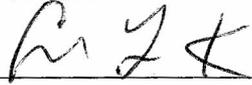


COMMUNICATING ABOUT AUTOIMMUNE THYROID DISEASE: INFLUENCES  
ON MARRIAGE AND CAREGIVING

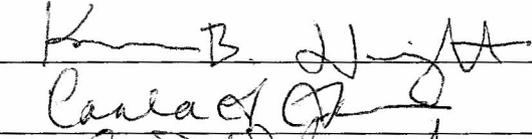
by

Denise K. Scannell  
A Dissertation  
Submitted to the  
Graduate Faculty  
of  
George Mason University  
in Partial Fulfillment of  
The Requirements for the Degree  
of  
Doctor of Philosophy  
Communication

Committee:

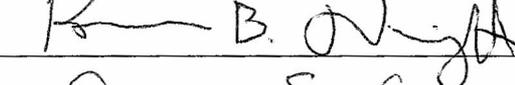


Director

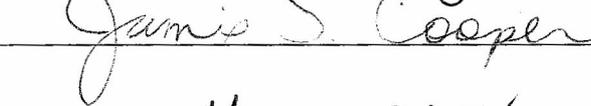




Department Chairperson

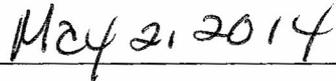


Program Director



Dean, College of Humanities  
and Social Sciences

Date:



Spring Semester 2014  
George Mason University  
Fairfax, VA

Communicating about Autoimmune Thyroid Disease: Influences on Marriage and  
Caregiving

A Dissertation submitted in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy at George Mason University

by

Denise K. Scannell  
Master of Arts  
Montclair State University, 1999

Director: Gary L. Kreps, University Professor  
Department of Communication

Spring Semester 2014  
George Mason University  
Fairfax, VA



This work is licensed under a [creative commons attribution-noncommercial 3.0 unported license](https://creativecommons.org/licenses/by-nc/3.0/).

## **DEDICATION**

I would like to dedicate this dissertation to my husband, Jeff – for making me smile, holding my hand and always loving me more.

I also would like to dedicate this to my parents, Becky and Richie Miller – for providing the love and encouragement to get me where I am today and never letting me give up on myself. You are my sunshine.

Lastly, I dedicate this to my son, Brady. I am so grateful to have you in my life. I am prouder than you will ever know.

## ACKNOWLEDGEMENTS

“To keep a lamp burning, we have to keep putting oil in it” – Mother Theresa

I would like to acknowledge the many women who participated in this research who are suffering from Hashimoto’s and Grave’s Disease. Thank you for sharing your inspiring and powerful stories with me and inviting me into your lives. I learned more from our conversations than could ever be reflected in the pages of this dissertation. I can only hope that this research will “move the needle” and encourage more inquiry into autoimmune thyroid disease and the struggles you and I live with every day. We all deserve a better, healthier life.

I would also like to acknowledge and thank each member of my committee for their guidance and support throughout the process of writing this dissertation. I am deeply grateful to Dr. Gary L. Kreps, chairman of my committee, for inspiring me and sharing his unending enthusiasm for the field of health communication. Thank you for your gracious guidance and support throughout this journey. I am also indebted to Dr. Carla L. Fisher for sharing her love of qualitative research, showing me the way and challenging me to take chances. I would also like to thank Dr. Kevin Wright for imparting his tremendous knowledge of communication competence and his thoughtful comments and critiques. I am humbled by the academic prestige of this committee and I feel very privileged to have gained your insights and advice throughout this process.

I would also like to extend thanks to Jessica Rowland and Joey Miller for their critical assistance in the development of this paper. You may think what you did was small – but you helped me in a big way.

I would also like to acknowledge my colleagues at MITRE for their continual support and encouragement throughout the last five years, especially John Piescik, Craig Petrun, and Chuck Watson.

Also, there is a group of people who deserve special acknowledgements – my friends and family. Thank you for putting up with me and for your support. It will be so nice to see you all again. I would specifically like to thank my sister, Debbie, for being there always.

## TABLE OF CONTENTS

	Page
List of Tables .....	vii
List of Figures .....	viii
List of Abbreviations .....	ix
Abstract .....	x
Chapter One: Statement of the Problem .....	1
Introduction .....	1
Statement of the Problem .....	2
Purpose of the Study .....	3
Chapter Two: Review of the Literature .....	5
Autoimmune Diseases .....	5
Autoimmune Thyroid Disease .....	7
Identity Transformation.....	10
Social Support .....	13
Marital Satisfaction .....	20
Communication Competence .....	21
Chapter Three: Statement of the Method.....	24
Survey.....	24
Sampling and Recruitment .....	24
Procedures and Measures .....	26
Data Analysis.....	27
Interviews .....	28
Sampling and Recruitment .....	28
Participants and Procedures.....	28
Qualitative Methods .....	32
Data Analysis.....	33
Ethical Considerations.....	35

Chapter Four: Results and Findings.....	36
Survey.....	36
Research Question 1 .....	36
Research Question 2 .....	40
Interviews .....	42
Research Question 3 .....	43
Research Question 4 .....	60
Research Question 5 .....	64
Chapter Five: Discussion .....	69
Research Question 1: Relational Communication Competence .....	69
Research Question 2: Marital/Partner Support Provided .....	70
Research Questions 3: Challenges of Autoimmune Thyroid Disease.....	71
Research Questions 4 and 5: Communication Strategies.....	72
Open Communication about Illness .....	73
Shared Understanding and Agreement .....	76
Communicating with Affirming/Encouraging Tone .....	77
Validating Changes to Identity .....	78
Creating Opportunities for Support .....	79
Implications for RHCCM and Future Research.....	80
Practical Implications .....	83
Limitations .....	87
APPENDIX A: Communication Competence Scale .....	88
APPENDIX B: Medical Outcomes Study: 36-Item Short Form Survey Instrument.....	92
APPENDIX C: Medical Outcomes Study: Social Support Survey Instrument.....	98
APPENDIX D: Social Support Questionnaire.....	100
References.....	104

## LIST OF TABLES

Table	Page
Table 1 Survey Sample .....	26
Table 2 Interview Sample: Relationship Status .....	29
Table 3 Interview Sample: Age .....	29
Table 4 Interview Sample: Length of Marriage.....	30
Table 5 Interview Sample: Length Since Diagnosis.....	30
Table 6 Analytical Coding of Interviews.....	34
Table 7 Communication Competence Score.....	37
Table 8 Quality of Life Score .....	38
Table 9 Overall Score for Perceived Social Support .....	38
Table 10 Test Between Subject Effects .....	39
Table 11 Multiple Comparisons.....	40
Table 12 Summary of Social Support Satisfaction for Husband .....	41
Table 13 Cross tabulation for Husband Support and Social Support Satisfaction .....	42

## LIST OF FIGURES

Figure	Page
Figure 1 Kreps' Relational Health Communication Competence Model (RHCCM) (Kreps, 1988) .....	22

## LIST OF ABBREVIATIONS

American Autoimmune Related Diseases Association, Inc. ....	AARDA
Kreps' Relational Health Communication Competence Model .....	RHCCM
IBM Statistical Package for Social Sciences .....	SPSS
Multivariate factorial analysis of variance.....	MANOVA
National Institutes of Health .....	NIH
Thyrotropin receptor antibody .....	TRAb

## **ABSTRACT**

### **COMMUNICATING ABOUT AUTOIMMUNE THYROID DISEASE: INFLUENCES ON MARRIAGE AND CAREGIVING**

Denise K. Scannell, Ph.D.

George Mason University, 2014

Dissertation Director: Dr. Gary L. Kreps

Autoimmune diseases are one of the most common forms of illnesses in the United States, affecting 23.5 million people (Walsh, 2000). The burden of this disease is disproportionately on women, who sustain 78.8 percent of all cases of autoimmune diseases (NIH, 2002). There is no cure for autoimmune diseases – only a life-long road of treatment of symptoms. Autoimmune diseases are complex to diagnose and treat and on-going social support plays a critical role in patients' adherence to medications and ultimately their health outcomes. A marriage is a critical source of social support during illness (Segrin & Badger, 2011). Marriage is defined within social support research as “strong-tie” support and is often used as a measure of social support (2011). However, the interpretation of needed support and the perception of received support by married couples may be riddled with challenges due to identity transformation once diagnosed with an autoimmune disease as well as due to lack of communication competence

within the relationship. Much research has been conducted to examine marriage and illness through the lens of perceived support. This research extends previous research to examine social support intention and interpretation within the context of marital relationships and communication strategies utilized to enable effective support specifically for autoimmune thyroid disease patients, namely Hashimoto's Disease and Grave's Disease. Within the framework of Kreps' Relational Health Communication Competence Model (RHCCM), this research examined the impact of marital social support, coping, identity transformation, and communication on health outcomes and the influences of marital communication interactions on patients' perceptions and requests for support as well as their ability to cope with their disease. The study employed both qualitative and quantitative analysis, including a survey of 619 women with autoimmune thyroid disease with questions examining quality of life, coping, communication competence, identity transformation and social support access and perception. Qualified survey participants (n=30) participated in open-ended interviews to further examine social support, illness identity, coping and communication within the context of marriage and their illness. The quantitative results from the survey indicated that low communication competent individuals were significantly less satisfied with their received social support and also had lower perceived quality of life. These results showed support for Kreps' Relational Health Communication Competence Model (RHCCM). Additionally, perceived social satisfaction scores were higher when support was available from the husband or partner. Qualitative results from the interviews showed that communication strategies most effective for a satisfying relationship during

illness were increased open communication about their illness, shared understanding of the disease and agreement on the impact of its symptoms, and inclusion of positive and encouraging tone in provided support. Additionally, communication strategies most effective for illness-related identity changes included validation of changes to identity, attentiveness to symptoms, and using communication to create opportunities for support. Study contributions and theoretical and practical implications were also discussed. Results obtained from both the surveys and interviews will be used to develop evidence-based best communication practices for couples to promote effective social support within marital relationships.

Keywords: autoimmune disease, autoimmune thyroid disease, Hashimoto's Disease, Grave's Disease, communication, health communication, social support, coping, communication competency, Relational Health Communication Competence Model, RHCCM

## **CHAPTER ONE: STATEMENT OF THE PROBLEM**

### **Introduction**

Although the science and medical community has made tremendous strides in understanding the root causes of many diseases, autoimmune diseases still remain mostly a mystery. After cardiovascular disease and cancer, autoimmune diseases are the most common form of illnesses in the United States, affecting 23.5 million people (NIH, 2002). The burden of these diseases falls disproportionately on women, who sustain 78.8 percent of all cases of autoimmune diseases (AARDA, 2013). These diseases are among the top ten leading causes of death for women in every age group up to the age of 65 (Walsh, 2000). Autoimmune diseases are a varied group of illness that involve almost every human organ system and include diseases of the nervous, gastrointestinal, and endocrine systems, as well as the skin and other connective tissues, eyes, blood and blood vessels (NIH, 2002). With autoimmune diseases, the body's immune system becomes misdirected and attacks the very organs it was designed to protect (2002).

Critical obstacles remain in the diagnosis and treatment of autoimmune diseases because symptoms often cross multiple medical specialties and the root cause is hard to pin down, if not impossible. Many women go years without being properly diagnosed and according to the American Autoimmune Related Diseases Association (AARDA), 45 percent of female patients are labeled "chronic complainers" in the earliest stages of their illness (AARDA, 2013). Although, there is an initial sense of relief of finally

understanding the “what” – diagnosis is only the beginning of a daily, life-long struggle. Ultimately, these women must grow to understand their new-found identity and how it fits into the life they had prior to their disease.

### **Statement of the Problem**

Many women living with an autoimmune disease report feeling isolated and depressed due to their illness (Arem, 2007). Although support from friends and family is initially available, support often fades after diagnosis and treatment begins because many do not understand the chronic nature of the disease or the ebbs and flows of physical and mental symptoms (2007). Additionally, as diagnosis can often take years, unexplained behavior and symptoms may have already taken its toll on relationships prior to knowing the patient suffers from an autoimmune disease (2007). Many autoimmune patients also report strained relationships with their doctors and find it a challenge to find a doctor who will not dismiss their symptoms and be their partners in the search for solutions (Shomon, 2005). For this reason, many patients find solace in informal social networks that deal specifically with the daily challenges facing autoimmune patients (2005).

Marriage plays a critical role in the wellness of many autoimmune patients (Segrin & Badger, 2011). In addition to medication, treatment often involves changes in diet and lifestyle which are most effective for the patient when they are integrated into the “norms” of the household (Shomon, 2005). Additionally, as many patients experience difficulty adjusting to some of the symptoms, the presence of “in home” support becomes an important element to maintain wellness (Arem, 2007).

Much research has been conducted to look at marriage, coping and perceived support (Goldsmith, Bute, & Lindholm, 2012; Chapman, 2004; Ferraro & Wan, 1986; Holmstrom & Burleson, 2011; Xu & Burleson, 2001). Marriage is defined within social support research as “strong-tie” support and is often used as a measure of social support (Goldsmith, Bute, & Lindholm, 2012; MacGeorge, Feng, Butler, & Budarz, 2004). Interpersonal communication is a key element to the perception and receipt of social support and therefore competent communication within the marriage context is essential to positive health outcomes (Kreps, 1988).

### **Purpose of the Study**

The interpretation of needed support and the perception of received support of married couples may be riddled with challenges due to identity transformation pre-and-post diagnosis of an autoimmune disease as well as lack of communication competence (Arem, 2007; Goldsmith & Fitch, 1997) This study examines how women with autoimmune thyroid disease, specifically Hashimoto’s Disease and Grave’s Disease, use relational communication competence within their marriages to generate the social support necessary to encourage wellness and manage identity transformation. This study seeks to extend current social support, health communication and illness identity research to examine social support intention and interpretation within the context of marital relationships. In addition, this study will assess the influences of communication competence on perceived social support within the marital context and communication strategies utilized to enable effective support for autoimmune thyroid disease patients. Within the framework of Kreps’ Relational Health Communication Competence Model

(RHCCM), this research will investigate the impact of marital social support quality on autoimmune thyroid disease health outcomes and the influences of marital communication interactions on patient perceptions and requests for support. This study proposes to answer the following research questions:

R1: How does relational communication competence influence quality of life and social support perception for autoimmune thyroid disease patients?

R2: How is social support provided within the context of marital relationships when one marital partner has autoimmune thyroid disease?

R3: What challenges do women describe encountering that they must cope with in their marital bond when they have autoimmune thyroid disease?

R4: What relational communication strategies do women describe enacting to cope with these challenges and maintain a satisfying bond?

The study also seeks to understand the meaning and influences of this change of role within the marriage context as well as potential approaches to communication to combat the potential conflict between married couples and maintain relational balance. To address this condition, the study will answer the following additional research question:

R5: What relational communication strategies are enacted to manage illness-related identity changes within the context of marriage?

## **CHAPTER TWO: REVIEW OF THE LITERATURE**

This chapter is a review of the available literature pertaining to autoimmune disease, autoimmune thyroid disease, illness identity, social support and communication competence within the parameters of health communication. Additionally, marriage satisfaction and intimacy is explored within the social support framework to highlight the need for effective communication competence for the autoimmune thyroid patient within that context.

### **Autoimmune Diseases**

According to the National Institutes of Health (NIH), approximately 23.5 million Americans suffer from one or more autoimmune diseases (NIH, 2002). The American Autoimmune Related Diseases Association, Inc. (AARDA) suggests the number is closer to 50 million (AARDA, 2013). The significant difference in the number of impacted is due to the number of diseases included in NIH approximation (2013). While the NIH limits their numbers to the 24 diseases for which good epidemiological studies are available, AARDA includes a broader spectrum of autoimmune diseases identified by researchers in their estimation. Researchers estimate there are between 80 – 100 classified autoimmune diseases, including Hashimoto's Disease, Sjögren's syndrome, multiple sclerosis, rheumatoid arthritis, Crohn's Disease and lupus, and suspect there are at least 40 additional diseases with roots in autoimmunity (2013). Autoimmune diseases

are one of the top leading causes of all deaths among women between the ages of 15 to 65 (Walsh & Rau, 2000). Additionally, these diseases represent the fourth largest cause of disability among women in the United States (AARDA, 2013).

The classification of autoimmune diseases refers to a varied group of illnesses that involve every aspect of the human organ system, including the nervous, gastrointestinal, and endocrine systems, as well as skin and other connective tissues, eyes, blood and blood vessels (NIH, 2002). In all of these diseases, the underlying problem is similar – the body’s immune system becomes misdirected and attacks the very organs it was designed to protect (2002). Autoimmunity has yet to be embraced by the medical community as a category of disease due the fact that autoimmune diseases cross many medical specialties, including rheumatology, endocrinology, hematology, neurology, cardiology, gastroenterology, and dermatology (AARDA, 2013). Since these specialties usually focus on diseases within their specialty, autoimmunity is not investigated as a singular cause. For this reason, despite general knowledge of the presence of autoimmunity, patients suffer from the lack of focus and a scattered treatment and diagnosis approach (2013).

Women are three times more likely than men to acquire an autoimmune disease (Jacobson, Gange, Rose, & Graham, 1997). Women face significant challenges in receiving a diagnosis of autoimmunity and many are labeled chronic complainers in the earliest stages of their illness (AARDA, 2013). Much of the challenge is due to the vagueness of symptoms in the beginning, fluctuation of symptoms and the ability to accurately describe symptoms to their physicians (The Society for Women's Health

Research and the National Women's Health Resource Center, Inc., 2002). Additionally, a large percentage of women are in their childbearing years and their symptoms are often not taken seriously or diagnosed as psychological or stress related (Walsh & Rau, 2000). In a typical scenario, women are shuffled from specialist to specialist and forced to undergo a battery of tests and procedures before a proper diagnosis is made, which can take years (2000). Delay in diagnosis not only poses significant threat to a women's health due to organ damage, but also impacts their mental well-being and trust in the medical community (AARDA, 2013).

### **Autoimmune Thyroid Disease**

One of the most common autoimmune diseases is autoimmune thyroid disease, which includes Hashimoto's Disease and Grave's Disease. Hashimoto's Disease has a ten to one prevalence in women over men (The Society for Women's Health Research and the National Women's Health Resource Center, Inc., 2002). With Hashimoto's Disease, the immune system makes antibodies that damage thyroid cells and interfere with their ability to make thyroid hormone (Shomon, 2005). Over time, thyroid damage can cause thyroid hormone levels to be too low resulting in the condition called "underactive thyroid" or hypothyroidism (2005). The thyroid, a small gland in the front of the neck, has an essential and critical role – the hormones it produces deliver oxygen and energy to every cell in the body (2005). Additionally, the functioning of most organs is affected as thyroid levels decrease (Arem, 2007). An underactive thyroid causes every function of the body to slow down, such as heart rate, brain function, and the rate the body turns food into energy resulting in both physical and mental symptoms (2007).

Some of the physical symptoms include fatigue, weight gain, constipation, hair loss or brittle hair, sensitivity to cold, muscle cramps, thickened skin and enlargement of the thyroid gland or goiter (2007). An underactive thyroid can also cause varying mental effects including depression, mental fog, memory loss, emotional instability, and loss of ambition, decreased ability to focus, slowing of thought and speech, irritability, agoraphobia (fear of open or public spaces) and manic behavior (2007).

Grave's Disease is an autoimmune thyroid condition characterized by an overactive thyroid, which produces too much thyroid hormone. Grave's Disease has a seven to two prevalence in women over men and accounts for seventy percent of overactive thyroid cases (The Society for Women's Health Research and the National Women's Health Resource Center, Inc., 2002). In Grave's Disease, the body produces an antibody called thyrotropin receptor antibody (TRAb) which mimics the action of the pituitary gland and overrides normal regulation of the thyroid (Gold, Pottash, & Extein, 1982). Some of the symptoms of this disease include nervousness, irritability, weight loss, fast or irregular heartbeat, heat intolerance, muscle weakness, exophthalmos (bulging eyes), and infertility (Arem, 2007). The more severe physical complications of Grave's Disease are the cardiac effects like heart failure and a condition called mitral valve prolapse, a heart valve abnormality (Evangelopoulou, et al., 1999). Some of the mental effects of Grave's Disease include social anxiety disorder, panic attacks, disorganized thinking, aggression, and bipolar disorder (Arem, 2007). Treatment for Grave's Disease can include radioactive iodine, anti-thyroid medications, corticosteroids and, in some cases, surgery to remove the thyroid.

Endocrinologists often treat the condition of hypothyroidism with thyroid hormone replacement treatment and regulate the treatment based on the levels indicated in a thyroid stimulating hormone (TSH) test (Shomon, 2005). However, there is a lack of agreement in the medical community as to the normal range of TSH and treatment approach is often determined by which reference range an individual doctor adopts (2005). In addition, with Hashimoto's Disease and Grave's Disease, many doctors only treat the resulting condition of hypothyroidism/hyperthyroidism and not the underlying autoimmune disease (Arem, 2007). Many doctors dismiss additional mental symptoms or lack the experience or training necessary to deal with complex autoimmune diseases which if not identified or properly treated can result in a lifetime of chronic illness and debilitating symptoms (2007).

Many people associate thyroid issues with weight problems and metabolism (Gulseren, et al., 2006). However, in many cases, the emotional and mood-related symptoms due to thyroid imbalance can be more severe than the physical ones (Arem, 2007). For this reason, many patients are often misdiagnosed with a mood disorder, bipolar disorder or clinical depression instead of a thyroid problem (Gold, Pottash, & Extein, 1982). One study indicated that 15 percent of screened depressed patients had an underactive thyroid (1982). In another, twenty percent of patients hospitalized because of severe depression had Hashimoto's Disease (Nemeroff, Simon, Haggerty, & Evans, 1985). Depression and mood swings are often overlooked in the treatment of autoimmune thyroid disease and can have a devastating effect to health outcomes, social support perception and relationship health.

Due to the physical and mental changes experienced by autoimmune thyroid disease patients, living with these diseases often has profound influences on interpersonal relationships. For example, thyroid patients often become moody, anxious, angry and irritable and the changes may be confusing and frustrating to their partner (Rockey & Griep, 1980). Arem suggests there are two phases that typically influence interpersonal relationships, the pre-diagnostic phase and the diagnostic phase (2007). During the pre-diagnosis phase, which can last for years, the personality of the patient may change drastically and without determining the cause many relationships suffer or deteriorate. After diagnosis, despite recognizing the presence of a disease, many patients are unable to understand, qualify or describe the mental and physical symptoms accurately and tend to disengage or distance themselves from relationships (2007). In an “Open Letter to Family and Friends of Thyroid Patients,” Shomon writes, “For those who suffer from this disorder and have loved ones who do not understand it, it can be quite difficult and frustrating while trying to explain just how you feel- performing the simplest task can feel as if you’ve just run a marathon. You are in constant pain and you start to question your own mortality” (Shomon, 2014 ).

### **Identity Transformation**

Many patients suffering from autoimmune thyroid disease claim to “not feel quite like themselves” (2011). Some of the key thyroid related changes in personality reported include impatience, irritability, withdrawn, lack of commitment or will to accomplish tasks, unexplained anger or aggression, inconsistent and irrational behavior (Arem, 2007). Coupled with the physical aspects of the disease, these changes can have a

significant impact on one's identity. According to communication theory of identity (CTI), one's identity is born out of interactions (Hecht, Warren, Jung, & Krieger, 2005). Communication is internalized as identity through social interaction influences and by assigning social categories to oneself (Hecht, 1993). The interactions described in CTI occur in four layers – personal, enacted, relational and communal (Hecht, Warren, Jung, & Krieger, 2005). The personal layer defines the self as the core of identity and includes such concepts as self-concept, self-image as well as self-cognitions (2005). Within the enactment layer, communication is the core of identity and manifests in how one communicates or performs their identity (2005). In the relational layer, relationships are the core of identity and identity is a product formed through relationships (2005). The final layer, communal, roots identity in groups and the characteristics defined by the group (2005). Identity gaps, or discrepancies between and among the four layers, can exist between and among any of the identity layers (2005). Jung and Hecht highlighted identity gaps between the personal-relational layers and personal-enacted layers as the results of communication (Jung & Hecht, 2004). These gaps manifested in communication satisfaction, feeling understood and conversational appropriateness within their study (2004).

Hecht and colleagues further extend CTI with the illness identity theory (2005). Illness identity theory proposes that at the personal level one experiences a change in how one views oneself and thinks about “who they are” in relation to their illness and physical and mental symptoms (Hecht, Warren, Jung, & Krieger, 2005). At the enacted level, a patient may perform or communicate their identity differently (2005). It is important to

note that in relation to autoimmune thyroid disease the performance of identity can either be intentional or unintentional due to hormonal influences associated with the disease. At the relational level, one will determine how and what to communicate about their illness (2005). This level is especially important in relation to social support seeking and communication competence. At the communal level, many congregate to individuals with the same illness to achieve support and share in a collective group identity (2005).

During the periods of change and adaptation to illness, patients experience a reorganization and reintegration of identities, roles, relationships and behaviors which may significantly alter their identity, how they define themselves or their relationships (Jung, 2013). Ultimately, when undergoing transformation due to illness, the social environment or context will also be impacted (Jung & Hecht, 2004). In one study of women with breast cancer, as they adopted their new illness identity, they worried how their relationships would be affected by information sharing, shared management of their illness in addition to fundamental changes to their identity, life course and sexuality (Weber & Solomon, 2008). It is important to note that the inability or restriction of expression of self, including the performance or enactment of illness, has been tied to depression (Jung, 2013). In a study of illness identity and mental illness, depression and isolation were examined within the context of hope and self-esteem, concluding that positive identity transformation is an important part of the process of improving health outcomes (Yanos, Roe, & Lysaker, 2010).

Other research has shown marital relationships have the potential to help shape and define how one views one's health and identity (Brown, 1995; Duck, 1994). Illness

identity within marriage has been shown to be enacted through everyday interactions and influence illness management and compliance to treatment (Bowlby, 2011; Hunt, Jordan, Irwin, & Browner, 1989; Ross, Mirowsky, & Goldsteen, 1990). According to a study of illness-identity narratives in marriage, discourse in marriage helps determine how identity is communicated and realized as well as what support is provided (Walker & Dickson, 2004). Through communication, marital partners construct meaning about the illness and negotiate its impact on the couple's lives and relationship (2004).

### **Social Support**

Social support from others has been found to assist coping and to exert beneficial effects on various health outcomes for patients (Schwarzer & Leppin, 1991; Veiel & Baumann, 1992). Social support has been defined in various ways, for example as "resources provided by others" (Cohen & Syme, 1985), as "coping assistance" (Thoits, 1986), as "a resource for coping" (Endler & Parker, 1990), and as an exchange of resources "perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (Shumaker & Brownell, 1984). A proposed explanation for the relationship between coping, social support and health relates social support as a form of coping (Thoits, 1986). This is due to the interrelated qualities of both concepts (1986).

Social support is also defined as "an umbrella term for various theories and concepts that link involvement with social relationships to health and well-being" (Goldsmith & Albrecht, 2011, p. 335). Weiss indicated that six conditions impact social support (Vaux, 1988). These include situational context, preferred outcomes, perceived cost and reward, attachment and abilities to provide support (1988). Although various

functions of social support have been identified, three categories are most consistently highlighted. They are emotional, informational and tangible support functions (Gottlieb, 1985). Emotional support is provided to an individual to enhance his/her emotional strengths, and shows that the person is accepted and valued (Vaux, 1988). This has also been called expressive support and esteem support (Cohen & Syme, 1985; Goldsmith, 2004; Goldsmith & Albrecht, 2011). Esteem support is a distinct form of emotional support that is provided to others with the intent of enhancing how they feel about themselves (Holmstrom & Burleson, 2011). Informational support is helping the individual to define and understand the problem in order to be better able to cope (Vaux, 1988). It is also known as advice and appraisal support (MacGeorge, Feng, Butler, & Budarz, 2004). Tangible or instrumental support is the provision of financial aid, material resources and other concrete services (Goldsmith & Albrecht, 2011). Cutrona categorized five levels or types of social support – material, emotional, esteem, network and informational (1988).

Social support is purported to increase self-esteem and feelings of environmental control (Pearlin, Lieberman, Menaghan, & Mullan, 1981). Thus marriage may increase one's ability to cope, either because there is someone there to provide coping assistance or because it enhances one's own coping capacity (Burman & Margolin, 1992).

According to a study by Xu and Burleson, women reported desiring significantly higher levels of support from their spouses than did the men in all types of support (Xu & Bureleson, 2001). The foundation of the study was the “support gap hypothesis,” which postulates that women receive less support than men in marriage.

A large body of social support research clusters around two main models – the buffer hypothesis and the main effects (or direct effects) model. Cassell and Cobb were specifically interested in the coping aspects of social support and the ability of strong support networks to provide a coping mechanism for extremely stressful situations (Vaux, 1988). The development this concept is what is known today as the buffer hypothesis. Another key model is the main-effect, or direct-effect, model (1988). Rather than intervening between stressors and the individual, this model proposes that social support directly benefits well-being by fulfilling basic social needs (Thoits, 1986). The difference between these two key models lies in the timing of support, with main-effect advocates implying a more continuous role for social support and buffering advocates emphasizing social support as a response to times of stress.

A multitude of cross-disciplinary researchers throughout the years have provided parameters for what constitutes social support and its definition ranging from how one interprets the social support received to how one learns or adopts models of social support (Cohen & Syme, 1985; Gottlieb, 1985; Vaux, 1988; Wright, Sparks, & O'Hair, 2013). The ability for patients to cope may also play a role in the adjustment process in terms of diagnosis and may be regarded as a means to determine perceptions of ones capacity to deal with stress (Bandura, 1982). Research suggests that social support can protect individuals against some of the harmful effects of stress (Afifi & Nussbaum, 2006). Gardner and Cutrona (2004) discuss family as an essential coping resource and describe social support within the context of family as communicative behavior that “is responsive to another’s needs, and serves the function of comfort, encouragement,

reassurance or caring, and/or the promotion of effective problem solving through information or tangible assistance” (p. 495).

Social support satisfaction refers to a person’s overall satisfaction with the support received from support network members (Sarason, Sarason, Shearin, & Pierce, 1987). Perceived communication competence has been shown to be positively connected with social support satisfaction (Albrecht & Goldsmith, 2003). According to Goldsmith and Albrecht, supportive communication is a “necessary condition for the quality of life and for healthful living” (Goldsmith & Albrecht, 2011, p. 335). Burleson contends that people vary in their ability to effectively communicate supportive messages during stressful situations, like chronic illness, and a certain level of cognitive complexity and skill is required (Burleson, 1994). Cognitive complexity is linked to a person’s ability to construct messages (1994). The relationship between communication competence and social support satisfaction appears to influence a variety of health outcomes (Kreps, 1988; Kreps, O’Hair, & Clowers, 1995), such as therapeutic communication and cognitive depression (Query & James, 1989; Query & Kreps, 1996; Query & Wright, 2003), and stress and chronic illness (Pettigrew & Pettigrew, 2011).

Social support is described as an interactive experience and is essentially communicative (Afifi & Nussbaum, 2006). For that reason, communication competency is essential to provide effective support and interpret a marital partner’s behavioral cues for needed support (Helgeson & Cohen, 1996). Social support can also have detrimental effects. It is seen as beneficial to the degree the support is communicated competently (Goldsmith, 1992), is non-face threatening (Caplan & Samter, 1999) and is

acknowledged and perceived as effective by the recipient (Burleson, 1994). Research on advice giving as supportive communication indicates that how advice is communicated impacts the perception of advice quality (Goldsmith & MacGeorge, 2000). According to Cutrona and Suhr (2004) spouses reacted more positively dependent on who had more control over the problem. In a study of cancer patients, advice was perceived as more helpful when it was from doctors than from family or friends (Dakof & Taylor, 1990). Studies show that partner support can encourage lifestyle change yet partner efforts may be interpreted as welcome support or as undesired control (Cohen & Lichtenstein, 1990; Franks et al., 2006; Lewis & Rook, 1999; Tucker & Anders, 2001; Tucker & Mueller, 2000). In a study of cardiac events, how patients and partners communicated and how they interpreted their communication was an important element of understanding interactions concerning change due to illness (Goldsmith, 2012).

Social support has been found beneficial in a patient's recovery from a variety of conditions such as stroke (Kwakkel, Wagenaar, Kollen, & Lankhorst, 1996), traumatic brain injury (Maitz & Sachs, 1995); breast cancer (Fisher & Miller-Day, 2006); and depression (Mickelson, 2001). Kulik and Mahler have studied men who had undergone coronary artery bypass graft surgery (1993). Those who received many hospital visits by their spouses were released earlier from the hospital than those who received few visits. In another study, they also found that emotional support from spouses had positive effects on patients after surgery (1993). Segrin and Badger illustrated that the well-being of men with prostate cancer can be affected by the social support they receive from family and friends (2011).

Social support is crucial for individuals experiencing the physical and psychological symptoms of autoimmune thyroid disease (Shomon, 2005). Autoimmune thyroid disease symptoms can intensify if the individual becomes overly stressed. Additionally – since many of the symptoms manifest in “invisible” ways (such as severe fatigue, confusion, and irritability) – many experience a loss of self-esteem and may seek isolation over support if their network does not validate their symptoms (Arem, 2007). According to Bowlby, society has been conditioned to presume disability is something that can be visually affirmed and verified and for this reason individuals may be met with skepticism, disbelief, and even hostility (Bowlby, 2011). Grunbach indicates that although invisible chronic illnesses are largely not recognized invisible “chronic conditions, not acute ailments, are now the most common problems in healthcare” (p. 4). Chronic invisible illness may not receive adequate social support from family and friends because it is easy to overlook or ignore symptoms that are not seen or verifiable (Bowlby, 2011). The “invisibility” of chronic illness can have serious psychological impacts (Donoghue & Siegel, 1992). “Without an objective explanation of her ailments, the suffering person is terribly vulnerable to the notion that she is suffering from psychosomatic illness or that she is depressed, neurotic, or hysterical” (1992, p. 47). With autoimmune thyroid disease, numerous patients experience unpredictable “flare-ups” or “bad days” when their symptoms worsen (Arem, 2007). Despite their change in health, their visual appearance may not change which can impact the social support they receive from their family and friends (2011).

Social support often plays a central role in a marriage (Cunningham & Barbee, 2000; Gagnon, Hersen, & Kabacoff, 1999, Segrin & Badger, 2011). Additionally, most married couples view their spouse as fundamental source of social support in their lives (Cutrona, 1990). Marriage also plays an important role in health maintenance and health problems (Segrin & Badger, 2011). Supportive communication from spouses is critical to maintaining wellness (2011). According to research, social support from close-tie support groups (like husband and family) is associated with lower psychological distress and depression (Baider, Ever-Hadini, Goldsweig, Wygoda, & Pretz, 2003). Marital support has also been shown to be important for mental health during times of illness. Studies have shown high marital support is associated with lower depression among patients with rheumatoid arthritis. (Manne & Zautra, 1989), breast cancer (Friedman, et al., 2006); and patients recovering from heart surgery (Waltz, Bandura, Pfaff, & Schott, 1988). Marital support also impacts health indirectly through promoting healthy behavior and enabling compliance (Kulik & Mahler, 1993). Specifically, couples show greater compliance with medical regimes (1993) and changing health behaviors, like diet and exercise (Thornton, et al., 2006). Studies also show a connection between marital satisfaction and self-reported physical symptoms and better overall self-reported health (Barnett, Davidson, & Marshall, 1991; Ganong & Coleman, 1991; Ren, 1997). For example, women diagnosed with chronic fatigue syndrome experiencing lower levels of marital support and satisfaction reported more concurrent symptoms than women with high levels of support and marital satisfaction (Goodwin, 1997).

## **Marital Satisfaction**

Chronic illness has been shown to alter preexisting relationships (Yelsma, 1995).

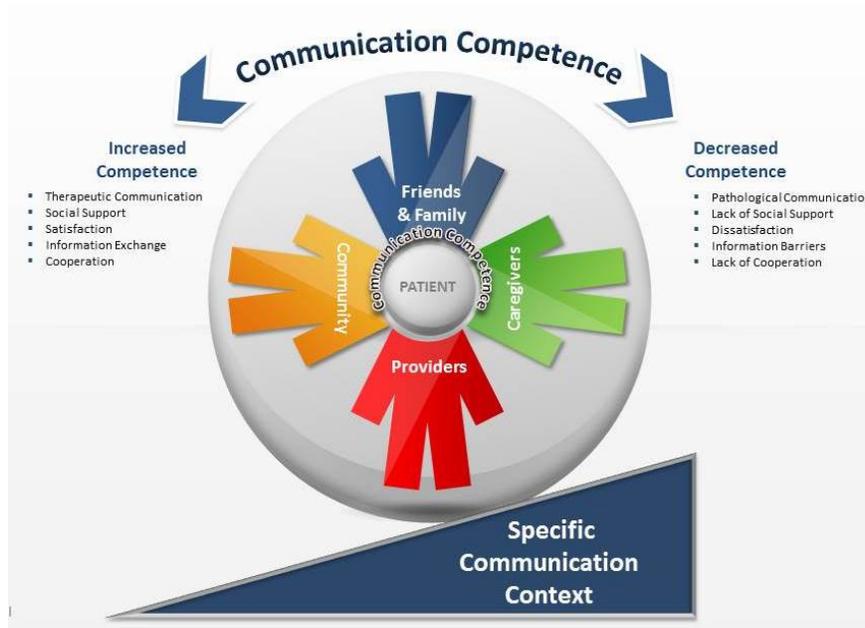
Research indicates lack of social support is associated with declines in marital quality and satisfaction (Acitelli, Kenny, & Weiner, 2001; Cobb & Davila, 2001; Matthews, Wickrama, & Conger, 1996). Additionally, negative life events, like an illness, are often associated with declines in marital satisfaction (Bradbury, Fincham, & Beach, 2000). A satisfying relationship within an intimate relationship as defined by Spanier (2001) includes characteristics of 1) agreement between partners on matters important to the relationship; 2) contentment with the present state of the relationship and commitment to its continuance; 3) expression of affection and sex in the relationship; 4) common interests and activities shared by the couple. The stress of an illness can impact communication and erode social support in a marriage (Cutrona, 1990). Marriages that maintain competent communication in times of illness experience less depression and marital dissatisfaction (Lorenz, Conger, Montague, & Wickrama, 1993).

Social support and intimacy within these relationships is important for the regaining of independence and control while patients are navigating and restructuring their transformed lives (1995). Wynne and Wynne define intimacy as a subjective relational experience in which the core components are trusting self-disclosure to which the response is communicated empathy (1986). They expand on this definition to include a key component of “willingness to share verbally or nonverbally, personal feelings, fantasies, emotionally meaningful experiences and actions, positive and negative, with expectation and trust that the other person will emotionally comprehend, accept what has been revealed, and will not betray or exploit this trust” (1986, p. 384).

Relational intimacy can serve as a buffer against psychological ill health as well as a contributor to wellbeing (Yelsma, 1995). Wunderer and Schneewind found that the positive associations between partners' relationship-focused standards (regarding boundaries, control/ power, and investment in the couple relationship) and partners' relationship satisfaction were mediated by the degree to which members of the couple communicated in ways that provided positive coping or support to each other in stressful life situations (2008). Intimacy is an important construct to enable couples to provide emotional support as well as have positive psychological and physiological outcomes (Yelsma, 1995).

### **Communication Competence**

Communication is a key element to the perception and receipt of social support (Goldsmith & Brashers, 2008). Communication is appropriate when a communicator does not violate communication rules and meets social expectations in a given situation (Spitzberg & Cupach, 1984). Effective communication occurs when a communicator achieves desired goals in communication (1984). Appropriate and effective communication usually requires knowledge about communication rules (cognitive ability), motivation for communication (affective ability), and skills to perform communication (behavioral ability) (1984). As posited by Kreps, communication competence is a "multidimensional construct based on a wide-range of communication abilities that are developed from a combination of communication knowledge and skills" (Kreps, 1988). He also emphasizes the essential nature of context and the abilities of individuals to adapt within specific relational settings (1988).



**Figure 1 Kreps' Relational Health Communication Competence Model (RHCCM) (Kreps, 1988)**

Kreps model of Relational Health Communication Competence (RHCCM) (Figure 1) illustrates a process by which communication competence influences health outcomes. The model depicts a wheel with spokes representing a patient's social support network and the hub of the wheel represents the patient, who is at the center of the network (1988). The network shapes the quality of the patient's health journey. The specific communication context determines the level of communication competence required to accomplish health related goals. The more complex and "rocky" the communication context, the more communication competence is required. Individuals with insufficient levels of communication competence, according to this model, are less likely to achieve successful health outcomes (2009). The model also indicates increased communication competence leads to "therapeutic communication, social support, satisfaction, information

exchange, and cooperation” while decreased competence leads to “ pathological communication, lack of social support, dissatisfaction, information barriers, and lack of cooperation” (Kreps, 1988). Since many autoimmune patients disengage or withdraw from communication from their partners, there is potential for low levels of communication competence within this context.

In this same study, social support satisfaction was a stronger predictor of communication competence than the size of one’s social network (1996). Due to the complex nature of autoimmune thyroid disease diagnosis and treatment and the potential for symptoms to affect their relationships, RHCCM will be applied to assess communication competence as it relates to perceived social support with their marital relationships and its potential impact to health outcomes.

## **CHAPTER THREE: STATEMENT OF THE METHOD**

This dissertation serves two key purposes: 1) to determine perceived social support and quality of life for autoimmune thyroid disease patients and the influence of communication competence on these perceptions and 2) observe the influences of communication competence on perceived social support and identity transformation and the strategies employed within the marital context for patients suffering from autoimmune thyroid disease. Obtaining this information required a mixed methods approach to ensure data collected provided a framework for multiple variable analyses to integrate with the detailed exploration of personal accounts of autoimmune thyroid disease patients. The reason for combining both quantitative and qualitative data is to better understand this research problem and to advocate for change for autoimmune thyroid disease patients (Creswell, 2009). The strength of the study will be greater by employing these sequential methods to enable greater applicability to a larger population for ultimately stronger proposed relational communication strategies.

### **Survey**

#### **Sampling and Recruitment**

The target population for the proposed study was women who met the following conditions: 1) diagnosed with autoimmune thyroid disease (Hashimoto's Disease and Grave's Disease) for a minimum of two years and 2) currently married, separated or

divorced. The importance of years associated with diagnosis was grounded in the assumption that the women have a clearer understanding of their disease post-diagnosis and have had time to understand their disease and the implications for social support. Additionally, it provided a greater reference time period for patient recollection and examples. Also the method for recruitment of the sample required women to be connected to informal social support groups and those new to the disease might not necessarily be aware or had extensive exposure to these groups. The goal in collection of this sample was to include women who can best account for their experience including perceived quality of life, social support perception and satisfaction, and communication competence.

Recruitment of the women for the survey was accomplished through social networking sites that provide information and social support to women with autoimmune thyroid disease. A request for participation in a survey was posted on these sites. The survey tool used was Survey Monkey. The sites included in this study include: About.com Thyroid Disease Facebook page, DearThyroid Facebook page, ThyroidMom Blog, NotCrazyJustSick Twitter feed, ThyroidMary Twitter Feed. Together these sites reach approximately 30,000 followers who are impacted with autoimmune thyroid disease. The sample size for the survey was 619 ( $N=619$ ). A breakdown of the sample by age, marital status and length and disease is in Table 1.

**Table 1 Survey Sample**

Age (in years) by percentage		Marital Status by percentage		Length of Marriage (if married) in years		Diagnosis (Disease)	
18-24	1%	Married	84%	2 -3 yrs	8%	Hashimoto's	96%
25-34	13%	Divorced	12%	4-7 yrs	11%	Grave's	4%
35-44	33%	Separated	4%	8-10 yrs	12%		
45-54	34%			Over 10	67%		
55-64	18%						
65-74	1%						

### **Procedures and Measures**

For the first phase of the study, a survey was constructed to obtain basic demographic information (age, sex, and years with the disease) as well as communication competence, perceived social support, social support satisfaction, and perceived coping. This survey was used to establish consent as well as exclude participants outside the parameters of the study. To measure perceived communication competence, this study used Wiemann's Communication Competence Scale (CSS) (Wiemann, 1977). Various studies have utilized the scale to report a Cronbach's alpha of between .899 and .920 (Query & Kreps, 1996; Query, 2003). To measure social support perception and quality of life perception, this study applied the Medical Outcomes Study (MOS) Survey and Social Support Survey by RAND Health which reported a greater than .91 across all Alphas (Herbourne & Stewart, 1991). Social support satisfaction was measured using the shortened form of the Social Support Questionnaire (Sarason, Sarason, Shearin, & Pierce, 1987). The levels of reliability for the shortened version have ranged from .89 to

.99 (Query, 1987; Query & Kreps, 1996; Query & Wright, 2003). For the survey, reliability of the scales were tested and yielded .91 for the Communication Competence Scale. Social support satisfaction perception yielded a .89 Alpha and the Medical Outcomes Quality of Life Scale yielded a .91 Alpha. The reliability coefficient for the SSQ in this study was calculated at .92 for the social support satisfaction subscale. These scales are located in Appendix A – D of this dissertation.

### **Data Analysis**

All quantitative data was analyzed in IBM Statistical Package for Social Software (SPSS) software. To test research questions one and two, a multivariate factorial analysis of variance (MANOVA) was conducted. To create the distinct communication competent groups (high, moderate, and low) and approach group size equivalence, the SPSS binning function was employed. Based on the frequency distribution, 35 percent of respondents were placed into the high communication competent group, with 31 percent and 33 percent of participants placed in the moderate and low groups respectively. To create distinct quality of life groups and perceived social support (high, moderate and low), SPSS binning function was also used. Based on the frequency distribution for quality of life, 33 percent of participants were placed in each group category. Similarly, based on frequency distribution of perceived social support, 34 percent were placed in low social support perception and 34 percent and 32 were placed in moderate to high social support perception respectively. Effect between variables was conducted to show mean group difference between the independent variable, communication competence, and the dependent variables, social support satisfaction, and quality of life.

## **Interviews**

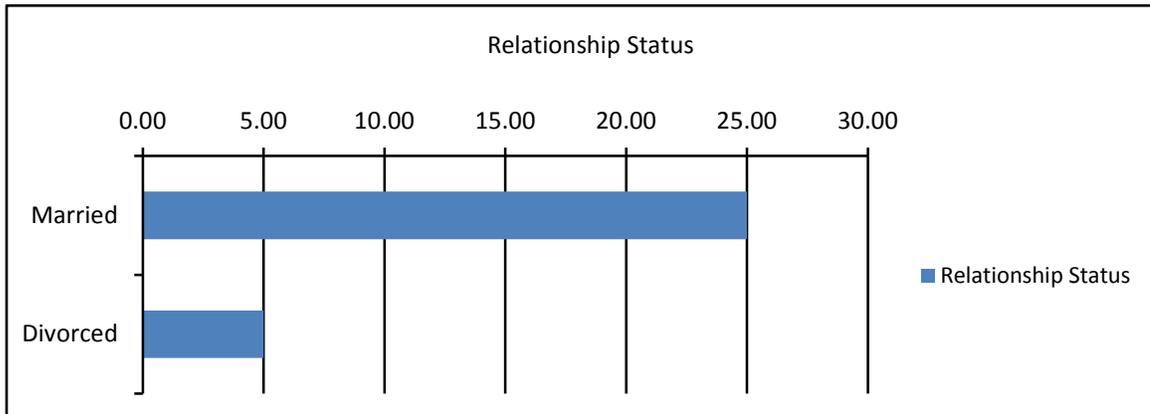
### **Sampling and Recruitment**

As part of the survey, participants were asked to opt-in to personal open-ended interviews to further examine social support communication within the context of marriage and their illness. All participants were selected from the survey based on their request to participate in an interview. Although 117 women requested to be interviewed, saturation was met at 30 ( $N=30$ ) interviews. Interview participants were selected in their order of response to the survey. The in-depth and context-sensitive studies inherent in qualitative research drive for a smaller sample size that is reflective of the phenomena under investigation rather than the statistical significance of quantitative research (Creswell, 2009). The sampling strategy for this research was criterion sampling due to the specificity of the situation under investigation. The selection criterion was indicated in the beginning of the current chapter.

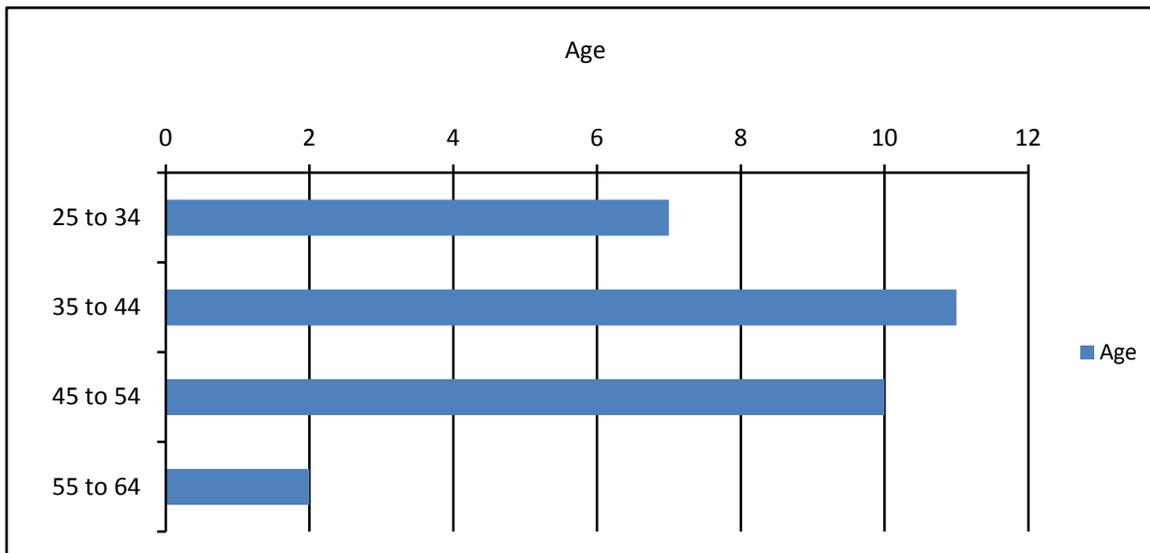
### **Participants and Procedures**

As indicated earlier, thirty women participated in the interview phase of the study. The characteristics of these participants are provided in the tables below.

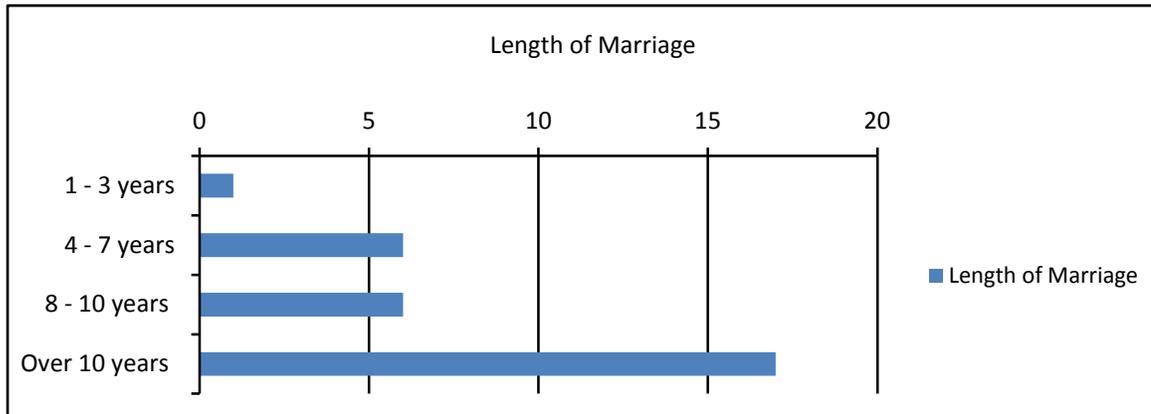
**Table 2 Interview Sample: Relationship Status**



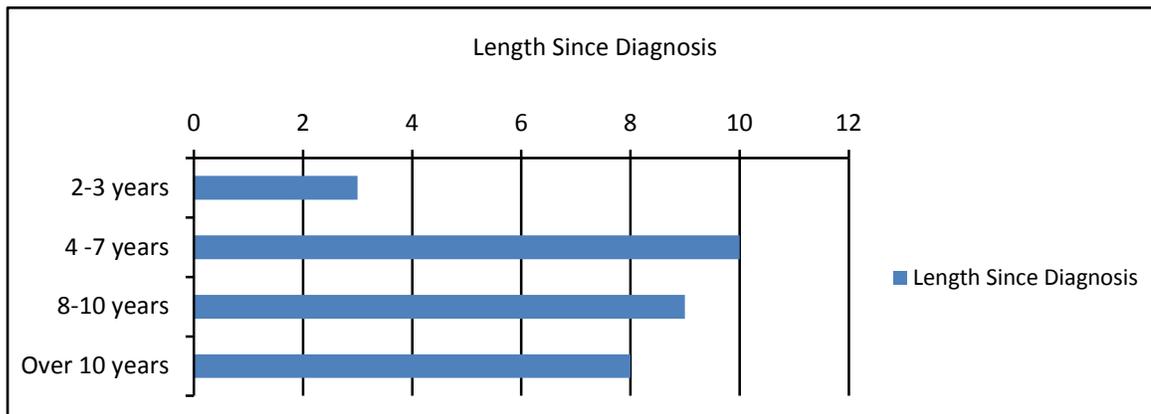
**Table 3 Interview Sample: Age**



**Table 4 Interview Sample: Length of Marriage**



**Table 5 Interview Sample: Length Since Diagnosis**



The nature of qualitative research allows the researcher and participant to work together to gain an understanding of the participant's experience. The interview phase of this research was conducted within an interpretative paradigm (Creswell, 2009). The personal interviews conducted over the phone averaged 75 minutes with the shortest interview being 60 minutes and the longest 90 minutes. The phone interviews answered questions related to past interactions and situations related to social support, relational communication, identity transformation and autoimmune disease impact. The phone

interviews were audio recorded and transcribed. Three interviews were conducted through email by participant request.

Because the interviews followed a semi-structured interview format, they were flexible and organic in nature. To ensure rigor and applicability across the sample, the study employed use of an interview guide with the intent of guiding basic questions to ask but also leaving room for stimulating discussion (Tracy, 2013). The advantage of the semi-structured interview guide was its allowance for more emergent understandings of autoimmune thyroid disease support communication strategies as well as to allow for the interviewees to express more complex viewpoints than would be allowed within the constraints of scripted questions (2013). Additionally, the semi-structured interviews enabled the capture of the stories related to the autoimmune experience as they developed in the conversation.

Many interview-based studies use transcription as the mode of data reduction (Kvale & Brinkman, 2009). In this research study, the interviews were transcribed verbatim, including utterances, to provide the maximum available textual data for analysis. To shorten the time of transcription, two professional transcribers were used in addition to the researcher to transcribe the notes. To protect the privacy of the participants, all transcriptionists were instructed to not include names, locations or other personally identifying information.

The transcriptions were coded to show the various themes that emerged within the interviews. Results obtained from both the surveys and interviews were used to develop

evidence-based best support communication practices for couples to promote effective social support within marital relationships.

### **Qualitative Methods**

A research approach is a general, but holistic and methodical roadmap associated with research purposes (Creswell, 2009). The strategy of this qualitative study was employed through interpretative design, which according to Creswell (2009) enables the research to draw as much as possible on the participant's views of the situation being studied. The study ultimately sought to understand the perspectives of participants, within the research focus, regarding themselves, their illness, and their marriage.

Qualitative data analysis requires deep immersion in the data as soon as practical (Tracy, 2013). This study employed an iterative analysis approach of content collected during the interviews. This iterative approach allowed the revisiting of the content throughout the process, as well as the connection of emergent themes within the content to refine focus and understanding (Srivastava & Hopwood, 2009). These categories were further refined through deeper review of the data until no new categories could be formed (Lindlof & Taylor, 2011). Throughout the interview process questions were added and eliminated based on response and emergent questions and themes. Data analysis was conducted during this study at the same time as the data collecting, interpreting and report writing (Creswell, 2009).

The iterative process of qualitative data requires beginning the interpretative process immediately after the first interview. Therefore, notes were captured and audio files were transcribed immediately after the first interview to develop preliminary themes

and make further annotations to guide subsequent interviews. Upon completion of the transcriptions, the researcher listened to the audio files again to validate the transcription accuracy. During this process, additional research information was collected and annotated as memos with the interviews. The transcripts, memos and notes taken during the interviews were all included in the analysis.

Commercially available qualitative data analysis software can aid in the content analysis of transcripts to identify common categories and collect participant information, like age and marital status (Tracy, 2013). The advantage of using software is simple coding, categorization of these codes into themes, and the ability to link notes and memos to specific areas of text. The actual analysis and manual coding was performed by the researcher using thematic analysis.

### **Data Analysis**

Qualitative data analysis is an inductive and iterative process (Lindlof & Taylor, 2011). The inductive nature refers to generating themes or theories based on the data. This forms the basic precept of qualitative research and the primary distinction from deductive quantitative research (2011). This research used the thematic analysis technique in reviewing the interview data. Thematic analysis involves searching across and within the data for patterns and themes then categorizing them (Creswell, 2009). In this study, the common themes were refined to several key themes and the data was re-analyzed to verify the themes were consistent across the data. Thematic analysis is well suited for exploratory studies when the focus is on “identifiable themes and patterns of living and/or behavior” (Aronson, 2014). Common themes were identified within the

codes using cluster analysis (Lindlof & Taylor, 2011). These themes were then further refined to several key themes and the data was re-analyzed to verify that the themes applied across the data. The summary of themes is located in Table 1 below.

<u>Themes</u>	<u>Subthemes</u>
Change in Physical and Mental Health	<ul style="list-style-type: none"> <li>• Mental (depression, anxiety, isolation, etc.)</li> <li>• Physical (fatigue, limitations, not feeling well)</li> </ul>
Coping with Symptoms and Diagnosis	<ul style="list-style-type: none"> <li>• Impact of Symptoms and Diagnosis Generally</li> <li>• Impact of Symptoms on Relationship with Husband/Partner</li> </ul>
Health Obstacles	<ul style="list-style-type: none"> <li>• Provider Experience</li> <li>• Inability to improve health</li> </ul>
Strategies for Maintaining a Satisfying Relationship	<ul style="list-style-type: none"> <li>• Enacted Openness and Trust</li> <li>• Shared Knowledge, Understanding and Agreement</li> <li>• Communicating with Affirming /Encouraging Tone</li> </ul>
Strategies for Adapting to Illness	<ul style="list-style-type: none"> <li>• Validating Changes and Identity</li> <li>• Communicating Attentiveness to Symptoms</li> <li>• Creating Opportunities for Support</li> </ul>

**Table 6 Analytical Coding of Interviews**

## **Ethical Considerations**

*Privacy.* Respect for the individual begins with protecting the participants' private information from disclosure (Kvale & Brinkman, 2009). Consideration of identity protection was considered throughout the interview process. Prior to beginning the interview, each person was assigned a unique code number to identify each participant. This was the only piece of information that connected the audiotape with the individual participant. The same code was used during transcription and data analysis to further protect the participant's identity and maintain confidentiality. All electronic data, including emails, audio files, transcribed documents, and notes, were encrypted and stored on a secure drive.

*Role of the Researcher.* Particularly in qualitative research, the role of the researcher as the primary data collection instrument necessitates the identification of personal values, assumptions and biases at the outset of the study (Creswell, 2009). The researcher's contribution to the research setting can be useful and positive rather than detrimental (2009). The researcher for this study also has autoimmune thyroid disease, specifically Hashimoto's Disease. Rather than hindering the interviews, the diagnosis allowed for more trusted, candid discussions. Additionally, the researcher brought knowledge of treatment, medications and medical practices to the discussions allowing for more time to be spent on the experiences of the participants during the interviews. Although every effort was made to ensure objectivity, the researcher's experience may shape the understanding and interpretation of the data.

## **CHAPTER FOUR: RESULTS AND FINDINGS**

This study was conducted in two phases to address the following two purposes: 1) assess the influence of communication competence on perceived social support and quality of life for autoimmune thyroid disease patients and 2) explore applied communication strategies during times of identity transformation within the marital context that influence social support and quality of life for these patients. The quantitative results related the first purpose and answered Research Questions 1 and 2. The qualitative findings addressed the second purpose of the dissertation, which answered Research Questions 3, 4, and 5.

### **Survey**

The survey phase of the research addressed Research Question 1 (RQ1) and Research Question 2 (RQ2). RQ1 investigated the influence of relational communication competence on reported quality of life and social support perception for autoimmune thyroid disease patients. RQ2 queried the type of social support provided to autoimmune thyroid disease patients by their spouse or partner and subsequent satisfaction of this support.

### **Research Question 1**

To answer RQ1, survey participants were placed in high, moderate and low communication competence categories based on the Statistical Package for the Social

Sciences (SPSS) visual binning procedure. Tables 7,8, and 9 illustrate the distribution of survey participants within these categories. The total number of valid participants was 300 (n=300) out of the total 619 participants in the survey (n=619). For quality of life, survey participants were placed in categories of low, moderate and high quality of life based on SPSS visual binning procedure. As noted in the previous chapter, quality of life subscales for pain, physical limitations and physical functioning were removed from the overall quality of life score due to the impact of the variables indicated in the reliability of scale test. The total number of valid participants for this variable was 366 (n=366). For perceived available social support, participants were placed in low, moderate and high quality of life based on SPSS visual binning procedure. The total number of valid participants was 323 (n=323).

**Table 7 Communication Competence Score**

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid <= 72.00	107	17.3	35.7	35.7
73.00 - 85.00	94	15.2	31.3	67.0
86.00+	99	16.0	33.0	100.0
Total	300	48.5	100.0	
Missing System	319	51.5		
Total	619	100.0		

**Table 8 Quality of Life Score**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Low	122	19.7	33.3	33.3
	Moderate	122	19.7	33.3	66.7
	High	122	19.7	33.3	100.0
	Total	366	59.1	100.0	
Missing	System	253	40.9		
Total		619	100.0		

**Table 9 Overall Score for Perceived Social Support**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Low	110	17.8	34.1	34.1
	Moderate	109	17.6	33.7	67.8
	High	104	16.8	32.2	100.0
	Total	323	52.2	100.0	
Missing	System	296	47.8		
Total		619	100.0		

For RQ1, the multivariate test with communication competence as the independent variable yielded Wilk's Lambda=.805,  $F=10.971$ ,  $p<=.05$ , and power=1.00 (See Table 10). Based on a test of univariates, results revealed that the dependent variable, quality of life, was statistically significant,  $F=14.6$ , 2 d.f.,  $p<=.05$ . Additionally, results for the dependent variable, perceived social support, was statistically significant,  $F=14.1$ , 2 d.f.,  $p<=.05$ .

**Table 10 Test Between Subject Effects**

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Noncent. Parameter	Observed Power <sup>c</sup>
Corrected Model	QOL Score with physical factors removed (Binned)	17.968 <sup>a</sup>	2	8.984	14.602	.000	29.203	.999
	Overall Score for Social Support Availability(Binned)	17.819 <sup>b</sup>	2	8.910	14.141	.000	28.283	.999
Intercept	QOL Score with physical factors removed (Binned)	1059.214	1	1059.214	1721.559	.000	1721.559	1.000
	Overall Score for Social Support Availability(Binned)	1048.505	1	1048.505	1664.203	.000	1664.203	1.000
BINCommCompA	QOL Score with physical factors removed (Binned)	17.968	2	8.984	14.602	.000	29.203	.999
	Overall Score for Social Support Availability(Binned)	17.819	2	8.910	14.141	.000	28.283	.999
Error	QOL Score with physical factors removed (Binned)	166.737	271	.615				
	Overall Score for Social Support Availability(Binned)	170.739	271	.630				
Total	QOL Score with physical factors removed (Binned)	1245.000	274					
	Overall Score for Social Support Availability(Binned)	1241.000	274					
Corrected Total	QOL Score with physical factors removed (Binned)	184.704	273					
	Overall Score for Social Support Availability(Binned)	188.558	273					

To further examine effect of communication competence on quality of life and perceived social support, effect between variables was tested (see Table 11). The test revealed statistical significance mean group differences for quality of life between the low communication competency group and moderate to high competency groups with both having  $p \leq .05$ . However, there was not a significant mean difference between moderate to high communication competency groups,  $p = .764$ , for quality of life. The test also revealed statistical significance mean group differences for perceived social support between the low communication competency group and moderate to high competency groups with  $p \leq .05$ ,  $p = .003$  respectively. However, there was not a significant mean difference between moderate to high competency groups,  $p = .192$  for perceived social support.

**Table 11 Multiple Comparisons**

Tukey HSD

Dependent Variable	(I) Communication Competence Score (Binned)	(J) Communication Competence Score (Binned)	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
						Lower Bound	Upper Bound
QOL Score with physical factors removed (Binned)	<= 72.00	73.00 - 85.00	.08	.117	.764	-.19	.36
		86.00+	.57*	.114	.000	.31	.84
	73.00 - 85.00	<= 72.00	-.08	.117	.764	-.36	.19
		86.00+	.49*	.118	.000	.22	.77
86.00+	<= 72.00	-.57*	.114	.000	-.84	-.31	
	73.00 - 85.00	-.49*	.118	.000	-.77	-.22	
Overall Score for Social Support Availability(Binned)	<= 72.00	73.00 - 85.00	.21	.118	.192	-.07	.48
		86.00+	.61*	.115	.000	.33	.88
	73.00 - 85.00	<= 72.00	-.21	.118	.192	-.48	.07
		86.00+	.40*	.119	.003	.12	.68
86.00+	<= 72.00	-.61*	.115	.000	-.88	-.33	
	73.00 - 85.00	-.40*	.119	.003	-.68	-.12	

Within the context of Kreps' Relational Health Communication Competence Model (RHCCM), in response to RQ1, low relational communication competence indicated lower quality of life and lower social support perception.

**Research Question 2**

To answer RQ2, the social support categories (tangible, emotional, affectionate) were divided to indicate which support was provided by husband/partner. After conducting a count of husband/provider, the test indicated a greater percentage of support was provided in the tangible support category. However, the percentage of tangible support was not significantly greater than other categories (see Table 12).

**Table 12 Summary of Social Support Satisfaction for Husband**

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Provides Affectionate Support * Social Support Satisfaction Score (Binned)	225	36.3%	394	63.7%	619	100.0%
Provides Emotional Support * Social Support Satisfaction Score (Binned)	156	25.2%	463	74.8%	619	100.0%
Provides Tangible Support * Social Support Satisfaction Score (Binned)	263	42.5%	356	57.5%	619	100.0%

Additionally, the applied overall satisfaction score within each category was cross-tabulated to determine the level of satisfaction within each category (see Table 13). The results did not significantly indicate the difference in level of satisfaction within each category. However, the participants receiving emotional support from their husband indicated more satisfaction than dissatisfaction when they were receiving that support.

**Table 13 Cross tabulation for Husband Support and Social Support Satisfaction**

Provides Affectionate Support \* Social Support Satisfaction Score (Binned) Crosstabulation

			Social Support Satisfaction Score (Binned)				Total
			Satisfied	Moderately Satisfied	Moderately Dissatisfied	Dissatisfied	
Provides Affectionate Support	Husband/Partner	Count	76	41	77	31	225
		% within Provides Affectionate Support	33.8%	18.2%	34.2%	13.8%	100.0%
Total		Count	76	41	77	31	225
		% within Provides Affectionate Support	33.8%	18.2%	34.2%	13.8%	100.0%

Provides Emotional Support \* Social Support Satisfaction Score (Binned) Crosstabulation

			Social Support Satisfaction Score (Binned)				Total
			Satisfied	Moderately Satisfied	Moderately Dissatisfied	Dissatisfied	
Provides Emotional Support	Husband/Partner	Count	68	33	51	4	156
		% within Provides Emotional Support	43.6%	21.2%	32.7%	2.6%	100.0%
Total		Count	68	33	51	4	156
		% within Provides Emotional Support	43.6%	21.2%	32.7%	2.6%	100.0%

Provides Tangible Support \* Social Support Satisfaction Score (Binned) Crosstabulation

			Social Support Satisfaction Score (Binned)				Total
			Satisfied	Moderately Satisfied	Moderately Dissatisfied	Dissatisfied	
Provides Tangible Support	Husband/Partner	Count	82	47	88	46	263
		% within Provides Tangible Support	31.2%	17.9%	33.5%	17.5%	100.0%
Total		Count	82	47	88	46	263
		% within Provides Tangible Support	31.2%	17.9%	33.5%	17.5%	100.0%

## Interviews

The interview phase of the research followed the survey phase and addressed Research Question 3 (RQ3), Research Q4 (RQ4) and Research Question 5 (RQ5). RQ3 and RQ4 examined the challenges women experienced due to autoimmune thyroid disease and their impact to their marriage or intimate relationship, as well as the relational communication strategies enacted to cope with these challenges. RQ5 explored the relational communication strategies most effective for managing illness related

identity changes within the context of marriage or a romantic relationship. The summary of interview participant characteristics is located in Chapter 3.

### **Research Question 3**

To understand the impact of their disease on their marriage and the subsequent relational communication strategies employed or discussed each participant answered questions related to illness-specific challenges. The themes revealed in the interviews as indicated in Chapter 3, Table 6, included change in physical and mental health, coping with symptoms and diagnosis, and health obstacles.

*Change in Physical and Mental Health.* Most of the participants in the interview openly related accounts of challenges connected to change in their physical and mental health throughout the disease trajectory (pre-diagnosis and post-diagnosis) as well as the impacts to who they are as a person during this time of transformation. As indicated in Chapter 2, autoimmune thyroid disease has numerous physical and mental symptoms, many which go unexplained due to length of time for diagnosis, misdiagnosis, and lack of understanding of the illness by the patient, their immediate family and friends, the medical community and the public. For many participants discussing these challenges during the interview was emotional, but many expressed relief at having their story heard.

Interview participants frankly discussed the physical changes such as extreme and unexplained weight gain, intense fatigue, skin infections/rashes, hair loss, and physical pain. Additionally, due to the illness and, in some cases, misdiagnosis and prolonged time to diagnose, many women experienced additional health challenges including further damage to their bodies and loss of pregnancy. One participant described some

of the physical aspects of the disease pre-diagnosis and the physical struggle she experienced while being pregnant.

A year later I got pregnant with my first daughter, the OB said I needed to gain at least 30 pounds or I would lose the baby and probably get sick myself. By the time I was 5 months along I'd gained nearly 100 pounds, my hair was falling out, I was broken out all over my face & I couldn't stay awake more than a few hours at a time. The OB said I was hypo & prescribed Synthroid...After I delivered a healthy baby girl I asked the OB about the Synthroid & he said I wouldn't need it anymore since I was no longer pregnant my thyroid would go back to functioning normally. For the next year I was depressed, scatterbrained, overwhelmed, no sex drive, weight was now in the normal range but fluctuated 10-15 pounds constantly.

Many women described fluctuations in physical symptoms. They discussed them in relation to their medication or "being off dose" and feeling a lack of control of their bodies. One woman with Grave's Disease described the intensity of her symptoms and how they made her feel.

When things are severe, I can have dozens of palpitations per hour, which freaks me out seriously, and I barely sleep. I have learned to recognize the symptoms before they get too severe. Sometimes my heart would race for extended periods of time in the middle of the night -similar to a panic attack- scaring the hell out of me. Several times I wrote a good bye note to my husband, thinking at any time, my heart was going to explode.

Due to the lack of understanding about what was happening to them or the relation of the symptoms and actions to the disease, or as one interview participant put it "the words to describe what was happening to me," many described having a difficult time explaining these symptoms to their husbands. Some also indicated that they did not communicate these symptoms to their husbands due to inability to adequately describe them or because they felt they would not be understood.

Weight gain and tiredness were also frequently mentioned as physical symptoms acquired pre-and-post diagnosis. Weight was consistently mentioned as being a never-ending struggle. Many participants that discussed this physical symptom also discussed loss of self-esteem and depression due to the change. One participant said,

The weight gain is a huge challenge, there's a whole vanity thing that is... I gained the weight very rapidly and I think that it's funny how people react to that and I'm very sensitive to people's reactions. So that's tough and it's frustrating for anybody when your dieting and exercising and doing everything you're supposed to do and nothing's happening and you know people are looking at you thinking stop eating the Big Mac's or something like that. I haven't had a Big Mac in like four years literally.

The symptom of fatigue was a frequently mentioned in the interviews as being an impediment and a frustrating change for the participants. Some of the frustration was described in terms of it being invisible and hard to describe to doctors and others. As most people experience some fatigue and tiredness, participants found articulating the difference between "thyroid tired" and general fatigue challenging. Also tiredness was described as one of the biggest deterrents to maintaining relationships, accomplishing tasks and being able to be effective at work.

Well the fatigue is definitely the biggest thing. Even if I get 9 or 10 hours of sleep, I'm so... it's not the same as exhaustion it's not the same as not getting enough sleep, it's like this dragging down feeling. It just feels like everything about me has slowed down and I can't put myself on the gas pedal to get going. And it can hit... you know I have good days and I have bad days. I have good hours and bad hours. So it could hit me in the middle of the work day and my job tends to require to kind of be on my toes a little bit and be ready to react to things and interact with people and so when I get that like horrible dragging down feeling I just can't think, I can't form sentences, I can't think beyond anything that I'm doing right there and then. It's a huge challenge in terms of doing as well as I would like to with my work.

Many described the symptom of fatigue as making them feel like people thought they were lazy or unreliable.

I couldn't muster energy or ambition to perform normal daily activities (shower, grocery shop, household chores, keep up with our businesses). I'd get stuff done, but it wore me out & I felt lazy & unreliable.

Mental symptoms of autoimmune thyroid disease varied between participants. The most prominent mental symptoms were depression, mental sluggishness (brain fog), irritability, and decreased interest or motivation. Recurrently in the interviews, women described how hard it was to describe these symptoms and the impact to their daily lives. During pre-diagnosis, women were told these symptoms were due to stress or "doing too much" and after diagnosis, many were frustrated with not being able to alleviate these symptoms. Not only were these symptoms harder to describe than the physical ones but it also impacted their ability to speak. At points in the interviews, many women stopped mid-sentence searching for the words to articulate what they were trying to say or they would stop and say "what were we talking about?" Many participants described how these symptoms, specifically lack of mental clarity, impeded communication with their husbands, specifically how it affected "finding the right words to say." Some of the participants described the experience as "re-learning communication." One participant said,

So that now that I have the disease and now that I have the brain fog and the challenges expressing these complex thoughts... I can – I have already gone through the hard part of struggling with ok "does this communicate or not" I just have to gold mine the words.

Or at least say – I have learned to say – I can't put this in words right now – give me a little while and I will get back to you.

During the interview, some described the emotional aspects of the disease in terms of loss of control and altering their sense of who they were and how they portrayed themselves to other people. Some participants described more dramatic changes to themselves, moving from outgoing to more introverted and isolated. One participant described the dramatic personality change in terms of loss of outgoing personality and participating in unhealthy behaviors to cope.

I used to be so bubbly in high school, everyone... even in my yearbook when, you know how kids sign the yearbook at the end of the year? So many people were writing stuff like, "Don't stop smiling", you know, "I'll miss your smile." Everyone just remembered me as so bubbly. Then, once this started, then the depression hit. I started drinking. So that's one thing that I attribute to the Hashimoto's is the um, yeah, the complete turnaround of my personality, the 180.

In some of the mental impact descriptions, participants described confusion from marital partners and friends specifically related symptoms of “crying all the time,” irritability, severe depression, and lack of motivation. They openly discussed their own confusion prior to diagnosis and even afterwards about “what they had” and “why they were acting” or “feeling this way” and the ignorance that these symptoms were related to an illness. In one account, a participant related interactions with her husband becoming strained as a result of her “constant crying.”

I will tell you that in the very beginning I guess when my thyroid was dying and I had no clue, it was pretty tough in the beginning because not knowing what I had and the thyroid controlling the hormones and adrenal glands and hormones and I also know that I

am one of those that with the least fluctuation of my hormones I'm off. So my husband had a very difficult time trying to understand why I cried at the drop of a hat and it didn't matter what was going on... That was hugely stressful in our relationship... you just know I'm sad, I'm not ready to slit my wrists, I'm not ready to take myself out in any way, but you just know that it didn't matter, if someone gave you a million dollars you were still going to be sad. There were just days when you couldn't deal with it and days when yes you could and you just move on and you got through it and whatever happened, happened, you're still sad. I mean I have a very, very loving husband, wonderful relationship, he is behind me 100% but the crying and the tears did take its toll quite a few times.

Due to the similarity of these symptoms with acute depression, many were prescribed antidepressants. Some participants related the frustration of explaining they were not depressed to their doctors and family.

So I went to an Endocrinologist for the tiredness, fog and without running any labs he offered me Ritalin. I refused it so he explained in his best condescending tone that I obviously did not understand depression, "It doesn't mean you sit on the bed crying. It's a chemical imbalance," and he wrote me two prescriptions for antidepressant medications. After taking those for about 2 months I threw them away, because I knew I wasn't depressed.

Another participant explained the challenges of making people understand the importance or impact of the illness and the resulting isolation.

It's trying to make other people understand and it's hard because it's not like when somebody has cancer and you can tell because they're doing chemo, they're doing radiation, you know what I mean. Whereas with this, it's like on the outside you look fine. But on the inside you know how you feel and you just don't feel yourself, you just don't want to be around anybody.

*Coping with Symptoms and Diagnosis.* Repeatedly participants articulated the numerous changes to their lives as a result of acquiring autoimmune thyroid disease.

Some of these changes were a symptom specific, like fatigue, pain, brain fog. Others

changes adopted by participants were behavioral, such as dietary restrictions and decrease in activity. Both of these changes were noted in the interviews as having impact on connections with their family and friends. For example, many participants adopted a gluten-free, dairy-free dietary change to accommodate autoimmune dietary protocols. These changes were documented in two ways. In some instances, the dietary changes were accepted by the husband or partner and jointly adopted. In other instances, the dietary changes were adopted by the participant but not adopted by the husband or partner. In the first example, the communication around diet and “what’s for dinner” became part of the communication between the couple and provided an opportunity for joint decisions and discussions related to disease management. One participant said,

He gets excited about going to the marketplace that we’ll be by ourselves because there’s all kinds of stuff that we’ve never seen. Even though he can cook, he doesn’t really, every once in a while he’ll see something and say what’s that and how do we fix it? So he tries to keep the excitement in. We’ll look up recipes and sometimes there good and sometimes... The experience of it all. Like I said, I never thought we would be sitting at a grocery store and go, “oh look we found these”, I don’t know what kind of eggplants they were but and he’s like let’s try this. He gets just as excited as I do and he doesn’t have to.

In the other cases, the dietary changes were not part of discussions around disease management and participants said they often felt disconnected or “not normal.” This was stated in the interviews as not feeling part of activities, like going out with friends or family dinners, and feeling separated from opportunities to engage in a meaningful way. One participant said,

It made me realize how important food is to who we are socially and as people and everything that's centered around that and I can no longer eat what people are eating, it's not fair for me. People don't even get that disconnect, they just say oh come and we'll make something different for you on the side or come and bring your own or whatever, that's so emotionally exhausting to me now and for sure I could be a good sport or muster it up and make it happen but Thanksgiving, is very challenging for me because the whole thing revolves around food and traditional food that I used to eat...But you know everyone expects "oh just come and bring your own turkey" or whatever and heat it up, but to eat your meal that's been reheated in the microwave alongside everyone's meal that they are partaking in together and enjoying together, it's not the same. It's not even close. It's not about eating and taking the food it's about sharing something together, being there with each other.

For some, coping meant not making the disease the core of their identity and fighting to maintain normalcy. To obtain this state, these participants described insulating their husband or partner from their disease, its impacts and daily struggles to create this sense of normalcy. As one participant stated,

I just tell myself, I just keep telling myself, "I'm not gonna let this get to me." I have the reins, I'm not gonna let this disease take me. I'm gonna keep *me*. And I wake up and as much as I'm tired, I just get up out of bed, do what I have to do and just keep it in the back of my mind that this doesn't define me. I'm gonna do everything I have to do and then I count down the hours from when I come home from work and dinner's done and everything else and I can crash. But that's what I do and as far as my memory, I just keep in the back of my mind that I got to try to remember this and if it's by writing down sticky notes than that's what I have to do to cope right now until I find the right combination of medication that makes me feel better. But I just keep telling myself, I'm not gonna let this get to me. I can't let this get to me. I'm too young to let it get to me.

Fatigue and other physical symptoms, like pain, were also mentioned frequently in interviews in relation to feeling disconnected. Recurrent in the data was mention of fatigue as being a barrier for participation in activities outside the home and related

feelings of isolation and loneliness. Frequently mentioned was also the concept of “living life on a smaller scale” or having a much “smaller life.”

I think that every day that I’m alive I’m just grateful because it could be so much worse. It totally could be worse and I have amazing things in my life so I think overall I cope ... I’ve never been into that like the self-pity or the questioning cause I just don’t, you’re not going to find the answer. Life is precious so I feel like I still enjoy my life just on a smaller scale.

Some participants indicated that limitations due to fatigue and other physical limitations impacted their ability to obtain social support outside the home. When the husband was supportive and helped the women see value in their lives, the participants seemed more accepting and able to cope with limitations. When support was absent and communication was not validating, participants mentioned they were depressed and isolated and saw their limitations and illness as a burden for their husband or partner.

There are so many times that I go to bed at night and if my child is healthy and safe and I was able to do what needs to be done for him and if I made dinner and maybe folded the laundry, I’m grateful.

In their quest to understand the disease themselves or obtain proper treatment, participants indicated frustration with their husband or partner not trying to understand or not validating their need to obtain answers. When, the husband did not read the information or participate in research, participants interpreted their response as disregard for the disease’s importance or significance. Additionally, continual failure to connect the symptoms to their disease frustrated the participant who felt they needed to constantly orientate their husband or partner to “the basics.” The husband or partner in some instances would try to “solve” the problem by providing solutions that indicated to the

participant lack of understanding of the disease and this resulted in similar frustration.

One wife stated,

Honestly I wish he could feel like I feel for about a week. His major... his big thing with me is did you exercise today and my big thing is I don't even feel like putting on shoes. So when I don't exercise, which is very often, and I'm just in one of those I feel like crap days, when was the last time you got on a treadmill? And I'll say I don't know. So if you exercise, you would probably feel better and he just doesn't get it. There is no exercise in the world that is going to make you feel like he does every day. So my biggest thing is I would like him to be in my body for about a week.

In some discussions, conflict between partners resulted from lack of understanding and blaming. When the husband or partner became frustrated with the participants symptoms or became overwhelmed by responsibilities, participants relayed ensuing conversations with combative or unconstructive tones. In turn, the participant would exhibit avoidance behaviors or equally combative or unconstructive tones.

Recurrent within the data was the stress of maintaining intimacy despite symptoms and its impact on relationship with husband or partner. Sex with husband or partner was indicated as an issue in some cases due to symptoms of low sex drive. Communication related to the impact of sex and intimacy on their marital satisfaction was captured as minimal in some cases, others a challenging obstacle to communication, and in yet others it was a means of "reinventing" their relationship within this context and developing understanding. One account described sex in their relationship as means of gratitude for support.

I don't pretend to have the answers but I do know that even though I have little to no desire for it, he still does. It's a give and take, when I see him being supportive for my weakness; I try and use

that in my mind to do things I don't want to do (like having sex). Sometimes it's just a matter of staying still long enough & counting the good things he does for me that I enjoy. I find that if I can be open to that for him, he's more open to things I need from him. Like I said it's not a cure all but it's something that we do that improves communication and helps us cope.

Many stressed intimacy as a strong need within their relationship to make them feel supported and understood as well as relieve stress. Intimacy in these instances was defined by closeness and affection versus sex specifically. Participants who indicated satisfaction with their relationships indicated this type of intimacy provided opportunities for more open communication and opportunities for honesty about how they were feeling. One participant stated,

He has learned to be a very excellent listener. And I have learned to say I don't need you to fix this right now I just need you to listen. Um, a lot of it is just him listening and being there with me and accepting me. And of course – hugs and cuddles. Um, hugs are very, very, very important. Mostly it's the listening, accepting and then the physical comfort of hugs and stuff like that.

Other observations within the data indicate recurrence of intimacy as a means to change the tone of their communication allowing for more humor about symptoms and positive support and less frustration and confrontation.

After diagnosis, many participants said they still had challenges being open about the illness symptoms and its impacts to their lives with their husband or partner either because of the guilt associated with burdening them or because they didn't feel their husband or partner would appreciate or understand the symptoms. Many relayed throughout the interviews lack of understanding and validation by their medical provider and they felt additional efforts to prove their actions and symptoms were related to illness

would be met with deaf ears by their husband or partner. Interview participants that did communicate openly with their husband or partner described feeling more supported and able to navigate their illness better.

My husband is really a very positive optimistic person so any time I go for blood or any time I'm scared they're going to find something else, I'm feeling really optimistic and feeling very supported so that's good. When I need him, like in the past, I have nodules so I needed biopsy and stuff like that; he's always there with me. You know when I just go for my regular appointments, I don't need him, but he calls as soon as the appointments to check in and he wants to hear everything. He's a great listener and like I said very supportive...it's definitely hard for him to hear me constantly say I'm tired...I came home from work and I was just sitting on this chair cause I was so tired, I couldn't even get up to hug him. And then I think to myself this man works 12 hours, comes home, and looks at his wife like it's so pathetic so I feel bad for him and I feel bad for me but I just don't have energy to get outside of myself... But I mean overall my husband if I need to talk about how I'm feeling or different options, he's there, he's supportive. He's very caring.

In some of the interviews, the topic of tangible and material support was recurring as it related to the additional responsibilities participants felt their husbands were experiencing due to their illness. These responsibilities related mostly to being the primary financial provider (in some cases only provider) and “picking up the slack” in the home due to impacts of the disease on their partner. Many felt communicating the need for emotional support was “asking too much” as they were already receiving so much support and communicated in their interview that they had tremendous guilt associated with the added responsibility on their husband.

I kind of have always relied upon my husband to sort of be the everything for me so I think most women have really good girlfriends or at least in my fantasies they do, I don't know. I was

one of these people that used to be really into Sex and the City and I would be so jealous of these women who just can share everything with these other women cause I just don't have that. For whatever reason, I've never had that. Forget about having three. But I do think it's really important to have other people in your life besides just your husband because I think it's, not a burden, but it's hard for one person to be the only person that you look to for support.

Lack of marital satisfaction was noted in a few interviews where support was absent.

These participants indicated a sense of overwhelming responsibility of household and family, in addition to the management of their illness, and did not address these concerns with their husbands consistently. These participants also indicated in their interviews that coping with their symptoms was a consistent problem and they often felt they were not successful in meeting their own health needs. As one participant recounted,

It's like I have to constantly remind him of how things are but then also you should see how much laundry I have right now and it's been sitting there. It's not just a day, it's been like two weeks and it's just like the dirty clothes get clean and they get put back in the pile to be folded that's never going to get folded and I've asked him to sit down and help me do it cause I physically can't carry all of it upstairs to do it and there's no way. I just wish that... its really effected things when he gets frustrated about the fact that things aren't getting done in the house and that I'm so tired and I don't know, he's tired of hearing the complaints and not having more things done in the house.

Fatigue was the most recurring symptom mentioned in interviews in relation to coping and impact to marital satisfaction. Many interview participants reported extreme daily fatigue that often made it impossible for them to get out of bed in the morning, let alone participate in quality time with their husband. For some the unwillingness to participate was related to the fear of making their condition worse. In these instances, participants recounted times where they did participate in activities, only to pay for that participation

through increased symptoms, specifically crippling pain and fatigue. Communication about the fear of not participating did not always occur which resulted in feeling of rejection for the husband or partner and guilt for the participant. In other recounts, unwillingness to participate was a constant battleground for their relationship and communication concerning activities was combative and defensive.

Like he'll want to do stuff, like he'll want to go out or something.  
And I'll be like I just don't feel like it...I just want to sit here all day and watch TV, but you can go out. That's like our conversation. He says I get the "I don't care" attitude.

Another area of frustration for participants within this topic was the need to prove they were actually sick and that their disease management was more complicated than just taking a pill. The participants said in their interviews that they often felt like their husbands or partners thought they were crazy, exaggerating their symptoms or were constant complainers. By not validating their symptoms, many participants felt less empowered to talk about their illness or seek support from their husband or partner or indicated asking for support would be interpreted as being confrontational or complaining.

I tend to lash out and my husband, I don't feel like I expect too much but whenever he gets home I would like to be able to go upstairs and take a shower and have a quiet moment but he isn't known for being overly sensitive or intuitive and so we kind of clash because I'm hypersensitive and he doesn't necessarily know how to address that. And he'll say things like, like if I say that I'm feeling bad, he's like well you always feel bad or your always sick or you know, why don't you get up and do something or whatever it is, he may say something about how the house is messy but if I... it takes every bit of energy I have just to take care of a 15 month old.

Many participants indicated that they did not expect their husband or partner to completely understand their symptoms. However, noticing their symptoms, recognizing they had a disease and being compassionate regarding their daily struggle allowed for more positive interactions.

Some days were a lot harder than others. I do have a really great husband who has really made it easy. He supports me cause when I was having days when I felt like I couldn't get through a day, he was there to help calm me down. He would step in, so I know have it probably little bit better than a lot of other woman especially ones that I've talked to that don't have the support. But like I said there were just days I didn't even want to open my mouth, I would feel like a zombie and just give up and sit down and I couldn't even do that.

Other participants noted a less dramatic identity change or a change they hid from other people to maintain a sense of “normal” to people in their lives. In these cases, their communication about their illness to their husband about their symptoms was limited or nonexistent. Some discussed their symptoms to their husband, partner or others in the context of other things like the impact of their work schedule or being overly busy in an effort to not connect their symptoms to their illness and not appear as a “complainer” or use their illness as an excuse.

*Health Obstacles.* Providers or doctors were often mentioned in the interviews as “inadequate,” “unknowledgeable,” and “uncaring.” One participant described an instance similar to others throughout the interviews of going to the doctor and being frustrated with the doctor's myopic view of thyroid tests and not listening to the participant's symptoms.

I tend to get along fairly well with most people especially on a professional level and the only time I had a problem was with my

endocrinologist...she was very like combative, I think she just, I don't want to say she didn't care but I think maybe she was frustrated or I think it took her by surprise, my diagnosis. And then when I didn't respond to the treatment and I just told her I thought she was being very adversarial instead of caring about me because she didn't say it could take time, give it a chance, she was just "Nope your fine. Your blood is fine and your fine."

Many participants also commented on the poor, disrespectful and hostile tone of their providers. Many described this as being an impediment to receiving proper care. One woman who had thyroid cancer talked about the poor treatment from her doctor when she was diagnosed.

You know a lot of that too is also the medical professions need to be better educated with how to deal with that because one thing that was so frustrating for me and I mean this is with people that have thyroid cancer that this happens a lot that people will say oh well you got the good cancer and all this crap. I hear that too much, that it's the good cancer, but it wasn't good. You know I had to have major surgery and the RAI that put me at 30% chance for developing cancer later and I'm not even 30.

Poor provider experience often created feelings being misunderstood and invalidated. Because of these characteristics, many participants expressed constantly changing providers to find one that would provide adequate care and respect that "they know their bodies best." This frequent change of doctor often delayed getting proper treatment.

Although the frustration was rooted in poor provider communication, effects carried over to husband and partner communication. Participants that separated their husbands or partners from their interactions with their providers often described feeling misunderstood and unsupported by their husband or partner specifically in relation to their symptoms. When the husband or partner did not communicate understanding or connect their symptoms to their disease, according to the participants, they were

reflecting the poor provider communication experienced by the participant. As one participant articulated, “Wow, you don’t get it either.”

Some interview participants indicated their preference for separation of husband or partner from their provider experience. These same interview participants also indicated less significant changes in their identity due to illness and were more empowered to manage their illness on their own. Additionally, these participants recounted less significant setbacks due to symptoms and preferred to not identify with their disease or communicate its impacts to others. This approach to involvement of husband or partner in disease management did not extend broadly within this group. More recurrent within the data were participants who either had significant involvement of their husband or partner in the management of their disease or had limited involvement of their husband or partner but desired an increase in this support.

Many of the participants recounted being treated for the condition of hypothyroidism and not being tested for autoimmune thyroid disease by their provider. The physical symptoms were often discounted as allergies, menopausal or “what happens to you when you get older.” Following diagnosis, recurrent in the interviews were accounts of not understanding the connection between their disease and their physical symptoms. They described physical symptoms that were “so hard to describe” and “debilitating.” One woman described the pain she experienced and the chronic infection due to the impact of her immune system, not realizing it was connected to her Hashimoto’s Disease at the time.

Everything was just so difficult and the pain that I started to get was just like almost indescribable, just ramped and weird and kind

of rolled around my body and going up the stairs and just doing anything was a problem. I couldn't sit at a computer, I lost my job... I still didn't make the connection from everything she was treating me for and Hashimoto's, it was like I had so many symptoms and downstream problems from Hashimoto's and it wasn't even recognizable anymore... And so I was fighting off all kinds of viruses and parasites and I was living with some, it was kind of like we were co-existing but they were starting to get the better of me.

Many participants conveyed an arduous journey to getting a correct diagnosis and obtaining optimal treatment and medication dosage. Additionally, many discussed adoption of significant diet and lifestyle changes to combat symptoms and achieve wellness. They noted they were engaged in constant search of that "one thing" that would make them feel better, conducting hours of research on the internet or scouring social media sites for what worked for other autoimmune thyroid disease sufferers. Many conveyed this journey was often traveled alone without participation or communication with their husband or partner. These participants expressed that the journey was theirs alone and they felt it necessary to take on the burden of getting well themselves. Others felt that since many of their approaches to wellness were not mainstream, their partner would not accept their approach, obstruct their ability to make the changes or not participate in the changes they felt they needed to become well.

#### **Research Question 4**

*Open Communication.* Open communication was a critical element to maintaining a satisfying connection with husband or partner recurrent in the interviews. As the condition and symptoms for many interviewed were constantly changing, needs of the participant were also fluctuating. As one woman said, "I have good days and I have bad

days with no inclining of when.” Effective open communication was discussed in terms of providing opportunities to talk about their symptoms and sharing information. One participant said,

He’ll be like how was your day? And all that. And I’ll be like oh I had one of those days, you know, my joints hurt. Or I feel like I’m choking and I’ll tell him and he’ll be like well are you alright? ... If I’m really tired, he’ll be like do you want me to just leave you alone and give you some time and I’m like if you could that’d be great.

For others, recalibrating expectations through open communication about activities that would allow time together but not impact the participants health resulted in more satisfying outcomes for both participant and husband or partner. In these instances, conversations occurred around what was acceptable for both parties but would not impact her health and emphasized mutual acknowledgment of what they value as a couple.

My husband and I have had to really pair down and really focus on what matters, you know, what our values are...So we find the things that we value, our families and loving our kids and loving each other and having a few core friends that we can be mutually encouraged by and that we want to live healthfully and I could make all the healthful choices in the world but it seems to be the case that it doesn’t really get me to where I want to be but I feel like it’s still better for my family and I think we’ve learned that being all American and running out and doing everything everyone else is doing and having fun and taking advantage of all these opportunities and network, doing social networking and just being out there. It’s not the life that we value, we value quietness and rest and peace and enjoying the things that God gives us.

The recognition of the husband or partner of symptoms and the need for the participant to not engage in activities was also present in the interviews. In these recounts, the participant would frankly communicate their symptoms or the “why” behind their

reluctance to participate in activities, and the husband or partner would respond with understanding and adjust their communication to accommodate the participant.

*Shared Knowledge, Understanding and Agreement.* Although many participants indicated they did not expect their husbands or partners to completely understand the symptoms, there was an expectation that the husband or partner would be actively engaged in trying to understand the disease. Because many participants were constantly researching the disease to gain greater understanding of their symptoms and potential treatment, they often shared articles with their husbands or partners. Participants expressed it was important for the partner to understand the “basics” of the disease and be able to put their symptoms in perspective.

My kids & husband are working hard to be understanding & I think it helps that we know why mommy gets so cranky and tired in the evenings so we try & plan for it. Like getting homework done earlier, asking them to pitch in more with cooking, cleaning, chores, etc.

Participants often interpreted lack of agreement and understanding of their disease as not believing they were sick or not thinking their disease was serious. One woman recounted of sharing information with her husband and not getting a serious response.

I was doing a lot of research on it and as I would find information I would share a little bit of that with him but he wasn't, again, real interested in it. As long as he knew it wasn't something serious then it was like okay you can deal with it... it doesn't have cancer attached to it or anything life threatening so he just really doesn't think it's serious.

Many mentioned the article from Mary Shomon, “An Open Letter to the Family and Friends of Thyroid Patients,” as key to assisting the husband or partner in understanding the disease and developing a common language to talk about the disease. One woman

described a constant battle with her husband to get him to understand the connection between her symptoms and her disease and the relief when he finally “got it” after reading this letter.

He was pretty impressed to learn that what he saw happening to me (the muscle spasms, insomnia, bleeding, mood swings, constipation, constant allergies, PMS/exhaustion, among many other visible symptoms) could be explained by something we were already aware of. (We knew I was hypothyroid but didn't know I wasn't getting optimal treatment for it) Seeing him understand & accept what we were reading gave me confidence to open up emotionally somewhat.

*Communicating with Affirming and Encouraging Tone.* The interview participants that indicated the presence of tangible and emotional support in their relationship described their communication as open and affirming. These participants described this connection as helping support them through actions as well as encouraging words and indicated a greater ability to cope with their illness.

I'm very lucky. Even though we've had the struggles that we've had, it's made us so closer. We often laugh about... we've had friends who were married before us, after us, and a lot of friends are no longer together and there not necessary having to deal with stuff that we've had to deal with between job losses and Hashimoto's and miscarriages and he's always like well it's just going to be me and you no matter what. I really, I count my blessings every day that I have him. And he's like baby or no baby, we're always going to be me and you and it breaks my heart to hear.

Husbands that were not supportive of symptoms and complained about participants being “always tired” or “always sick,” were viewed as unsupportive. Frequently in the interviews, participants mentioned this as a reason not to communicate with their husbands, saying “he will just get frustrated” or “he just doesn't understand.” Sometimes support was also mentioned as a negative to participants. This type of support was

recounted as not being sensitive to the needs of the participant or showing a lack of knowledge of their disease. Many participants recounted these instances of rejected support as starting a cycle of conflict. One woman described her experience with her husband having made her dinner and not timing it correctly with her morning pill.

He makes breakfast which is a nice gesture but then I'm like you know I just took my pill I can't eat right this second. And he's like well I'll just let it get cold then. And he gets frustrated about that because he tried to do a nice gesture but he forgets that I have to be mindful of that.

### **Research Question 5**

Research Question 5 (RQ4) focused on relational communication strategies employed by participants with autoimmune thyroid disease to manage illness-related identity transformation within their marriage or serious relationship. The majority of discussion within this area focused on the themes of *validating changes to identity*, *attentiveness to symptoms*, and *creating opportunities for support* as being the most effective relational communication strategies.

*Validating Changes to Identity.* Participants that heavily involved their partners in the management of their illness and included them in provider interactions expressed satisfaction with their husband or partner's understanding and willingness to provide support. Demystifying the treatment and discussion of symptoms with their provider allowed more open and honest dialogue around treatment and expectations between couples. Participants that partnered with their husband in the management of their disease also reported feeling less isolated and weary due to poor provider experience or the overwhelming nature of their illness. As one participant said, she had someone "on

her side of the ring.” Additionally, as “brain fog” was a recurrent noted symptom of interview participants, management also included participation in note taking during provider visits. Not only did this type of active participation help with coping, some participants indicated they used these notes to engage in further discussions with their husband or partner following provider visits.

He goes to every single doctor’s visit with me, he is thoroughly involved. And he even goes to the OBGYN with me in the room, like literally, he’s not there in front, he doesn’t get the play by play but he does go with me. He even takes notes for me and a lot of times even asking the doctors questions if there’s something that maybe I had talked to him previously about but yeah he takes notes, he gets as much information, he listens to me go on about everything.

Another recurring point in the interviews regarding validation was concerning autoimmune thyroid disease being a silent illness and not widely recognized or understood by providers and the public in general. Many participants felt these misconceptions were harming their ability to get well because their symptoms were not being taken seriously by their providers or others in their lives. In terms of husband or partner, participants indicated education of their husband or partner to disease symptoms was a constant area of frustration.

*Communicating Attentiveness to Symptoms.* Many participants expressed impatience with making their husband or partner aware of the depth of their symptoms and the serious impact on feeling well. One participant said,

I think being clear about what you’re feeling and not approach it like you are a victim but to approach it like you have this issue and yeah it sucks so much sometimes but the only thing you can do is try to find a way to control it and you need to be able to know how to ask for help with that. And that’s something I struggle with. I

always, I sometimes feel like he should just know that I'm feeling bad that I'm having a bad day or my joints hurt or I gained five pounds for no reason. And he doesn't know that stuff. It's not intuitive to him and you need to talk about it very openly. But not in a way where it's like oh my god I'm so tired all the time, more in a way of I need you to be aware that I'm tired and I need you to be sensitive of the fact that I might be moving a little slower today. And then to ask for help with that. Like I can't cook dinner tonight I need to take a nap. It's hard because it really depends how open the other person is to taking out a little bit extra but I think a major thing is just being grateful for what they're doing. If they let you take that nap, that's so wonderful, that's so generous of them and letting them know that you know how generous that is very important.

The majority of these comments related to the need to communicate effectively how thyroid symptoms made participants feel and translating the difference, for example, of being tired versus chronic fatigue, associated with autoimmune thyroid disease.

Participants commented that they felt much of the challenge associated with translating these symptoms was related to autoimmune thyroid disease being a silent illness. One participant commented that her romantic partner finally realized the severity of her symptoms and the impact on her being well when she became "off dose" (dosage was not optimal) and began exhibiting more visible symptoms (e.g. hair loss, extreme moodiness). Another participant said,

I don't think he quite... sometimes I can get frustrated with him cause I don't think he quite understands how much I'm feeling what I'm feeling. It's not just fatigue, it's extreme fatigue. It's not just joint pain; it's not being able to bend my fingers. And I think because I try to cope and I try to continue living a life that I think I would try to live if I didn't have this diagnosis, I think he assumes that it's not that bad. That what I'm feeling isn't as extreme as what it really is to me.

Some participants indicated developing the "habit of communication" was helpful because it provided opportunities to talk about their disease but did not make it the only

topic of discussion. Additionally, when the husband or partner brought attention to how they were feeling first in a positive, compassionate manner, the participants indicated feeling less guilty and less like they were complaining.

Communication approaches that were most effective for embracing these identity changes were validation and affirming tone. Husbands or partners, who adopted or accepted these changes in a positive way, were mentioned as more supportive and more engaged in overall disease management. Husbands or partners that did not validate these changes or referred to these changes in a negative manner were mentioned as unsupportive or obstructive in overall disease management.

*Creating Opportunities for Support.* Participants that were receiving social support from their husband or partner articulated in their interview that they would not feel comfortable asking for more support and felt tremendously guilty about requesting additional help. Much of the support provided to participants by their husband or partner was tangible support. Emotional support was only indicated in some of the interview transcripts. Others indicated “it would be nice” but would not request the support.

He steps in with our daughters; he takes care of them... He used to clean the house, do the laundry, and cook when I used to eat more food. He'll go to the grocery store if I can get a list together for him. We now have somebody that comes to the house 2 hours a week and she cleans things that I ask her to clean. He was supportive of hiring somebody to do that, despite our limited income. Again it's just his support and understanding and saying yep that's too much for you, if you need it do it. So I'm kind of the lucky one.

Many women described not being willing to ask for support, but hoped their husband would reach out and inquire about their needs. Many often felt frustrated because their

husband or partner did not “see” what they needed. Some took a more proactive approach in their communication and used daily inquiry as a means of providing opportunities to provide support and greater understanding of each other and their illness.

Ya know, our marriage relationships are the ones where we both show our worst and our best and it is also the one where we make the most assumptions because we assume that person is going to be there for us no matter what but we also assume that we understand them – that we know what they are thinking and what their motivations are when we can’t know that all the time. So asking those questions you know – one of the things that has really helped us is to not just ask “how was your day?” but to ask more personal, more intimate questions – like “what did you do today that you are proud of?” or “what happened today that made you sad?” or that affected your anxiety or your depression? Just getting involved in each other’s lives makes a huge difference.

Chapter Five will interpret the preceding quantitative and qualitative results. Salient limitations and directions for future research will also be discussed.

## CHAPTER FIVE: DISCUSSION

This final section provides an in-depth discussion of results for research questions one through five (RQ1, RQ2, RQ3, RQ4, RQ5), addresses relevant limitations, poses key directions for future research and provides practical implications for improving the lives of women with autoimmune thyroid disease. The first phase of this research explored the influence of communication competence on perceived social support and quality of life for autoimmune thyroid disease patients. The second phase studied applied communication strategies during times of identity transformation within the marital context that influence social support and quality of life for these patients. Both phases will be explicated within the context of providing additional support for Kreps' Relational Communication Competence Model (1988). Discussion will also highlight how this research expands understanding of illness-identity and social support research and health communication as a field of study in addition to providing practical approaches to change.

### **Research Question 1: Relational Communication Competence**

The first phase of this study sought to examine the impact of relational communication competence on social support and quality of life perception for autoimmune thyroid disease patients. As indicated in the results section, low communication competence did have significant statistical impact on social support and

quality life perception for these survey participants. Statistically significant mean group difference occurred between low and average and low and high competency levels. The average communication competency group showed no mean group significance with high communication competency. To explore this further, a one-way ANOVA between communication competence and size of social network was run. This test revealed no statistically significant mean group difference between high and average communication competence,  $p > .702$ . Therefore, no alternative explanation was provided for lack of significance for the mean group difference between high and average communication competence and social support satisfaction and quality of life perception. These results supported outcomes from previous studies researching social support, communication competence and stress with cancer patients (Query & Wright, 2003), as well as studies showing positive correlation between social support, communication competence, and cognitive depression (Query & Kreps, 1996). Results from this study also expanded these findings by looking at health outcomes more broadly to include quality of life. According to Kreps', O'Hair, and Clowers (1995),

Spouses can play important roles during communication exchanges that lead to productive health outcomes...the time has come to advance research that illuminates the important relationship between [marital] communication and health outcomes (p.250).

### **Research Question 2: Marital/Partner Support Provided**

Results indicated that for autoimmune thyroid disease participants that received support from their husband there was no difference in frequency between types of support provided (tangible, emotional, affectionate). Additionally, there was no difference in level of satisfaction within each type of support. To explore this further, a

one-way ANOVA was run to look at overall husband support in relation to overall level of perceived social support. The results indicate statistically significant mean group differences when the husband provided support for overall social support satisfaction. The mean group differences for dissatisfaction and moderate dissatisfaction was significant at  $p \leq .05$ . Additionally, the mean group differences between dissatisfaction with overall social support satisfaction was significant for both at  $p < .05$ . This indicates that although the type of support may not be significant, having husband support overall is an important element of overall social support satisfaction for autoimmune thyroid disease patients.

Previous studies have indicated that tangible support is the primary social support provided by men (Burleson, 2003). Although this gap in support is widely reported in research (Cutrona, 1990), the results of this survey indicate that tangible support although slightly different from the other types of support was not primary. This could indicate a gender generalization across the literature or it could potentially require further inquiry into social support provided within a marriage when the social network is limited as is the case for autoimmune thyroid disease patients.

### **Research Questions 3: Challenges of Autoimmune Thyroid Disease**

Research Question 3 (RQ3) investigated the specific challenges of autoimmune thyroid disease on intimate relationships, like marriage. As indicated in the research, many of the participants recalled significant physical and mental challenges that required daily vigilance in order to achieve some semblance of wellness. The chronic nature of the disease impacted many of the participants' ability to venture outside the home, or

participate in activities outside the home. For this reason, the impact to family was significant and the critical need for marital support was elevated. Marriage is purported to bolster coping abilities, either because there is someone there to provide coping assistance or because it enhances one's own coping capacity (Burman & Margolin, 1992). Therefore the support provided within the home for women with autoimmune thyroid disease is crucial to enable effective coping as well as overcome many of the health obstacles associated with living with the disease.

Since many of the symptoms of the disease manifested in “invisible” ways (such as severe fatigue, confusion and irritability), many participants experienced insufficient support from marital partners because the symptoms were not seen or verifiable. Additionally, because providers did not validate the symptoms or extend treatment beyond the condition, many participants felt isolated and discouraged. Grunbach indicates that although invisible chronic illnesses are largely not recognized invisible “chronic conditions, not acute ailments, are now the most common problems in healthcare” (p. 4). The inability for the participants to achieve positive health outcomes in many ways was related to the absence of social support within their home and with their provider, as well as constant struggle to cope with symptoms and on-going, inadequate diagnostic measures.

#### **Research Questions 4 and 5: Communication Strategies**

Research Question 4 (RQ4) and 5 (RQ5) explored relational communication strategies employed by couples when the wife or partner has autoimmune thyroid disease. RQ4 investigated communication strategies specific for maintaining a satisfying

relationship. RQ5 looked at communication strategies exercised for management of illness-related identity changes. As indicated in the results section, communication strategies that were most effective for maintaining a satisfying relationship for autoimmune thyroid disease patients included open communication about their illness, shared understanding of the disease and agreement on the impact of its symptoms, and affirming and encouraging tone used in their communication. Communication strategies most effective for illness-related identity changes included validating changes to identity, attentiveness to symptoms, and creating opportunities for support as being the most effective strategies.

### **Open Communication about Illness**

Open communication was most frequently mentioned as a key factor in the satisfaction of relationships for autoimmune patients between husbands or partners. For those that were successful, they were already using communication as a means of support and encouragement as a foundation for their relationship. Many had gone to marriage counseling to fine tune their communication skills in general. Therefore, a safe environment in which to discuss thoughts and feelings relative to their disease was already present. Since many participants were still learning how to talk about their disease, including articulating their symptoms, discussing diagnosis and on-going management, having this foundation of communication was critical. This is supported in previous research on “trusted self-disclosure” which indicated this type of communication served as buffer to psychological ill health as well as contributor to wellbeing (Yelsma, 1995).

Open communication also becomes a critical element in adapting to the illness and coping. As the condition and symptoms for many interviewed were constantly changing, needs of the participant were also fluctuating. As one woman said, “I have good days and I have bad days with no inclining of when.” Effective open communication allows for flexibility and perspective sharing enabling ongoing changes to be more successfully navigated within the relationship.

To understand openness as an important strategy for successful relationships, it is important to understand the role of openness for these relationships. Openness provided an opportunity to clarify what was valuable to the couple and negotiate needs within the context of the disease. It also provided a means to discuss the present state of the relationship and what impacts if any were being felt by either participant. Affectionate support was frequently mentioned within the context of openness as a means of providing encouragement and levity.

Many of the women mentioned a decrease in activity due to fatigue and pain. These symptoms often impacted what activities were shared by the couple. Many used openness as a means of negotiating appropriate activities that they both could share and re-evaluating what they valued as a couple.

Openness also included the depth of the information provided about their disease. Some participants were very open about general information (medical test results, types of medication, etc.) but were less open about details related to their specific symptoms. Lack of sex drive was often omitted from open communication. Some participants indicated that it was not discussed because they felt it could not be resolved by

medication. Some participants were satisfied with only providing high-level information about their disease and management and said it did not impact the support they received from their husbands or partner. In these cases, participants indicated they were able to better manage their symptoms by themselves. Some were open only to the degree that it would not increase the stress level of the husband or partner. The husband or partner that had household and financial responsibilities fell into this category for the participants. Participants described not wanting to add to their current responsibility level saying “he already does so much.” Ultimately, not being open about symptoms and disease management resulted in lack of understanding or awareness of the participant’s current condition and how to provide support. Studies indicate that knowledge of the marital partner’s experience allowed the husband to provide support that was more sensitive to the partner’s needs (Burlison, 2003). In turn, this support contributed to greater feelings of closeness and security (2003).

Also, as each participant was actively navigating their disease, level of openness also depended on trust. Some indicated they were depressed and anxious due to the disease and this impacted their ability to trust they would communicate effectively to their husband or partner. Trust also extended to their trust the husband or partner would be gracious in their response to their communication if it was not adequate. Wynne and Wynne describe this as a component of intimacy between married couples and as essential for the regaining of independence and control while they are navigating and restructuring their lives after illness (Wynne & Wynne, 1986). Trust is one of the most important dimensions of marital adjustment (Cutrona, 1990).

### **Shared Understanding and Agreement**

Closely coupled with open communication was the couples' shared understanding and agreement of the disease and the impact of symptoms. Although many participants indicated they did not expect their husbands or partners to completely understand the symptoms, there was an expectation that the husband or partner would be actively engaged in trying to understand the disease. This shared understanding was an important aspect of communication between couples. Many mentioned the article from Mary Shomon, "An Open Letter to the Family and Friends of Thyroid Patients," as key to assisting the husband or partner in understanding the disease and developing a common language to talk about the disease (Shomon, 2011). Some tactics employed by participants to increase understanding included sharing articles, discussing doctor visits and having the husband or partner attend doctor appointments. However, if the participant felt that understanding about the disease was not important to the husband or partner, they said they were frustrated and that he just doesn't "get it." The husband or partners' unwillingness to invest time to understand also impacted the degree of openness in communication and ultimately satisfaction with the relationship.

Participants often interpreted lack of agreement and understanding of their disease as not believing they were actually sick. In terms of illness identity theory, not validating they were sick was denying "who they were" in relation to their illness and physical and mental symptoms. This restriction of self, including the ability to be open about their symptoms and disease, can be tied to depression (Jung, 2013). Some participants did suggest they were depressed due to this lack of validation of their

identity. A small segment of this group was being treated for depression in addition to their disease.

Many symptoms of autoimmune thyroid disease are silent and not necessarily apparent to others. However, these symptoms can be quite severe. Agreement between couples as to associated symptoms and their impact is an important aspect of validation of the disease for the participant. Within the interviews, participants discussed the importance of agreement from their husband that symptoms, like fatigue and pain, were associated with the disease and “not in their head.” Not validating the presence of the participant’s symptoms often indicated poor support in the home (Goldsmith, Bute, & Lindholm, 2012). Additionally, participants often suggested they were frustrated and depressed and felt “alone” in managing their disease. A basic requirement for social support is accurate awareness of the other person’s challenges.

### **Communicating with Affirming/Encouraging Tone**

For some of the participants, the tone of communication was very important to their overall satisfaction. Husbands or partners that were encouraging and loving in their communication were seen as supportive regardless of their level of understanding of the disease. Many of the examples of this type communication were tied to emotional support, like assurance, humor, and affection. Some participants indicated when this type of communication was present they felt less isolated and depressed. When negative tones were used in statements like “you are always tired,” participants indicated they were less likely to be open about their symptoms because they felt like they were complaining or acting like a victim. Participants indicated when husbands or partners

communicated positively about helping, provided reassurance, and encouraged open communication about their feelings, they felt overall more satisfied with their relationship. In a study of women with postpartum depression, reassuring and encouraging communication between women and their families was essential for effective social support (Dearmen, 2011).

### **Validating Changes to Identity**

In many ways, participants described the diagnosis of autoimmune thyroid disease as life changing. There were numerous accounts within the interview transcripts of changes to their mental and physical self, self-concept, self-esteem and even the way they engaged with other people. They enacted this identity in numerous ways. Some became more isolated and removed from the relationships in their lives. Some became thirsty for information to try to find answers. Each mentioned the difficult road towards diagnosis and proper treatment that was in many ways more difficult than living with disease itself. Participants talked about how they looked healthy, but how they felt was quite a different story. Many discussed how they were not taken seriously by their doctors, friends, family and even their husbands or partners. Many of the women began having symptoms in their childbearing years and often these symptoms were dismissed as “part of getting older.” Even after they received the relief of finally understanding the “what,” participants still struggled with symptoms that seemed to come and go with no real answers. Validation of their illness was a constant struggle according to interview transcripts. Some of this struggle created on-going tension in their relationships. These struggles were realized in their communication with their spouse or partner. According

to research, these struggles were points of negotiation in the relationship in sharing a health transition (Fisher & Miller-Day, 2006). Communication is critical element in resolving transition struggles and learning how to adjust to new identities (Jung, 2013).

Due to their “self-imposed” isolation, many participants counted on their husbands more than ever to validate their new identity. This intimate relationship becomes a key social support resource to help ease participants into their new identity and, ultimately to wellbeing and health (Waltz, Badura, & Pfaff, 1988). Relational communication competency has a tremendous influence on the construction, maintenance, and modification of identity. Since identity affects how messages are produced and interpreted and motivates planned and enacted communication, identity also influences social support (Goffman, 1963; Hecht, Warren, Jung, & Krieger, 2005).

### **Creating Opportunities for Support**

Participants that were receiving social support from their husband or partner articulated in their interview that they would not feel comfortable asking for more support and felt tremendously guilty about requesting additional help. Much of the support provided to participants by their husband or partner was tangible support. Emotional support was only indicated in some of the interview transcripts. Others indicated “it would be nice” but would not request the support. This finding was slightly different from the survey data but supports other social support research findings (Cutrona, 1990).

The strategy for creating opportunities for support is connected to open communication and awareness of disease and symptoms. The more the couple

communicated about the disease and symptoms, the more likely the husband or partner seemed to pick on what support was needed – whether it was got to doctor’s appointments or just clean up the dishes after dinner. Husbands or partners that did not actively look for opportunities to provide support, often were described as being less interested in the disease overall or the symptoms the participants were experiencing.

### **Implications for RHCCM and Future Research**

Kreps’ Relational Health Communication Competence Model (RHCCM)

describes a process by which communication competence influences health outcomes.

Many studies have applied the model to investigate relational communication competence and social support (Query & James, 1989; Query & Kreps 1996; Query & Wright, 2003), as well as examining associations of relational communication competence with specific health outcomes (Query & Kreps, 1996; Query & Wright, 2003). This research supported these findings that insufficient communication competence, according to this model, impacts successful health outcomes. The parameters for this research refined the model by looking at health status concepts related to quality of life, specifically physical, social, and role functioning; psychological distress and well-being; general health perceptions; energy and fatigue; sleep; and pain. By applying a broader assessment of health outcomes in which to view the model, the research illustrated the practical application of the model to monitor health outcomes and criticality of communication competence as a determinant of well-being.

The model also posits that the more complex the communication context, the more communication competence is required for optimal health outcomes (Kreps, 1988).

Application of the model within the context of autoimmune thyroid disease supported the significant influence of relational communication competence on social support for a complex, transformative disease. As the participants indicated in the interviews, the physical and mental changes associated with their disease increased the need for more competent communication to achieve wellness and to cope with their illness.

Additionally, application of the model to autoimmune thyroid disease patients demonstrated the critical need for relational communication competence for patients with this complex “silent” illness, and its impact on quality social support within the home. Recommended extensions of this research could also include capturing relational interaction at different points in time to provide a more accurate picture of the interaction within marriage and influence of communication competency on health outcomes.

Much research has been conducted on illness identity and how it is enacted through communication (Hecht, Warren, Jung, & Krieger, 2005; Jung & Hecht, 2004). Based on the findings of this research, an extension of RHCCM would be the implications of relational communication competence on illness identity and the impact to recovery and wellness. During periods of change and adaptation to illness, patients experience a reorganization and reintegration of identities, roles, relationships and behaviors which may significantly alter one’s identity, how one defines oneself or one’s relationships (Jung, 2013). Identities are shaped through communication and therefore, communication competence becomes relevant to the enactment of identity. How participants characterized their identity was influenced by their experiences and interactions with their husband or partner. Many of the participants expressed

hopelessness and low self-esteem due to their disease. These manifestations are part of coping and impact the positive or negative development of illness identity (Hecht, Warren, Jung, & Krieger, 2005). As many of the discussions with participants were reflective of their experiences and occurred in one-hour interviews, many of the nuances of identity transformations were not able to be captured. Future research should try to capture daily interactions to enable pattern development and provide greater granularity to the understanding of illness identity within this frame.

This research also provided value to the field of health communication in general by shining a light on autoimmune diseases within the framework of communication competency and illness identity. Critical obstacles remain in the diagnosis and treatment of autoimmune diseases. Many of these diseases are “invisible” in addition to being chronic illnesses and causing impaired functions and disabilities. There is very little research investigating these diseases within the context of communication or that examine the implications of communication competency for this population on their quality of life and overall health. Future research needs to be conducted to investigate the on-going daily challenges of this disease within different contexts, like work environment and broader family context. Additionally, longitudinal studies need to be conducted to capture these variables over more extended periods of time to encapsulate the transformative nature of the disease and the on-going impact of relational communication competence.

## **Practical Implications**

*Tailored Communication for Marital/Partner Support.* Many of the participants shared information about their disease with their husband or partner that they got off the internet or through their social support networks. Although this information provided basic information about their disease, in many cases the husband or partner still did not understand the impact of the disease on their everyday living. For this reason, the information was not adequate to assist the husband or partner in providing needed support. One piece of information obtained from Mary Shomon, a leading thyroid disease advocate and author, entitled “An Open Letter to the Family and Friends of Thyroid Patients,” seemed to assist participants in explaining their disease to their husband or partner (Shomon, 2014). The letter provides basic information about thyroid disease, how a patient might feel, and their challenges. The letter provides the words that many thyroid patients in the midst of their illness struggle to find. One part of the letter says,

I'm here to ask you -- in a world where thyroid patients are disregarded, overlooked, misdiagnosed, abused, exploited, mocked, and ignored -- to be the person who truly "gets it" for the thyroid patient in your life. Be the person who understands that while thyroid disease may not be visible, it is causing your friend or loved one to suffer. Be the person who understands that even though celebrities aren't talking about thyroid disease, and sports figures aren't wearing bracelets to promote thyroid awareness, that this is a genuine, difficult, and life-changing diagnosis.

Additional tailored materials need to be developed to illustrate lifestyle and diet changes, medications and other relevant information for the husband or partner. Currently, they are receiving piecemeal information from the thyroid patient themselves or through web searches or social networking sites. Having information to guide their support and truly

“get it” will go a long way to improving their communication and enabling a healthy environment. Based on this research, an information packet should be developed to include discussion guides for marital partners to communicate openly about the disease as well as facilitate dialogue about potential adjustments that need to be made in the home to accommodate the participants and assist in achieving wellness. Additionally, information provided about the disease needs to extend beyond general disease facts to include more specific information related to adoption of health behaviors within the home. Also, the packet should include a letter, like Mary Shomon’s *Letter to Friends and Family*, tailored to the marital partner. The reason for a more custom letter is to directly address the intimate nature of the relationship and include some of the symptoms like low sex drive, self-esteem, appearance (weight gain, skin rashes), and the participants related need for support and acceptance.

*Local Availability of Social Support Network.* Participants’ networks often did not exceed two people and they continually indicated the support provided did not meet their needs of feeling understood or provide a safe place to talk about what they are going through on daily basis. The husband providing sole social support does not come without a cost to the relationship. According to research, social support requires a variety of resources, including time and energy, tangible goods, and emotional nurturance, which may lead to emotional exhaustion and relational strain (Albrecht & Adelman, 1987). Therefore, it is not practical or healthy for the husband or partner to be everything to the participant. Unfortunately, many participants indicated the reason for their limited network of friends and family was due to misunderstanding and frustration in their

communication about their disease, as well as effects of symptoms, like fatigue and pain. A few participants relayed the hope they could find friends, like in *Sex in the City*, who were there no matter what without judgment. Other participants mentioned that although they participated in social support networks, they were reading responses or getting information only, not interacting or communicating for emotional support. These participants indicated that it would be nice to have in-person support from people that were suffering from autoimmune thyroid disease. Due to these reasons, a local in-person support group, or small network of patients, should be created to discuss challenges, approaches to treatment and physician experiences as well as decrease loneliness and isolation. These support groups may also assist patients in their communication with their husbands.

*Integrative Approach of Provider /Doctor.* Many participants indicated a poor provider experience and difficulty achieving a diagnosis. Sixty percent of the 619 women that participated in the survey indicated they were misdiagnosed. Most of the interview participants indicated they were misdiagnosed and did not receive proper treatment. Some were misdiagnosed for over 10 years. This poses serious barriers to wellness for these women. Providers need to adjust their treatment approach to look beyond “the blood test” to the whole patient experience with autoimmune thyroid disease. As indicated in the review of literature, the majority of providers treat the associated conditions versus the root cause of the disease. Many doctors do not see a need to venture beyond this because it does not change their treatment protocol. However, not viewing autoimmune thyroid disease as a complex illness with both

physical and mental symptoms equates to inadequate care for the patient. Hippocrates said, “It is more important to know what sort of person has a disease than to know what sort of disease a person has” (2014). Although this was said over 2,000 years ago, many providers still treat the condition versus the patient. Providers need to extend the view of the patient beyond their condition or, in the case of autoimmune thyroid disease, their bloodtest to include the whole patient experience.

Within in one day of posting the survey, over 350 responses were received. Within a week, the response rate doubled. Within these responses, over 100 women asked to be interviewed. They desperately wanted their voices heard. One of the critical goals of participants was validation for their symptoms and awareness of their disease. Despite the fact that there are millions of women suffering from autoimmune thyroid disease, there is a limited number of promotional activities or awareness campaigns dedicated to the disease. This is concerning for numerous reasons. As it relates to this research specifically, lack of societal awareness or concern for this disease further exacerbates the lack of validation many of these women experience on a daily basis. Additionally, lack of awareness of the disease by the general public creates opportunities for misunderstanding of the disease symptoms and ignorance to the serious nature of the challenges associated with the disease. The purpose of this research was not only to investigate communication competence within the context of intimate relationships for women suffering from autoimmune thyroid disease, but to shed light on daily challenges many women inflicted with this disease experience. The hope is to insight future research and interest to bring these women the wellness they deserve.

## **Limitations**

This research had several limitations. First, the majority of the sample was collected from women who participate in on-line social networking groups specific to women who have autoimmune thyroid disease. Since many of the women that participated had the social support from women who were part of this network, social support perception may have been more positive than if other sampling methods were used.

Additionally, although the sample was diverse by regions of the United States and age, all the women that participated were Caucasian. However, the epidemiology of autoimmune disease indicates that in the United States the disease mainly impacts Caucasian women in child-bearing years (Vanderpump, 2005). Greater diversity could be achieved by expanding the study to include more autoimmune diseases.

Lastly, communication competence was only measured for the women who had the disease. The husband or partner did not complete the survey or participate in the interview. Therefore, the retrospective reports were purely from the women's point of view and may not have provided as much depth as if both participated. Also, the interviews were limited in time. Longer interviews, multiple interviews, or the inclusion of a daily diary might have provided an even deeper look into their challenges and communication approaches of the participants.

## APPENDIX A: COMMUNICATION COMPETENCE SCALE

Instructions: Complete the following questions and indicate whether you strongly agree (SA), agree (A), are undecided or neutral (N), disagree (D), or strongly disagree (SD). (Wiemann, 1977)

1. I find it easy to get along with others.  
SA    A    N    D    SD
2. I can adapt to changing situations.  
SA    A    N    D    SD
3. I treat people as individuals.  
SA    A    N    D    SD
4. I interrupt others too much.  
SA    A    N    D    SD
5. I am “rewarding” to talk to.  
SA    A    N    D    SD
6. I can deal with others effectively  
SA    A    N    D    SD
7. I am a good listener.  
SA    A    N    D    SD

8. My personal relations are cold and distant.  
SA A N D SD
9. I am easy to talk to.  
SA A N D SD
10. I won't argue with someone just to prove I am right.  
SA A N D SD
11. My conversation behavior is not "smooth".  
SA A N D SD
12. I ignore other people's feelings.  
SA A N D SD
13. I generally know how others feel.  
SA A N D SD
14. I let others know I understand them.  
SA A N D SD
15. I understand other people.  
SA A N D SD
16. I am relaxed and comfortable when speaking.  
SA A N D SD
17. I listen to what people say to me.  
SA A N D SD
18. I like to be close and personal with people.

SA    A    N    D    SD

19. I generally know what type of behavior is appropriate in any given situation.

SA    A    N    D    SD

20. I usually do not make unusual demands on my friends.

SA    A    N    D    SD

21. I am an effective conversationalist.

SA    A    N    D    SD

22. I am supportive of others.

SA    A    N    D    SD

23. I do not mind meeting strangers.

SA    A    N    D    SD

24. I can easily put myself in another person's shoes.

SA    A    N    D    SD

25. I pay attention to the conversation.

SA    A    N    D    SD

26. I am generally relaxed when conversing with a new acquaintance.

SA    A    N    D    SD

27. I am interested in what others have to say.

SA    A    N    D    SD

28. I don't follow the conversation very well.

SA A N D SD

29. I am a likeable person.

SA A N D SD

30. I am flexible.

SA A N D SD

31. I am not afraid to speak with people in authority.

SA A N D SD

32. People can go to me with their problems.

SA A N D SD

33. I generally say the right thing at the right time.

SA A N D SD

34. I like to use my voice and body expressively.

SA A N D SD

35. I am sensitive to others' needs of the moment.

SA A N D SD

**APPENDIX B: MEDICAL OUTCOMES STUDY: 36-ITEM SHORT FORM  
SURVEY INSTRUMENT**

(RAND Corporation , 2013)

1. In general, would you say your health is:	
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5
2. <b>Compared to one year ago,</b> how would you rate your health in general <b>now</b> ?	
Much better now than one year ago	1
Somewhat better now than one year ago	2
About the same	3
Somewhat worse now than one year ago	4
Much worse now than one year ago	5

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

(Circle One Number on Each Line)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
3. <b>Vigorous activities</b> , such as running, lifting heavy objects, participating in strenuous sports	[1]	[2]	[3]
4. <b>Moderate activities</b> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	[1]	[2]	[3]
5. Lifting or carrying groceries	[1]	[2]	[3]
6. Climbing <b>several</b> flights of stairs	[1]	[2]	[3]
7. Climbing <b>one</b> flight of stairs	[1]	[2]	[3]
8. Bending, kneeling, or stooping	[1]	[2]	[3]
9. Walking <b>more than a mile</b>	[1]	[2]	[3]
10. Walking <b>several blocks</b>	[1]	[2]	[3]
11. Walking <b>one block</b>	[1]	[2]	[3]
12. Bathing or dressing yourself	[1]	[2]	[3]

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

(Circle One Number on Each Line)

	Yes	No
13. Cut down the amount of time you spent on work or other activities	1	2
14. <b>Accomplished less</b> than you would like	1	2

15. Were limited in the <b>kind</b> of work or other activities	1	2
16. Had <b>difficulty</b> performing the work or other activities (for example, it took extra effort)	1	2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

**(Circle One Number on Each Line)**

	Yes	No
17. Cut down the <b>amount of time</b> you spent on work or other activities	1	2
18. <b>Accomplished less</b> than you would like	1	2
19. Didn't do work or other activities as <b>carefully</b> as usual	1	2

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

**(Circle One Number)**

Not at all 1

Slightly 2

Moderately 3

Quite a bit 4

Extremely 5

21. How much **bodily** pain have you had during the **past 4 weeks**?

**(Circle One Number)**

None 1

Very mild 2

Mild 3

Moderate 4

Severe 5

Very severe 6

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

**(Circle One Number)**

Not at all 1

A little bit 2

Moderately 3

Quite a bit 4

Extremely 5

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks** . . .

**(Circle One Number on Each Line)**

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of	1	2	3	4	5	6

energy?						
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6

32. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

**(Circle One Number)**

All of the time 1

Most of the time 2

Some of the time 3

A little of the time 4

None of the time 5

How TRUE or FALSE is each of the following statements for you.

**(Circle One Number on Each Line)**

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33. I seem to get sick a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5

36. My health is excellent	1	2	3	4	5
----------------------------	---	---	---	---	---

**APPENDIX C: MEDICAL OUTCOMES STUDY: SOCIAL SUPPORT SURVEY  
INSTRUMENT**

(RAND Corporation, 2010)

**Social Support**

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle one number on each line.

	<b>None of the time</b>	<b>A little of the time</b>	<b>Some of the time</b>	<b>Most of the time</b>	<b>All of the time</b>
<b>Emotional/informational support</b>					
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Someone whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5

Someone who understands your problems	1	2	3	4	5
<b>Tangible support</b>					
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to take you to the doctor if you needed it	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5
<b>Affectionate support</b>					
Someone who shows you love and affection	1	2	3	4	5
Someone to love and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5
<b>Positive social interaction</b>					
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5
Someone to do something enjoyable with	1	2	3	4	5
<b>Additional item</b>					
Someone to do things with to help you get your mind off things	1	2	3	4	5

## APPENDIX D: SOCIAL SUPPORT QUESTIONNAIRE

(Sarason I. , Sarason, Shearin, & Pierce, 1987)

Instructions: The following questions ask about people in your environment who provide you with help or support with both professional and personal issues. Each question has two parts. For the 1st part, please check the box next to all the people whom you can count on for help or support in the manner described. Please check ALL that apply. For the 2nd part, please indicate how satisfied you are with the overall support you receive. If you have no support for a question, please indicate the words, “No One”, but still report your level of satisfaction.

1. Whom can you really count on to be dependable when you need help?

- No One
- My Romantic Partner
- My Mother
- My Father
- My Sister(s)
- My Brother(s)
- Other Family Member(s)
- My Friend(s) (Other than individuals with whom you work)
- My Work Colleague(s)
- My Religious/Spiritual Advisor(s)
- Other (Please specify) \_\_\_\_\_

1a. How satisfied are you with the overall support you receive from the previously listed individual(s) to be dependable when you need help?

Please check one of the following options:

- Very Satisfied
- Fairly Satisfied
- A Little Satisfied
- A Little Dissatisfied
- Fairly Dissatisfied
- Very Dissatisfied

Whom can you really count on to help you feel more relaxed when you are under pressure or tense?

- No One
- My Romantic Partner
- My Mother
- My Father
- My Sister(s)
- My Brother(s)
- Other Family Member(s)
- My Friend(s) (Other than individuals with whom you work)
- My Work Colleague(s)
- My Religious/Spiritual Advisor(s)
- Other (Please specify) \_\_\_\_\_

2a. How satisfied are you with the overall support you receive from the previously listed individuals to help you feel more relaxed when you are under pressure or tense? Please check one of the following options:

- Very Satisfied
- Fairly Satisfied
- A Little Satisfied
- A Little Dissatisfied
- Fairly Dissatisfied
- Very Dissatisfied

3. Who accepts you totally, including both your worst and your best points?

- No One
- My Romantic Partner
- My Mother
- My Father
- My Sister(s)
- My Brother(s)
- Other Family Member(s)
- My Friend(s) (Other than individuals with whom you work)
- My Work Colleague(s)
- My Religious/Spiritual Advisor(s)
- Other (Please specify) \_\_\_\_\_

3a. How satisfied are you with the overall support you receive from the previously listed individuals to accept you totally, including both your worst and your best points? Please check one of the following options:

- Very Satisfied
- Fairly Satisfied
- A Little Satisfied
- A Little Dissatisfied

- Fairly Dissatisfied
- Very Dissatisfied

4. Who can you really count on to care about you, regardless of what is happening to you?

- No One
- My Romantic Partner
- My Mother
- My Father
- My Sister(s)
- My Brother(s)
- Other Family Member(s)
- My Friend(s) (Other than individuals with whom you work)
- My Work Colleague(s)
- My Religious/Spiritual Advisor(s)
- Other (Please specify) \_\_\_\_\_

4a. How satisfied are you with the overall support you receive from the previously listed individuals to care about you, regardless of what is happening to you? Please check one of the following options:

- Very Satisfied
- Fairly Satisfied
- A Little Satisfied
- A Little Dissatisfied
- Fairly Dissatisfied
- Very Dissatisfied

5. Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps?

- No One
- My Romantic Partner
- My Mother
- My Father
- My Sister(s)
- My Brother(s)
- Other Family Member(s)
- My Friend(s) (Other than individuals with whom you work)
- My Work Colleague(s)
- My Religious/Spiritual Advisor(s)
- Other (Please specify) \_\_\_\_\_

5a. How satisfied are you with the overall support you receive from the previously listed individuals to help you feel better when you are feeling generally down-in-the-dumps? Please check one of the

following options:

- Very Satisfied
- Fairly Satisfied
- A Little Satisfied
- A Little Dissatisfied
- Fairly Dissatisfied
- Very Dissatisfied

## REFERENCES

- AARDA. (2013, September 23). *Autoimmune Statistics*. Retrieved from American Autoimmune Related Diseases Association, Inc.: <http://www.aarda.org/autoimmune-information/autoimmune-statistics/>
- Afifi, T., & Nussbaum, J. (2006). Stress and adaptation theories: Families across the life span. In D. B. Braithwaite, *Engaging theories in family communication: Multiple perspectives* (pp. 276-292). Thousand Oaks: Sage.
- Albrecht, T., & Adelman, M. (1987). Dilemmas of supportive communication . In T. Albrecht, & M. Adelman, *Communicating Social Support* (pp. 240-254). Newbury Park: Sage.
- Albrecht, T., & Goldsmith, D. (2003). Social support, social networks and health. In T. Thompson, A. Dorsey, K. Miller, & R. Parrott, *Handbook of health communication* (pp. 263-284). Mahwah: Lawrence Erlbaum.
- Arem, R. M. (2007). *The thyroid solution: A revolutionary mind-body program for regaining your emotional and physical health*. New York: Ballantine Books.
- Aronson, J. (2014, April 8). *A pragmatic view of thematic analysis*. Retrieved from The Qualitative Report: <http://www.nova.edu/ssss/QR/BackIssues/QR2-1/aronson.html>
- Baider, L., Ever-Hadini, P., Goldsweig, G., Wygoda, M., & Pretz, T. (2003). Is perceived family support a relevant variable in psychological distress? A sample of prostate and breast cancer couples. *Journal of Psychosomatic Research*, 55, 453-460.
- Bandura, A. (1982). Self-efficacy mechanisms in human agency. *American Psychologist*, 37, 122-147.
- Bowlby, E. (2011). Serenity, courage, and wisdom: Life with an invisible disability. In M. Miller-Day, *Family communication, connections, and health transitions* (pp. 299-244). New York: Peter Lang Publishing.
- Bradbury, T., Fincham, F., & Beach, S. (2000). Research on the nature and determinants of marital satisfaction: A decade in review. *Journal of Marriage and the Family*, 62, 964-980.

- BrainyQuote. (2014). *Hippocrates Quotes*. Retrieved March 28, 2014, from BrainyQuote: <http://www.brainyquote.com/quotes/authors/h/hippocrates.html>
- Burleson, B. (1994). Comforting messages: Significance, approaches and effects. In B. Burleson, T. Albrecht, & G. Sarason, *Communication of social support: Messages, interactions, relationships, and community*. Newbury Park: Sage.
- Burman, B., & Margolin, G. (1992). An analysis of the association between marital relationships and health problems: An interactional perspective. *Psychological Bulletin*, *112*(1), 39-63.
- Caplan, S., & Samter, W. (1999). The role of facework in younger and older adults' evaluation of social support messages. *Communication Quarterly*, *47*, 245-264.
- Cohen, S., & Syme, S. (1985). *Social support and health*. Orlando: Academic Press.
- Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks: Sage.
- Cutrona, C. (1990). Social support as a determinant of marital quality: The interplay of negative and supportive behaviors. In G. Pierce, B. Sarason, & I. Sarason, *Handbook of social support and the family* (pp. 173-194). New York: Plenum.
- Dearmen, L. (2011). Working it out together: The role of family support in the management of postpartum depression. In M. Miller-Day, *Family communication, connections, and health transitions* (pp. 135-162). New York : Peter Lang Publishing.
- Endler, N., & Parker, J. (1990). Multidimensional assessment of coping: A critical evaluation. *Journal of Personality and Social Psychology*, *58*, 844 - 854.
- Evangelopoulou, M., Alevizaki, M., Toumanidis, S., Piperigos, G., Mavrikakis, M., Sotou, D., et al. (1999 , October). Mitral valve prolapse in autoimmune thyroid disease: an index of systemic autoimmunity? *Thyroid*, *9*(10), 973-937.
- Fisher, C., & Miller-Day, M. (2006). Communicating over a life span: The mother adult daughter relationship. In K. Floyd, & M. Morman, *Widening the family circle: New research on family communication* (pp. 3-20). Thousand Oaks: Sage.
- Friedman, L., Kalidas, M., Elledge, R., Chang, J., Romero, C., Husain, I., et al. (2006). Optimism, social support and psychosocial functioning among women with breast cancer. *Psycho-Oncology*, *15*(7), 595-603.
- Gold, M., Pottash, A., & Extein, I. (1982). Symptomless autoimmune thyroiditis in depression. *Psychiatry Research*, *6*, 261-269.

- Goldsmith, D. J., Bute, J. J., & Lindholm, K. A. (2012, February ). Patient and partner strategies for talking about lifestyle change following a cardiac event. *Journal of Applied Communication Research*, 65-86.
- Goldsmith, D., & Brashers, D. (2008). Communication matters: Developing and testing social support interventions. *Communication Monographs*, 75, 320-330.
- Goldsmith, D., & MacGeorge, E. (2000). The impact of politeness and relationship on perceived quality of advice about a problem. *Human Communication Research*, 26, 234-263.
- Goodwin, S. (1997). The marital relationship and health in women with chronic fatigue and immune dysfunction syndrome: Views of wives and husbands. *Nursing Research*, 46, 138-146.
- Gottlieb, B. (1985). Social networks and social support: An overview of research, practice and policy implications. *Health Education Quarterly*, 12, 5-22.
- Gulseren, S., Gulseren, L., Hekimsoy, Z., Cetinay, P., Ozen, C., & Tokatlioglu, B. (2006). Depression, anxiety, health-related quality of life, and disability in patients with overt and subclinical thyroid dysfunction. *Archives of Medical Research*, 37(1), 133-139.
- Hecht, M. (1993). A research odyssey: Towards development of a communication theory of identity. *Communication Monographs*, 60, 76-82.
- Hecht, M., Warren, J., Jung, E., & Krieger, J. (2005). The communication theory of identity: Development, theoretical perspectives and future directions. In W. Gudykunst, *Theorizing about Intercultural Communication* (pp. 257-278). Thousand Oaks: Sage Publications, Inc.
- Helgeson, V., & Cohen, S. (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational, and intervention research. *Health Psychology*, 15, 135-148.
- Herbourn, C., & Stewart, A. (1991). The MOS social support survey. *Soc Sci Med*, 32(6), 705-714.
- Holmstrom, A. J., & Burleson, B. R. (2011). An initial test of cognitive-emotional theory of esteem support messages. *Communication Research*, 32, 326-355.
- Jacobson, D. L., Gange, S. J., Rose, N. R., & Graham, N. M. (1997). Short analytical review: Epidemiology and the estimated population burden of selected autoimmune diseases in the United States. *Clinical Immunology and Immunopathology*, 84(3), 223-239.

- Jung, E. (2013). Delineation of threefold relationship among communication input variables, identity gaps, and depressive symptoms. *Southern Communication Journal*, 78(2), 163-184.
- Jung, E., & Hecht, M. (2004). Elaborating the communication theory of identity: Identity gaps and communication outcomes. *Communication Quarterly*, 52(3), 265-283.
- Kreps, G. (1988). Relational communication in health care. *Southern Speech Communication Journal*, 53(4), 344-359.
- Kulik, J., & Mahler, H. (1993). Emotional support as a moderator of adjustment and compliance after coronary bypass surgery: A longitudinal study. *Journal of Behavioral Medicine*, 16, 45-63.
- Kvale, S., & Brinkman, S. (2009). *Interviews: Learning the craft of qualitative research interviewing* (2nd ed.). Thousand Oaks: Sage.
- Kwakkel, G., Wagenaar, R., Kollen, B., & Lankhorst, G. (1996). Predicting disability in stroke: A critical review of literature. *Ageing*, 25, 472-503.
- Lindlof, T., & Taylor, B. (2011). *Qualitative Communication Research Methods* (3rd ed.). Thousand Oaks: Sage.
- Lorenz, F., Conger, R., Montague, R., & Wickrama, K. (1993). Economic conditions, spouse support, and psychological distress of rural husbands and wives. *Rural Sociology*, 58, 247-268.
- MacGeorge, E., Feng, B., Butler, G., & Budarz, S. (2004). Understanding advice in supportive interactions: Beyond the facework and message evaluation paradigm. *Human Communication Research*, 30(1), 42-70.
- Maitz, E., & Sachs, P. (1995). Treating families of individuals with traumatic brain injury from a family systems approach. *Journal of Head Trauma Rehabilitation*, 10(2), 1-11.
- Mickelson, K. (2001). Perceived stigma, social support, and depression. *Personality and Social Psychology Bulletin*, 27, 1046-1056.
- Nemeroff, C., Simon, J., Haggerty, J., & Evans, D. (1985, July 1). Antithyroid antibodies in depressed patients. *American Journal of Psychiatry*, 142, 840-843.
- NIH. (2002, March). *Autoimmune Disease Research Plan*. Retrieved August 19, 2013, from National Institutes of Health : <http://www.niaid.nih.gov/topics/autoimmune/Documents/adccreport.pdf>

- Pearlin, L., Lieberman, M., Menaghan, E., & Mullan, J. (1981). The stress process. *Journal of Health and Social Behavior*, 22, 2-21.
- Pettigrew, J., & Pettigrew, B. (2011). In sickness and in health: Coping with chronic illness while transitioning into marriage. In M. Miller-Day, *Family Communication, Connections, and Family Transitions* (pp. 245-266). New York: Peter Lange Publishing .
- Query, J., & Kreps, G. (1996). Testing a relational model of health communication competence among caregivers for individuals with Alzheimer's disease. *Journal of Health Psychology*, 1(3), 335-352.
- Rockey, P., & Griep, R. (1980). Behavioral Dysfunction in Hyperthyroidism. *Archives of Internal Medicine*, 140, 1194-1197.
- Sarason, I., Sarason, B., Shearin, E., & Pierce, G. (1987). A brief measure of social support: practical and theoretical implications. *Journal of Social and Personal Relationships*, 4, 497-510.
- Segrin, C., & Badger, T. (2011). Interdependence in family systems: Adjusting to breast and prostate cancer. In M. Miller-Day, *Family Communication, Connections, and Health Transitions* (pp. 19-55). New York: Peter Lang.
- Shomon, M. (2014, February 14). *When your family member or friend has thyroid disease: An open letter to the family and friends of thyroid patients*. Retrieved January 20, 2014, from About.com Thyroid Disease: <http://thyroid.about.com/od/bookssupportresources/a/letter-to-family-friends.htm>
- Shomon, M. J. (2005). *Living well with hypothyroidism: What your doctor doesn't tell you that you need to know*. New York: HarperCollins Publishers, Inc.
- Shumaker, S., & Brownell, A. (1984). Toward a theory of social support: Closing conceptual gaps. *Journal of Social Issues*, 40(4), 11-36.
- Spitzberg, B., & Cupach, W. (1984). *Interpersonal communication competence*. Beverly Hills: Sage.
- Srivastava, P., & Hopwood, N. (2009). A practical iterative framework for qualitative data analysis. *Journal of Qualitative Methods*, 8, 76-84.
- The Society for Women's Health Research and the National Women's Health Resource Center, Inc. (2002). *Autoimmune diseases in women*. Wayne: Berlex Laboratories, Inc.

- Thoits, P. (1986). Social support as coping assistance. *Journal of Consulting and Clinical Psychology, 54*, 416-423.
- Thornton, P., Kieffer, E., Salabarria-Pena, Y., Odoms-Young, A., Willis, S., Kim, H., et al. (2006). Weight, diet, and physical activity-related beliefs and practices among pregnant and postpartum Latino women: The role of social support. *Maternal and Child Health Journal, 10*(1), 95-104.
- Tracy, S. (2013). *Qualitative Research Methods*. Malden: Wiley-Blackwell.
- Vanderpump, M. (2005). The epidemiology of thyroid diseases. In L. Braverman, & R. Utiger, *The thyroid: A fundamental and clinical text* (pp. 398-496). Philadelphia: JB Lippincott-Raven.
- Vaux, A. (1988). *Social support: Theory, research and intervention*. New York: Praeger Publishers.
- Walker, K., & Dickson, F. (2004). An exploration of illness-related narratives in marriage: The identification of illness-identity scripts. *Journal of Social and Personal Relationships, 21*(4), 527-544.
- Walsh, S., & Rau, L. (2000). Autoimmune diseases: A leading cause of death among young and middle-aged women in the United States. *American Journal of Public Health, 90*, 1463 - 1465.
- Waltz, M., Badura, B., & Pfaff, H. (1988). Marriage and the psychological consequences of a heart attack: A longitudinal study of adaptation to chronic illness after 3 years. *Social Science & Medicine, 27*(2), 149-158.
- Weber, K., & Solomon, D. (2008). Locating relationship and communication issues among stressors associated with breast cancer. *Health Communication, 23*, 548-559.
- Wiemann, J. (1977). Explication and test of a model of communicative competence. *Human Communication Research, 3*, 195-213.
- Wunderer, E., & Schneewind, K. (2008). The relationship between marital standards, dyadic coping and marital satisfaction. *European Journal of Social Psychology, 38*(3), 462-476.
- Wynne, L. C., & Wynne, A. R. (1986). The quest for intimacy. *Journal of Marital and Family Therapy, 12*(4), 383-394.

- Xu, Y., & Bureleson, B. R. (2001). Effects of sex, culture, and support type on perceptions of spousal social support: An assessment of the "support gap" hypothesis in early marriage. *Human Communication Research*, 27(4), 535-566.
- Yanos, P., Roe, D., & Lysaker, P. (2010). The impact of illness identity on mental illness . *American Journal of Psychiatric Rehabilitation*, 13, 73–93.
- Yelsma, P. (1995). Husband and wife intimacy: Attributes of physiological recovery of myocardial infarction patients. In G. L. Kreps, & D. O'Hair, *Communication and Health Outcomes* (pp. 107-122). Annandale, VA: Hampton Press.

## **BIOGRAPHY**

Denise K. Scannell received her Bachelor of Arts degree from Douglass College at Rutgers University in 1994 with a double major in English and Journalism and a minor in Theater. She completed her Master of Arts in Communication, focusing on health and children, at Montclair State University in 1999. Denise currently works at The MITRE Corporation in McLean, Virginia, as a communication strategy advisor and health communication subject matter expert. She resides in Warrenton, Virginia with her husband, her six year-old son, and her two adorable pugs.