions of human struggling abound in literature. In the *Old Man and the Sea*, for example, Ernest Hemingway describes Santiago's three-day struggle to catch and bring to shore an enormous marlin despite hunger, fatigue, and sharks. The struggle between good and evil is a common theme in literature, as between the Bible's Devil and God, Shakespeare's *Othello* and Iago, Stevenson's *Dr. Jekyll and Mr. Hyde*, and evil human nature and goodness in Golding's *Lord of the Flies*. *Huckleberry Finn* experiences struggle in the form of an intrapersonal conflict between his belief that Jim should be treated as an inferior slave and his growing regard for Jim.

Literary depictions of struggles demonstrate that the word "struggle" is nuanced with not only several tenses and parts of speech, but also with several meanings. For the verb struggle, the *New Oxford American Dictionary* (Stevenson & Lindberg, 2010, p. 1728) provides the core sense, "make forceful or violent efforts to get free of restraint or

constriction,” as in “he struggled to break free.” The same dictionary provides four sub-senses of the verb struggle:

1) “strive to achieve or attain something in the face of difficulty or resistance,” as in “many families struggle to make ends meet,” 2) “have difficulty handling or coping with,” as in, “passengers struggle with bags and briefcases,” 3) “engage in conflict,” as in “politicians continued to struggle over familiar issues,” and 4) “make one’s way with difficulty,” as in “he struggled to the summit of the world’s highest mountain.” The noun struggle has similar core and sub-senses.

Nursing, medicine, and allied health literature portray struggles in various settings and manners (Hughes, Gudmundsdottir, & Davies, 2007; van Mens-Verhulst, Radtke, & Spence, 2004; Whittemore, Chase, Mandle, & Roy, 2002). Struggles portrayed among the chronically ill are particularly poignant because of the length, depth, and number of struggles. The struggles associated with chronic illness can be in the form of internal turmoil or external conflict (Moser, van der Bruggen, Spreuwenberg, & Widdershoven, 2008; Travers & Lawlers, 2008), not unlike the battles between internal or external forces described in many literary works. Struggling with chronic illness can also take the form of persevering despite a particular difficulty (Becker, 1993; Kvigne, Kirkevold, & Gjengedal, 2004), as did Santiago, the marlin fisherman.

Significance of the Study

Struggling associated with chronic illness is of particular importance to nurses because of their unique responsibilities. The American Nurses Association defines nursing as “the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of

human response, and advocacy in the care of individuals, families, communities, and populations” (2011, p. 1). While the direct care giving position of nurses allows them to recognize the struggling experience of others, the “optimization of health” role of nurses motivates them to determine how struggling affects patients’ health and whether interventions are warranted.

To recognize struggling and understand how it affects the health of others, nurses need knowledge of struggling. Knowledge originating from the discipline of nursing is particularly appropriate, for it focuses on “understanding human responses and determining the best interventions to promote health, prevent illness, and manage illness” (Burns & Groves, 2009, p. 2). Although research documenting the struggling response to chronic illness would assist nurses in understanding their patients and potentially in the assessment and support of struggling patients, this paper will demonstrate that such research is only in the infancy stage. The comprehensive description of struggling provided in this paper will provide groundwork for future studies, since descriptive research lays a foundation for research that explains, predicts, and controls phenomena (Burns & Grove, 2009).

Problem Statement

The struggles of people with chronic illness are incompletely documented in nursing literature. Specifically, a search for “struggle” or “struggling” on January 16, 2011 in the Cumulative Index to Nursing and Allied Health Literature (CINAHL) resulted in 1059 documents, and a search for “struggle” or “struggling” in the title and abstract resulted in 2713 documents. However, a search for “struggle” or “struggling” in the subject resulted in zero documents. Indeed, an examination of the documents with

struggling in the title revealed that most of these are not on the topic of struggling itself, but are examining another topic, with “struggle” or “struggling” added to the title to convey the challenge involved (Adamsen et al., 2009; Nochi, 1998). Examination further revealed a lack of an adequate definition of struggling, absence of a concept analysis of struggling, and a scarcity of struggling descriptions. Additionally, much of the struggling literature that does exist is not pertinent to chronic illness, dealing instead with reading difficulty, political conflict, change issues, or acute illness.

Much of the available literature describing the struggling experience of people with chronic illness describes a particular chronic illnesses of a particular population, thereby limiting its relevance (Kvigne et al., 2004; Sigurgeirsdottir & Halldorsdottir, 2008; Talseth, Gilje, & Norberg, 2003; Travers & Lawlers, 2008). At times a process very like a struggle is described, but with different terminology, such as obstacles people with chronic illness face in attempting to “achieve harmony within oneself” (Delmar et al., 2005, p. 204). In summary, the existing literature does not adequately describe or define struggling.

Purpose of the Study

The purpose of this research study was to address the rarity of literature describing and defining the concept of families struggling while managing chronic illness. This study addresses the process of struggling while managing chronic illness as identified by the Family Nursing Research Team of the Minnesota State University Mankato School of Nursing. The Family Nursing Research Team has conducted several research studies to understand the experience of families living with chronic illness, including the experience of struggling and its role in family reintegration. This paper

used the Family Reintegration in Chronic Illness Model developed by the Family Nursing Research Team as a theoretical framework (Meiers, Eggenberger, Bliesmer, Earle, & Krumwiede, 2005).

Research Questions

Two research questions guided this study:

1. How do families struggle while managing chronic illness?
2. What is the definition of struggling while managing chronic illness?

Operational Definitions

Chronic Illness - Presenting an overview and theory of chronic illness, Lapham (1986) defines chronic illness as “an illness lasting more than three months in a given year,” adding that other criteria often used “include the existence of a residual disability, the requirement of special training or rehabilitation, or the necessity of a long period of medical supervision, observation, or care” (p. 4).

Family - After acknowledging that definitions of family change with time and differ by discipline, Kaakinen, Gedaly-Duff, Coehlo, and Hanson (2010) define family as it relates to family health care nursing as “two or more individuals who depend on one another for emotional, physical, and economic support. The members of the family are self-defined” (p. 5). This definition is appropriate for the purpose of this paper.

Struggling - The core sense of the verb struggle according to the New Oxford American Dictionary (Stevenson & Lindberg, 2010, p. 1728) is to “make forceful or violent efforts to get free of restraint or constriction,” and this definition is initially used in this paper, where the restraint or constriction refers to chronic illness and the difficulties associated with chronic illness, and forceful efforts can include strenuous

cognitive, physical, spiritual, family, and sociocultural efforts. A more comprehensive description and definition of struggling generated from this study will be presented in Chapters IV and V.

Assumptions of the Study

This study was supported by the following assumptions:

1. People with chronic illness struggle.
2. The experience of struggling with chronic illness can be described.
3. Struggling while managing chronic illness can be defined.

Limitations of the Study

Several conditions limit the generalizability of the study.

1. The data is generated from a sample of only nine families.
2. Only one researcher is extrapolating struggling themes from the data.
3. All study participants are from the same general geographical area.
4. The qualitative nature of the study cannot demonstrate causality.

Conclusion

This chapter has delineated the need for a deeper understanding of struggling while managing chronic illness. Chapter II of this research study explores the professional literature to more fully understand the concept of struggling with chronic illness. Chapter III describes the research methods and derivation of struggling knowledge and relationships. Chapter IV presents findings of the study and uses the findings to describe struggling while managing chronic illness. Chapter V defines struggling while managing chronic illness, compares the results of this study with other

research, discusses the implications of this study for nursing practice, and makes recommendations for future struggling research.

Chapter II: Review of the Literature

Introduction

Struggling in the sense of strenuous effort despite difficulty and struggling in the sense of a clash or battle are both represented in nursing literature and in the literature of other disciplines. This chapter presents a review of literature on the concept of struggling. The various factors contributing to and resulting from struggling are also explored. To identify the existing literature describing struggling with chronic illness, 40 databases, including Academic Search Premier, CINAHL, EBSCO, SAGE, and Medline were searched. Search terms included “struggle” and “struggling,” in the title and abstract and were narrowed down to include only those that had subjects with chronic illness and/or discussed the meaning of struggling in relation to illness. Other struggling research not yet reviewed but referenced in the literature was obtained and subsequently reviewed as well. Non-scholarly articles were excluded, as were articles with no description of a struggling experience. Although the majority of articles in the literature review are from the nursing discipline, physical therapy, psychology, theology, social work, and philosophy disciplines are also represented.

The 40 articles and two books resulting from this extensive literature search and review were systematically synthesized to better understand the concept of struggling and are summarized in Table 1: Literature Review Table. Literature on struggling revealed three categories of struggling: intrapersonal struggling (including physical, cognitive,

spiritual, and existential intrapersonal struggling), family struggling, and sociocultural struggling.

Intrapersonal Struggling

The majority of struggles identified in the literature review are intrapersonal. Physical, cognitive, spiritual, and existential intrapersonal struggles are described in the literature.

Physical intrapersonal struggling.

Although most of the intrapersonal struggles described in the literature identify awareness, perception, or other thought processes as a component of the struggle, this section presents the intrapersonal struggles with physical aspects. For example, as Whittemore et al. (2002) describe, newly diagnosed type 2 diabetics struggle to incorporate recommendations into their lifestyle. The authors' interpretive research revealed a struggle between enjoyment of food and guilt over suboptimal choices resulting in blood sugar variability. However, struggle is one factor necessary to develop balance "between structure and flexibility, fear and hope, conflict and acceptance, diabetes and life" (p. 18). The struggle type 2 diabetics experience can also be described as vulnerability between old and new behaviors (Moser et al., 2008). Diabetics also struggle with self-image, between seeing themselves as healthy and accepting chronic illness as part of their lives (Moser et al., 2008). Comprehending, struggling, evaluating, and mastering are phases type 2 diabetics experience in the process of identification (Moser et al., 2008).

People living with irritable bowel syndrome (IBS) have been described as "struggling with an unfamiliar and unreliable body," and as struggling between the

limitations of an unreliable body and the “will to exceed limitations and become familiar with one self” (Hakanson, Sahlberg-Blom, Nyhlin, & Ternestedt, 2008, p. 29). Patients with chronic kidney disease requiring maintenance hemodialysis have been described as “struggling with time-consuming care” (Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2005, p. 294). Blijlevens, Hocking and Paddy’s (2009) exploration of the experience of adults with dyspraxia defined struggle as working or striving, and exerting energy and force” (p. 470). The investigators found that dyspraxia leads to a struggle with everyday living, including struggling with the physical world around them, struggling with their own physical self, and overcoming the struggle. The outcome of struggling could be despair and disappointment or achievement and surprises. Perseverance is a factor in overcoming the struggle with everyday living.

Lofgren, Ekholm, and Ohman’s (2006) work exploring strategies of women with fibromyalgia to control symptoms is unique in that it describes struggling as a never-ending process and as a positive response to grieving and accepting the diagnosis of fibromyalgia. The authors indicate that grieving fibromyalgia is a prerequisite for the life-long constant struggle against fibromyalgia consequences and symptoms. The struggle includes ‘walking a tightrope,’ learning/ being knowledgeable, creative solutions, pain as a guide, setting limits, positive thinking, taking care of oneself, and enjoying life.

Cognitive intrapersonal struggling.

Several descriptions of cognitive intrapersonal struggling are described in the literature. For example, Ekback, Wijma, and Benzein (2009) describe the experience of

women with hirsutism as one in which the women envision themselves without excess hair, thus transcending their bodies, resulting in a struggle back to a normal, healthy life.

Researchers have demonstrated that survivors of myocardial infarction (MI) struggle. Specifically, Johnson and Morse (1990) found that “the major process in the adjustment after an MI is the struggle to regain control” (p. 128). Responses such as defending their pre-MI actions, coming to terms with their diagnosis, learning how to live after an MI, and living again are all part of the struggle to regain a sense of control of their lives. Similarly, Fleury, Kimbrell, and Kruszewski (1995) identified that women healing after a cardiac event experience a struggle through uncertainty before establishing positive health patterns.

After analyzing the narratives of patients living with advanced cancer, Coyle (2004) ascertained that advanced cancer pain leads to a struggling process consisting of an internal dialogue. The internal dialogue processes previous experiences with pain and opioid side effects with current pain experiences and feelings about desires to live with mental clarity versus a desire to hasten death (Coyle, 2004). According to Nelson (1996), cancer may also lead to a struggle to gain meaning in the experience. In her work examining the experience of women living with breast cancer, she conceptualizes struggling as an aspect of uncertainty. Struggling to gain meaning captures the uncertainty experience. Subthemes include struggling with emotions, struggling to gain value through relationships and support systems, struggling to move forward despite uncertainty, struggling to return to normal, and struggling with multiple possible outcomes.

Travers and Lawler's (2008) qualitative research of Australians living with chronic fatigue syndrome (CFS) revealed that CFS sufferers endure threats such as disruption (including body failure, unpredictability, illness invisibility, functional impairments, dependency, and loss) and invalidation (such as disbelief, dismissal, stigma, and turning the abnormal into the normal). These threats to CFS sufferers result in a struggling self seeking renewal. The struggle is between guardianship (a defensive response characterized by assuming the burden of proof, internality, self-defense, and vigilance) and reconstructing (a renewing and redefining response characterized by reflection, a positive perspective, and an external focus). The authors assert that the theme of the struggling self extrapolated from their research is consistent with Paterson's Shifting Perspectives Model of Chronic Illness, in which chronic illness sufferers alternate between a wellness and an illness perspective (Paterson, 2001). Paterson asserts that the Shifting Perspectives Model more accurately depicts the experience of chronic illness than traditional linear models. Although Paterson does not use the term struggle, Travers and Lawler's aforementioned use of the model to describe the struggle of CFS sufferers is understandable in that Paterson describes a repeating cycle between a threat to control causing a focus on illness and a bouncing back causing a focus on wellness.

The experience of a stroke also leads to struggle, as Kvigne et al. (2004) found in their phenomenological research of 25 female stroke survivors. The women experienced at least five types of struggle, including both the particularly difficult type and of the conflicting forces type. The types of struggle the researchers described are "fighting off disabling feelings and maintaining the will to live, striving to regain the power to accomplish necessary and valued activities, striking a balance between attending to the

needs of others and addressing increased personal needs, attempting to maintain control of valued female roles and accept help, and negotiating relationships on equal terms” (p. 375). These struggles can be encompassed as a struggle to preserve the self and continue a meaningful life, which required interacting with the world in new ways. Other themes derived from the research included balancing contradictory feelings, uncertainty, vulnerability and transcendence. Becker’s (1993) research on the experience of stroke survivors also mined a struggling theme, that of struggling for a sense of continuity between the pre- and post-stroke periods. This struggle for a sense of continuity includes struggles to “reconcile the person they once were with the non-functioning person they had become” and to “carry out basic tasks of living that they had once taken for granted” (p. 153). One survivor was able to reconcile the struggle by reintegrating her old life with her new.

Sufferers of mental illness may experience cognitive struggles as well. Talseth et al. (2003) describe the struggle of suicidal patients to become ready for consolation as a struggle mediating a desire to be connected to others while in a state of disconnection with oneself. The suicidal person letting go of the struggle results in opening up and a readiness for consolation. Randall (1992) describes a different type of struggle experienced by suicidal persons: the struggle with the absurdity and captivity of the world. Hope and a will to live are necessary to confront that struggle. According to D’Abundo and Chally (2004), women with eating disorders initially struggled to gain control through eating disorders when other areas of their life seemed out of control. The researchers also describe the recovery period as a continuous struggle between recovery and relapse. Since expectations look to the future, Lindgren, Wilstrand, Gilje, &

Olofsson (2004) reason that clear expectations foster hopefulness. Further, shifting between unmet and met expectations heightens vulnerability. This understanding provides background for the authors' finding among women who self harm of a "struggle for hopefulness through expectations to be confirmed, whether met or unmet" (p.289). Subthemes include being seen or not being seen, being valued or stigmatized, being connected or disconnected, being believed or doubted, and being understood or not understood.

The struggling experienced when grieving a personal loss may have a positive outcome. In his interviews of grieving persons, Cody (1991) defined struggling as "*powering*, the process of pushing-resisting with the was, is, and not-yet all at once" (p. 67) and extrapolated the theme of "struggling in the flux of change" (p. 67), which may lead to a transformation, allowing the griever to move past the now and become in new ways.

Spiritual intrapersonal struggling.

Although spiritual struggling is a different concept from struggling with chronic illness, it is well-described in the literature and shares some commonalities with the struggles associated with chronic illness. Spiritual struggles are next defined and described.

Pargament, Murray-Swank, Magyar, and Ano (2005) define spiritual struggles as "efforts to conserve or transform a spirituality that has been threatened or harmed" (p. 247). The authors point to major crises and distresses, particularly those that force people to consider new ways of acting, relating and thinking, as antecedents to spiritual struggling. Likening crises to forks in the road, the authors demonstrate that the

consequences of spiritual struggles can be either hopelessness and despair or growth and transformation, depending on the person's capacity to resolve the struggle.

McConnell, Pargament, Ellison, and Flannelly (2006) also defined spiritual struggles as "efforts to conserve or transform a spirituality that has been threatened or harmed" (p. 1470). The authors measured spiritual struggles with a Negative Religious Coping subscale of RCOPE, a religious coping measurement tool. Respondents' answers demonstrated that spiritual struggling significantly predicted psychopathology, including depression, paranoid ideation, anxiety, phobic anxiety, somatization, and obsessive-compulsiveness. Further, individuals who had experienced recent illness had a stronger relationship between spiritual struggling and anxiety or phobic anxiety.

In another study using the same Negative Religious Coping subscale as a measure of spiritual struggling, positive answers to the statements "Wondered whether God had abandoned me," "Questioned God's love for me," and "Decided the devil made this happen" were predictive of mortality among elderly ill patients (Pargament, Koenig, Tarakeshwar, & Hahn, 2001). The authors speculate that the relationship could be because the struggle worsens physical health, because of personality or emotional differences in individuals who struggle religiously, or because religious struggle may lead to social isolation. Sherman, Simonton, Latif, Spohn, & Tricot (2005) also used negative religious coping to describe the religious struggles of multiple myeloma patients preparing for a stem cell transplant. The researchers determined that those struggling with their religion because of their cancer also had more depression, distress, pain, and fatigue. Of note, Koenig, Pargament, & Nielsen (1998) used the same measure to research relationships between religious coping and health, and found that while negative

religious coping related to poorer quality of life and worse physical health, learning to live with illness and accepting reality was correlated with better physical health.

Maunu and Stein (2010) found that adult children whose parents suffer from mental illness reported various amounts of personal loss as a result of their parents' illness. The adult children who experienced more loss also experienced more spiritual struggles than those who reported less loss. In this study spiritual struggles were defined as "religious/spiritual questions and concerns that having a parent with mental illness had raised" (p. 651).

Halstead and Hull (2001) chose the simple definition of struggling, "making one's way with effort," in their examination of the spiritual development of women with cancer. Their research revealed the theme of "struggling with paradoxes" (p. 1534). The multiple paradoxes described (such as wanting to be in control but needing to let go) are similar to the "movement between different aspects of being" (Wiklund, 2008, p. 2429) described in some existential struggling literature. Halstead and Hull's analysis of the experience of struggling is unique in that the processes described, such as deciphering meaning, letting go, redefining meaning, identifying growth, and reintegration are all encompassed within struggling, rather than in a linear process or as antecedents or consequences to struggling. The authors also noted that the women's experiences could not be separated into bodily, spiritual, and mental experiences. Rather, the authors described a holistic relationship between the women's minds, bodies, and spirits.

Existential struggling.

While some researchers have applied the term "existential" to the search for meaning in a spiritual context, others, wanting to avoid religious connotations or desiring

a broader meaning, have applied the term to “human thoughts on how to understand the world, the meaning of life, and how one should live it” (Wiklund, 2008, p. 2431).

Several studies demonstrate that chronic illness is associated with such contemplation, sometimes termed “existential struggling.” Wiklund’s exploration of the existential struggles of people living with addiction reveals a struggle between death and life during which people meet existential struggles. These struggles are defined as a “movement between different aspects of being,” (p. 2429) such as meaning and meaninglessness, connectedness and loneliness, and control and chaos. Wiklund’s research appears to indicate that others can promote growth in people living with addiction by promoting the positive aspects of the struggles, such as meaning, connectedness, and control.

Heightened awareness or perception of the limitations chronic illness imposes or the differences between the present self and the past self prompt existential struggle. For example, Paulson, Danielson, and Soderberg (2002) found that for men with fibromyalgia, feelings of not being the person one was when healthy involves a long process of struggling to live tolerably and find balance. Even so, after enduring, resisting, or sustaining through the struggle, the men could see the world “with new eyes” (p. 247). Chronic illness may also prompt the struggle to be deserving of care from care providers while at the same time be seen as valuable and able to manage oneself (Strandberg, Astrom, and Norberg, 2002). Henoeh and Danielson’s 2009 integrative literature review of existential concerns among cancer patients establishes the theme of struggling to preserve self-identity. A vulnerable situation, such as battling cancer, can threaten values, at which point a struggle to protect self-identity ensues. The person with

cancer may then redefine the situation and/or use helpful relationships (with others or with God).

Similarly, Stevens (1996) found that as HIV-positive women began to experience symptoms such as fatigue and wasting, they became fearful and experienced existential pain, feeling that the fatigue of AIDS changed their self-identity. They subsequently struggled to prevent HIV symptoms from taking hold, or taking over their lives through regimen noncompliance and health care avoidance. Sigurgeirsdottir and Halldorsdottir (2008) describe the existential struggle experienced by rehabilitating persons as a paradox between accepting a changed identity and holding on to aspects of the person they once were. Informants said the struggle made them feel vulnerable and caused them stress.

Family Struggling

In their analysis of the struggle of women with asthma who are also mothers, van Mens-Verhulst et al. (2004) describe the challenges these women face. The researchers explain that the mother role can include the exertion of childcare and housework and exposure to cleaning products, pets, campfires and other triggers that exacerbate asthma symptoms. Thus, mothers struggle to balance their perceived roles as mothers with their needs for rest and symptom management. When one parent has multiple sclerosis, struggles with teenage children may contribute to the parents as a couple feeling out-of-sync with one another (Starks, Morris, Yorkston, Gray, & Johnson, 2010). Nystrom and Svensson (2004) ascertained that fathers of adult schizophrenic people undergo a particular sequence of events. After the son or daughter is diagnosed with schizophrenia, the father feels shock, stress, and chaos, and that he has lost control. He subsequently

struggles to gain control, which involves a combination of “grieving a child who will not fulfill the dreams and hopes of the parent, keeping up self-esteem as men and fathers, and finally adapting to a previously unexpected life situation” (p. 375). The struggle for control has an origin in the father’s concern for his family. Ultimately, the father regains control of his own existential situation. Yamashita (1998) also identified a struggle followed by a positive outcome for parents of schizophrenic children. The author identified the theme of struggling alone among care-givers, which summarized the experience of being alone in knowing their son or daughter needed help but not having a diagnosis or information about the meaning of schizophrenia. After the struggling period, participants transcended their limitations, coming to an understanding and acceptance of the illness.

Siblings of schizophrenic patients struggle to understand what it is their siblings are experiencing before the diagnosis is made, and after the diagnosis is made, they struggle to understand what schizophrenia is (Barnable, Gaudine, Bennett & Meadus, 2006). Seven themes emerged in Coffey’s (2006) metasynthesis of studies describing the experience of parenting a child with chronic illness. One was “staying in the struggle” (p. 54), which meant not giving up and developing strategies to accurately assess their children or incorporate recommended treatments.

Sociocultural Struggling

A cancer diagnosis in urban poor persons may lead to sociocultural struggle. Hughes et al. (2007) describe a struggle “to survive both life and cancer,” referring to the difficulty in managing both basic survival of life in poverty and cancer care needs.

Parents of children diagnosed with cancer have struggled to obtain an initial evaluation and diagnosis, and subsequently felt relieved and vindicated when a diagnosis was finally made (Dixon-Woods, Findlay, Young, Cox, & Heney, 2001). Patients on maintenance hemodialysis for chronic kidney disease have been described as struggling to be seen as a human rather than something connected to a machine (Hagren et al., 2005). Similarly, patients with multiple sclerosis struggle for dignity and to be seen as worthy, despite their disease and the quality of their care (Lohne, Aasgaard, Caspari, Slettebo, & Naden, 2010). In some cases, these patients also struggle to receive the help they need from health care providers. Siblings of schizophrenic patients struggle not only to understand their siblings' symptoms and diagnosis, but also struggle with the health care system to obtain information about their siblings' health and to access adequate services for their siblings (Barnable et al., 2006). Soderberg, Lundman, & Norberg, (1999) found that fibromyalgia caused participants threats to the self, including lost freedom, threatened integrity, and a struggle to obtain relief and an understanding. Because being perceived as credible is associated with dignity, others discrediting the fibromyalgia and showing disrespect led the women to the additional interpersonal struggle for dignity.

Summary

Several themes are identifiable in struggling literature. Many chronic health conditions can lead to struggling, including stroke (Becker, 1993; Kvigne et al., 2004), dyspraxia (Blijlevens et al., 2009), cancer (Coyle, 2004; Halstead & Hull, 2001; Henoeh & Danielson, 2009; Hughes et al., 2007; Nelson, 1996; Sherman et al., 2005), eating disorders (D'Abundo & Chally, 2004), hirsutism (Ekback et al., 2009), cardiac events

(Fleury et al., 1995; Johnson & Moore, 1990), chronic kidney disease (Hagren et al., 2005), IBS (Hakanson et al., 2009), mental illness (Lindgren et al., 2004; Talseth et al., 2003), fibromyalgia (Lofgren et al., 2006; Paulson et al., 2002; Soderberg et al., 1999), diabetes (Moser et al., 2008; Whittemore et al., 2002), addiction (Wiklund, 2008), HIV (Stevens, 1996), CFS (Travers & Lawlers, 2008), MS (Lohne et al., 2010), and asthma (van Mens-Verhulst et al., 2004). Attempting to get a family member diagnosed (Barnable et al., 2006; Dixon-Woods, 2001; Yamashita, 1998) or having a family member with chronic illness (Coffey, 2006; Maunu & Stein, 2010; Nystrom & Svensson, 2004) can also lead to struggling.

Struggles may also occur between the person with chronic illness and other family members (Starks et al., 2010; Strandberg et al., 2002). Uncertainty or vulnerability (Fleury et al., 1995; Halstead & Hull, 2001; Kvigne et al., 2004; Moser et al., 2008; Nelson, 1996; Sigurgeirsdottir & Halldorsdottir, 2008); desire for control (D'Abundo & Chally, 2004; Halstead & Hull, 2001; Johnson & Morse, 1990; Kvigne et al., 2004; Nystrom & Svensson, 2004; Wiklund, 2008); acceptance of chronic illness (Halstead & Hull, 2001; Koenig et al., 2008; Kvigne et al., 2004; Lofgren et al., 2006; Moser et al., 2008; Whittemore et al., 2002; Yamashita, 1998); persevering or enduring (Becker, 1993; Blijlevens et al., 2009; Lofgren et al., 2006; Paulson et al., 2002); and growth, transcendence, reconstruction, or reintegration themes also emerged (Becker, 1993; Ekback et al., 2009; Halstead & Hull, 2001; Kvigne et al., 2004; Nelson, 1996; Pargament et al., 2005; Travers & Lawler, 2008; Wiklund, 2008; Yamashita, 1998).

People struggle with and for various concepts, including struggling with everyday living (Blijlevens et al., 2009), struggling for control (D'Abundo & Chally, 2004;

Nystrom & Svensson, 2004), struggling for meaning (Kvigne et al., 2004; Nelson, 1996), struggling for hopefulness (Lindgren et al., 2004), struggling for a tolerable existence (Paulson et al., 2002); struggling for dignity (Soderberg et al., 1999) and struggling to maintain an image of oneself (Strandberg et al., 2002).

Perhaps the most common theme apparent in the literature review is in the description of a thought process, more specifically, the awareness, interpretation, deciphering of meaning, or perception component of struggling. Sometimes the thought process is in the form of an acute awareness of illness-induced changes to the self, and a search for the meaning of one's changed life in the context of managing chronic illness, typically but not consistently termed existential struggling (Becker, 1993; Henoch & Danielson, 2009; Nystrom & Svensson, 2004; Sigurgeirsdottir & Halldorsdottir, 2008; Stevens, 1996; Strandberg et al., 2002; Wiklund, 2008). Other times the thought process is in the form of spiritual struggling, associated with questioning or redefining one's spirituality (Halstead & Hull, 2001; Koenig et al., 1998; Maunu & Stein, 2010; McConnell et al., 2006; Pargament et al., 2001). Several other studies describe a thought process as a component of struggling other than existential or spiritual struggling (Coyle, 2004; Lindgren et al., 2004; Lohne et al., 2010; Moser et al., 2008; Nelson, 1996; Paulson et al., 2002; Randall, 1992; Soderberg et al., 1999; Talseth et al., 2003).

While there is some corroboration amongst the articles in themes such as the perception component of struggling, there is also discordance among researchers in the conceptualization of struggling. For example, struggling is said to entail "working or striving, and exerting energy and force" (Blijlevens et al., p. 470); "*powering*, the process of pushing-resisting with the was, is, and not-yet all at once" (Cody, 1991, p. 67);

“making one’s way with effort” (Halstead & Hull, 2001, p. 1536); “a balance” (Nystrom & Svensson, 2004); and “movement between different aspects of being” (Wiklund, 2008, p. 2429). Usually struggling is followed by another state, sometimes negative (Barnable et al., 2006; Starks et al., 2010), sometimes positive (Cody, 1991; Dixon-Woods et al., 2001; Ekback et al., 2009; Fleury et al., 1995; Moser et al., 2008; Nelson, 1996; Nystrom & Svensson, 2004; Paulson et al., 2002; Sigurgeirsdottir & Halldorsdottir, 2008; Talseth et al., 2003; Whittemore et al., 2002; Yamashita, 1998), and sometimes either (Blijlevens et al., 2009; Wiklund, 2008). Although typically framed as a process with a beginning and end, struggling is occasionally conceptualized as a continuous, lifelong process (D’Abundo & Chally, 2004; Lofgren et al., 2006).

Conclusion

Although the literature review reveals some dissonance in researchers’ conceptualization of struggling, this paper will demonstrate that some congruence in the concept can be identified to assist in answering the research questions. Additionally, findings from analysis of qualitative data obtained from interviews of families managing chronic illness will be harmonized in a conceptual model. Chapter III will describe the methodology of the qualitative research.

Chapter III: Research Methods and Design

Introduction

As delineated in Chapter I, the purpose of this research study was to address the rarity of literature defining and describing the concept of families struggling while managing chronic illness. The rarity was addressed by integrating the literature review described in Chapter II with research findings from analysis of archived data. A grounded theory research study was used. The research design of the original study, data analysis, and scientific rigor are described in this chapter.

Research Study Design

Qualitative research is a systematic, interactive, subjective approach used to describe life experiences and give them meaning. The intent is inductive, that is meaning emerges from the data (Creswell, 2003). The goal of a qualitative research study is to holistically examine the whole rather than the parts (Burns & Grove, 2009, p. 22). The research design for this descriptive qualitative study approach used grounded theory methodology with a focus on family social processes as it is rigorous and particularly helpful in knowledge development related to families. This research method was originally developed to view the symbolic interactions of human behaviors; subsequently it was utilized to examine the family processes by scholars in the family social science arena (Strauss & Corbin, 1990).

Grounded theory is the rigorous systematic study that derives theory from the data (Strauss & Corbin, 1990). Grounded theory research is dynamic, and involves constant comparison between new data and data that has already been collected. Consequently, grounded theory research questions are relatively broad and tend to be oriented toward action and process. The analysis of the data allows the researcher to refine or specify the question. Grounded theory was developed by Glaser and Strauss in 1967. This qualitative, inductive approach (meaning that it moves from the specific to the more general) to research was a groundbreaking method to allow researchers a method to study how people make sense of their health experiences and resolve challenges. Their publication *Discovery of Grounded Theory* (Glaser & Strauss, 1967) “marked a dramatic breakthrough in nursing research by providing investigators with the tools to study health phenomena from the perspective of those experiencing them” (Schreiber & Stern, 2001, p.xvi). This research approach is useful in discovering what problems exist in a social scene and the processes persons use to handle them (Burns & Grove, 2009, p.25).

Original Study

As described in Chapter I, the original research study on families managing chronic illness was conducted by the Family Nursing Research Team at Mankato State University. The research team identified four assumptions (Meiers et al., 2005):

1. Families are on the front line of health care.
2. Knowledge development regarding family as the unit of care is in its infancy.
3. Care of the family is complex, changing and interwoven.
4. Families experiencing chronic illness present unique challenges.

These assumptions informed the research study of families managing chronic illness. The aims of the study were to describe the process that rural families employ to manage their chronic illness experience, and to build theory related to the family within the chronic illness experience.

Population sample and setting.

Interview transcripts and field note recordings of interviews with 9 families managing chronic illness served as the data for the study. Forty-six participant family members ranging in age from 6 years to 75 years (mean age 34) were interviewed following approval of the study by the Institutional Review Board of the University. Eligible participants were members of families where at least one member had a diagnosed chronic illness. These families lived in a rural community of less than 50,000. Participants were well-educated with 26 out of the 46 having attended college. The mean family income was \$69,000 (range \$10,000 – over 100,000). Chronic illness situations represented were HIV-AIDS, MS, Type I diabetes mellitus (DM), ankylosing spondylitis, lymphoma, chronic obstructive pulmonary disease (COPD), congenital muscular dystrophy manifesting in pulmonary failure and chronic renal failure.

Procedures for original study.

Recruitment.

The sample for the original study was achieved in a mixed-method manner. Six families initially self-nominated for participation in response to a regional newspaper advertisement. The researchers contacted families who indicated an interest and explained the study. At the time of this telephone contact, verbal permission for participation was obtained and the family interview was scheduled. Following interviews

with these six families, the researchers sought a purposeful sample of participants who could provide unique perspectives on chronic illness that were not obtained in the original sample. These families were also contacted by telephone, the study explained and initial verbal consent and interview scheduling completed. Prior to interviews, the researchers ensured informed consent for adults and assent for children between the ages of 9 and 18. At this time demographic information was also obtained from the families.

Data collection and preparation.

Data collection was done in conjunction with and guided by data analysis. Two members of the research team conducted each interview. All researchers participated in the interview process throughout the course of the study. Each of the two interviewers interacted with the family to enhance comfort and conversational style. Interviews lasted 1-2 hours and were conducted and audiotaped in the families' homes of all participants with the exception of one family who chose to be interviewed in a health care facility without involvement of the chronically-ill child. All family members were invited to participate and the interview was conducted in the presence of the family group. Data collection ceased when no new properties of the core category were found (Glaser, 1978; Glaser, 1992; Strauss & Corbin, 1990). All audio taped interviews were transcribed verbatim and entered into a word processing program for audit trail and peer debriefing procedures. Preparation of data, including subject identification, verbal accuracy, and presence of pauses or laughter, was completed by two researchers while listening to the tapes. Sandelowski (1993) suggests that the researcher engaged in qualitative research makes decisions about preparation of the data, features of the interview event, such as facial expressions and body movement and decides how they will appear in the interview

text. This was completed through the use of field notes and reflection on the interviews while reading the transcripts and listening to the tapes.

Interviews.

A semi-structured interview technique was used that incorporated the following questions as probes:

1. Describe your family for me.
2. What is your family's personality?
3. What does your family do?
4. What has meaning for your family?
5. Describe "Good Times" in your Family. What makes them good?
6. Describe "Bad Times" in your family. What makes them bad?
7. How does your family adjust to daily life?
8. Define family.
9. Describe the health of your family.
10. Who takes care of whom?
11. What are the needs of your family?
12. How do you meet the needs as a family?
13. How do you make sure everybody is safe?
14. How does your family see itself as part of the community?
15. Describe hard and easy times.
16. What kinds of things do you feel are hard for me to know and understand about your family?

17. What did it mean to you when you found out you had _____ [specific chronic illness]?

18. What influence has this chronic illness had on your family life?

Scientific Rigor of Original Study.

Rigor was established in the Family Nursing Research Team's study through measures described by Lincoln and Guba (1985) to ensure transferability, credibility, dependability, and confirmability. Transferability refers to the ability to transfer the study conclusions to another setting. Use of data exemplars enhanced the possibility that other researchers could judge the appropriateness of transferring the study findings to another setting. Credibility was achieved through researcher triangulation during the interview, analysis and writing phases of the project. Review of the data text was done to clarify and confirm categories. In addition, conducting all but one of the interviews in the naturalistic setting of the family home enhanced the potential for credibility of the data.

Dependability was achieved through use of audiotaped, transcribed verbatim transcripts that were reviewed for accuracy by the researchers. Confirmability was achieved through recording the decision-making process.

Research Study from Archived Data

The purpose of this research study is to address the rarity of literature defining and describing the concept of family struggling while managing chronic illness. This study took steps to address the process of struggling while managing chronic illness. Two research questions guided this analysis:

1. How do families struggle while managing chronic illness?
2. What is the definition of struggling while managing chronic illness?

Strauss and Corbin's (1990) paradigm model and grounded theory method was utilized to organize the information into six categories. Archived data from the original study was analyzed to identify the categories of causal conditions, phenomenon, context, intervening conditions, action/interaction strategies, and consequences. Several themes and subthemes emerged. The results of the analysis contributed to further refinement of the Theoretical Model of Family Reintegration in Chronic Illness (Meiers et al., 2005).

Data Analysis.

Data from transcripts of interviews of the nine families was analyzed following a grounded theory process (Strauss & Corbin, 1990). The data was labeled for concepts, phenomena and interpretations related to family struggling while managing chronic illness, and subsequently assembled into categories of processes. The data was axial coded to identify phenomena, causal conditions, context, intervening conditions, action strategies, and consequences. Ultimately, a single storyline, or core category emerged, linking the data together and providing some explanation for data variability.

Scientific Rigor.

This study was enhanced by sensitivity (Strauss & Corbin, 2010), the researcher's ability to pick-up on subtle nuances and cues in the data text that lead to meaning. Sensitivity allows the researcher to become immersed in the data in hopes of presenting the view of participants. "Sensitivity is a fascinating interplay of researcher and data in which understanding of what is being described in the data slowly evolve until finally the researcher can say, 'Aha, that is what they are telling me.' (at least from my understanding)" (Strauss & Corbin, 2010, p. 33).

Following approval of the project by the University Institutional Review Board, the archived data from the nine family interviews was analyzed. Identifying information was removed from the taped transcriptions and identity codes assigned. The coding record was stored in a locked area separate from the audiotapes and transcripts. Findings are reported anonymously.

Summary

This chapter described the research design of the original study, data analysis, and scientific rigor. Results of the data analysis will be described in Chapter IV.

Chapter IV: Study Findings

Introduction

The purpose of this research study was to address the rarity of literature defining and describing the concept of family struggling while managing chronic illness. This study addressed the process of struggling while managing chronic illness. Two research questions guided this analysis: 1) How do families struggle while managing chronic illness? and 2) What is the definition of struggling while managing chronic illness?

Analysis of nine interviews conducted by the Family Nursing Research Team with families managing chronic illness facilitated answers to these questions. The answer to the second question will be clearly developed in Chapter V. The answer to the first question will next be explored.

Findings

Strauss and Corbin's (1990) method involving open and axial data coding was used to organize, code, and analyze the data for relevant patterns. Following Strauss and Corbin's method, the data analysis revealed causal conditions, a core category termed a phenomenon, context, intervening conditions, action/interaction strategies, and consequences, which were summarized in a paradigm model.

The paradigm model.

Strauss and Corbin's (1990) paradigm model organizes data and makes connections between concepts with categories. The categories in the paradigm model are

causal conditions, phenomenon, context, intervening conditions, action/interaction strategies, and consequences. The core phenomenon in this paradigm model is struggling, which is preceded by the causal conditions perceiving uncertainty and/or vulnerability and ascribing negative meaning to managing chronic illness. Struggling occurs within the context of managing chronic illness. Intervening conditions for struggling are ineffective adapting and adapting. Action/ interaction strategies for struggling are denying, emphasizing loss, fostering independence, strengthening relationships, and turning to faith. Consequences of the action/interaction strategies are stagnating and reintegrating. The paradigm model is depicted in Figure 1: Struggling While Managing Chronic Illness Model. Each category of the paradigm model is next discussed.

Causal conditions.

Causal conditions are the “events, incidents, happenings that lead to the occurrence or development of a phenomenon” (Strauss & Corbin, 1990, p. 96). Causal conditions in the data centered around the concept of perceiving, first, perceiving uncertainty and/or vulnerability, and second, ascribing negative meaning to managing chronic illness.

Perceiving uncertainty and/or vulnerability.

In one of the families interviewed, Delene’s husband points out that the uncertain period before Delene received the definitive diagnosis of lymphoma was the most difficult, a period of struggling to obtain a diagnosis. He says, “Not knowing. That’s the mysterious part, not knowing. To help anybody else out to know that that process is about two weeks for the diagnosis and the biopsy and everything. That things do get

better. But the two weeks is the hardest part.” Receiving the diagnosis was also difficult, according to Delene, “I guess at first it’s just ‘it can’t be – it can’t happen to me.’” At some point the couple appeared to reach a turning point in their perception. Delene’s husband explained, “You got a job – you just get it done. Well here, we’ve got a job, we have to take care of this. But we don’t know what we’re doing, so once you get to that point of just how we’re going to do it and this is what we can do, then you start feeling better.” Delene added, “We tried to carry on as normal as possible.” This change in perception may have been due in part to finding hope. Delene’s husband recalled, “When we got with the oncologist... he’d say, ‘this is what we’re going to do,’ and that gave us a lot of hope – his confidence that we can lick this. During the diagnosis itself, you don’t know what you’re dealing with until you get that diagnosis – so there wasn’t a lot of hope in the diagnosis – but when you start talking about treatment after the diagnosis – that’s when hope started surfacing.” The hope may have made the family feel less vulnerable to lymphoma. Delene stated, “I guess we never focused on what would happen if chemo or radiation didn’t work.” Her husband added, “We just focused on a lot day by day.” Delene and her husband’s recollections suggest that perceiving uncertainty and vulnerability can lead to perceiving struggling, perception can change with time, and hope can decrease the perception of uncertainty, vulnerability, and struggling.

Ascribing negative meaning to managing chronic illness.

Managing chronic illness resulted in various perceptions among study participants. Some perceived great difficulty and expressed negative feelings regarding illness management, suggesting struggling. Mr. and Mrs. Grier were interviewed regarding their management of Mrs. Grier’s COPD and DM. When asked what it is like

to have COPD, Mrs. Grier described an array of negative perceptions: “It’s annoying and worrisome...[Diabetes is] a curse...It just infiltrates everything...You just have to train your head to think about it all the time...I feel so buried with all these problems that I can’t sort them out.” Mr. Grier, however, noted the difference in his perception, stating, “She sees the accumulation of everything...I view it as an acute situation, okay, you go into the hospital, but she views it as piling up one after another.”

In contrast, some families interviewed did not appear to ascribe negative meaning to chronic illness management. Mike, a 49-year old physical therapist with ankylosing spondylitis, has made several lifestyle changes as a part of managing his illness. He stops frequently when he travels, he has other family members bring him tools when he is working on household projects, he has changed his mode of exercise, and he splits off from a social group if he feels he may slow the group down. Yet, when asked how chronic illness has affected him and his family, he responded, “It wasn’t like we had to redo the home or anything like that.” His wife added, “I don’t think we’ve changed our activities that much.” When asked “Who takes care of who?” Mike’s wife stated, “We take care of each other.” Mike’s daughter was asked, “Your dad got worse over the year. What are your thoughts?” She replied, “None, really.” Mike’s wife added, “Probably not because Mike doesn’t talk about... Mike does not dwell on it.” The interview with Mike and his family suggests that perceiving struggling may not be related to significant lifestyle changes, but to a quality more difficult to measure, perhaps a personality trait or the meaning the family places on the illness. It is possible that the hope Mike shared of playing with his grandchildren decreased negative meanings the illness holds for him.

One husband and wife were interviewed regarding management of the husband's multiple sclerosis. When asked to describe the health of the family, the wife stated, "It's okay as long as we are not pregnant or have the flu." The couple were next asked, "Who takes care of whom?" to which the wife replied, "We all take care of each other." These responses demonstrate that chronic illness is not their identity. The interviewer further probed, "Do you routinely go in for checkups?" The husband responded, "As need arises, but he said I should probably come and start doing it about every year...It's just been a matter of saying that this is how things are, so what can you do about it." His wife added, "I think there is a lot of choices and you just make choices that are fun and you can do." The husband concluded, "We don't know what it's going to do...maybe it won't change at all." Despite the uncertainty of not knowing 'what [the multiple sclerosis is] going to do,' this couple did not discuss struggling themes. Their narratives suggest that they have adapted to the disease by accepting that they cannot change the diagnosis and gaining a sense of control in the choices they make.

Betty, a type II diabetic, and her family were asked, "What are some times that are sad or times that aren't as good – the bad times the family goes through?" Betty's husband, Greg, responded, "We've lost some pets...We really haven't had any deep negative things happen to us other than a few deaths which is normal." Greg did not identify managing Betty's diabetes as a hard time.

Charlie and his family manage his type I diabetes. When asked, "How would you describe your family?" family members responded in ways that did not focus on illness management, specifically: "Fun busy," "Busy," "Kind of always on the go, with sports and stuff." "I think we are the typical family." The family was also asked, "Who takes

care of whom?” One family member stated, “Everyone kind of takes care of anyone...We all kind of share.” This statement includes Charlie in the caring for other family members and doesn’t focus on Charlie’s illness. The family was also asked, “How is the health of your family?” One family member responded, “I think we are a fairly healthy family, we try to go for walks.” Charlie was asked directly, “Do you feel like you have been able to do everything that you wanted to do?” to which he responded, “Yes.” If this family perceived management of Charlie’s diabetes as a great difficulty and/or negative experience, these questions would have allowed ample opportunity for conveying that perception. Rather, the family members focused on strengths and normalcy in their responses.

The data in this study was not explicit as to why some families perceive greater difficulty in managing chronic illness than others. It is possible that the families not struggling with illness management have ascribed a more positive meaning to the illness than others, or are not as close to the time of initial diagnosis and are at a point when the illness and its management are stable. The data did suggest that those in the study who were more dependent on others for care perceived greater difficulty and ascribed a more negative meaning to their experience. This perception is next explored.

Being dependent on others for care may contribute to the negative meaning ascribed to managing chronic illness. Mr. and Mrs. Grier were interviewed regarding their management of Mrs. Grier’s COPD and DM. Mrs. Grier’s statements suggest perceptions of loss of control and increased dependence on others. She reflects, “Very sad, very sad. You know, I would like to go back when I was so very independent...We were just involved in everything. It was a nice life and it’s really changed...I have not

been able to do any washing and take care of my clothes. You know, that's important to be able to have things like that to do for yourself...it's so hard not to and then I still fall, I say that I am not going to have any more falls, but I do."

Susan and Bob assist their son, Jack, in the management of his muscular dystrophy. Although Jack's illness requires him to use a ventilator and has caused them to modify their dreams and significantly change their lifestyle, their perspective is strength-based. They described Jack's strong computer and writing skills and desire to go without a lot of adaptations at school. While Jack's parents did describe several struggles, most of the struggling occurred when they needed to depend on others for something, such as obtaining a diagnosis initially, receiving good care, securing financial assistance, and negotiating modifications at school.

Phenomenon.

The phenomenon is the "central idea, event, happening, incident, about which a set of actions or interactions are directed at managing, handling, or to which the set of actions is related" (Strauss & Corbin, 1990, p. 96). The phenomenon of interest in this study, struggling, appeared multiple times in the data, including various types of struggles. Some struggling themes in the data are more explicit than others, and some families struggle more than others. Consistent with types of struggles identified in the literature review, struggling with everyday living, struggling to obtain a diagnosis, spiritual struggling, and cognitive and existential struggling are identified in the data.

Struggling with everyday living.

Susan assists her son, Jack, in the management of his muscular dystrophy. She described several types of struggling, including physical struggling: "If a door is too

heavy, he can't open it; he has a real struggle at school.” She also described financial struggles, “My biggest frustration was trying to get some financial assistance...The worst was when you were trying to take care of your child and yet you still had to work and put food on the table.” Susan also described struggling to obtain a good and fair education for her son: “Some teachers grade on attendance and we are constantly trying to get exceptions and homework and try and figure out what he has missed...They had wanted to put him in a special education class then [for kindergarten]...so that was a challenge; we had to prove ourselves that he could do it and it actually benefited the school because the nurse kind of became the aide of the class.”

In one of the families interviewed, Betty, a mother of two, described the struggle to manage her diabetes. “I don't drink anymore. A beer once in awhile. Some days are better than others. Some days I have urges where I just have to eat – you know – and I know I shouldn't, but I just do, and then you pay for it – don't feel good, or whatever.... I should cut out after - before bed – 'cause I've gained weight, but when I get tired, food is kind of a comfort thing. Shouldn't be, but it is.”

Another mother helping manage her son Charlie's diabetes described a struggle not to let diabetes rule their lives. She explained, “I worry about his diabetes and him going away to college. But he needs to go to college, even though no-one will be there for him. It kind of interferes with us sometimes, but it does not rule our life, and it does not rule Charlie's life, he just has to eat different things.”

During Mr. and Mrs. Grier's interview discussing the management of her COPD and DM, Mrs. Grier delineated several struggles, including: “It's annoying and worrisome,” “[Diabetes is] a curse...It just infiltrates everything... You just have to train

your head to think about it all the time,” and “I feel so buried with all these problems that I can’t sort them out.” Pointing out the differences in their appraisals of the difficulty of managing her chronic illnesses, Mr. Grier stated, “She sees the accumulation of everything...I view it as an acute situation, okay, you go into the hospital, but she views it as piling up one after another.”

Colette, a young mother on dialysis due to chronic kidney disease, also described struggles with everyday living, stating, “I struggle more financially than he does...I get paid [disability] once a month and once that is gone I’m out and I am done...We don’t hardly ever buy anything.” In response to the question, ‘How would you describe hard and easy times?’ Colette’s boyfriend, Joe, replied, “Easy times would be to me is not worrying about everything. Hard times is struggling. Winters are hard for me...I am not really a cold blooded person.”

Struggling to obtain a diagnosis.

Other families have struggled to obtain a diagnosis when a family member’s symptoms are ambiguous. Delene, a 37 year old mother managing lymphoma, struggled with the diagnostic process along with her family, as her husband explains: “Not knowing. That’s the mysterious part, not knowing. To help anybody else out to know that that process is about two weeks for the diagnosis and the biopsy and everything. That things do get better. But the two weeks is the hardest part.”

Susan, mentioned above, described struggling to obtain a diagnosis for her son Jack.

“We knew something was wrong right away. He had a low Apgar. Right away it was three and then a five. I questioned it right away with a physician

whom I choose not to mention. I was basically scolded and said that I did not have other kids to compare to other moms who have kids, because other kids progress in different ways, so I have felt that something just was not right... And then when he was age one, we took him up to the university, and then we got a million diagnoses depending upon what department you were in.”

Jack’s father, Bob, added, “The first years of his life were horrible. I wouldn’t want to go through that again.”

Spiritual struggling.

Ross, a gay man managing AIDS, along with his parents discussed the family’s struggles with Ross’s sexuality and with the family’s spirituality and church membership.

Father: “Ross said that a gal from the paper called him and asked what his sexuality was and he had an interview with her and that was in the paper and that was real hard for me. I called our pastor and he worked me through it.”

Interviewer: “Because he wasn’t out to you yet?”

Father: “Yes, he was out. We never thought it was necessary for everyone in [the area] to know. We worked through it.”

Interviewer: “So that was a good and a bad time?”

Mother: “I would say a bad time.”

Father: “That brought us closer.”

Ross (Later): “[Moving] is going to be a hard time.”

Father: “Especially for my mother because Ross is very close to my mother. He goes down there and takes her to town, so when she finds out...”

Mother: “He hasn’t told her yet.”

Ross: “One of these days when it feels right, it almost felt right the other day.”

Debriefing after the family interview, one interviewer stated, “I think that the hard time when they said off tape that they had to leave their church. No matter what has happened, it sounds like they pull together and cope with the situation...I can’t remember what it was like; they forbid him to be there, but it was pretty tough.” While a later section will describe turning to religion/spirituality as an action/interaction strategy to struggling, this example demonstrates that turning to religion/spirituality can also be a cause of spiritual struggling.

Cognitive and existential struggling.

Mrs. Grier, mentioned above, expressed existential struggling, explaining, “I don’t feel like a real person anymore, I feel like I am a bother to everybody, like when we go someplace they all have to be watching where I go, what I need, I just hate it, and I don’t see any way out.”

Susan recalled some of her son, Jack’s, thought processes: “Sometimes he has said to me that it would be easier if he would be in a wheelchair. Or at one time, he had said that it would be easier if he were retarded. Then he would not have to know.” Jack’s father Bob added, “One day he just started crying because he just wanted to be normal like us, and that really hurt.”

Context.

The context is “the specific set of properties that pertain to a phenomenon; that is, the locations of events or incidents pertaining to a phenomenon along a dimensional range. Context represents the particular set of conditions within which the action/interactional strategies are taken” (Strauss & Corbin, 1990, p. 96). In this study,

the property pertaining to struggling and the condition within which responses to struggling occurred was managing chronic illness. Thus the context of the struggling phenomenon is managing chronic illness. The chronic illnesses of data participants in this study were HIV/AIDS, type I DM, ankylosing spondylitis, lymphoma, COPD, congenital muscular dystrophy manifesting in pulmonary failure, chronic renal failure, and multiple sclerosis.

Intervening conditions.

Intervening conditions refer to the “structural conditions bearing on action/interactional strategies that pertain to a phenomenon. They facilitate or constrain the strategies taken within a specific context” (Strauss & Corbin, 1990, p. 96). The intervening conditions identified in the study were ineffective adapting and adapting to managing chronic illness.

Ineffective adapting.

Study participants who did not accept the changes brought by chronic illness, clung to unrealistic expectations, or fought to control factors not within their control appeared to experience frustration and exhibit ineffective adaptation to chronic illness management. Mrs. Grier’s statements, “Very sad, very sad. You know, I would like to go back when I was so very independent,” and, “I just hate it, and I don’t see any way out” suggest ineffective adaptation due to a lack of acceptance of her illnesses. Colette’s daughter Emily, expressed frustration over the things in which her mother could not participate. The interviewer asked, “What do you think about that your mom can’t swim with you?” Emily responded, “Mad...I wish that she wouldn’t have medical problems so

she could do more stuff...It just makes me sad because she can't do a lot of things with me."

Adapting.

For the families interviewed, adapting to managing chronic illness involved acceptance, relinquishing control, and modifying expectations. For example, when asked about family dreams, Jack's mother answered, "Take it as it is...Just take it day by day." Her current expectations can be contrasted with her previous expectations. She explained, "Well, dreams become shattered. We thought that he was going to grow up and become president...My vision was so different than what our [family] is like...When he was four years old, I would think about what he would do about college and it would break my heart to think of anything else but being normal." Jack and his family experienced several struggles, particularly initially, but fewer and less intense struggles were described as the family learned to accept the illness and relinquish control, ultimately resulting in a positive "take it as it is" outlook.

Charlie's mother described the practical and adaptive approach the family has taken to managing Charlie's diabetes: "I worry about his diabetes and him going away to college. But he needs to go to college, even though no-one will be there for him. It kind of interferes with us sometimes, but it does not rule our life, and it does not rule Charlie's life, he just has to eat different things."

For Delene's family, relinquishing control involved letting others help, as her husband explained: "I think it was the willingness to let people help too. Some are so independent to not let people help. So you have to let that happen."

Mike made several adaptations to manage his ankylosing spondylitis, including taking frequent breaks on trips, minimizing trips up and down steps when doing housework, and his choice of exercise. Likewise, the couple managing multiple sclerosis demonstrate acceptance and adaptation in their statements, “It’s just been a matter of saying that this is how things are,” “I think there is a lot of choices and you just make choices that are fun and you can do,” and “There is nothing that I can do about it...so I can kind of compartmentalize it.”

Action/ interaction strategies.

Action/interaction strategies are “strategies devised to manage, handle, carry out, respond to a phenomenon under a specific set of perceived conditions” (Strauss & Corbin, 1990, p. 97). Action/ interaction strategies identified in the study are denying, emphasizing loss, fostering independence, strengthening relationships, and turning to faith.

Denying.

When asked how dialysis affects their family, Colette and Joe’s responses conveyed denying. Colette said, “It’s a lifetime thing...That’s why we really don’t talk about...” Joe interjected, “If we talk about it, it might make the situation worse.” Colette added, “We don’t talk about death much either.” It is possible that the denial is a protective response for Colette and Joe, a response that shelters them from more vulnerability and struggling.

Emphasizing loss.

Mrs. Grier’s previously referenced outlook embodies the action/interaction strategy of emphasizing loss. She lamented, “I’m never going to be what I would like to

be, I mean the way I was before these accidents...very sad, you know, I would like to go back when I was so very independent...We were just involved in everything...It was a nice life and it's really changed...I don't feel like I am a real person anymore." Jack's parents also emphasized loss when his father stated, "We been dealt a different pair of cards, we can't just pick up and go on vacation and anywhere that you want." His mother added, "Well, dreams become shattered, ah, we thought that he was going to grow up and become president." Regarding her mother's chronic kidney disease and dialysis, Colette's daughter Emily commented, "I wish that she wouldn't have medical problems so she could do more stuff."

Fostering independence.

Jack's mother's statements "I wanted Jack to do a lot of the stuff on his own" and "he is able to manage his own machine" embody the action/interaction strategy of fostering independence. Jack's father recalled, "The other night some friends wanted us to go out and get an ice cream cone, and then they wanted to show us their new fire place and we were not home by 11:30 p.m. and I left the cell phone in the car," Jack's mother added, "He was very aware of how vulnerable he is." Although he still feels vulnerable at times, gaining the independence of managing his own machine may have decreased Jack's sense of dependence on others and feelings of vulnerability.

Strengthening relationships.

A fourth action/interaction strategy identified was strengthening relationships. Delene said of friends who supported her during lymphoma, "I feel a lot closer to them than I did before. Just because they were there." Additionally, as captured above in the

struggling section, Ross's family felt that the media's coverage of his sexuality was a bad time that ultimately brought the family closer.

Turning to faith.

Several families exhibited the action/interaction strategy of turning to faith.

Betty, who is managing diabetes states, "Because we found in this church, it's just like a family." Her husband added, "It is the only sanctuary that is left for the family." Jack's father tied faith specifically to managing Jack's illness when he said, "You have to have a faith and things will work out." Similarly, Delene's husband recalled, "[Jesus Christ has] always been there for us and we've never had to ask. During Delene's illness, when we look back, seeing everything he put in our life."

Consequences.

Both action/interaction strategies and the absence of action/interaction strategies have outcomes or results, which can be intended and unintended (Strauss & Corbin, 1990). The consequences identified in this study were stagnating and reintegrating. The data indicates that while reintegration occurred when families effectively adapted to chronic illness management, ineffectively adapted families stagnated.

Stagnating.

Mrs. Grier's statement, "I would like to go back when I was so very independent" suggests a yearning for past times and lost abilities. Her comments, "I feel so buried with all these problems that I can't sort them out," and , "I just hate it, and I don't see any way out" imply stagnation rather than progress in reintegrating chronic illness management.

Reintegrating.

In contrast, the family managing the husband's multiple sclerosis exemplified reintegration of chronic illness management. His statement, "It's just been a matter of saying that this is how things are" demonstrates acceptance of his diagnosis and its implications. His wife indicated that the adaptations the family makes in managing illness have become a part of the family routine when she stated, "I think there is a lot of choices and you just make choices that are fun and you can do."

Conclusion

This chapter used data from interviews of families managing chronic illness to answer the research question, How do families struggle within the experience of managing chronic illness? The core phenomenon identified was struggling, which was preceded by the causal conditions perceiving uncertainty and/or vulnerability and ascribing negative meaning to illness management. Struggling occurred within the context of managing chronic illness. Intervening conditions for struggling were ineffective adapting and adapting. Action/ interaction strategies for struggling were denying, emphasizing loss, fostering independence, strengthening relationships, and turning to faith. Consequences of the action/interaction strategies were stagnating and reintegrating. The second research question, What is the definition of struggling while managing chronic illness? will be answered in Chapter V.

Chapter V: Discussion

Introduction

This study was able to answer both research questions: 1) How do families struggle while managing chronic illness? and 2) What is the definition of struggling while managing chronic illness? Reviewing pertinent literature and analysis of interviews with families managing chronic illness facilitated answering the questions. This chapter first consolidates findings from previous phases of the study to answer the research questions and then compares the findings to other research. The chapter concludes with implications for nursing practice and recommendations for future research.

How Families Struggle While Managing Chronic Illness

Themes from the interview data and the literature review harmonized to answer the first research question, How do families struggle while managing chronic illness? Families managing chronic illness struggled with everyday living, to obtain a diagnosis, with spiritual beliefs, and with cognitive and existential thoughts, encompassing mind, body and spirit struggles. Struggling occurred within and between individuals and groups. A thought process, more specifically, an awareness, interpretation, deciphering of meaning, or perception was a strong component of the struggling experience. These themes were extensively explored in Chapter IV.

A Definition of Struggling While Managing Chronic Illness

Second, a definition of struggling while managing chronic illness was sought. The literature review and dictionaries provided several definitions of struggling, none of which adequately captured the essence of struggles described in literature and in the interview data. Struggles described in the literature and data took place over time, sometimes waxing and waning in intensity and changing in character, indicating a process. Both the literature review and the interview data yielded the perception theme. A more apropos definition incorporating the process and perception concepts is required.

In light of this study's findings, struggling while managing chronic illness is defined as the perception of a difficult process (e.g., a battle, conflict, strenuous effort, or task) while managing chronic illness. The perception of great difficulty is often preceded by perception of vulnerability or uncertainty and/or ascribing negative meaning to chronic illness management. The difficult process can occur within the body, mind, or spirit of a person or group of persons.

This definition is unique from other definitions in the literature in several ways. This definition is specific to the chronic illness management experience. The definition acknowledges struggling as a process. The definition takes a holistic approach, acknowledging not only physical, but also cognitive and spiritual aspects of the struggling process. Additionally, other definitions of struggling focus on only the strenuous effort type of struggling (Blijlevens et al., p. 470; Halstead & Hull, 2001, p. 1536) or only the battle or conflict type of struggling (Nystrom & Svensson, 2004; Wiklund, 2008, p. 2429), while this definition is broad enough to encompass both types of struggling.

Most importantly, this definition focuses on thought processes. This is the first definition of struggling to include the word “perception.” This inclusion explains why different people describe similar experiences differently, why some people would say an experience is a struggle, others would call it a fight, a challenge, a lifestyle, or an insignificance. The perception of struggling is one of many possible meanings a person or family can ascribe to the experience of managing chronic illness.

Comparing a terminal cancer diagnosis in an infant and an adult enriches the understanding of the definition of struggling. Although an infant with terminal cancer could be said to physically struggle for life, this statement is a perception of others, and the infant does not have the mental capability to perceive the potential struggles associated with managing the terminal cancer. The family managing the infant’s cancer could struggle with the meaning of the experience for the family. The typical adult with terminal cancer, however, understands the vulnerability and uncertainty associated with a cancer diagnosis. The adult can ascribe meaning to the cancer experience. The adult is different from the infant because the adult could struggle not only physically, but also with existential concerns, spiritual questions, role changes, financial issues, caregiver expectations, etc. The adult with cognitive abilities can additionally experience struggles in the form of conflict, such as a desire for optimal care versus financial limitations, or a spiritual belief in the sanctity of life versus a desire to hasten death.

Comparison of Study Findings to Other Research

The understanding of struggling as a perception makes it relatable to other literature exploring perceptions, representations, and ascribed meanings of not only illness experiences, but also other experiences, such as pain and treatments. Melzack and

Casey's (1968) conceptual model of the sensory, motivational, and central control determinants of pain proposes that sensory, motivational, and cognitive-evaluative factors interact to provide perceptual information about the pain experience. Subsequent studies have substantiated the understanding that pain intensity is related to the meaning of pain. For example, the meaning (e.g., challenge, punishment, enemy) ascribed to cancer-related pain impacted pain, coping, and depression scores among patients (Barkwell, 1991), and the affective perception of pain influenced the rating of both labor and cancer pain on the visual analog scale (Price, Harkins, & Baker, 1987). As Vlaeyen, Crombez, & Goubert (2007) explain, "if pain patients consider the pain experience as a catastrophe, pain is experienced as more negative in comparison with a situation where they accept pain" (p. 184).

Conrad (1985) asserted that patients' perception of the meaning of medication in their lives had more to do with medication administration compliance than the provider-patient relationship. For example, changing medication regimens was one way epilepsy patients decreased their perceived dependence on both the prescribers and the prescriptions. Wong & Ussher (2008) demonstrated that people receiving anti-HIV treatment ascribed the meanings "treatments as 'life savers,'" "treatments as necessary evils," and "treatments as the last resort" to their anti-HIV treatments. The findings suggest that the meanings people ascribe to anti-HIV treatments correspond to their level of adherence.

Just as pain and treatments have different meanings to different people, physical illness has different meanings to different people. Hill's (1958) influential ABC-X Model of Family Stress provides groundwork for this understanding. A simplified

version of the model is $A+B+C \rightarrow X$. In the model, “A” represents a stressor (such as chronic illness), “B” refers to family strengths and available resources, “C” refers to the meaning the family ascribes to the stressor, and “X” is the possibility of family crisis. Whether or not the family goes into crisis is influenced by B and C. Many theorists have since expounded upon the ABC-X model in various ways. For example, Boss (1987) asserted that “the family’s perception of an event is a powerful, if not the most powerful, variable in explaining family stress.” Boss revised the “X” in the model to represent the degree of stress on the family, which could have an outcome of crisis or coping, or anything in between. A simplified version of Boss’s revision is $A \leftrightarrow B \leftrightarrow C = X \rightarrow$ $\begin{matrix} \text{Crisis} \\ \updownarrow \\ \text{Coping} \end{matrix}$. It is apropos to include struggling as one of the possible outcomes on the continuum between crisis and coping. In other words, if the stressor to a family, A, is chronic illness, B is available resources and strengths, C is the meaning of the chronic illness to the family, X is the degree of stress on the family A, B, and C create, then the outcome could be coping, struggling, crisis, or multiple other outcomes. Boss points out that the model is dynamic, changing as the variables flux in different magnitudes.

Congruent with the concept of illness having different meanings based on perception, Lipowski (1970) published a conceptual framework to address how psychological and social factors contribute to illness behavior. The framework proposed that a person’s reaction to illness stems from the meaning of the illness to the person. Possible categories of meaning in Lipowski’s framework were illness as a challenge, enemy, punishment, weakness, relief, strategy, irreparable loss, or value. These attributed meanings reflect previous experiences, culture, knowledge, and beliefs.

An example of how the meaning of the same illness might vary among different patients would be a diagnosis of celiac disease. For someone diagnosed in the 1970s before many gluten-free products were accessible, before the internet's boundless information was available, and before the creation of the many support groups now in existence, managing celiac disease could have meant challenge, enemy, or loss and perceived the management as a struggle. The same person's daughter diagnosed 30 years later certainly could assign the same meaning and have the same perception. Alternatively, the daughter, growing up eating gluten-free foods along with her mother, and learning about and gaining management-related support on the internet, might see the management of celiac disease as insignificant, and not perceive a struggle at all.

This study's findings also relate to findings of the Family Nursing Research Team, specifically the Theoretical Model of Family Reintegration in Chronic Illness. Similar to this study, the model also identifies family recognition of vulnerability and uncertainty as antecedents to struggling. In the model, recognition of vulnerability, uncertainty, and the alignment of caring strategies lead to family engagement with chronic illness, which includes connecting, pondering, relating, and struggling. The process is dynamic and cyclical. The findings of this study also found that struggling is dynamic, waxing and waning over time.

Implications for Nursing Practice

The expanded understanding of struggling with chronic illness management and its definition has several implications for nursing practice. For example, understanding that struggling has a strong perception component implies that struggling can be modified if the perception can be modified. Modifying struggling may be more desirable if the

struggling is associated with ineffective adapting and stagnating. The idea of modifying struggling can be related to the expanding body of knowledge about emotion regulation. For example, Leventhal, Brissette, and Leventhal (2003) describe emotion regulation strategies developed to assist those managing chronic illness to cope with such illnesses in part by managing illness-related distress. Similarly, Cameron and Jago (2008) propose that once illness representations and emotion representations are understood, coping strategies can be employed to regulate the emotions.

Nurses can help those managing chronic illness identify its associated representations and meaning, which in some cases is struggling. Additionally, in those identified as struggling, nurses can identify the intervening conditions, action/interaction strategies, and consequences manifest in the family. Subsequently, nurses can determine whether struggling management interventions are appropriate. Additional research would be instrumental in assisting nurses in the identification and management of struggling. Additional research directions are next addressed.

Future Research Directions

The data used in this study was unique in exploring the experience of managing chronic illness from a family perspective and was therefore able to describe and define struggles experienced by families as a whole managing chronic illness. At the same time, the data was generated from a sample of only nine families, all study participants were from the same general geographical area, and this author was the only researcher extrapolating struggling themes from the data. Other studies examining the struggling experience of families with chronic illness would augment this study's findings.

The new definition of struggling can serve as a springboard to the creation of a tool to measure struggling. Because struggling has a perception component, the tool would need to capture respondents' thought processes. This tool might be similar to the Consequences section of the Illness Perception Questionnaire (IPQ), which assesses cognitive representations of illness (Weinman, Petrie, Moss-Morris, & Horne, 1996). The IPQ asks the respondent how much he or she agrees with statements such as "My illness has not had much effect on my life," "My illness has strongly affected the way I see myself as a person," and "My illness has had major consequences on my life."

A tool measuring struggling would enable the generation of a body of struggling research. Longitudinal studies would add depth to the understanding of struggling as a process and help determine how the perception of struggling changes with time. Gaining understanding of the experience of struggling over time would reveal whether the struggling process has predictable sequential phases or whether people alternate between different perceptions, consistent with Paterson's Shifting Perspectives Model of Chronic Illness, in which chronic illness sufferers alternate between a wellness and an illness perspective (Paterson, 2001). A tool measuring struggling could also be used to assess struggling before and after nursing interventions, to help determine what interventions are most useful.

Conclusion

By extrapolating common themes from nursing literature and family interviews, this study provided a new and more comprehensive understanding and definition of the struggling experience in families managing chronic illness. This study's identification of

the importance of cognitive aspects, such as assigned meaning and perception, in the struggling experience has contributed to the body of nursing knowledge.

References

- Adamsen, L., Andersen, C., Midtgaard, J., Moller, T., Quist, M., & Rorth, M. (2009). Struggling with cancer and treatment: young athletes recapture body control and identity through exercise: qualitative findings from a supervised group exercise program in cancer patients of mixed gender undergoing chemotherapy. *Scandinavian Journal of Medicine & Science in Sports*, 19(1), 55-66.
- American Nurses Association. (2011). *What is Nursing?* Retrieved from <http://www.nursingworld.org/EspeciallyForYou/StudentNurses/WhatisNursing.aspx>
- Barkwell, D. P. (1991). Ascribed meaning: A critical factor in coping and pain attenuation in patients with cancer-related pain. *Journal of Palliative Care*, 7(3), 5-14.
- Barnable, A., Gaudine, A., Bennett, L., & Meadus, R. (2006). Having a sibling with schizophrenia: a phenomenological study. *Research & Theory for Nursing Practice*, 20(3), 247-264.
- Becker, G. (1993). Continuity after a stroke: Implications of life-course disruption in old age. *Gerontologist*, 33(2), 148.
- Blijlevens, H., Hocking, C., & Paddy, A. (2009). Rehabilitation of adults with dyspraxia: health professionals learning from patients. *Disability & Rehabilitation*, 31(6), 466-475.

- Boss, P. (1987). Family Stress: Perception and Context. In M. Sussman & S. Steinmetz (Eds.). *Handbook of Marriage and Family*, (pp. 695-723). New York: Plenum.
- Burns, N., & Grove, S. K. (2009). *The practice of nursing research* (6th ed.). St. Louis, MO: Saunders/Elsevier.
- Cameron, L. D., & Jago, L. (2008). Emotion regulation interventions: A common-sense model approach. *British Journal of Health Psychology*, 13(2), 215-221.
- Cody, W. (1991). Grieving a personal loss. *Nursing Science Quarterly*, 4(2), 61-68.
- Coffey, J. (2006). Parenting a child with chronic illness: a metasynthesis. *Pediatric Nursing*, 32(1), 51-59.
- Conrad, P. (1985). The meaning of medications: Another look at compliance. *Social Science & Medicine*, 20(1), 29-37.
- Coyle, N. (2004). In their own words: seven advanced cancer patients describe their experience with pain and the use of opioid drugs. *Journal of Pain & Symptom Management*, 27(4), 300-309.
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed method approaches* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- D'Abundo, M., & Chally, P. (2004). Struggling with recovery: participant perspectives on battling an eating disorder. *Qualitative Health Research*, 14(8), 1094-1106.
- Delmar, C., Boje, T., Dylmer, D., Forup, L., Jakobsen, C., Moller, M., & ... Pedersen, B. (2005). Achieving harmony with oneself: life with a chronic illness. *Scandinavian Journal of Caring Sciences*, 19(3), 204-212.

- Dixon-Woods, M., Findlay, M., Young, B., Cox, H., & Heney, D. (2001). Parents' accounts of obtaining a diagnosis of childhood cancer. *Lancet*, 357(9257), 670-674.
- Eckback, M., Wijma, K., & Benzein, E. (2009). "It is always on my mind": women's experiences of their bodies when living with hirsutism. *Health Care for Women International*, 30(5), 358-372.
- Fleury, J., Kimbrell, L., & Kruszewski, M. (1995). Life after a cardiac event: women's experiences in healing. *Heart & Lung*, 24(6), 474-482.
- Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. (1992). *Emergence vs. forcing: Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.
- Glaser, B. G. & Strauss, A. L. (1967). *The discovery of grounded theory; strategies for qualitative research*. Chicago: Aldine Pub. Co.
- Hagren, B., Pettersen, I., Severinsson, E., Lutzen, K., & Clyne, N. (2005). Maintenance haemodialysis: patients' experiences of their life situation. *Journal of Clinical Nursing*, 14(3), 294-300.
- Hakanson, C., Sahlberg-Blom, E., Nyhlin, H., & Ternstedt, B. (2009). Struggling with an unfamiliar and unreliable body: the experience of irritable bowel syndrome. *Journal of Nursing & Healthcare of Chronic Illnesses*, 1(1), 29-38.
- Halstead, M., & Hull, M. (2001). Struggling with paradoxes: the process of spiritual development in women with cancer. *Oncology Nursing Forum*, 28(10), 1534-1544.

- Henoch, I., & Danielson, E. (2009). Existential concerns among patients with cancer and interventions to meet them: an integrative literature review. *Psycho-Oncology*, 18(3), 225-236.
- Hill, R. (1958). Generic features of families under stress. *Social Casework*, 49, 139-150.
- Hughes, A., Gudmundsdottir, M., & Davies, B. (2007). Everyday struggling to survive: experiences of the urban poor living with advanced cancer. *Oncology Nursing Forum*, 34(6), 1113-1118.
- Johnson, J., & Morse, J. (1990). Regaining control: the process of adjustment after myocardial infarction. *Heart & Lung*, 19(2), 126-135.
- Julliard, R. (2008, August 8). IOC President Rogge welcomes athletes to Beijing. *IOC News*. Retrieved from <http://www.olympic.org/media?articleid=53416>
- Kaakinen, J. R., Gedaly-Duff, V., Coehlo, P. D., & Hanson, S. M. H. (2010). *Family health care nursing: Theory, practice and research* (4th Ed.). Philadelphia: F.A. Davis Co.
- Koenig, H. G., Pargament, K. I., & Nielsen, J. (1998). Religious coping and health status in medically ill hospitalized older adults. *Journal of Nervous and Mental Disease*, 186(9), 513-521.
- Kvigne, K., Kirkevold, M., & Gjengedal, E. (2004). Fighting back -- struggling to continue life and preserve the self following a stroke. *Health Care for Women International*, 25(4), 370-387.
- Lapham, E.V. (1986). Chronic Illness: Overview and theory. In E.V. Lapham & K. M. Shevlin (Eds.), *The impact of chronic illness on psychosocial stages of human*

development (pp. 3-14). Washington, DC: National Center for Education in Maternal and Child Health.

Leventhal, H., Brissette, I., & Leventhal, E. A. (2003). The common-sense model of self-regulation of health and illness. In I. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behavior*. (pp. 42-65). New York: Routledge.

Lincoln, Y. & Guba, E. (1985). *Naturalistic Inquiry*. Thousand Oaks, CA: Sage Publications.

Lindgren, B., Wilstrand, C., Gilje, F., & Olofsson, B. (2004). Struggling for hopefulness: a qualitative study of Swedish women who self-harm. *Journal of Psychiatric & Mental Health Nursing*, 11(3), 284-291.

Lipowski, Z. J. (1970). Physical illness, the individual and the coping process. *Psychiatry in Medicine*, 1, 91-102.

Lofgren, M., Ekholm, J., & Ohman, A. (2006). 'A constant struggle': successful strategies of women in work despite fibromyalgia. *Disability & Rehabilitation*, 28(7), 447-455.

Lohne, V., Aasgaard, T., Caspari, S., Slettebo, A., & Naden, D. (2010). The lonely battle for dignity: individuals struggling with multiple sclerosis. *Nursing Ethics*, 17(3), 301-311.

Maunu, A., & Stein, C. H. (2010). Coping with the personal loss of having a parent with mental illness: young adults' narrative accounts of spiritual struggle and strength. *Journal of Community Psychology*, 38(5), 645-655.

- McConnell, K. M., Pargament, K. I., Ellison, C. G., & Flannelly, K. J. (2006). Examining the links between spiritual struggles and symptoms of psychopathology in a national sample. *Journal of Clinical Psychology, 62*(12), 1469-1484.
- Meiers, S. J., Eggenberger, S. K., Bliesmer, M., Earle, P., & Krumwiede, N. K. (2005). *An emerging model for family caring: Testing of the Family Reintegration in Chronic Illness (FRCI) Model*. [Poster Presentation]. Mankato, MN: Minnesota State University.
- Melzack, R. & Casey, K. L. (1968). Sensory, motivational, and central control determinants of pain: A new conceptual model. In D. Kenshalo (Ed.), *The skin senses: Proceedings of the first International Symposium on the Skin Senses* (pp. 423-439). Springfield: Thomas.
- Moser, A., H, Spreeuwenberg, C., & Widdershoven, G. (2008). Autonomy through identification: a qualitative study of the process of identification used by people with type 2 diabetes. *Journal of Nursing & Healthcare of Chronic Illnesses, 17*(7B), 209-216.
- Nelson, J. (1996). Struggling to gain meaning: living with the uncertainty of breast cancer. *Advances in Nursing Science, 18*(3), 59-76.
- Nochi, M. (1998). Struggling with the labeled self: people with traumatic brain injuries in social settings. *Qualitative Health Research, 8*(5), 665-681.
- Nystrom, M., & Svensson, H. (2004). Lived experiences of being a father of an adult child with schizophrenia. *Issues in Mental Health Nursing, 25*(4), 363-380.

- Pargament, K., Koenig, H., Tarakeshwar, N., & Hahn, J. (2001). Religious struggle as a predictor of mortality among medically ill elderly patients: a 2-year longitudinal study. *Archives of Internal Medicine*, 161(15), 1881.
- Pargament, K. I., Murray-Swank, N. A., Magyar, G. M. & Ano, G. G. (2005). Spiritual struggle: A phenomenon of interest to psychology and religion. In W. R. Miller & H. D. Delaney (Eds.), *Judeo-Christian perspectives on psychology* (pp. 245-268). Washington, DC: American Psychological Association.
- Paulson, M., Danielson, E., & Soderberg, S. (2002). Struggling for a tolerable existence: the meaning of men's lived experiences of living with pain of fibromyalgia type. *Qualitative Health Research*, 12(2), 238-249.
- Paterson, B. (2001). The Shifting Perspectives Model of Chronic Illness. *Journal of Nursing Scholarship*, 33(1), 21-26.
- Price, D. D., Harkins, S. W., & Baker, C. (1987). Sensory-affective relationships among different types of clinical and experimental pain. *Pain*, 28, 297-307.
- Randall, A. B. (1992). *The mystery of hope in the philosophy of Gabriel Marcel, 1888-1973*. Lewiston, NY: The Edwin Mellen Press.
- Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Advances in Nursing Science* 16(2), 1-8.
- Schreiber, R. S. & Stern, P. N. (2001). *Using grounded theory in nursing*. New York: Springer Pub Co.
- Sherman, A. C., Simonton, S., Latif, U., Spohn, R., & Tricot, G. (2005). Religious Struggle and Religious Comfort in Response to Illness: Health Outcomes among Stem Cell Transplant Patients. *Journal of Behavioral Medicine*, 28(4), 359-367.

- Sigurgeirsdottir, J., & Halldorsdottir, S. (2008). Existential struggle and self-reported needs of patients in rehabilitation. *Journal of Advanced Nursing*, 61(4), 384-392.
- Soderberg, S., Lundman, B., & Norberg, A. (1999). Struggling for dignity: the meaning of women's experiences of living with fibromyalgia. *Qualitative Health Research*, 9(5), 575-587.
- Starks, H., Morris, M., Yorkston, K., Gray, R., & Johnson, K. (2010). Being in- or out-of-sync: couples' adaptation to change in multiple sclerosis. *Disability & Rehabilitation*, 32(3), 196-206.
- Stevens, P. (1996). Struggles with symptoms. Women's narratives of managing HIV illness. *Journal of Holistic Nursing*, 14(2), 142-160.
- Stevenson, A. & Lindberg, C. A. (Eds.). (2010). *New Oxford American dictionary* (3rd ed.). New York: Oxford University Press.
- Strandberg, G., Astrom, G., & Norberg, A. (2002). Struggling to be/show oneself valuable and worthy to get care: one aspect of the meaning of being dependent on care -- a study of one patient, his wife and two of his professional nurses. *Scandinavian Journal of Caring Sciences*, 16(1), 43-51.
- Strauss, A. L. & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.
- Talseth, A., Gilje, F., & Norberg, A. (2003). Struggling to Become Ready for Consolation: Experiences of Suicidal Patients. *Nursing Ethics*, 10(6), 614-623.
- Travers, M., & Lawler, J. (2008). Self within a climate of contention: Experiences of chronic fatigue syndrome. *Social Science & Medicine*, 66(2), 315-326.

- van Mens-Verhulst, J., Radtke, H., & Spence, C. (2004). The private struggle of mothers with asthma: a gender perspective on illness management. *Patient Education & Counseling*, 54(1), 79-86.
- Vlaeyen, J. W. S., Crombez, G., & Goubert, L. (2007). The psychology of chronic pain and its management. *Physical Therapy Reviews*, 12, 179-188.
- Weinman, J., Petrie, K. J., Moss-Morris, R. & Horne, R. (1996). The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, 11, 431-445.
- Whittemore, R., Chase, S., Mandle, C., & Roy, C. (2002). Lifestyle change in type 2 diabetes: a process model. *Nursing Research*, 51(1), 18-25.
- Wiklund, L. (2008). Existential aspects of living with addiction -- part I: meeting challenges. *Journal of Clinical Nursing*, 17(18), 2426-2434.
- Wong, W. K. T., & Ussher, J. (2008). How do subjectively-constructed meanings ascribed to anti-HIV treatments affect treatment-adherent practice? *Qualitative Health Research* 18(4), 458-468.
- Yamashita, M. (1998). Family coping with mental illness: a comparative study. *Journal of Psychiatric & Mental Health Nursing*, 5(6), 515-523.

Table 1: Literature Review Table

Source	Purpose	Sample/ Design	Measuring, Defining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Barnable, Gaudine, Bennett, & Meadus, 2006. Having a sibling with schizophrenia: a phenomenological study.	Explore the impact of having a brother or sister with schizophrenia	Van Manen's Hermeneutic Phenomenology. 6 Canadian individuals		Sibling of schizophrenic → struggling → helplessness and frustration	1. Struggling to understand the symptoms (prior to diagnosis). Struggled to understand the illness after diagnosis. 2. Struggling with the system due to difficult access, lack of information
Becker, 1993. Continuity after a stroke: Implications of life-course disruption in old age.	Examine life-course disruption caused by stroke and attempts to restore continuity	Kaufman's methodological approach. 216 stroke survivors. U.S. Hospital		Stroke → struggles	Two struggles: to "reconcile the person they once were the non-functioning person they had become" and to "carry out basic tasks of living that they had once taken for granted" summarized as struggle "to regain a sense of continuity." Incremental gains. One woman reintegrated the old life with the new. Identifying signs of continuity testified to the ability to persevere.
Blijlevens, Hocking, & Paddy, 2009. Rehabilitation of adults with dyspraxia: Health professionals learning from patients.	Explore the experience of adults with dyspraxia, after discharge from inpatient care, in the course of their everyday activities.	Phenomenological analysis of interviews and videotapes of five New Zealand males	"To struggle involves working or striving, and exerting energy and force" (p. 470). Authors did not provide a source for this definition.	Dyspraxia → struggling with everyday living → despair and disappointment as well as surprises and moments of achievement Persevering helped overcome struggle	"The findings revealed the participants' experience of struggling with everyday living and their attempts to overcome the difficulties they experience. Three major themes were identified: struggling with their world, which encompasses aspects of tools, space, time, receiving help and the way requiring help changed their relationships; the being of struggle, which has three aspects – their body, thoughts and limited ability to give voice to their experience; and overcoming the struggle by talking their way through tasks, pacing themselves, persevering, and limiting the barriers they face" (p. 469).
Cody, 1991. Grieving a personal loss.	Uncover the structure of the lived experience of grieving a personal loss	Parse's research methodology. Extraction-synthesis. Four American participants	Struggling is "powering, the process of pushing-resisting with the was, is, and not-yet all at once."	Personal loss → struggle → "move beyond the now and create new ways of becoming"	Parse's powering and transforming concepts identified as themes

Source	Purpose	Sample/ Design	Measuring, Def- ining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Coffey, 2006. Parenting a child with chronic illness: A metasynthesis.	Create a comprehensive chronicle of the phenomena of parenting a child with a chronic illness	Analysis of 11 qualitative studies regarding parenting a child with chronic illness. Noblit & Hare's approach.		Parenting a child with chronic illness → Struggle	Seven themes emerged. One was "Staying in the struggle" (p. 54), which meant not giving up and developing strategies to accurately assess their children or incorporate recommended treatments.
Coyle, 2004. In their own words: Seven advanced cancer patients describe their experience with pain and the use of opioid drugs.	Phenomenologic al inquiry into the experience of living with advanced cancer and how it affects attitudes	Analysis of narratives of 7 patients living with advanced cancer. Reinharz method.		According to abstract: Pain of advanced cancer → Struggle with self, God, with desire to live or readiness to die (I did not note an explicit explanation of a struggle with self or God)	Pain of advanced cancer leads to a struggling process consisting of an internal dialogue. The internal dialogue processes previous experiences with pain and opioid side effects with current pain experiences and feelings about desires to live with mental clarity versus desire to hasten death.
D'Abundo & Chally, 2004. Struggling with recovery: Participant perspectives on battling an eating disorder.	Explore the process of recovery in women and girls with eating disorders	20 American women recovered/ing from an eating disorder. Constant comparative method.		Other aspects of life out of control → struggle for control → more severe eating disorder sx → continuous struggle btwn partial recovery and some relapse	Women struggled to gain control through eating disorders when other areas of their life seemed out of control. Recovery from eating disorders is a continuous struggle between recovery and relapse.
Delmar et al. 2005. Achieving harmony with oneself: life with a chronic illness.	Find out what it means to live with a chronic illness	Paul Ricoeur method. Phenomenological-hermeneutic. 18 Danish patients (DM, UC, and MI rehab).			Although not about struggling, seems to parallel Pargament's findings. For example, achieving harmony with oneself is influenced both by hope, which moves the patient toward acceptance, and by the pressure of doubt, which can shake the hope and cause the patient to drift toward despair and hopelessness. Individual can swing like a pendulum between despair and exhilaration.
Dixon-Woods, Findlay, Young, Cox, & Heney, 2001. Parents' accounts of obtaining a diagnosis of childhood cancer.	Understand parents' experiences of the time before diagnosis of childhood ca.	Semistructured interviews with 20 families looking for themes until saturation reached. United Kingdom		Suspicious symptoms in child → parent struggles to get child evaluated → Parent feels vindicated, relieved	"Some parents who had to struggle to get their child investigated felt vindicated or relieved, and that cancer was at least an identifiable diagnosis for which something could be done" (p. 673).

Source	Purpose	Sample/ Design	Measuring, Defining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Ekback, Wijma, & Benzein, 2009. "It is always on my mind": women's experiences of their bodies when living with hirsutism.	Describe and interpret women's experiences of their bodies when living with hirsutism	10 Swedish women with hirsutism interviewed. Qualitative latent content analysis.		Hirsutism → struggle → normal, healthy life	"By using their imagination, the women could transcend their bodies and envision themselves without hair. This could be seen as a struggling back to normalcy, to a healthy life."
Fleury, Kimbrell & Kruszewski, 1995. Life after a cardiac event: women's experience in healing.	To describe the experience of women's recovery after an acute cardiac event	13 Amer. women post-cardiac event. Grounded theory method, qualitative data generation & analysis		Cardiac event → struggle through uncertainty → establish positive health patterns	Women healing after a cardiac event experience a struggle through uncertainty before establishing positive health patterns
Gadow, S., 1980. Body and self: A dialectic.	Medical philosophy			Struggle → Reenactment vs. transcendence Struggle → Skill cultivation Illness → ↑Struggle	The experience of feeling encumbered by the body represents a struggle between the self and the object body as a person attempts to overcome limitations. In illness, the body refuses to reliably perform and is a hostile obstacle to the self, exacerbating struggle. A person can either take a direction involving trying to comprehend the parts of the body which results in merely reenacting the struggle, or transcend the struggle by attempting to develop the self through the object body. This transcendence results in a reuniting of the self and the body. An example is the effortless use of a skill cultivated through struggle.
Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2005. Maintenance haemodialysis: patients' experiences of their life situation.	Examine how patients suffering from CKD on maintenance haemodialysis experience their life situation.	41 Swedish patient interviews. Content analysis to ID themes.		CKD → Struggling	Struggling with time consuming care and struggling to be seen as a human being with an identity.

Source	Purpose	Sample/ Design	Measuring, Defining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Hakanson, Sahlberg-Blom, Nyhlin, & Ternestedt, 2009. Struggling with an unfamiliar and unreliable body: the experience of irritable bowel syndrome.	To describe the phenomenon living with irritable bowel syndrome from a life-world perspective	Phenomenological method used to interview 9 Swedish people with IBS according to the method of Giorgi.		IBS → Struggle	Participants are “struggling with an unfamiliar and unreliable body,” and struggling between the limitations of an unreliable body and the will to “exceed limitations and become familiar with one self” (p. 32). They have a “determination not to let the illness take over” (p. 36).
Halstead & Hull, 2001. Struggling with paradoxes: The process of spiritual development in women with cancer.	Examine the process of spiritual development in women diagnosed with cancer within 5 years of initial treatment	10 American women, 2 semi-structured interviews, grounded theory analysis	“ ‘Struggle’ implies making one’s way with effort” (p. 1536).	This one is unique in that the processes described are all encompassed within struggling, rather than in a linear process or as antecedents or consequences. Cancer would be the only antecedent.	“Struggling With Paradoxes is a three-phase process consisting of Deciphering the Meaning of Cancer for Me [includes “attempting to maintain coherence using old and new ways”], Realizing Human Limitations [includes asking difficult questions and letting go], and Learning to Live With Uncertainty [includes redefining meaning, identifying spiritual growth, reintegration, and facing the possibility of recurrence]” (p. 1536). “The women engaged in spiritual strategies as they attempted to resolve the struggles” (p. 1537). “The interpretation of the data reflects the interrelationship of the individual’s body, mind and spirit in a holistic way” (p. 1541). “When the women accepted their limits of control, they were able to move on to phase III” (p. 1542). The multiple paradoxes described (such wanting to be in control but needing to let go) are similar to moving between different aspects of being.
Hench & Danielson, 2009. Existential concerns among patients with cancer and interventions to meet them: An integrative literature review.	Explore existential concerns among ca. pts (components, related concepts, targets of invn)	109 articles meeting inclusion criteria reviewed for themes		Cancer → Struggling	“Existential components from the qualitative studies were divided into two main themes: struggle to maintain self-identity and threats to self-identity.”

Source	Purpose	Sample/ Design	Measuring, Def- ining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Hughes, Gudmundsdottir, & Davies (2007). Everyday struggling to survive: experiences of the urban poor living with advanced cancer.	To understand the meaning of dignity to the urban poor and to describe their experiences living with advanced cancer	14 American patients with stage III or IV solid tumors. Qualitative approach using interpretive phenomenology.		Cancer diagnosis in urban poor → struggle	“Struggling to survive both life and cancer.” Basic survival of life in poverty versus cancer care needs.
Johnson & Morse, 1990. Regaining Control: the process of adjustment after myocardial infarction.	Examine the process of adjustment that individuals experience after having an MI.	Grounded theory approach to interview 14 MI survivors. Canada		MI → Struggle	“the major process in the adjustment after an MI is the struggle to regain control” (p. 128). Responses such as defending their pre-MI actions, coming to terms with their diagnosis, learning how to live after an MI, and living again are all part of the struggle to regain a sense of control of their lives.
Koenig, Pargament, & Nielsen, 1998. Religious coping and health status in medically ill hospitalized older adults.	Examine associations between religious coping, nonreligious coping, and health status.	577 American inpatients over age 55. Info gathered on religious coping, nonreligious coping, global indicators of religious activity, and health measures. Statistical analysis.	Negative religious coping (NRC) scale used but not defined as struggling in this article. However, this article and its measure is later referenced as struggling by McConnell, Pargament et al. (2006). Pargament and colleagues developed the scale and used NRC to define struggling.	Struggling → Poor quality of life, worse physical health, depression. Acceptance → Improved health.	While negative religious coping related to poorer quality of life and worse physical health, learning to live with illness and accepting reality was correlated with better physical health.

Source	Purpose	Sample/ Design	Measuring, Defining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Kvigne, Kirkevold, & Gjengedal, 2004. Fighting back—struggling to continue life and preserve the self following a stroke.	Explore how female stroke survivors experienced their life following a stroke and how they managed their altered situation	25 Norwegian women interviewed three times during 1-1/2 yrs after stroke. Longitudinal, phenomenological. Method of Golgi.		Stroke→ struggling to preserve self, continue meaningful life	Five aspects of the struggle: “fighting off disabling feelings and maintaining the will to live, striving to regain the power to accomplish necessary and valued activities, striking a balance between attending to the needs of others and addressing increased personal needs, attempting to maintain control of valued female roles and accept help, and negotiating relationships on equal terms.” Other themes include struggle to balance contradictory feelings, uncertainty, vulnerability. Women “had to reorganize their life while trying to maintain their most cherished values, positions, and activities.” “A major aspect of the struggle of these women encompassed finding new ways of interacting with the world.” Struggle directed toward transcendence, required “reinterpretation, reevaluation, renegotiation, and reconfirmation.”
Lindgren, Wilstrand, Gilje, & Olofsson, 2004. Struggling for hopefulness: A qualitative study of Swedish women who self-harm.	Describe how people who self-harm experience received care and their desired care	9 Swedish women. Qualitative content analysis.		Self harm → Struggle for hopefulness	Two main themes: “Expecting to be confirmed while being confirmed fosters hopefulness” and “expecting to be confirmed while not being confirmed stifles hopefulness” (p. 284). Subthemes include being seen or not being seen, being valued or stigmatized, being connected or disconnected, being believed or doubted, and being understood or not understood. The overall theme is “a struggle for hopefulness through expectations to be confirmed, whether met or unmet” (p. 289).

Source	Purpose	Sample/ Design	Measuring, Def- ining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Lofgren, Ekholm, & Ohman, 2006. 'A constant struggle': Successful strategies of women in work despite fibromyalgia.	Explore strategies used by working women with fibromyalgia to control pain, fatigue, and other symptoms.	Qualitative. Diaries, focus groups, interviews. Content analysis, grounded theory. 12 Swedish informants.	Not explicit, but struggle arose from difficult lives, necessity for endurance.	Fibromyalgia → Grieve (accept) → life-long constant struggle against fibromyalgia consequences and symptoms. Social support facilitates the constant struggle.	Grieving fibromyalgia is a prerequisite for the life-long constant struggle against fibromyalgia consequences and symptoms, which includes 'walking a tightrope,' learning/ being knowledgeable, creative solutions, pain as a guide, setting limits, positive thinking, taking care of oneself, and enjoying life. Positive spirit, action oriented.
Lohne, Aasgaard, Caspari, Slettebo, & Naden, 2010. The lonely battle for dignity: Individuals struggling with multiple sclerosis.	Find out how persons suffering from MS experience and understand dignity and violation in the context of rehab	Phenomenological-hermeneutic approach to extract content from narratives of 14 Norwegian pts with MS		MS → Struggle	Participants struggle to receive help from outside their family and friends. They also struggled for dignity and worth, despite the MS.
Maunu & Stein, 2010. Coping with the personal loss of having a parent with mental illness: Young adults' narrative accounts of spiritual struggle and strength.	Describe adults' loss due to their parents' mental illness, and perceptions of their religious faith journey and spiritual struggles	Examines personal accounts of 9 young American adults who have parents living w mental illness. Miles and Huberman procedure.	Spiritual struggle: "religious/spiritual questions and concerns that having a parent with mental illness had raised" (p. 651).	Having a parent with mental illness → spiritual struggles	"Young adults who reported experiencing more personal loss due to their parents' mental illness also reported feeling more confused on their faith journey, and reported experiencing more spiritual struggle relative to participants who reported experiencing less personal loss" (p. 645).

Source	Purpose	Sample/ Design	Measuring, Defining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
McConnell, Pargament, Ellison, & Flannelly, 2006. Examining the links between spiritual struggles and symptoms of psychopathology in a national sample.	Investigate the relationship between spiritual struggles and various types of psychopathology symptoms in individuals who had and had not suffered from a recent illness.	1629 American individuals solicited through online advertising completed a 135-item online survey	Spiritual struggles defined: "efforts to conserve or transform a spirituality that has been threatened or harmed." Associated with expressions of conflict, question, doubt. Assessed w/ Neg Religious Coping subscale of RCOPE	Negative religious coping plus illness or injury → anxiety and phobic anxiety	Spiritual struggling, as measured by negative religious coping, significantly predicted psychopathology, including depression, paranoid ideation, anxiety, phobic anxiety, somatization, and obsessive-compulsiveness. Further, individuals who had experienced recent illness had a stronger relationship between spiritual struggling and anxiety or phobic anxiety.
Moser, van der Bruggen, Spreeuwenberg, & Widdershoven (2007). Autonomy through identification: a qualitative study of the process of identification used by people with type 2 diabetes.	Clarify the process of identification with diabetes as a dimension of autonomy as described by people with type 2 diabetes	Qualitative descriptive and exploratory design and inductive approach/ grounded theory. 15 Dutch people with T2DM.		Comprehending → struggling → evaluation and mastery of diabetes care.	The struggle type 2 diabetics experience can also be described as vulnerability between old and new behaviors (Moser et al., 2007). Diabetics also struggle with self image, between seeing themselves as healthy and accepting chronic illness as part of their lives. Comprehending, struggling, evaluating, and mastering are phases type 2 diabetics experience in the process of identification (Moser et al., 2007).
Nelson, 1996. Struggling to gain meaning: Living with the uncertainty of breast cancer.	Provide insight into uncertainty experiences for women living with breast cancer.	Hermeneutic phenomenology and photographic hermeneutics. 9 American women between 2-6 yrs post-treatment for breast cancer.		Breast ca → Uncertainty, struggle to find meaning and gain understanding → Growth through meaning and understanding	Struggling conceptualized as an aspect of uncertainty. Struggling to gain meaning captured the uncertainty experience. Subthemes included struggling with emotions, struggling to gain value through relationships and support systems, struggling to move forward despite uncertainty, struggling to return to normal, and struggling with multiple possible outcomes.

Source	Purpose	Sample/ Design	Measuring, Def- ining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Nystrom & Svensson, 2004. Lived experiences of being a father of an adult child with schizophrenia.	Analyze and describe lived experiences of being a father of an adult child with schizophrenia.	“Interpretation of interviews with 7 Swedish fathers of sons or daughters with schizophrenia” (p. 363). Life-world hermeneutic.	The “struggle appears to be characterized by a balance between a reciprocal action consisting of grieving a child who will not fulfill the dreams and hopes of the parent, keeping up self-esteem as men and fathers, and finally adapting to a previously unexpected life situation” (p. 375).	Diagnosis → Shock, perceived loss of control → Struggle to gain control (grieving, maintaining self esteem, adapting) → Regain lost control (at least concerning their own existential situation)	After the son or daughter is diagnosed with schizophrenia, the father feels shock, stress, and chaos, and that he has lost control. He subsequently struggles to gain control, which involves a combination of “grieving a child who will not fulfill the dreams and hopes of the parent, keeping up self-esteem as men and fathers, and finally adapting to a previously unexpected life situation” (p. 375). The struggle for control has an origin in the father’s concern for his family. Ultimately, the father regains control of his own existential situation.
Pargament, Koenig, Tarakeshwar, & Hahn, 2001. Religious struggle as a predictor of mortality among medically ill elderly patients.	Investigate longitudinally the relationship between religious struggle with an illness and mortality	596 American inpatients aged 55 or older. Longitudinal cohort study	Measured by the negative religious coping subscale of the RCOPE tool. 7 items that assess punishing God appraisals, interpersonal religious discontent, demonic appraisals, spiritual discontent, and questioning God’s powers.	Religious struggle → mortality	Three measures (“wondered whether God had abandoned me,” “questioned God’s love for me,” and “decided the devil made this happen”) were predictive of increased risk for mortality. The authors speculate that the relationship could be because the struggle causes poorer physical health, because religious struggle is associated with emotional or personality differences, or because religious struggle may result in social alienation.

Source	Purpose	Sample/ Design	Measuring, Defining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Pargament, Murray-Swank, Magyar, and Ano (2005). Spiritual struggle: A phenomenon of interest to psychology and religion. In <i>Judeo-Christian perspectives on psychology</i>	Compare and contrast psychology models with Judeo-Christian perspectives	Discussion	“Efforts to conserve or transform a spirituality that has been threatened or harmed” (p. 247).	Crises, distress → Spiritual struggling → hopelessness and despair or hope and transformation.	The authors point to major crises and distresses, particularly those that force people to consider new ways of acting, relating and thinking, as antecedents to spiritual struggling. Likening crises to forks in the road, the authors demonstrate that the consequences of spiritual struggles can be either hopelessness and despair or growth and transformation, depending on the person’s capacity to resolve the struggle.
Paulson, Danielson, & Soderberg, 2002. Struggling for a tolerable existence: The meaning of men’s lived experiences of living with pain of fibromyalgia type.	Elucidate the meaning of men’s lived experiences of living with pain of fibromyalgia type	Phenomenological hermeneutic interpretation of interviews with 14 Swedish men		Fibromyalgia → Struggling for a tolerable existence → Seeing the world with new eyes	Feelings of not being the person one was when healthy involves a long process of struggling to live tolerably and find balance. After enduring, resisting, or sustaining through the struggle, the men could see the world “with new eyes” (p. 247).
Randall, 1992. The mystery of hope in the philosophy of Gabriel Marcel, 1888-1973.	A study of Marcel’s writing on hope and suicide, among other categories	Philosophy.			Suicidal persons struggle with the absurdity and captivity of the world; hope and a will to live are necessary to confront that struggle.
Sherman, Simonton, Latif, Spohn, & Tricot, 2005. Religious struggle and religious comfort in response to illness: Health outcomes among stem cell transplant patients.	Evaluate religious coping among multiple myeloma pts undergoing a work-up for autologous stem cell transplant	213 American patients with multiple myeloma	The Brief RCOPE 14-item tool used to evaluate positive and negative religious coping.	Cancer → Struggle with religion → distress, depression, pain, fatigue Possible reciprocal relationship between religious conflict and poor health outcomes	“Patients who struggled with their religion in response to cancer had greater difficulties with general distress and depression, and to a lesser extent, with pain, fatigue, and daily physical functioning” (p. 364).

Source	Purpose	Sample/ Design	Measuring, Def- ining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Sigurgeirsdottir & Halldorsdottir, 2008. Existential struggle and self-reported needs of patients in rehabilitation.	Increase understanding of patients' experience of rehabilitation and their self-reported needs in that context.	Phenomenological study; 16 interviews with 12 Icelandic rehabilitating people		Reason for rehabilitation → existential struggling → "vulnerable and more easily sent off balance"	"Some described how they were trying to tackle two paradoxical processes at the same time: the need to adapt to a change in self-identity and holding on to aspects of the old life and self" p. 387. Stressful process. Harder to cope.
Soderberg, Lundman, & Norberg, 1999. Struggling for dignity: The meaning of women's experiences of living with fibromyalgia.	Elucidate the meaning of women's experiences of living with fibromyalgia	Phenomenological-hermeneutic interpretation of interviews with 14 Swedish women		Fibromyalgia → Struggle to achieve relief, struggle for dignity Disrespect, discrediting → Struggle for dignity	Fibromyalgia caused participants threats to the self, including lost freedom, threatened integrity, and a struggle to obtain relief and an understanding. Because being perceived as credible is associated with dignity, others discrediting the fibromyalgia and showing disrespect led the women to the additional interpersonal struggle for dignity.
Starks, Morris, Yorkston, Gray, & Johnson, 2010. Being in-or out-of-sync: Couples adaptation to change in multiple sclerosis	Examine how couples adapt to the challenges of MS and identify possible risk factors for relational stress.	Semi-structured interviews with 8 American couples		Struggles with parenting teenagers → additional demands for parents, contribute to out-of-sync condition	"For those with adolescent children in the home, there were additional demands when the needs of the adolescents were in conflict with those of the person with MS. This often put the partner without MS in the middle, creating additional stressors and contributing to being out-of-sync."
Stevens, 1996. Struggles with symptoms. Women's narratives of managing HIV illness.	Derive a holistic view of the symptom experiences of women living with HIV/AIDS.	Multi-staged narrative analysis of interviews of a racially diverse sample of 38 American HIV-infected women		HIV symptoms → fear, existential pain → Struggle to prevent HIV from taking hold (including healthcare avoidance and "non-compliance")	As HIV-positive women began to experience symptoms such as fatigue and wasting, they became fearful and experienced existential pain. They subsequently struggled to prevent HIV symptoms from taking hold, or taking over their lives through regiment noncompliance and health care avoidance.

Source	Purpose	Sample/ Design	Measuring, Def- ining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Strandberg, Astrom, & Norberg, 2002. Struggling to be/show oneself valuable and worthy to get care. One aspect of the meaning of being dependent on care – a study of one patient, his wife and two of his professional nurses.	Illuminate the meaning of being dependent on care, when it appears ‘negative.’	Phenomenological-hermeneutic interpretation of interviews with an older, hospitalized man with a chronic disease, his wife, and two of his professional nurses. Sweden.		Fear of abandonment + experience of being a burden → Struggle to maintain image of self as a valuable/ worthy person	“The meaning of being dependent on care is understood as a two-dimensional struggle for existence. One dimension of the struggle is about to be/show oneself worthy to get care, as dependency on care holds a fear to be abandoned. The other dimension of the struggle is about to be/show oneself valuable as a human being, as identity is built upon being able to manage oneself and be strong” (p. 43).
Talseth, Gilje, & Norbert, 2003. Struggling to become ready for consolation: experiences of suicidal patients.	“Describe a process of consolation revealed by two suicidal patient’s experiences” (p. 615).	Two Norwegian suicidal pts hosp. for psychiatric care. Secondary analysis. Thematic structural analysis. Phenomenological hermeneutic study		Suffering↔ Struggling Struggling→Suicide Struggling→ Perspective shift, readiness for consolation	“Struggling with longing for closeness and desiring to share despair while being objectified and disconnected...Letting go of the struggle and getting at the root of despair feels good, requires strength, and inspires courage. A shift in perspective surfaces and uplifts, liberating the light of life in the midst of darkness” (p. 619).
Travers & Lawler, 2008. Self within a climate of contention: experiences of chronic fatigue syndrome	Examine the illness experiences, specifically the experiences of self for people with CFS	Grounded theory methods, semi-structured interviews with 19 Australian adults		Sociocultural threats → Intrapersonal struggle	CFS sufferers endure threats such as disruption (including body failure, unpredictability, illness invisibility, functional impairments, dependency, and loss) and invalidation (such as disbelief, dismissal, stigma, and turning the abnormal into the normal). These threats to CFS sufferers result in a struggling self seeking renewal. The struggle is between guardianship (a defensive response characterized by assuming the burden of proof, internality, self-defense, and vigilance) and reconstructing (a renewing and redefining response characterized by reflection, a positive perspective, and an external focus).

Source	Purpose	Sample/ Design	Measuring, Defining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Van Mens-Verhulst, Radtke, & Spence, 2004. The private struggle of mothers with asthma: a gender perspective on illness management.	Determine how mothers with chronic illness manage their illness	11 Dutch and Canadian women/ Qualitative approach, semi-structured interviews			The mother role can include the exertion of childcare and housework and exposure to cleaning products, pets, campfires and other triggers that exacerbate asthma symptoms. Thus, mothers struggle to balance their perceived roles as mothers with their needs for rest and symptom management
Whittemore, Chase, Mandle, & Roy (2002). Lifestyle change in type 2 diabetes. A process model.	Describe the integration of T2DM treatment recommendations into existing lifestyle while participating in a nurse-coaching intervention.	Interpretive method elicited data from nurse-coaching sessions, notes, and interviews of 9 American women with T2DM. Data reduction and analysis.		Struggle → balance	Newly diagnosed type 2 diabetics struggle to incorporate recommendations into their lifestyle. The authors' interpretive research revealed a struggle between enjoyment of food and guilt over suboptimal choices resulting in blood sugar variability. However, struggle is one factor necessary to develop balance "between structure and flexibility, fear and hope, conflict and acceptance, diabetes and life" (p. 18).
Wiklund, 2008. Existential aspects of living with addiction – Part I: meeting challenges.	Explore the existential aspects of living with addiction.	Hermeneutic approach. Secondary analysis of interviews with 9 Swedish men and women	"Movement between different aspects of being" (p. 2429).	Addiction → Struggle → Continued drug use vs. Growth and strength to deal with struggles	Wiklund's exploration of the existential struggles of people living with addiction reveals a struggle between death and life during which people meet existential struggles. These struggles are defined as a "movement between different aspects of being," (p. 2429) such as meaning and meaninglessness, connectedness and loneliness, and control and chaos. Wiklund's research appears to indicate that others can promote growth in people living with addiction by promoting the positive aspects of the struggles, such as meaning, connectedness, and control.

Source	Purpose	Sample/ Design	Measuring, Def- ining Struggling	Struggling Antecedents and Consequences	Other Struggling Findings
Yamashita, 1998. Family coping with mental illness: A comparative study.	Compare culturally diverse families' reactions to mental illness, help-seeking behaviors, and transformative processes.	12 Canadian and 14 Japanese care- giving families of persons who had been diagnosed with schizophrenia for at least 10 mos. Newman's theory of health as praxis heuristic inquiry.		Struggling → transcendence, understanding, acceptance	The author identified the theme of struggling alone among the Canadian care-givers, which summarized the experience of being alone in knowing their son or daughter needed help but not having a diagnosis or information about the meaning of schizophrenia. After the struggling period, participants transcended their limitations, coming to an understanding and acceptance of the illness.

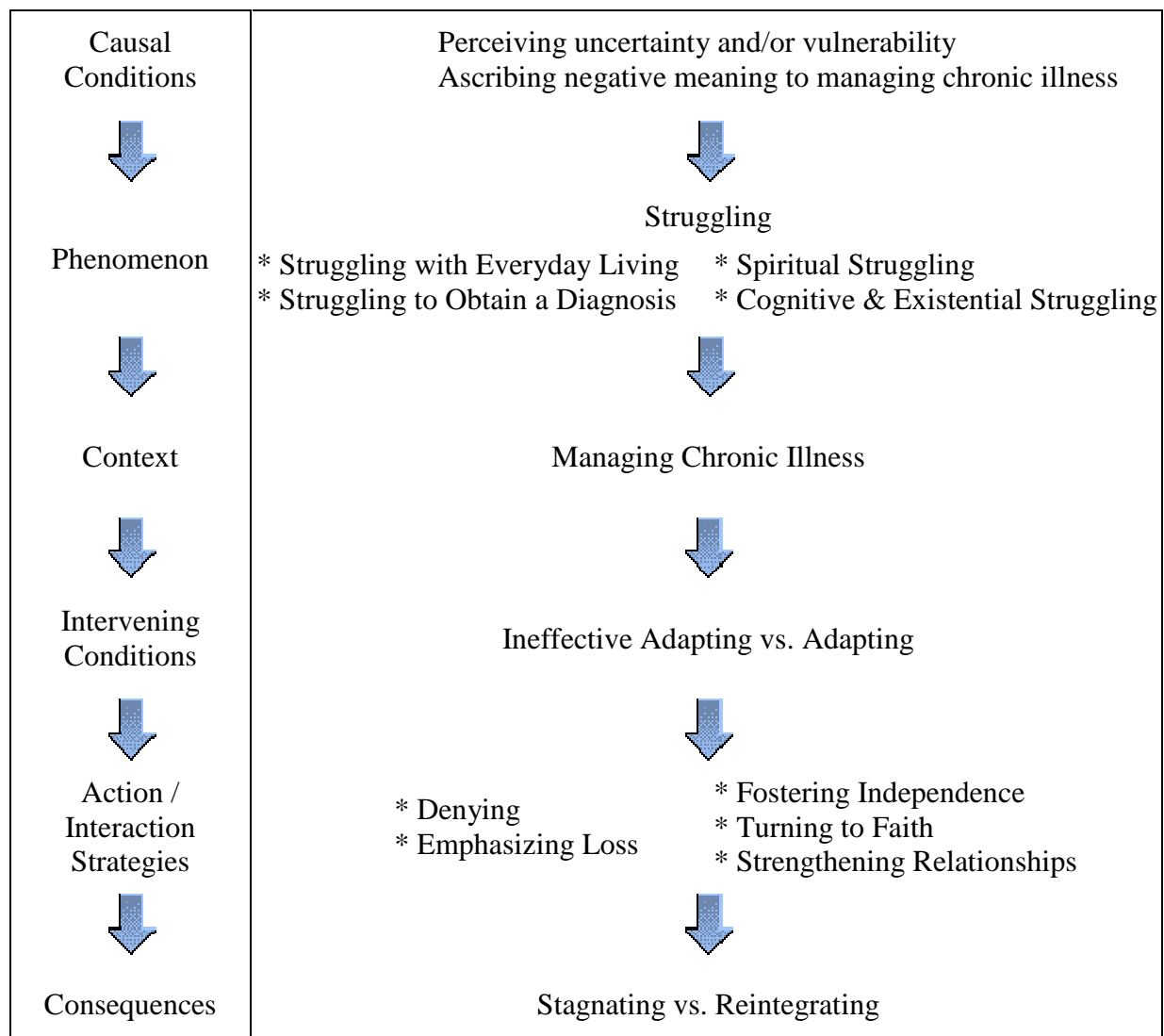


Figure 1. Struggling While Managing Chronic Illness Model