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FUNCTIONAL MASTERY OF HEALTH OWNERSHIP IN PATIENTS WITH
INFLAMMATORY BOWEL DISEASE

by

MARIA F. DONNELLEY

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
School of Nursing

Susan Yarbrough, Ph.D., Committee Chair

College of Nursing & Health Sciences

The University of Texas at Tyler
May 2018

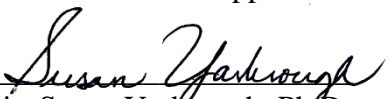
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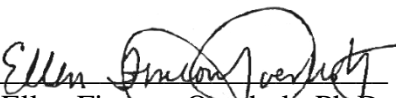
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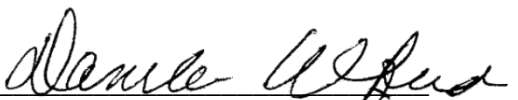
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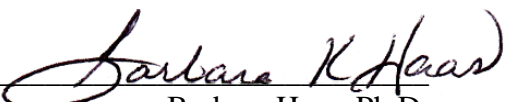
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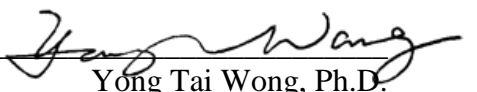
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Dedication

For my grandchildren

Weller and Linden,

Axel and Elliott,

Fin, Teo, Ona, and Luc,

and for all my grandchildren to come after this.

Never stop learning, dreaming, and finding your true selves.

Trust that God has walked before you and has mapped your every step.

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There are not enough words to express my gratitude to and for my children and family who never wavered in their belief in me and created a foundation for me to stand on. Matthew, Stephanie, Christopher and Katherine, and my ever-present cheerleaders David, Daidie, Elliott, Owen, and my wonderful mother, Nonnye, never doubted I would be here. Thank you for walking beside me.

My deepest thanks and gratitude go to my friends who have stood by me through this journey. Too numerous to name, my heart is filled with your encouragement and support. I am proud of Cheri Mixon, who has been steadfast at my side and decided to begin her own journey of reaching higher in her nursing education to achieve her dream to become an advocate for patients. I could not have kept my goal in front of me if it had not been for Dr. Catherine Selber, my incredible friend, mentor, and one-person marching band.

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I thank God for opening a door in my life that I only dreamed of going through. He walked this path before me and marked my every step. This is His journey, and it is His strength that kept me here. I am humbled by this accomplishment and pray I can do with it what He intends.

Table of Contents

List of Tables	iv
List of Figures	v
Abstract	vi
FUNCTIONAL MASTERY OF HEALTH OWNERSHIP IN PATIENTS WITH	vi
Chapter 1 Overview of the Dissertation Research Focus	1
Introduction of Manuscripts	2
Chapter 2 Functional Mastery of Health Ownership: A Model for Optimum Wellness	4
Abstract	4
Significance of Functional Mastery in Nursing	6
Developing a Plan for Mastery	6
Concept Identification	7
Targeted Literature Search	8
Discussion of Study Results	9
Construct of Functional Mastery of Health Ownership	12
Conclusion	15
References	17
Chapter 3 Health Stewardship: A Concept for Best Health Outcomes	21
Abstract	21
Health Stewardship: A Concept for Best Health Outcomes	22
Nursing and Health Stewardship	23
Literature Review	24
Tenets of Health Stewardship	28
Conclusion	29
References	31
Chapter 4 Functional Mastery of Health Ownership in Patients with Inflammatory Bowel Disease	34
Abstract	34
Functional Mastery in Patients with Inflammatory Bowel Disease	36
Review of the Literature	38
Quality of Life	38
Person's Plan for Health	40
Self-efficacy	41

Social Resources and Social Support.....	42
Personal Perception of Mastery	44
Personal Characteristics	45
Functional Mastery	47
Theoretical Framework.....	49
Conceptual and Operational Definitions.....	52
Research Questions.....	54
Design	54
Methods	54
Sample.....	54
Protection of Human Subjects	56
Instruments.....	56
Data Collection	61
Analysis	61
Research Findings.....	63
Descriptive Analysis of Categorical Variables	63
Descriptive Analysis of Continuous Variables and Bivariate Analysis.....	65
Multivariate Analysis.....	66
Discussion.....	67
Strengths and Limitations	72
Strengths	72
Limitations	73
Recommendations.....	74
Summary and Conclusion.....	75
References.....	76
 Chapter 5 Summary and Conclusion	 89
References.....	91
 Appendix A. IRB Approval, University of Texas, Tyler.....	 93
Appendix B. MEC Permission for Study, Austin Gastroenterology, Austin, Texas	94
Appendix C. E-mail Letter to Participants.....	95
Appendix D. Consent in Qualtrics Opening Page	96
Appendix E. Permissions for Instrument Use.....	97
Appendix F. Personal Health Inventory.....	100
Appendix G. IBD Self-efficacy Scale.....	103
Appendix H. Multidimensional Scale of Perceived Support	104
Appendix I. Pearlin Mastery Scale	105
Appendix J. Demographic and General Health Information	106

Appendix K. Patient Activation Measure	109
Biographical Sketch	110

List of Tables

Table 1 *Conceptual and Operational Definitions*.....53

Table 2 *Descriptive Analysis of Demographic Categorical Variables (N = 151)*.....64

Table 3 *Descriptive Analysis of Continuous Variables and Bivariate Analysis (N = 151)*66

Table 4 *Multiple Linear Regression Analysis (N = 151)*.....67

Table 5 *Analysis of Significant Moderating Effect of Gender and Social Support on Functional Mastery (N = 151)*.....68

List of Figures

Figure 1. Functional mastery of health ownership model.16

Figure 2. Functional mastery of health ownership model for IBD.....52

Abstract

FUNCTIONAL MASTERY OF HEALTH OWNERSHIP IN PATIENTS WITH INFLAMMATORY BOWEL DISEASE

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The University of Texas at Tyler
May 2018

Inflammatory bowel disease (IBD; Crohn's and ulcerative colitis) is an incurable autoimmune disease causing overwhelming physical distress and psychological adaptation. The negative disease symptoms effect all aspects of everyday life. The physical and biological burdens of the disease progression can be complicated and long-term. Not all patients have a positive outcome throughout their health journey. This dissertation is an exploration of the associations between an individual's personal characteristics and life situation and the ability to function fully and achieve mastery of their health within the parameters of their disease burden. The first manuscript, *Functional Mastery of Health Ownership: A Model for Optimum Health*, provides an operational definition of functional mastery as it applies to patients with chronic illness or altered life situation, and sets the foundation for the dissertation study. The second manuscript, *Health Stewardship: A Concept for Best Health Outcome*, introduces the

concept of individual responsibility for health as a path to optimum wellness that is intrinsic to achieving functional mastery. The primary research in the fourth chapter utilizes the Functional Mastery of Health Ownership (FMHO) model (Donnelley, 2017) to assess individual predictive influences that lead to the achievement of health mastery and optimum health in a patient population with IBD. The discovery of what causes some to succeed and others to not move forward is necessary to provide patients with tools to achieve wellness.

Chapter 1

Overview of the Dissertation Research Focus

In the United States, it is estimated that 3.1 million adults are diagnosed with inflammatory bowel disease (IBD; Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016), with hospitalization rates for Crohn's disease increasing 35.1% from 2003 (44.2 per 100,000) to 2013 (59.7 per 100,000; Malarcher et al., 2017). The increased prevalence brings with it the need for nurses and health care providers to understand not only the disease process and consequences of IBD, but also the life situations and personal characteristics of patients that influence their ability to adapt to this chronic illness and move toward best health.

The negative disease burden of IBD restricts easy and spontaneous movement through life. The focus of daily life becomes symptom management. Easy access to toilets, fear of bowel urgency, and the inability to hold the bowels are the backdrop patients use as they plan activities (CCFA, 2014; Frohlich, 2014; Smith et al., 2002; Taft, Keefer, Leonhard, & Nealon-Woods, 2009). Chronic inflammation of the digestive tract causing bleeding, ulcerations, uncontrollable diarrhea, and the inability to eat without pain contribute to the negative disease burden of IBD.

While caring for the patient population with IBD, it became evident to the researcher that though some individuals are successful in the management of their disease, becoming fully functional within the physical and psychological parameters of IBD, others are unable to attain optimum wellness or mastery of their health situation. It

is the intent through this dissertation to discover the reasons and differences between who are successful when faced with the life-long challenge of IBD and who are not. The predictive assessment using the Functional Mastery of Health Ownership (FMHO; Donnelley, 2017) model to explore the outcome of mastery can guide practitioners and integrate into a holistic care path for patients to achieve best health.

Introduction of Manuscripts

The observations of patients who were cared for in an ambulatory endoscopy clinical setting by the researcher lead to the realization that chronic illness in this general population was common and almost expected. These patients were considered “well,” but diagnoses and pharmacological treatments for conditions such as obesity, high blood pressure, and diabetes were often part of the health history. Long-term dependence on medical treatments provided by practitioners often took the place of individual participation in personal wellness. *Functional Mastery of Health Ownership: A Model for Optimum Wellness*, the first manuscript in chapter two, develops a predictive model to explore the relationships between persons, their health situation, and the ability to master and take ownership of their health.

The concept of health stewardship is explored in chapter three. The manuscript, *Health Stewardship: A Concept for Best Health Outcomes*, introduces the need for personal engagement in health and wellness by individuals to achieve their best health outcomes no matter where they are on the health continuum. The concept of health stewardship is intrinsically linked to health ownership and mastery of health. Without the recognition that taking care of oneself is foundational, mastery of health or life situation may not be achieved.

Chapter four contains the third manuscript, *Functional Mastery of Health Ownership in Patients with Inflammatory Bowel Disease*, the foundations of this dissertation. The study involved patients with the diagnosis of IBD and measured the influences of their personal characteristics and life situations on the achievement of mastery of their health. Through this predictive correlational study, the researcher was able to discover the association between the needs and circumstance that bridge the gap toward the achievement of optimum health.

Chapter 2

Functional Mastery of Health Ownership: A Model for Optimum Wellness

Abstract

The aim of this paper is to introduce the Functional Mastery of Health Ownership (FMHO) model and to develop an operational definition of functional mastery as it applies to a positive health outcome for patients with chronic illness or an altered life situation. Daily functioning within the negative disease burden of chronic illness is the goal of individuals living within the constraints of morbidity. Functional mastery fosters health ownership and helps to predict successful control over life circumstances for optimum wellness within the parameters of the limitations of the effects of illness. Significant to nursing, the FMHO conceptual framework uses four foundational influences to assess a patient's ability to not only master function within the disease process, but also to sustain function and best health over time. The FMHO model provides a tool for practitioners to enable individualized care as patients move through the disease process and adapt to changes over time.

KEYWORDS: chronic illness, health outcome, mastery, nursing model

Functional Mastery of Health Ownership: A Model for Optimum Wellness

Bridging the gap between self-management of illness and sustaining optimal positive health outcome and wellness is the concept that forms the construct of functional mastery. Chronic illness is the most prevalent form of life-long physical and psychological disruption, responsible for seven out of 10 deaths annually and accounting for 86% of the health care costs in the United States (Center for Disease Control and Prevention, 2016). Working within the parameters of illness or life situations and the ownership of that illness or situation, the impetus to function fully with the goal of mastering an altered life-course is found in an individual's perception and intention toward optimum wellness. Managing the complex and sometimes unpredictable symptoms of chronic illness while navigating through life effectively is an arduous task. Full adaptation to illness and the fluctuating physical and psychological burden experienced with chronic disease is essential to functioning and stability. Success in mastery can be envisioned for individuals as meeting the responsibilities inherent in illness, thus determining health outcome over time (Holman & Lorig, 2004).

Functional Mastery of Health Ownership (FMHO) is a nursing model designed to evaluate the actions and circumstances of individuals as they follow a life-course with chronic disease. Predictive in purpose, the model identifies influences and perceptions of self, thereby creating a personal blueprint for success. The purpose of this paper is to develop an operational definition of functional mastery as it applies to the achievement of positive health and to offer a conceptual framework for patients and health care providers seeking the best health and long-term wellness outcomes. This FMHO framework is guided by the constructs and concepts from Dorothea Orem's Theory of Self-Care (TSC),

Barbara Resnick's Theory of Self-Efficacy (TSE), and Pearlin and Schooler's study of coping (1978). Though considered here with the focus on physical illness, the FMHO model is adaptable to areas not physical in nature that require mastery of situation for a successful outcome.

Significance of Functional Mastery in Nursing

Developing a Plan for Mastery

The plan for a model for mastery began while working with the patient population in an ambulatory endoscopy clinic. Individuals with diabetes, obesity, chronic heart disease, and depression are found at high rates in a population considered 'well.' Lifestyle adaptation and motivation for betterment are often a struggle, over-ridden by feelings of futility, status-quo, and lack of motivation for participation in decision making. There is a difference between who is successful when faced with health adversity and who is not, and the reasons can be unclear. Exploration of what causes some to succeed and others to not move forward is necessary to provide patients with tools to create wellness.

In the context of the model, success in functioning at any level of disease burden is considered *mastery*. It is what we strive for in our patient populations. The FMHO Model was created to predict mastery. It provides a guide for practitioners for treatment and creates an opportunity for individuals to connect with their own motivations and their potential for best health.

Functional mastery in nursing enables individualized patient care while fostering health ownership for optimum wellness. Chronic illness is a lifetime event that is dynamic rather than stagnant and requires individuals to adapt to changes in disease

burden over time (Auduly, Norbergh, Asplund, & Hörnsten, 2009). As care for chronic illness has moved from acute care settings to home settings, health management becomes more the responsibility of the individual and less that of the healthcare team; care becomes patient-centric with control and responsibility driven by the individual rather than the provider (Johnston, Rogerson, Macijauskiene, Blaževičienė, & Cholewka, 2014; Knight & Shea, 2014). Health management in chronic illness has become a collaboration between the individual, the family or social network, and the healthcare team, with the individual actively involved in care and planning (Holman & Lorig, 2004; McCorkle et al., 2011). Creating a model for functioning fully through the course of disease over time fosters patient independence, participation, and ownership of health outcome.

Individual adaptation to the physical and psychological outcomes of long-term disease processes requires nurses to take a role in defining functional mastery for individuals, addressing needs and goals, and providing the skills, information, and resources necessary to be successful (McCorkle et al., 2011). Managing chronic disease through mastery of the symptom burden and disease impact is essential for reaching the greatest potential of health no matter how limiting the illness. Nurses and the health care team must inherently become advocates for independence when guiding individuals through care (Ryan & Sawin, 2009).

Concept Identification

Understanding the basic meaning of function, mastery, health, and ownership is important as these concepts underpin the theoretical framework. The Oxford Dictionary defines *functional* as an adjective: “working, affecting the operation, rather than the structure of something, designed to be practical and useful, relating to the way in which

something works or operates” (Oxford Dictionary, “Functional,” 2016, p. 1). Synonyms of functional are effective, operational, viable, flourishing, and productive, whereas antonyms include ineffectual, useless, nonoperational, and unproductive (Merriam-Webster, “Functional,” 2015). *Mastery* is defined as “knowledge and high-level skill that allows the use and understanding of something; complete control of something; possession or display of great skill or technique” (Merriam-Webster, “Mastery,” 2015, p. 1). Mastery can be further explained as a comprehensive skill or knowledge in a subject, proficiency, expertise, and skillfulness, with the opposite meaning inability, ignorance, and weakness (Oxford Dictionary, “Mastery,” 2016). *Health* is defined as a noun: “the condition of being well and free from disease,” and *ownership* as the state of owning, or belonging to oneself (Merriam-Webster, “Health,” 2015, p. 1; “Ownership,” 2015, p. 1).

Targeted Literature Search

A targeted search was conducted in three databases, Medline, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO using a combination of search terms *mastery*, *functional*, *health*, *chronic illness*, and *ownership*. The focus of the search was to find previous studies examining the effect of mastery of illness or situations on functional success over time. Medline and CINAHL combined databases revealed 71 articles relating to mastery, function, and health, while 156 were found in PsycINFO using the same terms. After thorough searches of each database, duplicate articles were found across the three databases showing saturation of information and content. Seven articles were chosen from the 227 total for specific relevance to mastery over illness or situation, the outcome concept in the health ownership model. Articles related to aging, elder coping, and function address this

concept and are relevant to the structure of the model. The mastery of mathematics and functional task mastery not related to illness were included to broaden and define the scope of functional mastery. Articles not specific to mastery of a situation or goal and not relevant to this issue were discarded.

Discussion of Study Results

Mastery has been studied as a precursor to improved health status and learned tasks as it influences the ability to adapt to physical and psychological changes over the course of illness or time. Fluctuations in life situations and conditions affect belief in and confidence of oneself that are foundational to the success and ability associated with mastery. Sargent-Cox, Butterworth, and Anstey (2015) in a study of mastery of physical functioning as it affects outcome of successful aging found that high mastery of physical activity was associated with better health throughout aging. Participants were studied in age-related cohorts (20, 40, and 60 years). Mastery was measured at three wave intervals using Pearlin and Schooler's 7-item Likert scale (Pearlin and Schooler, 1978) to evaluate self-rated personal beliefs about control of situations and determination of motivation for success. Function was measured using hand grip exercise tools for determination of physical function. A key significant finding was the between-person positive relationship between mastery of physical activity, functional health outcomes, and psychological health in all cohorts ($p < .001$).

In another study with patients diagnosed with Multiple Sclerosis (MS), mastery was found to be part of a person's self-concept, rather than the measured capability to perform physical tasks (Krokavcova et al., 2008). In this study about functional disability and the extent patients perceive themselves as being able to control events and situations

that affect their lives during the course of chronic disease, Krokavcova and colleagues (2008) found positive associations among mastery, functional ability, and perceived health status in individuals with MS. Older individuals (over age 45) reported significant association between mastery and disability ($r = -.0.34$; $p \leq 0.01$) with better perceived health status. This was not found in younger participants.

Pearlin, Nguyen, Schieman, and Milkie (2007), through interview and self-report, explored the sources of mastery in the elder population over the life course. Pearlin et al. defined mastery as a construct referring to an individual's control over life circumstances that evolves from experiences gained through overcoming adverse conditions; it is the "capacity to protect health and well-being" (p. 165). This construct aligns with the functional mastery model as mastery is realized with optimum health over time and life experience with the disease process. Noteworthy is the finding in the elder population that mastery comes from overcoming stressors over time, leading to the ability to master current and acute stress. Pearlin and colleagues found that over the life-course, however, the oldest old, rather than continuing to build on mastery, become fragile when faced with adversity. The authors propose the strong psychosocial resources present earlier in life may be missing for the oldest old, suggesting, therefore, that a meaningful support system is likely to be integral to mastery and control. Though not directly related to the concept of mastery in chronic illness, this study was included for relevance in understanding elder needs and the influence of social determinants when confronting the need for mastery of health.

López-Espuela and colleagues (2016) conducted a longitudinal study of acute stroke patients measuring functional outcome in relation to return to independence over

time. Measuring age, gender, stroke severity, and baseline functional status, the study showed that health outcome and functional status improved for patients with rehabilitation after six months with a return to near pre-stroke ability. Kwon, Kim, and Lee, in their qualitative and self-assessment correlational study, reported the functional ability of patients diagnosed with juvenile rheumatoid arthritis (JRA) was statistically positively correlated ($r = 0.748$, $p = < .001$) with health-related quality of life (2015). Juvenile rheumatoid arthritis (JRA) is a long-term, debilitating condition with physical impairments and symptoms interfering with the ability to function normally at an early age, resulting in a generally poor quality of life for children with JRA (Cartwright, Fraser, Edmunds, Wilkinson, & Jacobs, 2015). Active involvement with treatments for symptom relief and social adaptation decreased the negative disease burden of JRA, which would likely allow for improved functional mastery.

The meaning and uses of functional mastery in other disciplines aids in the understanding of disease management in chronic illness and adaptation to life situations. In leadership, functional mastery is focused on expertise, depth of knowledge about a chosen field, and a credibility in performance and perspective (Leaderonomics, 2014). Leach (2015) offered that functional mastery demonstrates accomplishment in a vocation, credibility, and effective engagement. Knets (2014) takes functional mastery into the study of mathematics. He describes it as the highest level of mastery and the ability to self-assess difficulty. Students respond positively when they understand the concept behind the process and finding the answer to problems. Meadows-Orlans, Spencer, and Koester (2004) use the concept of functional mastery in the assessment of deaf infants as it applies to adaptability within a changing environment. The implication in this study

was that “more mastery is better” (2004, p. 102). The variety of understandings of mastery and its positive impact within these studies emphasizes the need for specific understanding of a situation, effective engagement, and the adaptation to change involved in mastery within chronic illnesses.

Creating a plan for mastery can be explored for any altered life situation or barrier to health, and can be modified for use in areas other than for physical wellness

Chronic illness (not limited to the following)

- Inflammatory Bowel Disease Diabetes
- Obesity Stroke Depression

Adaptation to altered physical body

Grief and loss

Life coaching

Construct of Functional Mastery of Health Ownership

At the time of diagnosis, individuals are faced with the onerous task of changing the structure of their lives to adapt to a chronic and invasive disease process, while learning, coping, and focusing efforts to reach and maintain optimum health. Inspired by previous research and patient need, the FMHO model is predicated on an association between the distinct situations in an individual’s life that determine the ability to cope with disease burden and subsequent quality of life over time. Four foundational influences are expected to have a direct effect on mastery of health: a person’s plan for health, self-efficacy, social resources, and personal perception of mastery (see Figure 1). Each influence can be measured to assess mastery, ability, or readiness for participation and independence in care.

A person's plan for health begins with a connection between the individual, the present state of health, and the desire for reaching optimum wellness. The exploration of health as being an achievable goal or to the opposite, wellness being unattainable, through the lens of the patient is paramount to setting the stage for ownership of health. The possibility of what is attainable is within the plan for health. A person who does not believe better is possible or questions a different future for health will not hold the same vision and impetus for change as a person who expects and desires change. Included within the person's plan for health is an evaluation of those ideas and realities an individual holds as valuable, important, or meaningful, and whether those are powerful enough to create a desire to master health needs and changes. The Veteran's Administration, using the Personal Health Inventory, has established the work of proactive healthcare that is driven by the individual for achievement of goals that are created by choosing possibilities for health, fostering a path to move forward from illness, or improve a lack of physical or psychological wellbeing (2013). These goals are focused on specific health needs as well as a broader desire to live fully regardless of the real or perceived parameters of illness. An underlying respect for person and place in this foundational influence is evident as the individual is given the ability to connect for themselves the goals, possibilities, and value of mastering their life.

The foundational influence of self-efficacy is the individual's personal belief in their ability, personal power, and confidence to move into a place of optimum wellness and mastery of their personal situation. Efficacy beliefs and confidence are essential measurements for how certain the individual is that they can accomplish movement toward mastery (Scherbaum, Cohen-Charash, & Kern, 2006). Resnick's Theory of Self-

Efficacy posits that individuals exercise influence over what they do and the decisions and choices made for behavior (Smith & Liehr, 2014). In the FMHO model, a positive outcome expectation exists for behaviors and beliefs that are used to explain an individual's choice for health mastery.

Social resources and the interventions by others to meet needs are the social determinants in an individual's life, or the social support system available to help or intervene either with physical participation or through encouragement and psychological intervention. A study by Dilioro, Hennessy, and Manteuffel (1996) found the individual's social support is important for medication adherence in individuals with epilepsy, while Walker et al. (2014) also studied the influence of a support system on individual self-management in epilepsy and found social support was an integral part of success. Though these studies did not focus on mastery, social support and intervention by others can be used as a precursor for the desire to master health outcome.

Personal perception of mastery is the internal measure of a person's discernment or awareness of what mastery means and whether a belief is present or could be present to attain a positive health status. It is the control over illness or circumstance that is decided by the individual through beliefs about themselves and their personal ability to move toward the best outcome (Pearlin, Nguyen, Schieman, & Milkie, 2007). Though similar to self-efficacy (the confidence an individual possesses to manage illness; Simpson & Jones, 2013), in the FMHO model, personal perception of mastery is concerned with the achievement of mastery or possibilities for control over all aspects of wellbeing, not merely functioning within illness or circumstance.

Age, gender, socioeconomic status, health status, and the physical ability to carry out self-care are the moderators for adaptation. These personal demographics are variables that can strengthen or help determine the effect of a person's foundational influences on mastery. Exploring the relationships among and between these variables on mastery as predictors will help in understanding the ability of an individual to move to a positive place for mastery and wellness.

Functional mastery includes contexts that are necessary for success and require a commitment from the individual. These contexts, ownership of illness, conscientious self-care, health stewardship, commitment to disease adaptation over time, and maintenance of health promotion behaviors, have an influence over the long-term achievement of optimum wellness and decreased disease burden. Each involves personal choice, motivation, and a belief in a positive outcome. With the ability to be measured over time, these contexts are the outcome of mastery, and represent the predicted behaviors that will sustain wellness within the disease burden.

Conclusion

The pervasive long-term effects of chronic disease have a high negative health outcome for an individual. Providing a tool that healthcare professionals can use to influence and maximize the impact of mastery on health outcomes is imperative. Such a model does not yet exist. The Functional Mastery of Health Ownership model is designed to explore the association among individual characteristics and foundational influences that determine a person's ability to work within an illness to achieve optimum wellness and life potential. The FMHO model is considered dynamic and will change as research influences the current structure.

The FMHO model does not address specific interventions for mastery or the actions needed to bring an individual to desire or attain mastery and ownership of illness. It does, however, provide a foundational body of information specific to an individual that allows for the creation of a plan for health going forward, based on personal characteristics, behaviors, and beliefs. Though targeted toward mastery of physical health and positive health outcome in chronic disease, the FMHO model can be viewed as a seminal model, using the foundational influences and moderators to guide outcome for acute illness that requires an individual to function fully for recovery. Individuals with non-physical life altering events such as grief, loss, and coping with traumatic life experiences can use the FMHO model to find a path to mental and psychological health after a disruptive situation. The exploration of personal drive and choices for change to overcome barriers to wellness in all areas of life is possible using Functional Mastery.

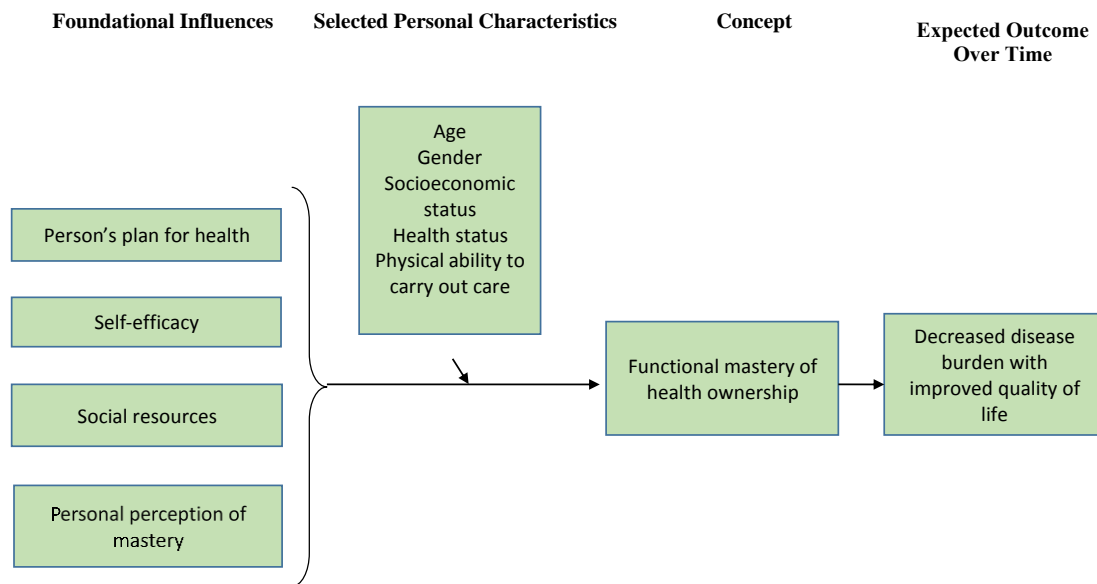


Figure 1. Functional mastery of health ownership model

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Chapter 3

Health Stewardship: A Concept for Best Health Outcomes

Abstract

The concept of health stewardship and responsibility for self, marks a shift from adopting a paternalistic approach to care, with decision-making the main remit of healthcare practitioners, towards encouraging and empowering individuals to take increasing responsibility for their healthcare and outcomes. The main aim of nursing is to achieve optimal health outcomes for every patient. Exploring health stewardship as a path to wellness will assist healthcare practitioners to guide patients living with a chronic disease to be as healthy as possible.

Keywords: chronic disease, health management, health stewardship, self-care, wellness

Health Stewardship: A Concept for Best Health Outcomes

With a rise the incidence of chronic disease, whereby patients often have increasing and complex care needs, and the associated cost of healthcare, it is important for nurses and other healthcare practitioners to explore the concept of health stewardship. In this context, the author defines health stewardship as the care of one's self that results in a positive health experience motivated by personal decisions. It is dependent on the individual's ability and desire to achieve optimal health.

Treatment and care largely provided in acute and long-term care settings is increasingly being provided in patients' homes and outpatient settings (Haas & Swan, 2014). This requires patients to take increasing responsibility for, and involvement in, their care and health management. The movement of healthcare from mainly managing and treating the symptoms of disease towards encouraging overall wellness by considering physical, emotional and spiritual health, represents person-centered rather than provider-centered care that promotes ownership of the disease process and increased independence among patients (Johnston et al., 2014; Knight & Shea, 2014).

The author's interest in health stewardship began while working in an outpatient endoscopy center. The patients who visited the center were considered 'well' with few care needs. However, many of the patients had comorbidities, including diabetes, obesity, chronic heart disease and depression, and they were dependent on multiple medicines that were creating an illusion of health – the false perception that they were healthy because the medicines they were taking were masking their symptoms. This reduced their motivation to make the necessary lifestyle changes to improve their overall health.

It is unclear why some patients are motivated to improve their health and achieve optimal health outcomes while others lack motivation or do not have the tools or skills to do so (Donnelley, 2017). Exploring stewardship as a general concept through various perspectives and disciplines can provide an insight into how people can achieve meaning or purpose by pursuing optimal health outcomes.

Nursing and Health Stewardship

Wellness and the achievement of optimal health is a lifelong pursuit. Illness, particularly chronic illness or disease, is not static and often requires people to make decisions about care while adapting to changes in their health and priorities over time (Orem, 2001). It is important that healthcare practitioners encourage and empower patients to take ownership of their health and guide management of health during life-changing events, including illness and ageing.

During a period of ill health, healthcare practitioners should encourage patients to adopt the necessary health, behavior and lifestyle changes to reduce the negative effects of illness, using an individualized approach that considers the perceptions, intentions and needs of each patient. This is particularly important when an individual takes ownership and stewardship of their health and the self- management of a long-term condition. Medicine adherence, understanding the physical nature of the chronic illness or disease, seeking assistance from healthcare practitioners, and recognizing how personal actions affect health, are central to the success of an individual's health stewardship (Cooper et al., 2010; Plevinsky et al., 2016).

The shift from provider-driven healthcare to person-centered healthcare affects the way disease is managed. Care and treatment are increasingly guided by the physical,

emotional and spiritual effect that disease has on the patient compared with a sole focus on managing the physical symptoms of disease. The patient and the healthcare practitioner collaborate in decision-making and developing an appropriate care pathway. Fostering an environment consistent with the patient's beliefs about self, the disease and the desire to achieve optimal health encourages positive engagement with health stewardship (Karnilowicz, 2011).

Health stewardship is realized as the person assumes responsibility for health management through diligent and holistic self-care, with the aim of achieving positive health outcomes (Ryan & Sawin, 2009). It is essential for a partnership to be formed between the healthcare team and the patient to achieve the goal of optimal health. Health stewardship and the ownership of what is happening in illness or disease requires that healthcare practitioners address individual patient goals and needs, while developing an active and flexible plan of care that changes as the patient's physical and psychosocial needs alter (McCorkle et al., 2011).

Healthcare practitioners can become advocates for their patients as they guide and support patients to achieve wellness by engaging in conversations about quality of life, symptom burden and disease activity, unmet needs and the importance of self-care (Rochelle & Fidler, 2012). Nurses are usually the first and main point of contact for patients and, therefore, are in a unique position to discuss, promote and encourage health stewardship.

Literature Review

Health stewardship during illness or for disease prevention is not extensively represented in the literature. The author undertook a literature search of CINAHL

(Cumulative Index to Nursing and Allied Health Literature), MEDLINE, PubMed, and PsychINFO using the term health stewardship, which produced limited results. Health AND (used as a Boolean operator) stewardship and the incorporation of all combinations of the terms wellness and chronic illness were used to broaden the search. No studies were found that specifically measured or evaluated personal health stewardship and the effect on the individual and on health outcomes; however, two authors addressed the issue within a broader discussion of health. Thorne (2008) used the concept of stewardship in the context of chronic disease self-management and Unruh and Hutchinson (2011) described stewardship in terms of its effect on the meaning and purpose of life. The exploration and understanding of stewardship in healthcare and other disciplines provides insight into both the definition and use of the term when referring to personal health.

The responsibility to actively protect health is a priority for people who have experienced ill health. Murphy and Roberts (2008) described stewardship as the promotion of ‘what is intrinsically valuable in an experience’. In the context of this discussion, health stewardship is a combination of actions resulting in the management of one’s health with a responsibility to achieve optimal outcomes.

Thorne (2008) contrasted stewardship in chronic illness with ineffective provider-driven choices for treatments that involved established or predetermined medical interventions. Because there is no cure for chronic illness, the goal of care should focus on encouraging the patient to accept stewardship of their health. Engagement in health stewardship involves understanding the perspective of the patient to enable self-care and treatment to be individualized. Patients, as respected owners of their health and their

illness or disease, can engage in health stewardship by making informed decisions about their care (Thorne, 2008).

Thorne (2008) stated that the scientific and medical orientation of chronic disease treatment limits the authority a person has over stewardship and the recognition that the patient is a partner in their care. In a longitudinal, exploratory and descriptive research study of 22 patients with type 1 diabetes, Paterson and Thorne (2000) found that people who were encouraged to make decisions about daily care had improved self-management of their diabetes.

Stewardship has been described as an intrinsic component of nursing. Murphy (2009) linked stewardship in nurse leaders to self-identity and virtue. Decision-making by nurses involves personal and moral values to ensure high standards in the quality of healthcare. Robinson (2009) considered nurse educators and the students they teach as 'sacred stewards of nursing'. Educators teach that nurses are stewards of patients' health and they must be committed to upholding the trust others have in their care.

Stewardship in nursing involves valuing and respecting patients' priorities and self-determination. Nurses become stewards or teachers to patients who may not have the expertise or experience in the disease process, but who understand the consequences of their illness.

In a prospective qualitative study, Unruh and Hutchinson (2011) used hermeneutic phenomenology to determine the effect that gardening had on people with chronic disease or who were coping with a life-changing event. All participants were living with a chronic progressive disease or grieving the death of a loved one. Using stewardship as a theme, participants said they felt they were good caretakers of their

gardens. This assisted them to reappraise their spirituality and purpose. It was found that being a ‘good’ steward created meaning and purpose while reducing stress. When questioned about stewardship, those participants who answered (nine men and ten women) felt they practiced stewardship in their garden, caring for it as if it were a living being. The meaning and purpose identified in this study is similar to the empowerment and self-awareness identified by patients as they choose to become responsible for their health and outcomes (Gibson et al., 2015).

The concept of stewardship has also been discussed in religious, biblical and spiritual understandings of purpose. Giles (2007) explored stewardship of self as a biblical principle with the assertion that stewardship promotes a healthy lifestyle and empowers people to have a positive self-image. Stewardship of self involves meeting physical, emotional and spiritual needs and ensuring that resources remain to care for others. Physical, emotional and spiritual strengths are depleted without stewardship of self.

Giles (2007) also linked stewardship of self to self-esteem. With higher self-esteem, there is greater and increasingly successful stewardship. People with low self-esteem and self-image have a less positive outlook regarding behavior and health outcomes. The lack of self-esteem that can accompany chronic disease further supports Giles’ (2007) belief that if one is unable or unwilling to recognize one’s self-worth, stewardship of self is likely to be absent. Chronic disease or a traumatic life event can result in an inability to choose positive self-care, limiting the successful stewardship of health.

Whelchel (2012) identified four principles of stewardship: ownership, responsibility, accountability and reward. In general, stewards devote a significant amount of thought and effort to maintain the condition of that held valuable, fundamentally knowing the seriousness of their commitment. Stewardship of health requires a belief in the value of self, with a commitment and responsibility to owning and caring for physical, emotional and spiritual well-being.

Tenets of Health Stewardship

The tenets of health stewardship and the desire to care for oneself include the ownership of wellness and authority over decision-making (Giles, 2007; Thorne, 2008), with the aim of reducing the effect of illness (Knight & Shea, 2014; Box 1). Health stewardship requires a level of health literacy to understand the choices and decisions required to aim for and ultimately achieve optimal health outcomes (Murphy & Roberts, 2008).

Another fundamental tenet of health stewardship is the belief in personal worth (Giles, 2007; Whelchel, 2012). The physical being is inherently valuable and deserves a commitment to optimal health (Murphy & Roberts, 2008; Thorne, 2008).

By following the tenets of health stewardship, patients can:

- » Aim for optimal health during an episode of ill health (Thorne, 2008).
- » Meet physical, emotional and spiritual needs (Giles, 2007).
- » Recognize that good is being done by taking care of one's self (Unruh & Hutchinson, 2011).
- » Improve overall health outcomes (Thorne, 2008).
- » Increase confidence and self-worth.

It cannot be assumed that every person desires or requires optimal health. As previously discussed, some patients may perceive that they are healthy because the medicines they are taking mask their symptoms. Other patients may have little or no desire to know about the outcomes of, or complications associated with, their illness because of fear or lack of knowledge about the illness or disease (Katavić et al., 2015). A precursor to health stewardship and its tenets is the motivation to achieve optimal health outcomes through the ownership and acceptance of the individual's situation. Ryan et al. (2009) discussed motivation towards health as being self-determined, autonomous and intentional. Jowsey et al. (2011) found that motivation was a significant positive factor in successful health management. To be well and seek optimal health outcomes, it is necessary to take care of one's self while accepting the responsibility for personal choices (Orem, 2001).

BOX 1. Tenets of health stewardship

- ❖ Ownership of health and authority over decision-making
- ❖ Diligence in health management with the intention to reduce the effect of illness
- ❖ Understanding choices and decisions that can optimise health
- ❖ Belief in personal worth
- ❖ Commitment to optimal health outcomes and wellness
- ❖ Protection of health
- ❖ Responsibility for wellness

(Giles 2007, Murphy and Roberts 2008, Thorne 2008, Knight and Shea 2014)

Conclusion

Health stewardship is an important concept in healthcare, particularly for individuals experiencing the challenges of chronic illness or traumatic life events. Health

stewardship and the commitment to wellness require personal choice, motivation and self-belief. Although health stewardship does not guarantee optimal health, the individual's interpretation of wellness and how they identify with illness or disease is the starting point for adherence to treatment. Guided by the tenets of health stewardship, healthcare practitioners can encourage patients to aim for optimal health. The role of the healthcare practitioner is to translate the concepts of stewardship observed across other disciplines into an individual context while guiding patients to find meaning and purpose during challenging times.

Healthcare practitioners have an obligation to guide treatment choice and care pathways while considering the patient's needs and preferences. Inherent in this is the sharing of knowledge and expertise with the patient. An active and collaborative partnership between healthcare practitioners and patients enables informed decision-making.

Encouraging patients to engage in health stewardship and take ownership of decision-making and their health will ultimately enable patients to shape their health outcomes.

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Chapter 4

Functional Mastery of Health Ownership in Patients with Inflammatory Bowel Disease

Abstract

Background/Problem: Inflammatory bowel disease (IBD) is an incurable autoimmune disease causing overwhelming physical distress and psychological adaptation.

Purpose: To explore the associations between foundational influences and personal characteristics on the achievement of mastery of health in patients with IBD.

Research Questions: The study assessed the association between a person's foundational influences as predictors on the achievement of functional mastery and the extent to which selected personal characteristics influence mastery.

Theory: Orem's Theory of Self-Care, Resnick's Theory of Self-Efficacy, and Pearlin and Schooler's study of the structure of coping guided this study. The conceptual framework used was the Functional Mastery of Health Ownership model.

Methods: A predictive correlational study design using self-administered questionnaires was used. A convenience sample of 151 adults with a diagnosis of IBD for at least one year was recruited from the patient population of a gastroenterology medical practice.

Analysis: Data were analyzed using multiple regression with standard entry factor loading. Foundational influences were evaluated as predictors for mastery, with moderation exploration between significant selected personal characteristics and mastery.

Results: Portions of the model were found to be significant and account for 44% of the variance ($p < .001$; $R^2 = .44$, Adjusted $R^2 = .41$). Significant relationships were found among mastery and IBD self-efficacy, perception of mastery, and current health status.

Females had higher mastery scores than males

Significance: These findings support the use of a modified FMHO model to predict needs that enable individualized stewardship of health for patients with IBD.

Keywords: Inflammatory bowel disease, mastery, function, health, influence, self-efficacy, gender

Functional Mastery in Patients with Inflammatory Bowel Disease

Inflammatory bowel disease (IBD) is a chronic, incurable autoimmune disease affecting an estimated 3.1 million Americans, with 70,000 new cases diagnosed annually. The majority are young adults who experience the onset of the disease in childhood (Crohn's and Colitis Foundation [CCFA], 2014; Dahlhamer, Zammitti, Ward, Wheaton, & Croft, 2016; Morrison, 2008). The incidence of IBD is 5 to 15 per 100,000 people, with a peak incidence between the ages of 15 to 35 years (Centers for Disease Control and Prevention [CDC], 2014). Worldwide, 15% to 60% of patients with IBD will require surgery within the first 10 years from diagnosis, and 10 percent will become disabled from the condition (Bernstein, Loftus, Ng, & Lakatos, 2012; Morrison, 2008).

The patient experience with IBD is one of physical distress and psychological adaptation that changes the individual's perception of 'normal,' causing activities of daily living to be severely altered (Kemp, Griffiths, & Lovell, 2012; Morrison, 2008). Movement through life is constrained by the necessity of assuring easy access to toilets, bowel urgency, the inability to hold the bowels, and the fear of incontinence in which the stigma can be difficult to accept (CCFA, 2014; Frohlich, 2014; Smith et al., 2002; Taft, Keefer, Leonhard, & Nealon-Woods, 2009). Lack of control over the disease and the humiliation felt because of uncontrollable symptoms can create isolation and feelings of powerlessness (Kemp, et al., 2012; Banovic, Gilibert, & Cosnes, 2010). The quality of life of an individual with IBD decreases as chronic inflammation of the digestive tract causes bleeding, ulcerations, uncontrollable diarrhea, and the inability to eat without pain.

Although the negative impact of the chronic disease burden is seen across this patient population, it has been shown that gaining control through self-management of

the effects of IBD is imperative for quality of life and positive health outcomes over time (Audulv, Norbergh, Asplund, & Hörnsten, 2009). The actions and decisions made by the individual with IBD can have a direct effect on illness adaptation and the motivation for wellness (Audulv et al., 2009; Jowsey, Pearce-Brown, Douglas, & Yen, 2011). While working within the parameters of the physical and psychological effects of illness or life situation and the ownership of that illness or situation, the impetus to function fully with the goal of mastering the altered life-course of IBD can be found in an individual's perception and intention toward optimum wellness.

The physical, psychological, and biological burdens of disease progression can be complicated and long-term. Not all patients have a positive outcome or comply with what is necessary for the best possible experience and outcome throughout their health journey. There is a difference between who is successful when faced with health adversity and who is not, and the reasons can be unclear (Donnelley, 2017). Full adaptation to illness and the fluctuating physical and psychological burden experienced with IBD is essential for optimal functioning and the stability of health throughout life. Individuals and their health care providers can become proactive in long-term IBD care and treatment rather than reactive to acute events if predictive health risk assessments are used as part of a comprehensive and coordinated plan for care (Burnette, Simmons, & Snyderman, 2012). The study of functional mastery of health ownership addresses the need for predictive assessment with the purpose to explore the relationships among foundational influence factors (i.e., a person's plan for health, IBD self-efficacy, social resources, and personal perception of mastery), selected personal characteristics (i.e., age, gender, race, marital status, living situation, socioeconomic status, insurance coverage,

time since diagnosis, and current health status), and the achievement of functional mastery and ownership of health. The discovery of what causes some to succeed and others to not move forward is necessary to provide patients with tools to create wellness.

Crohn's disease and ulcerative colitis, both maladies considered in the diagnosis of IBD, have a similar disease burden and consequences. Therefore, both diagnoses will be included in the study as 'IBD'. Found in the literature are the concepts of self-management, motivation, and coping as avenues for health control and betterment. In this research study, self-management, motivation, and coping were not defined or explored specifically, but rather were used for understanding behaviors or feelings that can be precursors to functional mastery.

Review of the Literature

Quality of Life

Much of the research reviewed specific to individuals with IBD revealed studies of the personal perception of the disease burden on the quality of life and life experience. Quality of life was not measured in this study, but as an outcome variable in the conceptual model of functional mastery it is discussed with the intent to support the purpose of this research. Studies of quality of life can aid in understanding the role of disease burden and a person's ability or desire to achieve best health. Kemp et al. (2012) conducted a meta-synthesis to understand the health and social needs of patients with IBD. A compromised life, disruption, humiliation, and isolation were commonly reported across 86 personal accounts, along with the finding that gaining control of the changes caused by the disease had a positive impact on quality of life. Using Leventhal's Self-regulation model, Rochelle and Fidler (2013) found individuals experienced poor quality

of life ($p = < .001$) with low personal control over IBD and showed the value for patients to be involved in their health and health needs. Two studies, Audulv et al. (2009) and Pihl-Lesnovska, Hjortswang, Ek, and Frisman (2010), used grounded theory to identify and describe the meaning of quality of life and to understand the self-management process in IBD. Both studies found quality of life increased with personal integration and involvement in self-management and decision-making. Gethins, Duckett, Shatford, and Robinson (2011) evaluated self-management over time and reported fewer physician and hospital visits as the personal role in care and decisions increased. Personal control and self-management were studied in patients with IBD using the Self-Discrepancy Theory and it was found that individuals who have accepted and adapted to living with the disease minimized the negative impact and found a greater sense of control (Cooper, Collier, James, & Hawkey, 2010). In a longitudinal study using multiple variables, Banovic, et al. (2010) discovered that poor general health stemming from anxiety and depression was associated with low quality of life, with a high correlation between active disease and anxiety and depression

Throughout the studies, a common theme was found. Increased control or management of IBD and the symptom burden along with increased personal decision-making enabled a better quality of life and decreased the negative impact of the disease. A review of the literature for the foundational influences and personal characteristics also revealed an overall connection between patient control, personal engagement, and coping ability as having a positive influence on the movement toward best health.

Person's Plan for Health

Personal knowledge of the disease, expectation of outcome (either positive or negative), and actions or beliefs for functioning through life within a state of illness are the principles underlying a person's plan for health (Gaudet, 2014). The premise for developing a person's plan for health lies in the discovery of the individual's intent for what is possible to achieve moving forward in their health situation. A person's plan for health does not address specific health conditions, but rather the desire that an individual has to meet their unique health needs in order to experience the best quality of life within the parameters of their illness or situation. A person's plan for health is linked to the outcome of functional mastery as it requires the individual to have the intention to succeed.

Personal engagement in care is essential to health success, and without a commitment to self any plan for care or wellness will fail (Gaudet, 2014). The self-assessment of goals and motivation creates a foundation for supporting change and discovering solutions that are purposeful, holistic, and patient-centered. Adding to this concept of an individual's plan and intention for health, Estelle-Brazzell Horton (2014) studied the meaning and perception of personal health responsibility (PHR) using open-ended questions and a semi-structured interview in a one-case pilot study. Though the study was limited using one individual, findings showed PHR requires active positive behavior toward health and an attitude for following through with taking care of oneself. A retrospective cohort study exploring the use of an Online Personal Action Plan found that personal engagement in health care empowers individuals to take control of their disease management and health and wellness goals (Henry, Shen, Ahuja, Gould, &

Kanter, 2016). Though not specifically addressing a person's personal plan, these studies reinforce the notion for the necessity of an individual to take an active part in their own health care and wellness to achieve the best outcome.

Self-efficacy

Self-efficacy is widely recognized as an individual's personal belief in their ability, personal power, and influence over events to move toward a place of optimum wellness and mastery of their personal situation (Bandura, 1997). Simpson and Jones (2013) describe self-efficacy as the confidence an individual possesses to manage illness, noting that if confidence is present, the individual feels empowered and self-management increases. In a targeted literature search, few articles were found addressing the role of self-efficacy specifically to individuals with IBD, though numerous articles studied self-efficacy in other chronic diseases, life situations, and disciplines not related to health care. Studies frequently discussed coping and self-management as forms of self-efficacy. Plevinsky, Greenley, and Fishman (2016) discussed self-efficacy as it related to the ability to self-manage IBD, finding an emphasis on problem-solving skills as a positive association to increased self-efficacy and improved health outcome. In a study to examine self-efficacy in patients with chronic obstructive pulmonary disease (COPD), higher levels of self-efficacy were significantly associated with lower levels of anxiety ($r = .61$), and depression ($r = -.58$; Simpson & Jones, 2013). Studying the differences in self-efficacy factors over time in persons with morbid obesity and COPD, Bonsaksen, Fagermoen, and Lerdal (2014) revealed that obese individuals with higher physical activity, employment, and greater control over health behaviors had increased self-

efficacy, while those with COPD experienced higher self-efficacy when symptom burden was low and health literacy was high.

Adding to the role of self-efficacy specific to health status, it was found that self-efficacy had a significant positive effect on quality of life in cancer survivors ($p < .001-.006$; Moreno, et al., 2017), with consistent findings of low self-efficacy associated with worse overall health status in cardiac patients (OR = 1.9, $p < .0001$; Sarkar, Ali, & Whooley, 2007). Lorig (1993) and Lorig and Holman (2003) discuss finding enhanced self-efficacy associated with positive changes in health status.

Self-efficacy has been discussed as an influence on the outcome of actions taken for health and the management of life situations, noting a greater belief in one's capability can be a predictor to the expectation to move toward positive health behaviors (Gandoy-Crego, Clemente, Gómez-Cantorna, González-Rodríguez, & Reig-Botella, 2016). Gecas (1989) linked self-efficacy to mastery as a precursor for motivation to master challenges with resulting positive health consequences.

Social Resources and Social Support

Social support has been defined as “a network of family, friends, neighbors, and community members that is available in times of need to give psychological, physical, and financial help” (National Cancer Institute [NCI], n.d., p. S). Feeney and Collins (2015) discuss the importance of relationships as support in the context of thriving through adversity, noting that support received can be either functional and tangible, or implicit and indirect (emotional or motivational). The perception of the support given as well as the actual support, either positive or negative, can affect an individual's movement forward to health.

In an earlier study of individuals with epilepsy, Dilioro, Hennessy, and Manteuffel (1996) found that social support was important for medication adherence. More recently, Walker et al. (2014) found social support in patients with epilepsy was an integral part of individual self-management success. Alexopoulou et al. (2016) studied the effects of social support in hemodialysis patients and discovered that support from significant others, family, and friends increased the overall quality of life ($r = 0.395$, 0.399 , and 0.359 , respectively, $p < 0.001$).

A systematic review of social support and social networks of post-stroke patients found that poor support or the loss of pre-stroke support was associated with increased depression, decreased quality of life, and slower physical recovery (Northcott, Moss, Harrison, & Hilari, 2016). Participants whose social support remained stable post-stroke had a greater sense of achievement and confidence. As a predictive variable, individuals with a strong connection to social resources for support prior to stroke had less depression and better outcomes. The predictive nature of social support as an important measure of disease adjustment was also found for individuals with rheumatoid arthritis. In a longitudinal study, Curtis, Groarke, Coughlan, and Gsel (2004) found increased support was strongly associated with increased positive affect ($\beta = 0.13$, $p < .001$) and physical function ($\beta = 0.17$, $p < .001$).

Lönnfors, Vermeire, and Avedano (2014) found an improved quality of life was reported by individuals who participated in patient organizations specific to IBD. Social community, networking, and online communities also serve as a means of support and resource for individuals with chronic disease. The social connections gained through internet social media outreach create an accessible environment for peer-to-peer sharing

and support (Grajales, Sheps, Ho, Novak-Lauscher, & Eysenbach, 2014). Though not traditional avenues, internet interactions and the personal connections cultivated can be considered meaningful for individuals as they seek to expand their support community.

In summary, social resources and support have been shown to increase empowerment, self-management, and positive interactions while fostering acceptance of physical and psychological changes. Therefore, social support is an important variable to study in the exploration of functional mastery as a determinant for success. It is significant to note in the discussion of social support specific to IBD patients, the overwhelming physical impact of the disease creates a personal barrier to sharing the symptom burden with others (Frohlich, 2014). This inherently creates social isolation and the inability to reach out to others for support. The perception or reality of being ‘in community’ or alternatively, facing IBD without the support of others, can help explain success or failure to master one’s situation.

Personal Perception of Mastery

The understanding of the meaning of mastery for an individual is foundational in how one recognizes the implications and importance of moving toward wellness. Few studies specific to the personal perception of mastery have been done. Through a seminal study on coping and the responses to life changes, Pearlin and Schooler (1978) found that how one perceives the ability to cope is in part measured by how mastery, or the control of circumstances, is regarded. The perception of mastery is linked to gaining control over chronic illness and whether that control is maintained.

Using secondary analysis of qualitative research, the perception of mastery in young adults with long-term conditions was found to be associated with personal control

of activities, treatments, and medication regimes. These young adults perceived negative mastery, or lost the sense of mastery, when medical control of their condition, environment, and autonomy was lost (Heaton, Räisänen, & Salinas, 2016). Surtees and colleagues (2010) investigated mastery and the association with mortality in cardiovascular disease (CVD) using a prospective population study. Mastery in this context reflected personal perception of the capacity to control circumstances that impact an individual's life. With a focus on measuring coping resources, an assessment tool modified from Pearlin and Schooler's Mastery Scale measured the extent to which life events or opportunities were perceived as being under the individual's control or were perceived as fatalistic with no personal control. The results showed a decrease in mastery score (meaning less perceived control) was associated with a 20% increased risk of CVD mortality after adjusting for age and gender ($p < .0001$). A study of perceived mastery in caregivers of patients with dementia showed that as stress and role overload increased, mastery in the ability to care for others decreased, creating the need for a change in the caregiver role (Infurna, Gerstorf, & Zarit, 2013).

Personal Characteristics

Explored in the study of functional mastery were demographics and health status. Age, gender, race, marital status, living situation, socioeconomic status, health insurance coverage, time since diagnosis, and current health status are characteristics that may influence the achievement of mastery. Age has been associated with mastery, finding middle and advanced age contribute to high mastery as life experiences and personal attainment play an integral part in maintaining control over circumstances. As age progresses to the elder years, mastery and the confidence in one's self declines (Pearlin,

Nguyen, Schieman, & Milkie, 2007; Schieman & Turner, 1998). Socioeconomic status (SES) has been shown to be a determinant to health and the ability to pay for or find health care (CDC, 2017; Goudge et al., 2007). Pampel, Krueger, and Denney (2010) found low SES negatively affects the incentives and motivations for health and the adoption of healthy behaviors or for changing unhealthy behaviors. Financial hardship was also described as a barrier to seeking care and self-management behaviors, and negatively affected motivation toward wellness (Jowsey et al., 2011). Kennedy & Erb (2002) found the cost of prescription medications was more highly associated with noncompliance to medication usage in disabled individuals with incomes below the poverty level than with individuals having incomes above the poverty level, OR = 1.6, 95% CI [1.3, 2].

Time since IBD diagnosis (disease duration) has been shown to have a significant effect on perceived quality of life ($p < .01$). Individuals with longer disease duration experienced better health-related quality of life (Jäghult, Saboonchi, Johansson, Wredling, & Kapraali, 2011). Current health has been shown to affect how an individual perceives mastery and the ability to function fully. Ward and Ward (2012) found the self-reported health status of fair or poor was lower for those with higher levels of personal mastery, OR = .86, 95% CI [0.79, 0.92], $p < .0001$. A change in the level or intensity of IBD, remission versus exacerbation or flare-up, inherently effects how a person experiences daily life activity and the ability to carry out care. A higher symptom burden, poorer functioning, and less general well-being were found to be significantly associated with exacerbation (Larsson, Löf, Rönnblom, & Nordin, 2008). As subjective

assessments, these variables become relevant to how patients view the physical impact of IBD and what they can accomplish each day.

Functional Mastery

Mastery has been studied as a precursor to improved health status and learned tasks as it influences the ability to adapt to physical and psychological changes over the course of illness or time. Bandura (1997) discusses needing resiliency through adversity to attain mastery, while the mastery experience itself is the process for change; mastery can be understood as ‘whatever it takes to succeed.’ Mastery has also been conceptualized as the personal power and influence an individual has on themselves, leading to independence in managing well-being and health (Schieman & Turner, 1998). Pearlin and Schooler (1978) defined mastery as a construct referring to an individual’s control over life circumstances that evolves from experiences gained through overcoming adverse conditions; mastery is the “capacity to protect health and well-being” (Pearlin, et al., 2007, p. 165). Therefore, mastery is associated with optimum health over time and life experience with the disease process. In the academic discipline, mastery has been associated with a focus on learning tasks, understanding content, and the ability to reflect these as outcome measurements in testing of knowledge or observational assessments (Guskey & Anderman, 2013).

In two similar studies of aging individuals and individuals with multiple sclerosis (MS), greater mastery and functional ability were found with increased physical activity, with a positive relationship to psychological health and an increased perception of better health (Krokavcova et al., 2008; Sargent-Cox, Butterworth, & Anstey, 2015). Individuals with MS were also found to have a significant negative association between mastery and

disability or poor health status ($r = -0.34, p < .01, ES = .34$; Krokavcova et al., 2008).

Shaul (1995) completed a qualitative longitudinal study to discover the experiences of women who had learned to live with and manage rheumatoid arthritis and found mastery was associated with adaption over time to changes in the disease burden effecting all life arenas.

Roepke and Grant (2011) preformed a systematic review of existing articles ($N = 32$) to explore the association between personal mastery and cardiometabolic health, finding that higher levels of mastery supported increased perceived control over health leading to improved health outcome. Similarly, Surtees et al. (2010) found an association between a higher sense of mastery and a reduced risk of mortality from a cardiovascular event.

Through interview and self-report, Pearlin et al., (2007) explored the sources of mastery in the elder population that occurred over the life course. Noteworthy was the finding that mastery resulted from overcoming stressors over time, leading to the ability to master current and acute stress. Pearlin and colleagues found that over the life-course the oldest old, rather than continuing to build on mastery, became fragile when faced with adversity. The authors propose that the strong psychosocial resources present earlier in life may be missing for the oldest old, suggesting that a meaningful support system is likely to be integral to mastery and control.

López-Espuela and colleagues (2016) conducted a longitudinal study of acute stroke patients measuring functional outcome in relation to return to independence over time. Measuring age, gender, stroke severity, and baseline functional status, the study showed that health outcome and functional status improved for patients with

rehabilitation after six months with a return to near pre-stroke ability ($p < .001$). Noted also, social isolation and limited social support were associated with poor recovery ($p = .003$). Kwon, Kim, and Lee (2015), in their qualitative and self-assessment correlational study, reported the functional ability of patients diagnosed with juvenile rheumatoid arthritis (JRA) was positively correlated ($r = 0.748, p < .001$) with health-related quality of life. Juvenile rheumatoid arthritis is a long-term, debilitating condition with physical impairments and symptoms interfering with the ability to function normally at an early age, resulting in a generally poor quality of life (Cartwright, Fraser, Edmunds, Wilkinson, & Jacobs, 2015). Active involvement with treatments for symptom relief and social adaptation decreased the negative disease burden of JRA, which would likely allow for improved functional mastery.

The overarching premise to all studies reviewed is that a sense of achieved empowerment is associated with individuals finding motivation, control over situation, and an improved quality of life. The discovery of functional mastery using a person's plan for health, self-efficacy, social support, and the perception of mastery as parameters for insight can inform both the individual and the practitioner to changes that are needed to achieve the best health outcomes.

Theoretical Framework

This study is guided by the constructs and concepts from Orem's Theory of Self-Care (TSC; Orem, 2001), Resnick's middle range Theory of Self-Efficacy (TSE; Smith & Liehr, 2014), and Pearlin and Schooler's study of the structure of coping (Pearlin & Schooler, 1978).

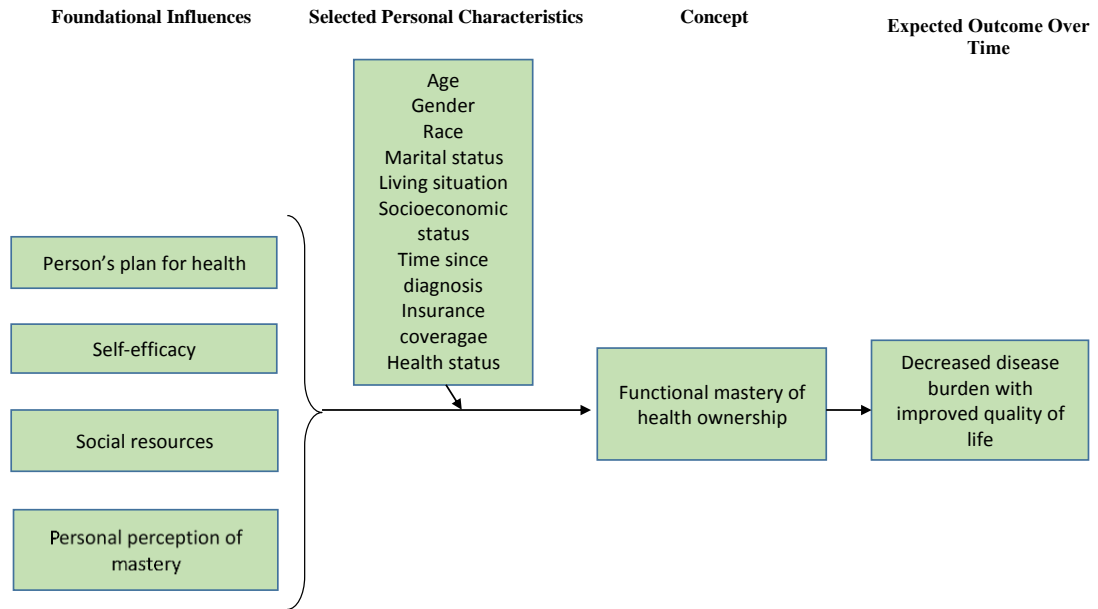
Orem's TSC posits that an individual has the power to act deliberately to identify needs and then be motivated to reach the desired outcome, with the implication that individuals possess an intention to do good for themselves (2001). Orem discusses the need for a person to connect their social and physical environment with their health to move forward into wellness. Using this notion in the context of functional mastery and the foundational influences, it is important, as well, to connect the intangible aspects of a person's life and their perceptions to find the possibility for best health. Orem's discussion of health as a state of "soundness and wholeness" (p. 186) and wellness as a "sense of [an individual's] perceived condition" (p. 186) reinforces the idea that wellness can be found in any state of health. The study of functional mastery considers both the physical state of the person and their perception of wellness to discover success or lack of success in living with chronic illness or altered life situation.

Based on Bandura's (1997) definition of self-efficacy, Resnick describes self-efficacy as an individual's judgement of his or her capabilities to organize and execute courses of action with the assumption that people can exercise influence over what they do (Smith & Liehr, 2014). Resnick (2002) and later with colleagues (Shaughnessy, Michael, & Resnick, 2012), builds on this with the addition of outcome expectations and anticipation of a positive outcome, suggesting that the stronger a person's belief in the outcome of their actions, the more likely that outcome will be realized. Outcome expectations rather than self-efficacy expectations may be better predictors of the behavior and beliefs needed for functional mastery. This supports the discovery of the role of perception and personal expectations.

Though not a theory of mastery but rather a concept for discovery, the personal perception of mastery is an important underpinning to this study. Pearlin and Schooler (1978) described mastery as the control over life events an individual perceives as being under personal control rather than being resigned to the outcome. The integration of mastery perception as a measurement will aid in discovering a person's discernment or awareness of what mastery means and whether a belief is present or could be present to support the attainment of a positive health status. The study of social resources on the influence of mastery is guided by Pearlin and Schooler, as well, as the authors posit that these resources are the network of interpersonal relationships that are available for support (1978).

The conceptual framework that will be used in this study is the Functional Mastery of Health Ownership (FMHO) model for IBD (see Figure 2; Donnelley, 2017). Based on the theoretical underpinnings discussed above, clinical experience, and existing literature, the model was developed to explore the predictive influences on health outcome in patients with IBD. Inspired by patient need, the FMHO model is predicated on an association between the distinct situations in an individual's life that can determine the ability to adapt to disease burden and the achievement of mastery of their health (Donnelley, 2017). As measured variables, the four foundational influences included in the model (a person's plan for health, self-efficacy, social resources, and the personal perception of mastery) were expected to have a direct effect on mastery of health. Adapted for this study, selected personal characteristics (age, gender, race, marital status, living situation, socioeconomic status, insurance coverage, time since diagnosis, and

current health status) were the demographic variables proposed to be beneficial and have an effect on the achievement of mastery of health.



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Figure 2. Functional mastery of health ownership model for IBD.

Conceptual and Operational Definitions

The conceptual and operational definitions of the FMHO model are explained in Table 1.

Table 1

Conceptual and Operational Definitions

Variable	Conceptual definition	Operational definition
Person's plan for health	The goals of an individual, the present state of health, and the desire for reaching optimum wellness (Gaudet, 2014).	VHA Personal Health Inventory (PHI; U.S. Department of Veterans Affairs, 2013). Composed of 23 Likert-type items rated on a scale of 1-10 with a possible low of 23 and high of 230. The questions address life, well-being, and optimal health, considers present health in relation to current life, relationships, and future goals and desires.
Self-efficacy	Personal belief about ability, personal power, and influence over events to move toward a place of optimum wellness and mastery of their personal situation (Badura, 1997; Resnick, 2002).	IBD-Self-Efficacy Scale (IBD-SES; Keefer, Kiebles, & Taft, 2011). Consists of 29 questions with four domains using a Likert-type scale of 1-10 with a possible low of 29 and high of 290. The four domains: management of stress and emotions, medical care, symptoms and disease, and maintaining remission.
Social resources	Support in an individual's life available to help or intervene either with physical participation or through encouragement and psychological intervention (NCI, n.d.).	Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988). A 12-item 7-point Likert scale is used. Measurement of social support is found by summing across items and dividing by four. Lower scores show low perceived social support and higher scores perceive high support.
Personal perception of mastery	A person's discernment or awareness of what mastery means and whether a belief is present (Pearlin & Schooler, 1978).	Pearlin Mastery Scale (Pearlin & Schooler, 1978). The 4-point 7-item Likert scale measures an individual's level of mastery, with five negatively and two positively worded items. The score range is 7 to 28, with higher scores indicating greater levels of mastery (National Longitudinal Surveys, 1992).
Personal Characteristics	Age, gender, race, marital status, living situation, socioeconomic status, insurance coverage, time since diagnosis, and current health status.	Demographic and health data will include age, gender, race, marital status, living situation, socioeconomic status, insurance coverage, time since diagnosis, and current health status and will be coded as categorical and ordinal data.
Functional Mastery	The ability to function to potential within the disease process (Donnelley, 2017).	Patient Activation Measure, short form (PAM-10; Hibbard, Mahoney, Stockard, & Tusler, 2005). Consists of a 10 question 5-item Likert-type scale ranging from 1 (<i>disagree strongly</i>) to 4 (<i>agree strongly</i>), with 5 (<i>not applicable</i>). Eight of 10 questions need to be answered for a valid score. Four outcome levels are measured in the survey: level 1 (disengaged and overwhelmed), level 2 (becoming aware, but still struggling), level 3 (taking action), and level 4 (maintaining behaviors and pushing further).

Research Questions

The purpose of this study is to assess the associations between the foundational influences as predictors of the achievement of functional mastery, and to identify selected personal characteristics that are beneficial to this outcome. The research questions were:

1. Which foundational influences (patient's plan for health, IBD self-efficacy, social support, and personal perception of mastery) are associated with the achievement of functional mastery?
2. To what extent do selected personal characteristics (age, gender, race, marital status, living situation, socioeconomic status, insurance coverage, time from diagnosis, and current health status) influence the achievement of functional mastery?

Design

A predictive correlational study design was used to explore the association between a person's plan for health, IBD self-efficacy, social support, and perception of mastery on the achievement of functional mastery. The strength of the effect of age, gender, race, marital status, living situation, socioeconomic status, insurance coverage, time from diagnosis, and current health status were measured for influence on the achievement of mastery of health (Portney & Watkins, 2015).

Methods

Sample

A convenience sample from the outpatient population with the diagnoses of IBD, Crohn's disease, and ulcerative colitis being treated at a gastroenterology (GI) medical practice in central Texas was invited to participate in the study ($n = 2166$). Using a secure

medical records site, ICD-9 and ICD-10 diagnostic codes were used to identify the sample with the inclusion of diagnoses of Crohn's disease without complications, ulcerative colitis without complications, and inflammatory bowel disease. An email containing an explanation of the study with a link to the study survey was sent to these patients using a secure, patient password-protected electronic communication portal. An explanation of the study and the survey were also sent to all physicians in the GI practice and the 11 GI medical office managers. At one month after the initial email, a follow-up reminder email was sent to the same patient population to ensure an adequate sample size.

A priori power analysis using G*Power 3.0.10 was run to determine the sample size needed for this study and was calculated using F tests - Multiple Regression: Omnibus (R^2 deviation from zero; Faul, Erdfelder, Buchner, & Lang, 2009). With seven predictor variables, a regression resulting in a medium effect size of 0.15, an alpha of 0.05, and a power of 0.80 found a minimum sample of 103 study participants was needed. The licensing agreement for the use of the PAM-10 instrument required a minimum sample size of 150 individuals (T. Belfanti, personal communication, June 29, 2017). The current sample size of 151 participants met this requirement and provided sufficient statistical power.

Inclusion criteria were as follows: male or female; 18 years or older; ability to read and understand English; definitive IBD diagnosis of one year or longer; IBD either in remission or active status; an active GI clinic patient portal account, and access to the internet for electronic survey completion. Exclusion criteria were no access to the patient portal or the electronic survey.

Protection of Human Subjects

The proposal for this study was submitted to the University of Texas at Tyler (UT Tyler) Institutional Review Board (IRB) for approval (see Appendix A). After approval, the proposal and IRB acceptance notification were submitted to the Medical Executive Committee (MEC) at the gastroenterology medical practice for permission (see Appendix B). Following the receipt of all approvals, an email invitation explaining the study and voluntary participation was sent to all possible participants through a secure patient password-protected electronic portal (see Appendix C). The link to the secure Qualtrics survey was included in the email. When the survey was accessed by the patient, the first page consisted of an internet-based consent that contained the following: full disclosure of the study process, data collection methods, potential risks, possible benefits, statement of confidentiality and protection of all information following HIPPA guidelines, the right to withdraw from the study at any time, and the researcher's contact information (see Appendix D; Portney & Watkins, 2015).

Instruments

Data for the predictor variables were obtained utilizing the Personal Health Inventory (PHI), IBD-Self-efficacy Scale (IBD-SES), Multidimensional Scale of Perceived Social Support (MSPSS), and Pearlin's Mastery Scale (PM). A demographic survey consisting of 9 items (age, gender, race, marital status, living situation, socioeconomic status, insurance coverage, time since diagnosis, and current health) was used for collection of the personal characteristic data. The Patient Activation Measure (PAM-10) was used to measure functional mastery outcome. Permission and instructions for use of all instruments are found in Appendix E.

Personal Health Inventory. A person's plan for health was measured using a modified version of the VHA Personal Health Inventory (PHI; U.S. Department of Veterans Affairs, 2013; see Appendix F). Each of the 23 questions is rated on a 1-10 response scale, with 1 (*low*) to 10 (*high*) for current or desired health state. Total scale scores range from 23 to 230. Higher scores mean a greater satisfaction with the current health situation or a greater desire to improve the situation. The questions address life, well-being, and optimal health, and consider present health in relation to current life, relationships, and future goals and desires. The initial comprehensive PHI utilized both quantitative and qualitative data (17 open-ended questions) and was piloted at six VA medical centers with subsequent studies conducted on 100 veterans for test question assessment. Validity of the PHI was established in the VA pilot study using a collaborative qualitative process to identify key words from the study population. An iterative approach to develop a set of codes was utilized, and these were applied to scoring responses. The PHI is a validated instrument with the distribution of codes indicating the tool is achieving the intended purpose to help veterans establish personal health goals (Bokhour, Hogan, & Volkman, 2013). The instrument has been adapted by the researcher with permission for relevance to the IBD patient population without loss of meaning and intent.

The reliability for the adapted 23-item PHI instrument used in this study showed a Cronbach's alpha = .94. The instrument was analyzed for both current and desired health status. The reliability for current health situation found a Cronbach's alpha = .93, with reliability for desired state of health showing Cronbach's alpha = .91. These values reveal good internal consistency not measured in previous PHI instrument use.

IBD Self-efficacy Scale. The IBD Self-efficacy Scale (IBD-SES) was used to measure self-efficacy and consists of 29-items (see Appendix G). Using a 10-point Likert scale, items are rated from 1 (*not at all sure*) to 10 (*totally sure*). Total scores range from 29 to 290. Lower scores indicate lower self-efficacy. Four subscale domains are measured in this questionnaire: 1. Managing stress and emotions; 2. Managing medical care; 3. Managing symptoms and disease; and 4. Maintaining remission. The internal consistency of the scale is excellent (Cronbach's $\alpha = 0.96$) with correlations of all items ranging from 0.43-0.83. Test-retest from time 1 to time 2 was 0.90 ($p < .001$), finding a positive correlation with perceived health competency ($r = 0.76$) and a negative correlation with perceived stress ($r = - 0.70$). The total scores in all domain subscales were positively correlated demonstrating concurrent validity (Keefer, Kiebles, & Taft, 2011). The internal consistency in this study was a Cronbach's alpha = .97, consistent with the strong internal consistency in the original instrument assessment.

Multidimensional Scale of Perceived Social Support. The Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988) was used to measure social support in this study (see Appendix H). The scale assesses support from three sources: family, friends, and significant others. A 12-item 7-point Likert scale is used, ranging from 1 (*very strongly disagree*) to 7 (*very strongly agree*), with lower scores indicating low perceived social support and higher scores indicating high perceived support. The total score is found by summing across all 12 items and dividing by 12. The potential range of scores is 12 to 84. A Cronbach's alpha = .88 was reported showing good internal consistency. Test-retest reliability showed a Cronbach's alpha of .85, demonstrating good internal reliability and stability over time (Zimet et al., 1988).

Validity was found in the support of the predicted hypothesis, perceived social support would be negatively related to reported anxiety and depression symptoms, meaning high levels of perceived social support were associated with low levels of the symptoms of depression and anxiety ($r = -.25; p < .01$). Reliability in this study found Cronbach's alpha = .96 for the overall scale, showing good internal consistency.

Pearlin Mastery Scale. Personal perception of mastery was measured using the Pearlin Mastery Scale (PM; Pearlin & Schooler, 1978; see Appendix I). The scale consists of 7-items that are rated on a 4-point Likert scale that measures an individual's level of perceived mastery, with five negatively and two positively worded items ranging from 1 (*strongly disagree*) to 4 (*strongly agree*). Reverse coding is required for the five negatively worded items prior to scoring. The total score ranges from 7 to 28, with higher scores indicating greater levels of perceived mastery (National Longitudinal Surveys, 1992). No data for reliability were available in the original study, but in subsequent research, the 7-item scale showed good internal reliability (Cronbach's $\alpha = .80$; Surtees et al., 2010). However, the original research found the five negatively worded items have factor loadings ranging from 0.76 and 0.56, with the two positively worded items having factor loadings of -.047. No tests to evaluate validity were found, however, strong validity is suggested as the PM scale has been used alongside other measures of psychological well-being and has been translated and used extensively across disciplines (Brady, 2003). The PM scale showed strong internal consistency in this study (Cronbach's $\alpha = .83$).

Demographic and General Health Information. Selected personal characteristics (age, gender, race, marital status, living situation, socioeconomic status,

insurance coverage, time since diagnosis, and current health status) were obtained for demographic data (see Appendix J). Current Health Status consisted of six questions regarding health condition within the past two weeks and was adapted from the IBD Questionnaire for relevance to this study. Reliability in this study revealed a strong internal consistency (Cronbach's $\alpha = .90$).

Patient Activation Measure. Functional mastery was measured using the short form of the Patient Activation Measure (PAM-10) to assess patient self-reported knowledge, skill, and confidence for self-management of IBD (Hibbard, Mahoney, Stockard, & Tusler, 2005; see Appendix K). The PAM-10 is a 10-item 5-point Likert-type scale, ranging from 1 (*disagree strongly*) to 4 (*agree strongly*), with 5 (*not applicable*). Eight of 10 questions need to be answered for a valid score. Scoring ranges from 0-100, with 0 (*no activation*) to 100 (*high activation*). Raw scores were converted into an activation score by Insignia Health, LLC as required the agreement for use in this study. Four outcome levels are measured in the survey: level 1 (disengaged and overwhelmed), level 2 (becoming aware, but still struggling), level 3 (taking action), and level 4 (maintaining behaviors and pushing further). The PAM-10 short form was adapted from the original PAM-22 and follows the first short-form iteration, PAM-13. The short form has demonstrated the same reliability of 0.85. Construct validity is found as individuals with chronic illness having higher activation report significantly better health ($r = .38, p < .001$) and have significantly lower rates of medical visits ($r = -.07, p < .01$). Preventive behaviors and disease-specific self-management behaviors are strongly linked to activation scores. Reliability of PAM-10 in this study revealed strong internal consistency (Cronbach's $\alpha = .85$), consistent with previous findings.

Data Collection

After university IRB approval and permission was granted from the MEC of the GI medical practice, data collection began using the secure password-protected patient portal internet communication site available to active patients of the GI medical practice. An email containing an explanation of the study with a link to the Qualtrics survey was sent by the researcher to eligible participants identified on the secure medical records site ($n = 2166$). This resulted in 138 responses. At one month, a reminder email that included the original participation email text was sent to the same patient population, resulting in a total of 207 survey responses at two months, satisfying the needed sample size. Data were screened prior to data analysis for missing data and incomplete answers, or surveys completed by ineligible participants (i.e. diagnosis of IBD of less than 1 year), leaving a total of 151 study participants. The de-identified data were stored on a password-protected computer. Access to the data was available only to the researcher, dissertation chair, and statistician.

Analysis

Data were downloaded into Statistical Package for Social Sciences (SPSS) version 25 for analysis. A multiple linear regression was calculated to predict mastery of health in IBD patients based on personal health inventory, IBD self-efficacy, social support, perception of mastery, and demographic information. A preset alpha of .05 for significance and a 95% confidence interval were applied throughout the analysis. Internal consistency (Cronbach's alpha) was measured for all instruments and normalcy of variables was confirmed. All data were checked for effective outliers and missing data. Analysis was run with and without outliers and revealed no significant changes in

the study results. Missing data were reconciled using the mean of the valid items. The PAM-10 survey data was analyzed by Insignia Health LLC and returned to the researcher for inclusion in SPSS analysis.

Data were analyzed in three phases. All continuous variables were entered using descriptive statistics, finding means, standard deviations, and minimum and maximum values, with frequencies and percentages for categorical variables. Bivariate analysis was then run to produce inferential findings. Paired *t*-tests, one-way ANOVAs, and Pearson's *r* correlations were used to identify which variables were significantly related to PAM scores. The explanatory variables related to PAM scores at $p < .05$ were entered for the third phase of data analysis. A two-step hierarchical multiple regression analysis was conducted in this phase of the analysis. Moderating effects of gender and current health status between PHI current health, PHI desired health, IBD self-efficacy, social support, and perception of mastery and the achievement of mastery were first examined. A final multiple regression analysis was then conducted to explore the interactive effect of the significant personal characteristic, gender, with the foundational influences.

Parametric test assumptions for normality, homoscedasticity, and linearity were performed for inferential analysis and revealed no significant problems. Outlier scores (scores two standard deviations from the mean) were identified for each continuous study variable, and inferential analysis was repeated with and without the outlier scores. Outcomes showed the extreme scores did not change the statistical significance of the study results. Therefore, without evidence of undue effect on study findings, these were included in the study. Unacceptable levels of multicollinearity were found in the final

regression (PHI current scale and IBD self-efficacy), and subsequently the PHI current scale was removed from the model. This resulted in acceptable levels of collinearity.

Missing data were found in four items on the continuous standardized scale model. Therefore, the mean of the valid items was used to score each measure, with an inclusion criterion for participant responses of at least 80% of the items for each scale. One study participant failed to meet the criteria and was excluded from the analysis. As mentioned previously, all study instruments revealed satisfactory levels of internal consistency.

Research Findings

Descriptive Analysis of Categorical Variables

The descriptive analysis of categorical study variables is presented in Table 2. The sample was predominantly female ($n = 92$, 60.9%) compared to males ($n = 59$, 39.1%). Ages ranged from 18 to greater than 70, with over half the participants between the ages of 18 and 59 ($n = 87$, 57.6%). Over 90% of the study sample were of a white racial identity ($n = 139$, 92.1%) and non-Hispanic identity ($n = 144$, 95.4%). The majority of participants were married or in a partnership ($n = 109$, 72.9%), with 126 reported not living alone (83.4%). The income of participants varied, with the majority having an annual income greater than \$80,000 ($n = 83$, 55%). The entire sample reported having health insurance ($n = 151$, 100%); nearly all reported having insurance that provided coverage for IBD medications and treatments ($n = 139$, 92.1%).

Table 2

Descriptive Analysis of Demographic Categorical Variables (N = 151)

Variable	<i>n</i>	%
Gender		
Male	59	39.1
Female	92	60.9
Age		
18–29	21	13.9
30–39	23	15.2
40–49	19	12.6
50–59	24	15.9
60–69	36	23.8
70 or older	28	18.5
Racial identity		
White	139	92.1
Black	4	2.6
Asian	4	2.6
Multiple race	4	2.6
Hispanic ethnicity		
Yes	7	4.6
No	144	95.4
Marital status		
Single/never married	25	16.6
Married/domestic partner	109	72.2
Widowed	3	2.0
Divorced	14	9.3
Lives alone		
Yes	25	16.6
No	126	83.4
Income		
< \$21,000	5	3.3
\$21,000–\$49,999	22	14.6
\$50,000–\$79,999	33	21.9
\$80,000–\$99,999	19	12.6
≥ \$100,000	64	42.4
Not reported	8	42.4

Variable	<i>n</i>	%
Has health insurance		
Yes	151	100.0
No	0	0.0
Insurance covers IBC medications and treatments		
Yes	139	92.1
No	8	5.3
NA	4	2.6

Descriptive Analysis of Continuous Variables and Bivariate Analysis

Descriptive statistics of continuous study variables and correlation coefficients were calculated (see Table 3). The average PAM score measuring functional mastery was 71.88 ($SD = 17.25$) indicating a moderate level of mastery achieved by this sample. The PHI survey included both current health status (how participants perceive their health now) and desired health status (what they would like their health to be in the future). Findings showed PHI current health status ($M = 7.08$; $SD = 1.70$) had a slightly lower mean score compared to PHI desired health status ($M = 8.96$; $SD = .97$). The remaining variables showed moderate to high mean outcomes. Years since Diagnosis revealed a mean of 13.31 with high standard deviation (10.54). Scores for PHI Current Health show a high correlation to both IBD SES ($r = .90, p < .01$) and Current Health ($r = .78, p < .01$).

Table 3

Descriptive Analysis of Continuous Variables and Bivariate Analysis (N = 151)

Variable	Mean	SD	FM	PHIC	PHID	MSPSS	PM	IBD-SES	CURRH	YRS
Functional Mastery (PAM Score)	71.88	17.25	—	.54**	.38**	.30**	.52**	.56**	.36**	.15
PHI Current	7.08	1.70		—	.60**	.57**	.54**	.90**	.78**	.11
PHI Desired	8.96	.97			—	.33**	.32**	.50**	.33**	.12
MSPSS	5.58	1.34				—	.38**	.58**	.45**	-.04
PM	3.03	.59					—	.55**	.46**	.05
IBD SES	7.41	1.87						—	.82**	.16
Current Health	5.06	1.38							—	.14
Yrs Since IBD Diag.	13.31	10.54								—

Note. * $p < .05$ (2-tailed), ** $p < .01$ (2-tailed).

FM = Functional mastery; PAM = Patient Activation Score; PHIC = Personal Health Inventory Current; PHID = Personal Health Inventory Desired; MSPSS = Multidimensional Scale of Perceived Social Support; PM = Pearlin Mastery Scale; IBD-SES = Inflammatory Bowel Disease Self-efficacy Scale; CURRH = Current Health Status; YRS = Years Since Diagnosis

Independent samples *t*-test and one-way ANOVA analyses examining PAM scores with explanatory study variables indicated that females ($M = 74.64$, $SD = 16.84$) evidenced a significantly higher mean PAM score relative to males ($M = 67.57$, $SD = 17.15$), $t(149) = 2.50$, $p = .014$. However, PAM scores did not vary at a statistically significant level by study participant age, racial identity, Hispanic ethnicity, marital status, status of living alone, annual income, or if insurance covered IBD medications and treatments.

Multivariate Analysis

Tolerance (.145) and VIF (6.883) scores for PHI Current Health were indicative of multicollinearity. The correlation between PHI Current Health and IBD SES was $r = .90$, greatly exceeding recommended parameters of acceptable multicollinearity. A low Beta coefficient in a screening regression ($p = .131$) showed no significant contribution to

the model. This resulted in the exclusion of PHI Current Health from the final regression model. Data from IBD SES also revealed a high VIF (7.054) but was not excluded due to its significance to mastery outcome in a screening regression ($p = .004$).

Table 4 presents the multiple linear regression analysis calculated to predict functional mastery of health ownership based on personal health inventory desired, IBD self-efficacy, social support, perceived mastery gender, years since IBD diagnosis, and current health. Analysis using ANOVA showed a significant regression outcome for the overall model ($F(7, 143) = 16.118, p < .001$), with the correlation coefficient $R = .664$. The model shows a large effect size and strong correlation and explained 44% of the variance in the dependent PAM score ($R^2 = .44$, Adjusted $R^2 = .41$). Data revealed that at the multivariate level, females had significantly higher PAM scores relative to males. Significant relationships to PAM scores were found for Current Health Status, IBD SES scores, and PM scores. The model showed PAM scores were not significantly related to PHI Desired Health, MSPSS, and years since IBD diagnosis.

Table 4

Multiple Linear Regression Analysis (N = 151)

Variable	<i>B</i>	<i>SE</i>	β	<i>p</i>
PHI desired	.79	1.33	.05	.55
IBD SES	5.87	1.24	.63	.001
MSPSS	-.80	1.01	-.06	.43
PM	8.30	2.22	.29	.001
Gender	-4.79	2.35	-.14	.04
Years since IBD diagnosis	.14	.11	.08	.21
Current health	-3.51	1.42	-.28	.01

Note. Model = $F(7, 143) = 16.12, p < .05, R = .664, R^2 = .44$, Adjusted $R^2 = .41$.

In order to assess the moderating effects of the personal characteristics, interaction effects were examined for those that were significant during bivariate

analysis. Significance was found for gender ($p = .014$) and current health ($p = .000$) on the outcome of mastery. The interactions between gender and current health were then tested for moderation effect between the predictor variables PHI desired health, IBD self-efficacy, social support, and perceived mastery and the achievement of mastery. Significant interaction effect was found only between gender and social support ($R = .43$, $R^2 = .18$, $Adj R^2 = .67$, $p = .002$).

Table 5 presents the indirect effects of the predictors and the interaction effect of gender. Analysis using ANOVA showed a significant regression outcome ($F(8, 142) = 14.99$, $p < .05$), with a correlation coefficient $R = .677$ and explains 46% of the variance in the dependent PAM scores ($R = .46$, Adjusted $R^2 = .43$). Independent t -test analysis indicated that in the presence of low social support, males had lower mean PAM scores ($M = 55.82$, $SD = 16.81$) than females ($M = 69.02$, $SD = 16.86$). With higher social support, the mean increased for males more dramatically ($M = 80.09$, $SD = 16.81$) than for females ($M = 77.35$, $SD = 16.29$).

Table 5

Analysis of Significant Moderating Effect of Gender and Social Support on Functional Mastery (N = 151)

Variable	<i>B</i>	<i>SE</i>	β	<i>p</i>
PHI desired	.61	1.32	.03	.65
IBD SES	5.75	1.23	.62	.000
MSPSS	-5.77	2.42	-.45	.02
PM	8.07	2.20	.29	.000
Gender	-27.23	10.32	-.77	.009
Years since IBD diagnosis	.11	.11	.06	.32
Current health	-3.60	1.40	-.29	.01
Gender X Social Support	4.03	1.81	.75	.03

Note. Model = $F(8, 142) = 14.99$, $p < .05$, $R = .677$, $R^2 = .46$, Adjusted $R^2 = .43$

Discussion

This study was conducted to explore the associations between the foundational influences in a person's life that are considered important in framing daily and long-term health in patients with IBD and the achievement of functional mastery, or the ability to function fully, within the disease process. The study also addressed the moderating effects of gender and current health status between PHI current health, PHI desired health, IBD self-efficacy, social support, and perceived mastery and the direct effect of personal characteristics on mastery. Significant relationships were found among gender, current health, IBD self-efficacy, and perceived mastery.

Literature has shown an association between the individual personal characteristics examined in this study and mastery or better health management. However, the results showed only gender and current health status were meaningful. These two personal characteristics had significant direct effects on the outcome and were therefore examined for moderation effects between the independent variables and the achievement of functional mastery. Interestingly, it was found that the only significant interaction effect was between gender and social support and mastery.

When comparing mean scores for social support between females and males, females scored higher with low social support than men, and increased only slightly higher with high social support. Men, however, showed a dramatic increase in functional mastery with higher social support. This is also found in previous study findings comparing gender differences in supportive care that revealed women expected emotional support from care providers, felt better informed than men about psychosocial support, and required more time from providers for support with a greater desire for more

information, while men felt less informed about emotional support, thought educational materials were an important aspect of support, and expressed fewer needs (Clarke, Booth, Velikova, & Hewison, 2006; Faller et al., 2016). The findings in this study are also consistent with those found in a study of depressive symptoms and social support. Men who had a higher level of social support experiences a decrease in depressive symptoms (Almquist, Landstedt, & Hammarström, 2017). Hajek and colleagues (2015) found gender had a significant moderator effect on social support and health related quality of life, showing a strong positive impact of social support in men with no significance found in women.

The PHI survey included both current health status (how participants perceive their health now) and desired health status (what they would like their health to be in the future), meaning low scores showed a lower level of health and higher scores indicated better health. Findings showed PHI current health status had a slightly lower mean score compared to PHI desired health status indicating that overall, participants have a desire to improve their health status. PHI desired health status was not significantly associated with mastery and does not necessarily translate into mastery of the current health situation. In this study, what one wants in the future did not necessarily predict mastery of the current health situation.

Though both PHI current health and IBD self-efficacy had a positive association with mastery, IBD self-efficacy had a stronger relationship to mastering the disease course of IBD than recognizing the present effects on daily living. Self-efficacy has been extensively studied in individuals with chronic illness (Plevinsky et al, 2016.; Gandoy-Crego, et al., 2016; Gecas, 1989; Lorig, 1993; Lorig & Holman, 2003), and the findings

of this study are consistent with prior research. Belief in self and the ability to achieve mastery in functioning with IBD can be used as a strong predictor of health outcome in patients and creates an avenue for individual exploration.

Participants reported a high-level of social support, but this did not show significance in the association with functional mastery. Prior research has shown that as a coping mechanism for illness or a life situation, social support is necessary for success (Walker et al., 2014; Alexopoulou et al., 2016; Curtis et al., 2004). The negative physical and psychological manifestations of IBD is high, causing isolation with the disruption of social interaction and wellbeing. A previous study found that because of these limitations there is a desire to not burden others with needs or to share information (Frohlich, 2014). This could be evidenced in this study and sets the stage for further research into the meaning and relationship of targeted personal and specific social support to wellness in IBD rather than the generalization of a support system.

The significant findings for perception of mastery are consistent with previous studies (Heaton, Räisänen, & Salinas, 2016; Infurna, Gerstorf, & Zarit, 2013; Pearlin & Schooler, 1978; Surtees et al., 2010) that found overall positive effects on health when an individual believes they have control over illness or life situation. When determining a holistic care path for patients, these findings show the importance of knowing if an individual believes they are in control of their IBD and how that can affect success in achieving mastery of their health. Taking the discussion beyond that of physical wellness and addressing the psychological implications for perception of mastery and health ownership is needed in the IBD population.

The nonsignificant findings in this study for the effect of time since diagnosis is inconsistent with past research (Jäghult et al., 2011; Shaul, 1995) and lends itself to further studies across generations of individuals with IBD. Though living longer with IBD as with any disease process or experience would, without study, intuitively be thought to increase mastery and the ability to create a course of wellness, it was not borne out in this research.

The analysis of the foundational influences, though supported through literature as predictive in association to functional mastery, found limited significance throughout the study. Modification of the FMHO model from this initial application in the IBD population is needed to find relevance to not only this population but in other areas where predicting strengths and need are important to patient care.

Strengths and Limitations

Strengths

The strengths of this study include the introduction of a predictive model for mastery of health and the multiple variables addressing the patient with IBD that lead to success in achieving best health. As has been shown, previous studies have identified the individual independent variables as precursors to mastery, but none have brought them together to discover a personal profile revealing areas that need strengthening to assist an IBD patient toward mastery and wellness. This study addressed the gap in the literature and research and provided a comprehensive instrument for prediction of patient needs and strengths. Though the model has strong reliability, the comparison of individual influences and characteristics for significance or lack of significance to predict mastery can be used to modify a more relevant model of discovery going forward.

Patients cared for by the researcher in the GI clinical setting report they are not routinely asked information regarding their ability to manage their health situations and have not been given questionnaires to complete. The study population were recruited from this GI medical practice and through personal email correspondence have discussed the same experience. The depth of this study is pertinent to any practitioner caring for IBD patients. Comprehensive assessment of well-being and attitudes toward disease burden and mastering health is crucial to holistic care. Bringing this model forward to practitioners with the creation of an easily accessible tool for patient assessment will be a positive step toward elevating and personalizing care.

Limitations

Limitations were revealed in participant recruitment using ICD-9 and ICD-10 codes for diagnosis. It was found through personal response to the researcher from 34 patients and from subsequent viewing of many individual patient records, the ICD codes were entered in error at GI medical office visits. A number of patients were miscoded and received the invitation to participate in error. This created a better understanding for the researcher of the response rate of 9.5% ($n = 207$) participants out of 2166 initial invitations sent. Future research using the patient database should be expanded in diagnostic scope to reach a larger patient population.

Generalization was an external threat to this study. The setting for this study was a large central Texas gastroenterology practice with a patient base that included a comprehensive cross-section of the general area population. Though the model variables explained adequate PAM scores for the larger population outside the geographic area of this study, the high percentage of individuals identifying racially and ethnically as white,

non-Hispanic demonstrates the caution needed in generalizing the findings to areas where race and ethnicity are more diverse. Also found was the majority of participants in this study population had an annual income greater than \$80,000. This cannot be interpreted geographically for individuals who are in underserved or non-affluent areas. With the same consideration, insurance coverage (100% in this study) cannot be generalized across the greater population while assessing the association of the lack of health coverage and the lack of access to care. A comparable study in diverse areas is needed to find relevance for mastery and associations with race, ethnicity, income, and insurance coverage.

Recommendations

The Functional Mastery of Health Ownership model had not been previously tested. With the findings of this study supporting an association of mastery with four variables, a foundation is laid to support further research using this model to explore more specific measurement of variables as well as refine potentially antecedent and intervening variables. Future studies will be designed to further establish validity and reliability of the overall model.

The variables within the FMHO model in its present construct were limited for significance in findings. The modification of survey instruments used to more specific disease or population relevance might be needed rather than instruments that are used across multiple domains of research. Because demographic data were not meaningful overall in this study, it would be prudent for future use to modify the information collected to best reflect the population. Furthermore, this study shapes the discussion of the need for exploration of influences and characteristics utilizing one model for a comprehensive assessment to inform care. Future research can include the expected

model outcome of decreased disease burden over time with improved quality of life will further the ability of the practitioner to create care paths for optimum health outcomes.

As stated above, broadening the scope of the patient population to represent a wider geographical area to include undeserved areas and areas with greater diversity is necessary to create a full picture of the needs across the greater population. Though insurance coverage was measured in this study, access to care was not. Exploring this with different and diverse populations will add to the knowledge needed to improve care. Considering of the significant findings of gender, social support, and the achievement of mastery, the implications for research exploring men's health, social support, and wellness could greatly improve overall health outcomes in this population.

Summary and Conclusion

As was found in the literature review, mastery of illness or situation results in positive outcomes. Shaul (1995) describes mastery occurring as an evolution over time. Empowerment, control, motivation, and adaptation are common underpinnings throughout the literature and are linked to mastering illness. However, not found in the literature review is the study of the foundational influences in the context of functional mastery and the association for achieving health and wellness. The gap for comprehensive patient care is seen in the lack of discovery of the motivations, reasons, or beliefs a person holds for the achievement of wellness. True, also, is the need for the practitioner to realize a person's plan for health, IBD self-efficacy, social resources, and the perception an individual has of mastery are important variables needed to guide patients with IBD toward reaching their full health. Findings from this study suggest not all foundational influences have a significant association with the achievement of

mastery. Personal characteristics showed a minimal outcome for significance which contrasts to the findings in the literature. This, as discussed previously, could be associated with the limited diversity within this study population. However, as a starting point for exploration, the findings may guide practitioners toward discovering patient needs that might not be addressed. Bridging the gap and connecting these concepts for optimum wellness provides a true basis for holistic care by empowering individuals to reach their potential.

Inflammatory bowel disease is a pervasive and complicated long-term illness, with a high negative health outcome as the individual must learn to live with the distressing and dynamic health changes over the life course. This program of research focused on the influences in a person's life that enables success in health at any place on the health continuum. Functional mastery is not merely managing disease, it is rather the ownership of self and a commitment to reach a 'personal best' in circumstance and illness. As a health model, patients can become proactive with the guidance of practitioners. As a predictive model considering circumstance, functional mastery can be explored for any altered life situation and non-physical related life events that require a choice for positive change.

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Chapter 5

Summary and Conclusion

The negative disease burden of IBD is the umbrella under which one structures daily life. As managing this chronic illness becomes a lifestyle, it is imperative for individuals to explore the influences and circumstances in their lives that make it possible to find best health. This opens the door for nurses and other health care providers to begin the discussion of adequate self-care and disease management. Achieving mastery over the physical and psychological burdens of IBD can create optimum health over a life time while experiencing any stage of the illness. The impetus for this dissertation was the desire to find out what causes some to achieve best health and some to not.

Functional mastery was explored as the culmination of health beliefs, desires, and life circumstances that effect how a person could achieve this goal. Health stewardship was identified in a previous manuscript (Donnelley, 2018) as being part of the underlying concepts that can create a personal drive for mastery and for becoming the owner of health and the driver for positive change. Though not included in this body of research, guiding individuals to adopt the belief that they are responsible for the care of themselves, regardless of circumstance, disease burden, or treatments, is foundational for fully functioning within a disease process or life-altering circumstance. The study in this dissertation was an initial step to explore areas of strength or need in the IBD population and gave insight into how individuals feel they have achieved mastery and are

comfortable with their care. It would be worthwhile to explore health stewardship and health ownership and the association to the achievement of mastery.

As was noted in Chapter 1, IBD is pervasive and debilitating. However, the negative physical consequences were only touched on in this paper. The findings from this study can be used by health care providers as a marker for the importance of knowing our patients. By educating providers first in the relationship of health, belief, and circumstance in those cared for, holistic and meaningful care can guide patients to develop for themselves the desire to achieve mastery.

It is the hope of this researcher to move forward to further explore patient perspectives on mastery and wellness, not only in the IBD population, but in other health circumstances and non-physical life events requiring comprehensive support of the whole person. Future research should consider the role of health care providers and explore patient mastery from the caregiver perspective. As the medical care model is changing, the ability to adapt holistic care within a larger care system inherently brings with it the need to know our patients as individuals with health goals as well as knowing our own beliefs for patient care.

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Appendix A. IRB Approval, University of Texas, Tyler



THE UNIVERSITY OF TEXAS AT TYLER
3900 University Blvd. • Tyler, TX 75799 • 903.565.5774 • FAX: 903.565.5858

Office of Research and
Technology Transfer

Institutional Review
Board

October 17, 2017

Dear Ms. Donnelley,

Your request to conduct the study: *Functional Mastery of Health Ownership in Patients with Inflammatory Bowel Disease*, IRB #F2017-27 has been approved by The University of Texas at Tyler Institutional Review Board as a study exempt from further IRB review. This approval includes a waiver of signed, written informed consent. In addition, please ensure that any research assistants are knowledgeable about research ethics and confidentiality, and any co-investigators have completed human protection training within the past three years, and have forwarded their certificates to the IRB office (G. Duke).

Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter:

- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity
- **Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others**
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.
- Exempt with waiver

Best of luck in your research, and do not hesitate to contact me if you need any further assistance.

Sincerely,

Gloria Duke, PhD, RN
Chair, UT Tyler IRB

Appendix B. MEC Permission for Study, Austin Gastroenterology, Austin, Texas



October 12, 2017

To whom it may concern:

The Austin Gastroenterology/Austin Endoscopy Center Medical Executive Committee (MEC) reviewed Ms. Maria Donnelley's request to conduct a nursing model study in IBD patient population via a de-identified patient survey at the Q3 MEC meeting.

The committee unanimously passed a motion giving Ms. Donnelley permission to proceed with her study effective immediately.

Respectfully,

Carl Frank, M.D., MEC Chairperson

Dana DeSapio, MSN, RN, CASC, CGRN,
Nurse Administrator, MEC

Eduardo Alcocer, MD Scott D. Becker, MD Shad Dabaghi, MD Kenneth K. Ellis, MD Daniel S. Emmett, MD Robert Frachtman, MD Carl D. Frank, MD Harish K. Gagneja, MD
Christopher M. Godell, MD Benjamin D. Havemann, MD C. Kevin Hsu, MD Pradeep Kumar, MD Chad J. Long, MD Craig H. Lubin, MD Gerald W. Mank, III, MD Binh V. Pham, MD
Vijayrama R. Poreddy, MD Dan C. Rice, MD Muna Lin Ridgeway, MD Glenn C. Robinson, MD Inder M. Singh, MD Richard M. Sperling, MD F. Douglas Srygley, IV, MD
William N. Stassen, MD Jessica M. Trevino, MD Stephen J. Uts, MD George Willeford, II, MD John J. Ziebert, MD Bruce Levy, MD, JD - Chief Executive Officer

Administration • 9211 Waterford Centre Blvd. #200 • Austin, TX 78758 • 512/420-0186 • fax 512/420-0397
P.O. Box 10597 • Austin, TX 78766

Appendix C. E-mail Letter to Participants

My name is Maria Donnelley. I am a Certified Gastroenterology Registered Nurse working at Austin Gastroenterology. I am conducting research on health and wellness in patients with Crohn's and ulcerative colitis. I am interested in how you feel, what keeps you well, and what you find difficult to manage with your health.

You are invited to participate in this research survey. It is voluntary, and you are free to quit at any time. By clicking on the link below you will be given the opportunity to contribute to the study and remain anonymous. The information provided by you will not be recorded in your medical records. A consent form is on the first page of the survey for you to read and understand. Participation in this study will in no way effect the treatment you receive.

https://uttyler.az1.qualtrics.com/jfe/form/SV_cBm1fTrEAC16n8F

Thank you for considering taking the time to participate. I look forward to finding a better path to a healthier future for patients living with IBD.

Maria Donnelley PhD(c), RN, CGRN, CIC

Appendix D. Consent in Qualtrics Opening Page

Please read the information on this page before you continue. It is important that we provide you with this information so that you are able to give your informed consent.

The purpose of this study is to find out how individuals with Crohn's and ulcerative colitis feel about their health, how they take care of themselves, and if there is enough support to help when needed. We want to know if you have a feeling of being in control of your health so we can find out what the best care is that we can give.

To take part in this survey, you must be a man or woman aged 18 or older with a diagnosis of Crohn's or ulcerative colitis over 1 year. You can be in remission now or having symptoms.

Your participation is voluntary and you can quit at any time during the survey. Your answers are anonymous and in no way will interfere with any care you are or will have. All data collected will be stored on Qualtrics.com with a secure password that is only accessible by the researcher, Maria Donnelley PhD(c), RN, CGRN, CIC. After all the studies are finished, the results will be published in an academic journal. No identifiable information is ever included.

The Institutional Review Board (IRB) of the University of Texas, Tyler, has approved this study. If you have any questions or concerns, please email Maria Donnelley (mariadonnelley@patriots.uttyler.edu) or Dr. Gloria Duke (gduke@uttyler.edu) at the Office of Sponsored Research.

Clicking on the yes button below will be interpreted as a statement of informed consent, and the study will begin

Have you read the above information and do you consent to taking this survey?

Yes

No

Appendix E. Permissions for Instrument Use

1. Personal Health Inventory

Ruben, Andrew <Andrew.Ruben@va.gov>
To: mariadonnelley@yahoo.com
Jul 3 at 10:52 AM

Good morning Ms. Donnelly,

Thank you for your email and congratulations on your PhD dissertation, your topic sounds very interesting. You may use and adapt VA Office of Patient Centered Care & Cultural Transformation's PHI for your dissertation. We only request that you provide a reference and attribution to the "U.S. Department of Veterans Affairs, Office of Patient Centered Care & Cultural Transformation" in your work, as it pertains to the PHI.

Please let me know if you have any other questions. Have a great day!

Andrew Ruben

Communications Officer, VHA10NE | VA Office of Patient Centered Care & Cultural Transformation

2. IBD Self-efficacy Scale

Keefer, Laurie <laurie.keefers@mssm.edu>
To: Maria Donnelley
Jul 3 at 7:39 AM

Hi Maria,

Sorry for the delay. I was out of the country. Attached is the scale which you can use free of charge. Please cite the article when describing the instrument. Also, if you get a large cohort to complete, I would appreciate the de-identified data. I am trying to make a short-form .

LK

3. Patient Activation Measure (PAM-10)

Teresa Belfanti <tbelfanti@insigniahealth.com>

To: Maria Donnelley

Jul 26 at 11:32 AM

Maria,

Thank you for the additional information regarding your study. Your online order of a PAM license for your research has been approved.

Pursuant to the terms of your order, I have attached the documents you will need to use PAM:

- PAM survey and coaching guidance (PAM 10 License Package)
- Excel sheet for entering and tracking PAM survey responses.

Once your data is captured on the Excel sheet you can submit it to me at tbelfanti@insigniahealth.com. I will have the surveys scored and return the results to you.

In addition to submitting the Excel sheet, the research license requires that you share your entire de-identified data set with Insignia Health when you send your survey capture spreadsheet.

Please feel free to contact me if you have any questions. We look forward to working with you on this effort.

Sincerely,

Teresa Belfanti

Insignia Health, LLC

952.582.4374

tbelfanti@insigniahealth.com

4. The Multidimensional Scale of Perceived Social Support (MSPSS), Published Consent from Author

The MSPSS is free to use. Please simply credit the following paper (and any others that are relevant), if you use the scale: Zimet GD, Dahlem NW, Zimet SG, Farley GK. The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment* 1988;52:30-41 <http://gzimet.wixsite.com/mspss>

Appendix F. Personal Health Inventory

Please fill this out to the best of your ability. There are not right or wrong answers. This is just about you and finding your best health and wellness.

On the following scale, mark the number that best describes you.

1. Physical Scale:

1	2	3	4	5	6	7	8	9	10
<i>Miserable</i>						<i>Great</i>			
(pain, weak, drained)						(high-energy, strong, fit)			

2. Mental/Emotional Scale:

1	2	3	4	5	6	7	8	9	10
<i>Miserable</i>						<i>Great</i>			
(anxious, angry, hopeless, alone)						(happy, hopeful, connected, content)			

3. Life Scale: How is it to live your day to day life?

1	2	3	4	5	6	7	8	9	10
<i>Miserable</i>						<i>Great</i>			
(very hard, exhausting)						(easy, fulfilling)			

For each area below, consider where you are now and where you would like to be. Mark the number that best describes you now and you in the future.

Working the Body: “*Energy and Flexibility*” Movement and physical activities like walking, dancing, gardening, sports, lifting weights, yoga, cycling, swimming, and working out in a gym.

4. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

5. Desired State: Where would you like to be?

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Recharge: “*Rest and Sleep*” Getting enough rest and sleep and participating in activities that help you feel recharged and fueled.

6. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

7. Desired State: Where would you like to be?

1 2 3 4 5 6 7 8 9 10

Food and Drink: “*Nourish and Fuel*” Eating healthy well-balanced meals with plenty of fruits and vegetables each day. Drinking enough water and limiting sodas, sweetened drinks, and alcohol.

8. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1 2 3 4 5 6 7 8 9 10

9. Desired State: Where would you like to be?

1 2 3 4 5 6 7 8 9 10

Personal Development: “*Personal life and Work life*” Learning and growing. Developing abilities and talents. Balancing responsibilities where you live, volunteer, and work.

10. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1 2 3 4 5 6 7 8 9 10

11. Desired State: Where would you like to be?

1 2 3 4 5 6 7 8 9 10

Family, Friends, and Co-Workers: “*Hearing and Being Heard*” Having caring and supporting relationships where you feel heard and connected to the people you love and care about. The quality of your communication with family, friends and your co-workers.

12. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1 2 3 4 5 6 7 8 9 10

13. Desired State: Where would you like to be?

1 2 3 4 5 6 7 8 9 10

Spirit and Soul: “*Growing and Connecting*” Having a sense of purpose and meaning in your life. Feeling connecting to something larger than yourself. Finding strength in difficult times. This may include your faith or religion, meaningful community organizations, or other sources of comfort and strength like music, nature, or the arts.

14. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1 2 3 4 5 6 7 8 9 10

15. Desired State: Where would you like to be?

1 2 3 4 5 6 7 8 9 10

Surroundings: “*Physical and Emotional*” Feeling safe and having comfortable, healthy spaces where you work and live. The quality of the lighting, color, air, and water. Decreasing unpleasant clutter, noises, and smells.

16. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1 2 3 4 5 6 7 8 9 10

17. Desired State: Where would you like to be?

1 2 3 4 5 6 7 8 9 10

Power of the Mind: “*Strengthen and Listen*” Tapping into the power of your mind to heal and cope. Listening to your inner thoughts, paying attention, and noticing. Using mind-body techniques like relaxation, breathing, biofeedback, or guided imagery.

18. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1 2 3 4 5 6 7 8 9 10

19. Desired State: Where would you like to be?

1 2 3 4 5 6 7 8 9 10

Professional Care, Prevention: Being able to get my preventive care, such as a flu shot or a cancer screening, and dental care that has been recommended by my providers.

20. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1 2 3 4 5 6 7 8 9 10

21. Desired State: Where would you like to be?

1 2 3 4 5 6 7 8 9 10

Professional Care, Intervention: If you are under the care of a healthcare professional, how well you understand your health problems, the treatment plan and what you are supposed to be doing for your health.

22. Current State: Rate yourself on a scale of 1 (low) to 10 (high)

1 2 3 4 5 6 7 8 9 10

23. Desired State: Where would you like to be?

1 2 3 4 5 6 7 8 9 10

Appendix G. IBD Self-efficacy Scale

Over the past 2 weeks, how confident have you felt in your ability to perform each of the following tasks?
Please mark the number that best fits how you feel now.

1 2 3 4 5 6 7 8 9 10
not sure at all somewhat sure totally sure

Managing your stress and emotions	
	1. Keep from getting stressed?
	2. Do something to make yourself less stressed?
	3. Keep from getting discouraged?
	4. Do something to make yourself feel better when discouraged?
	5. Keep from feeling sad or down in the dumps?
	6. Do something to make yourself feel better when sad?
	7. Keep sadness or anxiety from interfering?
	8. Do something to make yourself feel better when your sadness or anxiety interferes?
	9. Get emotional support from family or friends?
Managing your medical care	
	10. Follow the instructions for your prescription medications?
	11. Take your prescription medication at the appropriate times?
	12. Take the medications to prevent a flare up of your IBD as directed?
	13. Work with your doctor or nurse to reach an agreement on a treatment plan?
	14. Ask your doctor about your illness?
	15. Discuss openly with your doctor any problems related to your medications?
	16. Work out differences with your doctor?
	17. Ask your doctor about your medications?
Managing your symptoms and disease	
	18. Reduce your symptoms in general?
	19. Keep sleep problems from interfering?
	20. Keep physical discomfort or pain from interfering?
	21. Keep diarrhea and/or urgency from interfering?
	22. Keep any other symptoms or health problems you have from interfering?
	23. Decrease your fatigue?
	24. Keep fatigue from interfering?
Maintaining remission	
	25. Manage your disease in general?
	26. Keep your disease in remission?
	27. Engage in self-care? (exercise, rest, diet, etc.)
	28. Engage in/continue with a stress management program?
	29. Maintain your sense of well-being?

Appendix H. Multidimensional Scale of Perceived Support

Please mark the number that best shows how you feel about the statement.

	Mark "1" if you Very Strongly Disagree							
	Mark "2" if you Strongly Disagree							
	Mark "3" if you Mildly Disagree							
	Mark "4" if you are Neutral							
	Mark "5" if you Mildly Agree							
	Mark "6" if you Strongly Agree							
	Mark "7" if you Very Strongly Agree							
1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2.	There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3.	My family really tries to help me.	1	2	3	4	5	6	7
4.	I get the emotional help & support I need from my family.	1	2	3	4	5	6	7
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7
6.	My friends really try to help me.	1	2	3	4	5	6	7
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7

Appendix I. Pearlin Mastery Scale

**Please check the box beside each statement that best describes how you feel.
There are no right or wrong answers, and no answer is better than another.**

	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
1. There is really no way I can solve some of the problems I have				
	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
2. Sometimes I feel that I'm being pushed around in this life				
	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
3. I have little control over the things that happen to me				
	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
4. I can do just about anything I really set my mind to				
	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
5. I often feel helpless in dealing with the problems of life				
	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
6. What happens to me in the future mostly depends on me				
	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
7. There is little I can do to change many of the important things in my life				

Appendix J. Demographic and General Health Information

Please answer the questions below by marking the answer that best describes you. All information is confidential and will be used to help guide better decisions for care.

1. What is your age?

18-29 _____ 30-39 _____ 40-49 _____ 50-59 _____ 60-69 _____
70 and older _____

2. What is your gender? F _____ M _____

3. Do you consider yourself Hispanic/Latino: a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race?

Yes _____ No _____

4. Which of the following races do you consider yourself to be (select one or more):

____ White
____ Black or African-American
____ American Indian or Alaskan Native
____ Asian
____ Native Hawaiian or Pacific Islander
____ From multiple races

5. What is your marital status?

Single, never married _____ Married or domestic partnership _____
Widowed _____ Divorced _____ Separated _____

6. Do you live alone? Yes _____ No _____

7. What is your annual household income?

Up to \$20,999 _____ \$21,000-\$49,999 _____ \$50,000-\$79,999 _____
\$80,000-\$99,999 _____ \$100,000 and above _____

8. Do you have health insurance? Yes ___ No ___
9. Does your insurance cover your IBD medications and treatments? Yes ___ No ___
10. How long has it been since you were diagnosed with IBD? _____ years

Please mark the answer that best describes how you are now.

8. How often in the past 2 weeks have you felt generally unwell?
- A) All of the time
 - B) Most of the time
 - C) A good bit of the time
 - D) Some of the time
 - E) A little of the time
 - F) Hardly any of the time
 - G) None of the time
9. Many patients with bowel problems often have worries and anxieties related to their illness. These include worries about getting cancer, worries about never feeling better, and worries about having a relapse. In general, how often during the last 2 weeks have you felt worried or anxious?
- A) All of the time
 - B) Most of the time
 - C) A good bit of the time
 - D) Some of the time
 - E) A little of the time
 - F) Hardly any of the time
 - G) None of the time
10. How much difficulty have you had as a result of your bowel problems doing leisure or sports activities you would liked to have done during the last 2 weeks?
- A) A great deal of difficulty; activities made impossible
 - B) A lot of difficulty
 - C) A fair bit of difficulty
 - D) Some difficulty
 - E) A little difficulty
 - F) Hardly any difficulty
 - G) No difficulty; no limit for sports or leisure activities

11. How satisfied, happy, or pleased have you been with your personal life during the past 2 weeks?

- A) Very dissatisfied, unhappy most of the time
- B) Generally dissatisfied, unhappy
- C) Somewhat dissatisfied, unhappy
- D) Generally satisfied, pleased
- E) Satisfied most of the time, happy
- F) Very satisfied most of the time, happy
- G) Extremely satisfied, could not have been more happy or pleased

12. How often during the last 2 weeks have you had to ask for help with tasks from others?

- A) All of the time
- B) Most of the time
- C) A good bit of the time
- D) Some of the time
- E) A little of the time
- F) Hardly any of the time
- G) None of the time

13. How often has the feeling of fatigue or being tired and worn out stopped you from completing your normal tasks during the last 2 weeks?

- A) All of the time
- B) Most of the time
- C) A good bit of the time
- D) Some of the time
- E) A little of the time
- F) Hardly any of the time
- G) None of the time

Appendix K. Patient Activation Measure

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by marking your answer. Your answers should be what is true for you and not just what you think the doctor wants you to say. If the statement does not apply to you, mark N/A.

1. When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2. Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3. I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5. I am confident that I can tell a doctor concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6. I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
8. I know how to prevent problems with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
9. I am confident I can figure out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
10. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

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Biographical Sketch

NAME: Maria F. Donnelley

POSITION TITLE: Doctoral Student

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE	Completion Date MM/YYYY	FIELD OF STUDY
Samuel Merritt Hospital School of Nursing	RN, Diploma	06/1976	Nursing
University of Phoenix	BSN	07/2007	Nursing
University of Texas, Tyler, TX	Ph.D.	05/2018	Nursing

A. Personal Statement

My area of interest and program of research and exploration is wellness and the achievement of optimum health through mastery and ownership of health. My doctoral work focused on the achievement of mastery and health in the patient population with inflammatory bowel disease (IBD). This pervasive disease leaves some patients able to thrive within disease parameters and some to not find health. At the same time, through direct patient care of a general population, I found a lack of both physical and psychological health in individuals who are deemed healthy. The impetus for my pursuit of research was to investigate the reasons why some individuals seek and obtain health and wellness and why some do not. There is need within the health care community to focus on personal health ownership to create a path for wellness that begins with the individual. With the development of a model for exploring health mastery, I have the unique opportunity to effect change with the expansion of study in the areas of the achievement of mastery, health stewardship, and the pursuit of optimum quality of life. I have recently enjoyed contact with RNs working in other countries who are beginning to explore these possibilities and hope to collaborate on these concepts.

B. Positions and Honors

Positions and Employment

2011–Present Staff nurse, Infection Preventionist, Risk Manager, Austin Gastroenterology, Austin, TX

2007–2010 Staff nurse, Infection Preventionist, Endoscopy Center of Santa Rosa, Santa Rosa, CA

1982–2007 Leadership, presidency, board of director positions, Various not-for-profit institutions and organizations, Sonoma County, CA

1976–1978 Staff nurse, critical care, Kaiser Permanente Hospital, Walnut Creek, CA

Presentation

2015 Infection Risk: Endoscope Update
Texas Society for Gastroenterology and Endoscopy, 40th Annual Texas Program, Fort Worth Texas, September 20, 2015

Professional Memberships

STTI, Sigma Theta Tau International, Honor Society of Nursing (invited)
APIC, Association for Professionals in Infection Control and Epidemiology
SGNA, Society of Gastroenterological Nurses and Associates
ECCO, European Crohn's and Colitis Organisation

C. Contributions to Science

Donnelley, M. (2017). Functional mastery of health ownership: A model for optimum health. *Nursing Forum*. <http://dx.doi.org/10.1111/nuf.12223>

Donnelley, M. Health stewardship: A concept for best health outcomes. *Nursing Standard*, 32(21), 41-45. doi: 10.7748/ns.2018.e10799