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Women and Thyroid Disease: Treatment Experiences and the Doctor-Patient Relationship

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Abstract

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MSEd, Youngstown State University, 2003

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Dissertation Submitted in Partial Fulfillment
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Abstract

Thyroid disease, a chronic illness, affects nearly 200 million people worldwide and is more common among women than in men. Numerous factors make diagnosing and treating thyroid disease in women challenging. The standard blood test for diagnosing thyroid disease and determining treatment effectiveness is inconsistent in its accuracy. Many women with thyroid disease are misdiagnosed or struggle with symptoms even once receiving treatment. Although thyroid disease is highly prevalent among women and the doctor-patient relationship is known to influence treatment outcomes, there is a gap in the literature regarding the treatment experiences of women with thyroid disease and the doctor-patient relationship. The purpose of this phenomenological study was to explore female thyroid patients' experiences of treatment and the doctor-patient relationship. Sixteen female thyroid patients, ages 18 and older and members of an international online support group, were individually interviewed via online chat. Data interpretation was guided by social constructionism and feminist theory and was accomplished via Moustakas's analytic method. Themes related to the doctor-patient relationship were identified, including the culture of the medical profession, diagnostic bias, and gender differences in communication. Emergent themes included patient education level, patient self-advocacy behaviors, and the use of natural thyroid medication. The results of this study may contribute to positive social change by enhancing doctors' understanding of thyroid disease in women and the influence of the doctor-patient relationship in determining positive treatment outcomes, thus equipping doctors with enriched knowledge for providing their female thyroid patients with the highest quality of care.

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Dr. Ruth Crocker—Thank you so much for sharing your wisdom with me during this long journey. Your guidance and patience have been invaluable.

My study participants—Thank you for trusting me with your experiences. Together, we will acquire the treatments that we need and deserve. We will overcome the debilitating effects of thyroid disease and help to ensure better outcomes for individuals yet to be diagnosed.

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Chapter 1: Introduction to the Study

Introduction

Approximately 200 million people worldwide have been diagnosed with thyroid disease, a chronic illness (Rajoria et al., 2010). According to the American Association of Clinical Endocrinologists (AACE, 2013), approximately 30 million Americans are affected by thyroid disease, although more than half remain undiagnosed. Across cultures, the prevalence of thyroid disease is much higher among women than among men (Canaris, Manowitz, Mayor, & Ridgway, 2000; Cassidy, Ahearn, & Carroll, 2002). In fact, women have an estimated 1 in 7 chance of developing thyroid disease (Godfrey, 2007).

A number of factors make proper diagnosis and treatment of thyroid disease challenging. For example, according to Adams (2008) and Dayan (2001), the most commonly used blood test (thyroid stimulating hormone [TSH]) for diagnosing thyroid disease can produce misleading results. More specifically, although use of all three main thyroid function tests (TSH, free T3, free T4) produces the most thorough analysis of thyroid function, the TSH test tends to be used alone (Dayan, 2001). Because of this, clinically important diagnoses (e.g., hyperthyroidism, hypothyroidism) are sometimes missed. In addition, as thyroid dysfunction produces symptoms similar to those of other disorders (e.g., depression, menopause), thyroid disease is often misdiagnosed and left untreated (Canaris et al., 2000; Godfrey, 2007; Simmons, 2010). Likewise, as the TSH test tends to be used alone to determine treatment effectiveness, many women with thyroid disease continue to experience symptoms even when they are receiving treatment

(Bunevicius & Prange, 2006). In the face of such challenges, a doctor-patient relationship based on mutual trust and collaboration helps to ensure positive treatment outcomes (Houle, Harwood, Watkins, & Baum, 2007; Munch, 2004). In addition, effective communication between doctors and patients is critical in both the diagnosis and management of thyroid disease (Shimabukuro, 2008; Simmons, 2010). However, the culture of the medical profession, diagnostic bias, and gender differences in communication may interfere with doctor-patient discourse (Cheney & Ashcraft, 2007; Hamberg, Risberg, & Johansson, 2004; Hoffmann & Tarzian, 2001; Kaiser, 2002; Munch, 2004). An exploration of women's experiences in the treatment of thyroid disease, especially relative to these three points, may contribute to better understanding on the part of doctors and thus more effective doctor-patient communication and relationships.

Despite the pervasiveness of thyroid disease in women and the importance of the doctor-patient relationship in positive treatment outcomes, there is a gap in the literature regarding the treatment experiences of women diagnosed with thyroid disease, particularly regarding the doctor-patient relationship. Therefore, the purpose of this phenomenological study was to explore female thyroid patients' experiences of treatment and the doctor-patient relationship.

The phenomenological research approach was used, as it is designed to examine the meaning of experiences about a particular phenomenon (e.g., thyroid disease) across several individuals who have experienced it (Creswell, 2007). The theoretical perspectives used to guide data interpretation included feminism and social constructivism. More specifically, the following issues were addressed in regard to their relationship with women's treatment experiences: (a) the culture of the medical profession (see Kaiser, 2002; Thomas, 2001), (b) diagnostic bias (see Hamberg et al., 2004; Hoffmann & Tarzian, 2001; Munch, 2004), and (c) gender differences in communication (see Cheney & Ashcraft, 2007; Tannen, 2007).

The following paragraphs provide a review of the literature relevant to the study, followed by the problem statement, the purpose and nature of the study, research questions, conceptual framework, definition of terms, assumptions and limitations, and the significance of the study.

Background of the Study

The incidence of thyroid disease is higher than previously thought (Canaris et al., 2000), affecting an estimated 30 million Americans (AACE, 2013) and 200 million people worldwide (Rajoria et al., 2010). Of the 30 million Americans with thyroid disease, more than 15 million remain undiagnosed (AACE, 2013). Across cultures, the prevalence of thyroid disease is much higher in women than men (Canaris et al., 2000; Cassidy et al., 2002). Approximately 1 out of every 7 women develops thyroid disease, and its prevalence increases with age (about 20% in women over age 60; Godfrey, 2007). The two predominant conditions resulting from thyroid disease are hyperthyroidism and hypothyroidism, with Grave's disease and Hashimoto's disease, respectively, as the most common causes (Zeitlin et al., 2008). Both conditions cause a wide range of somatic and psychiatric symptoms.

Hyperthyroidism

Hyperthyroidism is the result of excessive thyroid hormone production (AACE, 2002) and is frequently associated with anxiety, panic, and phobias (Aslan et al., 2005). In the United States, the most common cause of hyperthyroidism is Grave's disease, an autoimmune form of thyroid disease (Bunevicius & Prange, 2006). Individuals with hyperthyroidism experience heat intolerance, hot flashes, absent menses, insomnia, decreased libido (Godfrey, 2007), rapid heartbeat, sweating, and tremors (Aslan et al., 2005) and may present with diffuse goiter and ophthalmological abnormalities (Ginsberg, 2003).

Hypothyroidism

Hypothyroidism results from the undersecretion of thyroid hormones from the thyroid gland (AACE, 2002) and is frequently associated with depressive disorders (Aslan et al., 2005). In the United States, the most common cause of hypothyroidism is Hashimoto's disease, an autoimmune form of thyroid disease (Erdal et al., 2008). Individuals with hypothyroidism experience fatigue (Bono, Fancellu, Blandini, Santoro, & Mauri, 2004), lethargy, apathy, difficulty concentrating (Aslan et al., 2005), weight gain, dry skin, and decreased libido (Godfrey, 2007). In extreme cases, the individual may experience slowing of thought processes, progressive cognitive impairment, hallucinations, and delusions (Bono et al., 2004).

Diagnosis

The TSH blood test is the most commonly used test in the initial screening for thyroid disease (Dayan, 2001) and is considered the "gold standard" for determining thyroid dysfunction (Adams, 2008, p. 1). However, as the use of all three main thyroid function tests (TSH, free T3, free T4) produces the most thorough analysis of thyroid function, the effectiveness of the TSH test alone has been debated by endocrinology experts (Adams, 2008; Beckett, & MacKenzie, 2007). Furthermore, abnormalities in thyroid function present with symptoms similar to those of other disorders and can be mistaken for other conditions (Canaris et al., 2000; Godfrey, 2007; Simmons, 2010). For example, hyperthyroidism and hypothyroidism are frequently misdiagnosed as anxiety and depressive disorders, respectively (Aslan et al., 2005; Godfrey, 2007). Postpartum thyroiditis, which affects more than 8% of women, is sometimes mistaken for depression (Fassier et al., 2011). In older patients, symptoms of hyperthyroidism and hypothyroidism often lead to inaccurate diagnoses of menopause or dementia (Godfrey, 2007; Shimabukuro, 2008). Thus, it is vital that physicians conduct a thorough assessment of their patients, including an ongoing discussion of symptoms, to ensure proper diagnosis and treatment.

Treatment

Hyperthyroidism. Three types of treatments are currently available for hyperthyroidism: (a) surgical intervention, (b) antithyroid drugs, and (c) radioactive iodine (AACE, 2002). Thyroidectomy is usually performed only when thyroid cancer is suspected. Although antithyroid drugs have been used for over 60 years, remission rates are variable, and relapses are frequent. Radioactive iodine (RAI) is the standard treatment for hyperthyroidism in the United States. Regardless of the treatment chosen, individuals treated for hyperthyroidism become euthyroid, then hypothyroid, and require lifelong thyroid hormone replacement therapy (AACE, 2002).

Hypothyroidism. An individual with hypothyroidism requires lifelong thyroid hormone replacement therapy (AACE, 2002). Levothyroxine (T4; brand name Synthroid) is the most commonly used and is recommended by the AACE. However, some experts recommend the addition of T3 (liothyronine; name brand Cytomel) due to its antidepressant effects (Dayan, 2001; Joffe, 2006).

As previously mentioned, proper treatment of thyroid disease is dependent upon accurate diagnosis. Misdiagnosis of thyroid disease delays treatment and can result in progressive psychological and physiological problems (Heinrich & Grahm, 2003; McDermott & Ridgway, 2001) including psychosis (Gaitonde, Rowley, & Sweeney, 2012; Heinrich & Grahm, 2003) and potential heart failure (Hak et al., 2000; Roberts & Ladenson, 2004). These risks highlight the importance of an effective doctor-patient relationship in ensuring proper diagnosis and positive treatment outcomes.

The treatment experiences of women with thyroid disease might be best examined from social constructionist and feminist viewpoints, as both worldviews emphasize individuals' experiences in social contexts (Docherty & McColl, 2003; Fernandes, Papaikonomou, & Nieuwoudt, 2006; Hearn, 2009). From a social constructionist viewpoint, patients' interpretations of their illness experience are important in understanding and treating illness. The feminist viewpoint suggests that female patients' interpretations of their experiences are influenced by social constructs (e.g., health and illness; masculine and feminine) related to the body and gender issues (Docherty &

McColl, 2003). Because social constructs come from patients, physicians, and social institutions (Hearn, 2009), women's experiences with thyroid disease diagnosis and management may be influenced by the culture of the medical profession, diagnostic bias, and gender differences in communication.

Culture of the Medical Profession

In the Western medical profession, health-care practitioners are taught via the medical model to base their diagnostic and treatment decisions on "objective evidence" of disease (e.g., blood tests) and to disregard patients' subjective experiences of illness (Hoffmann & Tarzian, 2001). Additionally, as argued by Annandale and Clark (2000), health has become "marketed as a result of lifestyle choice" (p. 58). In other words, the patient is totally responsible for his or her condition; if a person is overweight, then he or she must lack self-control. According to Vanderford, Stein, Sheeler, and Skochelak (2001), the traditional medical culture has encouraged physicians to behave in a paternalistic or authoritative manner when faced with differing treatment expectations from their patients. Traditional doctor-patient relationships are characterized by authoritarian and paternalistic approaches in which the physician controls the interview, makes a diagnosis, and chooses the treatment plan without the patient's input (Ehrenreich & English, 2005; Vanderford et al., 2001). Research indicates that these types of doctor-patient interactions are related to lowered patient satisfaction and negative treatment outcomes (Bradley, Sparks, & Nesdale, 2001; Chrisler & Parrett, 1995; Copeland, Hudson Scholle, & Binko, 2003; Krupat, 1999; Stokes, Dixon-Woods, & Williams, 2006).

Diagnostic Bias

According to Hoffman and Tarzian (2001), women’s complaints are often not taken seriously by medical professionals because women are viewed as overly emotional and likely to exaggerate their symptoms. Research indicates that physicians are more likely to interpret men’s symptoms as biological and women’s symptoms as psychosocial—that is, that women’s symptoms are a result of a mental, rather than physical, illness (Chrisler, 2001; Hamberg et al., 2004; Hoffmann & Tarzian, 2001).

In their study on the treatment experiences of women with chronic pain, Werner and Malterud (2003) purported that the medical profession encourages a normative, gendered view of illness, which results in a perceived need for women to work harder in order to be perceived as credible patients. As a result, female patients can become wary of honestly communicating their symptoms and the psychosocial effects of those symptoms (Peters et al., 2008).

Gender Differences in Communication

It has been argued that gender differences in medical treatment can be partially explained by gender differences in communication. Whereas men tend to describe their symptoms in a frank and confident manner, women often give generalized descriptions of their symptoms (Hamberg et al., 2004). In addition, women tend to use contextual or more subjective information (e.g., impact on personal relationships) in their symptom reports, while men’s reports tend to be objective descriptions of physical symptoms (Hoffmann & Tarzian, 2001). Although these generalizations do not apply to all men and women, variations in communication patterns across genders have the potential to influence how physicians and patients interact (Hamberg et al., 2004; Platt, 2008; Sandhu, Adams, Singleton, Clark-Carter, & Kidd, 2009).

With regard to conversation during medical consultations, evidence suggests that there is a significant disparity between the communication styles preferred by patients and those preferred by physicians. Platt (2008) reported some of this evidence, noting that doctors commonly complain about verbose patients who tell long stories when doctors ask questions. Additionally, Platt noted that doctors use their authority to encourage patients to communicate in the doctors' preferred styles. Doctor-patient relationships are affected by communication, and gender differences in communication styles could amplify these effects.

In summary, an effective doctor-patient relationship helps to ensure proper diagnosis and positive treatment outcomes (Copeland et al., 2003; Houle et al., 2007; Munch, 2004). An ineffective doctor-patient relationship, on the other hand, has the potential to result in misdiagnosis, delayed or inappropriate medical treatment, and termination of the doctor-patient relationship (Chrisler & Parrett, 1995; Copeland et al., 2003; Houle et al., 2007; Stokes et al., 2006). The nature of the doctor-patient relationship, and hence women's treatment experiences related to thyroid disease, may be influenced by the culture of the medical profession, diagnostic bias, and gender differences in communication. Additional influential factors include sexism in healthcare, the medical education system, and economics, all of which are discussed in detail in Chapter 2.

Problem Statement

Thyroid disease affects approximately 1 out of every 7 women, and its prevalence increases with age (Godfrey, 2007). When properly diagnosed and treated, individuals with thyroid disease should return to normal endocrine function and experience a reduction in psychological and physiological symptoms (AACE, 2002; Bono et al., 2004; Constant et al., 2006). However, due to factors that can make proper diagnosis and treatment challenging (e.g., symptoms resemble other disorders, TSH blood test used alone), women with thyroid disease are often misdiagnosed and receive ineffective medical treatment (Canaris et al., 2000; Dayan, 2001; Godfrey, 2007), which can lead to chronic and worsening health problems (Cappola & Cooper, 2015; Gaitonde et al., 2012; Hak et al., 2000; Heinrich & Grahm, 2003; McDermott & Ridgway, 2001; Roberts & Ladenson, 2004).

The nature of the doctor-patient relationship has the potential to determine positive or negative treatment outcomes (Chrisler & Parrett, 1995; Copeland et al., 2003; Stokes et al., 2006). Numerous studies have been conducted about the influence of the doctor-patient relationship on the treatment outcomes of chronic illness (see Auerbach et al., 2002; Copeland et al., 2003; Docherty & McColl, 2003; Hamberg et al., 2004; Houle et al., 2007; Kralik, Koch, Price, & Howard, 2004; Kralik, Telford, Price, & Koch, 2005; Krupat, Yeager, & Putnam, 2000; Roter, Hall, & Aoki, 2002; Street, Gordon, & Haidet, 2007; Werner & Malterud, 2005; Zandbelt, Smets, Oort, Godfried, & de Haes, 2006). However, there exist no studies in this area related to women with thyroid disease specifically, and even in studies that mention chronic illness generally, thyroid disease is rarely mentioned. Likewise, although studies have suggested that physician and patient gender influences diagnosis and treatment decisions (Di Caccavo & Reid, 1998; Hamberg et al., 2004; Platt, 2008; Sandhu et al., 2009), no such studies have been conducted with female thyroid patients. Despite the pervasiveness of thyroid disease in women and the importance of the doctor-patient relationship in positive treatment outcomes, there is a gap in the literature regarding the treatment experiences of women diagnosed with thyroid disease, particularly regarding the doctor-patient relationship. Exploring the treatment experiences of women with thyroid disease and how the doctor-patient relationship affects their treatment experiences is imperative for better determining the needs of female thyroid patients, and therefore for more accurately diagnosing and effectively treating this debilitating and potentially life-threatening disease.

Purpose of the Study

Exploration of the disease experience among people with thyroid disease is vital for understanding how individuals cope with their chronic illness, thus increasing the potential for the attainment of adequate treatment (Thomas, 2001). Understanding and constructing meaning for chronic illness may be particularly important for women because issues related to the body are instrumental in the formation of female self-identity (Fernandes et al., 2006) and treatment experiences may differ by gender (Hamberg et al., 2004; Hoffmann & Tarzian, 2001; Miaskowski, 1999). In addition, the quality of care that patients receive is directly related to the nature of the doctor-patient relationship (Chrisler & Parrett, 1995; Dugdale, Seigler, & Rubin, 2008; Houle et al., 2007). Therefore, the purpose of this phenomenological study was to explore female thyroid patients’ experiences of treatment and the doctor-patient relationship.

Nature of the Study

This study used the phenomenological research approach because it examines the meaning of experiences about a particular phenomenon (e.g., thyroid disease) across several individuals who have experienced the phenomenon (Creswell, 2007). The research questions in this study were best addressed via qualitative methodology because the purpose of this study was to explore the treatment experiences of women with thyroid disease. According to Marshall and Rossman (2006), human behavior cannot be fully understood without knowledge of the framework within which people interpret their thoughts, feelings, and actions (p. 53). Thus, the use of open-ended questions in each interview was an appropriate method for capturing the experience of the phenomenon (Creswell, 2007).

Using an interview guide sheet (see Appendix A) I created, data were obtained from 16 female members (including myself) of The Thyroid Support Group, an international online support group for individuals with thyroid disorders, via interviews using X-IM, an encrypted online chat program (see http://www.x-im.net/). The recommended sample size of a minimum of 10 participants for phenomenological research corresponds to the traditional quantitative research designs based on statistical power analyses conducted by Onwuegbuzie and Johnson (2004). See Chapter 2 for a discussion of literature related to methodology, including an in-depth discussion of literature related to data collection methods. The nature and methods of the study, including the reliability and validity of the interview guide sheet, are discussed in Chapter 3.

Research Questions

Based upon social constructivism and feminist theory, this study answered the following research questions: “What are the treatment experiences of women with thyroid disease?”; “How does the doctor-patient relationship affect their experiences?”; and “Do their experiences differ based on the doctor’s gender?” These research questions are coded as RQ1, RQ2, and RQ3, respectively, and are listed next to their corresponding interview questions in the interview guide (see Appendix A). The research questions are discussed in further detail in Chapter 3.

Conceptual Framework

In this study, data interpretation was guided by social constructionism and feminist theory. Social constructionism and feminism are worldviews that are compatible with qualitative research approaches because both emphasize individuals’ experiences in social contexts (Docherty & McColl, 2003; Fernandes et al., 2006; Hearn, 2009). Whereas social constructionism assigns a general significance to social and cultural constructs in understanding the illness experience (Findlay, 1993; Docherty & McColl, 2003; Hearn, 2009; Martin & Peterson, 2009), feminist writers make specific arguments about women’s perceptions of their bodies in light of socio-historical facts (Bohan, 2002; Cosgrove, 2003; Fernandes et al., 2006; Shields, 2007). The conceptual framework for the study is discussed in further detail in Chapter 2.

Definition of Terms

The following terms are used throughout the paper and are defined below for ease of reading.

Euthyroid: Normal serum TSH (0.4–4.0 mIU/L) regardless of free thyroxine (fT4) concentration (Walsh et al., 2006). In this state, the individual is considered to have normal thyroid function (AACE, 2002).

Free thyroxine (fT4): The amount of T4 hormone that is not bound to protein and is therefore able to enter cells (normal range is 4.5–11.2 mcg/dL; AACE, 2002). Generally, if the fT4 level is high, the individual is hyperthyroid. In contrast, if the fT4 level is low, the individual is most likely hypothyroid (Aslan et al., 2005).

Free triiodothyronine (fT3): The amount of T3 hormone that is not bound to protein and is therefore able to enter cells (normal range is 100–200 ng/dL; AACE, 2002). Generally, if the fT3 level is high, the individual is hyperthyroid. In contrast, if the fT3 level is low, the individual is most likely hypothyroid (Aslan et al., 2005).

Thyroid stimulating hormone (TSH): TSH, also known as thyrotropin, is secreted from cells in the anterior pituitary and stimulates the thyroid to synthesize and release the thyroid hormones T3 and T4 (Aslan et al., 2005). The normal range for TSH is 0.4–4.0 mIU/L (AACE, 2002).

Thyroglobulin antibodies (TgAb): Antibodies to thyroglobulin, the precursor in the synthesis of thyroid hormones. Detection of TgAb indicates Hashimoto's disease (Thyrasyvoulides & Lymberi, 2004).

Thyroperoxidase antibodies (TPOAb): Antibodies to thyroperoxidase, the enzyme that catalyzes thyroid hormone formation. Detection of TPOAb indicates Hashimoto's disease (Thyrasyvoulides & Lymberi, 2004).

Thyroxine: Also known as T4. One of the two main thyroid hormones secreted by the thyroid gland (Hall, 2010). When used as a medication, T4 is called *levothyroxine* (name brand Synthroid™).

Tri-iodothyronine: Also known as T3. One of the two main thyroid hormones secreted by the thyroid gland (Hall, 2010). When used as a medication, T3 is called *liothyronine* (name brand Cytomel™).

TSH receptor antibodies (TRAb): Antibodies to the TSH receptor on the thyroid follicular cell membrane. Detection of TRAb indicates Grave's disease (Takamura et al., 2003).

Assumptions

The assumptions that exist in the study have been made in reference to participant criteria. The criteria for inclusion in the study were as follows: (a) female, (b) aged 18 years and older, (c) with a diagnosis of thyroid disease, and d) a member of The Thyroid Support Group. As the study was conducted via the Internet and I did not meet with the participants face to face, the participants' ages and gender could not be verified. Likewise, the participants' thyroid disease diagnoses were self-reported. These assumptions allowed for the use of a purposeful (criterion) sample appropriate to a qualitative study rather than a representative, generalizable sample of the larger population (Creswell, 2007).

In addition, a number of participants considered vulnerable may have been included, but were not targeted, in this study. Vulnerable populations include (a) pregnant women; (b) residents of a mental health facility; (c) mentally/emotionally disabled individuals; (d) individuals who might be less than fluent in English; (e) traumatized individuals; and (f) economically disadvantaged individuals. Determining whether or not an individual fits into any of the aforementioned categories would have required asking invasive questions unrelated to the study. Furthermore, verification was impossible due to the nature of the Internet. Participants were informed that they had the right to leave the study at any time for any reason, without explanation.

As discussed in detail in Chapter 3, measures were taken in the study to protect participants, including the use of consent forms, confidentiality, and secure storage of data.

Delimitations

This study was delimited as follows: Participants were females aged 18 years and older who had a thyroid disease diagnosis. Although thyroid disease is most common in women ages 35 and older (Godfrey, 2007), thyroid disease can occur at any age and is influenced by genetic and environmental (e.g., smoking) factors (Manji et al., 2006). Excluding participants under age 35 would have likely precluded individuals who experienced thyroid disease early in life due to genetic and environmental factors (Godfrey, 2007; Manji et al., 2006), which would have eliminated an important subset of experiencers. Eliminating participants over age 35 would have precluded those individuals who experienced thyroid disease late in life due to an age-related decline in the thyroid hormones T3 and T4 (Begin, Langlois, Lorrain, & Cunnane, 2008; Morganti et al., 2005). This would have eliminated another important subset of experiencers. Thus, the wide age range is a form of maximum variation for the phenomenon that was studied—thyroid disease in women (Creswell, 2007).

The participants were members of an online support group who chose to participate in the study and who were able to access and install X-IM software on their computers. Although participants could be from anywhere in the world, the sample was delimited to individuals who were able to write in the English language.

Limitations

A limitation of the study is the potential for personal bias, as I have a thyroid disease diagnosis and have been a member of The Thyroid Support Group since 2004. In order to control for this limitation, reflexive journaling was used during data collection and analysis. According to Moustakas (1994), when conducting phenomenological research, it is important for the researcher to identify his or her opinions or bias on the subject being studied. Therefore, I maintained a journal about personal feelings and opinions so they could be separated from the data. Moreover, Chapter 3 of this study contains a discussion of the role of the researcher in which my background and history as a thyroid patient are disclosed.

While research indicates that online support groups are desirable among adults with chronic illnesses, Internet users tend to be young, Caucasian, and have convenient access to a computer (Fox & Jones, 2009; Kraut, Olson, Banaji, Bruckman, & Couper, 2004). As such, the results of the study may not be generalizable to older, non-Caucasian individuals who do not have convenient computer access. Another limitation is that the sample was self-selected, which means that the sample may vary systematically and therefore may not be representative of most female thyroid patients.

Significance of the Study

Thyroid disease causes a wide range of somatic and psychiatric symptoms that can be difficult to distinguish from those of other disorders. As such, many individuals with thyroid disease are misdiagnosed and experience progressive psychological and physiological problems (Canaris et al., 2000; Godfrey, 2007; Heinrich & Grahm, 2003; McDermott & Ridgway, 2001; Simmons, 2010). Within the prevalent culture of the medical profession, these problems are particularly troublesome for female patients, who may be met with sexism and marginalization in traditional doctor-patient relationships (Hoffman & Tarzian 2001; Platt, 2008; Werner & Malterud, 2003).

Numerous studies on chronic illness have indicated that diagnosis, treatment decisions, and treatment outcomes are related to physician and patient gender (Di Caccavo & Reid, 1998; Hamberg et al., 2004; Platt, 2008; Sandhu et al., 2009) and the nature of the doctor-patient relationship (Copeland et al., 2003; Houle et al., 2007; Munch, 2004). Expanding upon this research to explore the treatment experiences of women diagnosed with thyroid disease could contribute to positive social change by enhancing our understanding of how women experience the phenomenon of treatment of thyroid disease and the doctor-patient relationship, and ultimately help to determine the factors related to positive treatment outcomes. Proper diagnosis and effective management of thyroid disease can benefit female patients by preventing misdiagnosis or delayed diagnosis, thus minimizing the potential for progressive health problems (Godfrey, 2007).

Considering that there are an estimated 158,288,693 women living in the United States (U.S. Census Bureau, 2012) and that approximately 1 in every 7 women develops thyroid disease (Godfrey, 2007), approximately 22,612,670 women in the United States may be expected to have thyroid disease. If the findings of the study are used in crafting follow-up studies of a quantitative nature, the results of such studies may benefit the approximate 22,612,670 women dealing with thyroid disease, as well as secondarily benefit the families and communities who support them. The results of such follow-up studies may, in turn, indirectly reduce healthcare costs (Darer, Hwang, Pham, Bass, & Anderson, 2004; Keck, Kessler, & Ross, 2008; Leifer, 2003; McKee & Peyerl, 2012; Rothman & Wagner, 2003) along with the incidence of complaints and litigation resulting from dissatisfied patients (Firth-Cozens, 2008a, 2008b). In light of the widespread nature of thyroid disease, the potential for a decrease in misdiagnosis and a reduction in complaints, litigation, and healthcare costs constitutes a substantial contribution to positive social change.

I intend to publish a condensed version of this study in a scholarly journal so that healthcare professionals can use the information in practice and future research. According to Creswell (2007) and Schensul and LeCompte (1999), researchers must shape the language of research results with their audience(s) in mind. As such, the findings of this research will be presented in a scholarly manner, but with minimal use of technical jargon. Some of the participants' quotes will be used in order to personalize the results. Recommendations for further research will be provided, in addition to suggestions for how patients and doctors might be able to work collaboratively and communicate more effectively with each other.

Summary and Transition

Approximately 1 out of every 7 women develops thyroid disease, and its prevalence increases with age, yet the most commonly used blood test for diagnosing thyroid disease and for determining treatment effectiveness can produce misleading results. Because of this, clinically important diagnoses are missed, and many women with thyroid disease continue to experience symptoms even when they are receiving treatment. In addition, even once diagnosed with thyroid disease, female patients have reported that their physicians are not responsive to their complaints.

Despite the pervasiveness of thyroid disease in women, there is a gap in the literature regarding the treatment experiences of women diagnosed with thyroid disease, particularly regarding the doctor-patient relationship. Therefore, the purpose of this phenomenological study was to explore female thyroid patients' experiences of treatment and the doctor-patient relationship.

Data were collected from 16 female members (including myself) of The Thyroid Support Group via individual online chat interviews. Using ATLAS.ti software and the analytic method recommended by Moustakas (1994), data interpretation was guided by social constructionism and feminist theory. Themes related to the culture of the medical profession, diagnostic bias, and gender differences in communication were identified.

Chapter 2 presents the literature search strategy, the conceptual framework for the study, and a review of the literature related to the chosen methodology. A thorough review of the literature on the doctor-patient relationship, the culture of the medical profession, diagnostic bias, and gender differences in communication is given. Finally, a summary of the chapter is provided.

Chapter 3 contains a description of the research design and approach of the study, including a detailed discussion of the benefits of using a qualitative design over a quantitative design for the population that was studied. In addition, the suitability of phenomenology as opposed to other qualitative methods is explained. The context of the study is provided, along with a description of the participants and the role of the researcher. The procedures and instrumentation used for data collection are detailed, as are the steps taken to ensure the protection of participants. Finally, data analysis, trustworthiness, interpretation, and dissemination are discussed.

Chapter 4 presents the themes derived from the data analysis and is supplemented with direct quotations from the participants' responses to interview questions. Evidence of data quality is also discussed.

Chapter 5 provides an interpretation of the findings based on the relationship among the themes, research questions, and theories presented in Chapter 2. The chapter concludes with a discussion about limitations of the study, recommendations for future research, the dissemination of findings, implications for social change, and conclusions.

Chapter 2: Literature Review

Introduction

This chapter contains a review of the literature on the treatment experiences of women with thyroid disease. It is argued that women with thyroid disease experience the doctor-patient relationship as fraught with difficulty owing to the culture of the medical profession, diagnostic bias, and gender differences in communication. As the nature of the doctor-patient relationship is related to patient satisfaction and treatment outcomes, an understanding of the treatment experiences of women with thyroid disease may help to enhance the potential for proper diagnosis and effective treatment in female thyroid patients' interactions with medical professionals.

The following section provides a description of the literature search strategy used, followed by an overview of thyroid disease. The conceptual framework for the study is described, and a review of the literature related to the chosen methodology is given. A thorough review of the literature on the doctor-patient relationship, the culture of the medical profession, diagnostic bias, and gender differences in communication is given. Finally, a summary of the chapter is provided.

Literature Search Strategy

The effort to develop this literature review began in March 2009 with searches in the EBSCOhost and ProQuest databases. Subsequent narrowing of the search included the use of the following databases: Academic Search Premier, Alt HealthWatch, CINAHL Plus with Full Text, ProQuest Dissertations & Theses Full Text, ERIC, Health Source: Nursing/Academic Edition, MEDLINE with Full Text, ProQuest Nursing &

Allied Health Source, ProQuest Central, ProQuest Health and Medical Complete, ProQuest Psychology Journals, Psychology and Behavioral Sciences Collection, PsycARTICLES, PsycBOOKS, PsycINFO, SocINDEX with Full Text, and Sociological Collection.

The initial search included the use of the terms *women* and *thyroid disease* and was expanded to include the terms *diagnosis*, *treatment*, *gender*, and *doctor-patient relationship*. Upon collection of relevant articles, the following search terms were added in June 2009: *diagnostic bias*, *culture* and *medical profession*, *doctor education*, *gender differences* and *communication*, *attitudes*, *perceptions*, *power*, *empathy*, *patient autonomy*, *patient competence*, and *patient credibility.* Between September 2009 and October 2010, a review of the reference lists in each article resulted in the collection of additional journal articles and books. Between November 2010 and February 2012, the aforementioned databases were searched for articles related to conducting research on the Internet. The following search terms were used: *online research*, *Internet research*, *online interviews*, *synchronous*, *asynchronous*, *chat*, and *ethical considerations*. In September 2012, an additional search of the aforementioned databases was conducted to gather articles regarding economic issues associated with chronic illness. The following search terms were used: *chronic illness* and *economic issues*, *misdiagnosis* and *delayed diagnosis*, and *healthcare costs*. In December 2012 and January 2013, the aforementioned databases were searched in order to gather literature about the steps that various research, educational, and medical institutions have taken to enhance awareness of gender issues in medicine. The following search terms were used: *women* and *medical* *profession*, *women* and *inclusion* and *research, doctor-patient relationship* and *gender*, and *doctor-patient relationship* and *women*.

After conducting the study and writing Chapter 4, I searched the aforementioned databases one more time in order to ensure that Chapter 5 would be written with consideration of the most recent literature available. From March 2015 through June 2015, the following search terms were used, and the resulting literature was incorporated into Chapters 1, 2, and 5: *women* and *thyroid disease, diagnosis* and *treatment, natural thyroid medication, doctor-patient relationship, gender, shared decision making, patient self-advocacy behaviors, switching doctors, self-medicating, health information-seeking,* and *patient education level*. Thus, searching of the literature took place from March 2009 through January 2013 and then again from March 2015 through June 2015.

Overview of Thyroid Disease

Thyroid disease affects an estimated 30 million Americans (AACE, 2013) and 200 million people worldwide (Rajoria et al., 2010). It is estimated that of the 30 million Americans with thyroid disease, more than half are undiagnosed (AACE, 2013). Thyroid disease is more prevalent in women than men, regardless of culture, and occurs in approximately 1 out of every 7 women (Canaris et al., 2000; Cassidy et al., 2002; Godfrey, 2007). Women's risk for developing thyroid disease increases with age (about 20% in women over age 60; Godfrey, 2007). Hyperthyroidism and hypothyroidism are the two predominant conditions that result from thyroid disease, with Grave's disease and Hashimoto's disease, respectively, as the most common causes (Zeitlin et al., 2008). Both conditions cause a wide range of somatic and psychiatric symptoms.

Hyperthyroidism

Hyperthyroidism results from the overproduction of thyroid hormone by the thyroid gland (AACE, 2002), and tends to be accompanied by symptoms of anxiety and panic disorders (Aslan et al., 2005). Other symptoms associated with hyperthyroidism include heat intolerance, hot flashes, absent menses, insomnia, decreased libido (Godfrey, 2007), rapid heartbeat, sweating, and tremors (Aslan et al., 2005), diffuse goiter, and ophthalmological abnormalities (Ginsberg, 2003). Grave's disease, an autoimmune form of thyroid disease, is the most common cause of hyperthyroidism in the United States (Bunevicius & Prange, 2006; Goolsby & Blackwell, 2004).

Hypothyroidism

Hypothyroidism is caused by the undersecretion of thyroid hormones by the thyroid gland (AACE, 2002), and often presents with symptoms of major depression and bipolar depression (Aslan et al., 2005). Other symptoms that tend to occur with hypothyroidism include fatigue (Bono et al., 2004), lethargy, apathy, difficulty concentrating and slowing of thought processes (Aslan et al., 2005; Bono et al., 2004), weight gain, dry skin, and decreased libido (Godfrey, 2007). In extreme cases, the individual may experience slowing of thought processes, progressive cognitive impairment, hallucinations, and delusions (Bono et al., 2004). Hashimoto's disease, an autoimmune form of thyroid disease, is the most common cause of hypothyroidism in the United States (Erdal et al., 2008; Goolsby & Blackwell, 2004).

It is important to note that the most common causes of thyroid disease are autoimmune in nature, as autoimmune diseases tend to co-occur. In fact, approximately

25% of women who have an autoimmune disorder will develop thyroid disease (Godfrey, 2007). A definitive diagnosis of thyroid disease requires a physical examination and thorough history of the patient (Goolsby & Blackwell, 2004).

Diagnosis

Making a definitive diagnosis of thyroid disease has shown to be challenging due to a number of factors. Namely, the "gold standard" thyroid-stimulating hormone (TSH) blood test for diagnosing thyroid disease tends to be used alone (Adams, 2008, p. 1), despite evidence that the use of all three main thyroid function tests (TSH, free T3, free T4) produces the most thorough analysis of thyroid function (Beckett & MacKenzie, 2007; Dayan, 2001; Rivera, Sampson, & Sola, 2015). As an example of how TSH testing alone can produce misleading results, TSH values can be within the normal range while free T3 and/or free T4 values indicate thyroid dysfunction (Dayan, 2001). Thus, when the TSH blood test is used alone for initial screening of thyroid disease, clinically important diagnoses (e.g., hyperthyroidism and hypothyroidism) may be missed. In addition, although approximately 13 million Americans with thyroid disease remain undiagnosed (Goolsby & Blackwell, 2004), the U.S. Preventive Services Task Force indicated a lack of evidence for recommending for or against routine screening for thyroid disease in adults, thus leaving the use of this potentially beneficial diagnostic measure to the discretion of individual practitioners (Helfand, 2004). Even further, thyroid disease is often mistaken for other conditions due to the similarity in its symptoms to other disorders such as major depression, bipolar depression (Aslan et al., 2005; Pearce, 2015), postpartum depression, psychosis (Fassier et al., 2011), anxiety and panic disorders, phobias (Aslan et al., 2005), menopause, and dementia (Godfrey, 2007; Shimabukuro, 2008). Thus, a thorough assessment, including a physical examination and complete history of the patient, is vital for ensuring proper diagnosis and treatment of an individual with thyroid disease (Goolsby & Blackwell, 2004).

Treatment

Hyperthyroidism. Radioactive iodine (RAI), antithyroid drugs, and thyroidectomy are the three types of treatments available for hyperthyroidism in the United States (AACE, 2002). An ablative dose of RAI is considered the treatment of choice for hyperthyroidism. In cases of patients who are pregnant or nursing, antithyroid drugs are considered safer than RAI. However, remission rates are variable and relapses are frequent when antithyroid drugs are used alone (Goolsby & Blackwell, 2004). Thyroidectomy tends to be performed only when cancer of the thyroid is suspected. Regardless of the treatment chosen, individuals treated for hyperthyroidism become euthyroid and then hypothyroid, and they require lifelong thyroid hormone replacement therapy (AACE, 2002; Goolsby & Blackwell, 2004).

Hypothyroidism. Lifelong thyroid hormone replacement therapy is the only treatment option available in the United States for individuals with hypothyroidism (AACE, 2002; Goolsby & Blackwell, 2004). The most commonly used medication is levothyroxine (T4; brand name Synthroid), which is recommended by the AACE. Some experts recommend the addition of T3 (liothyronine; name brand Cytomel) for its antidepressant effects (Dayan, 2001; Joffe, 2006). The dosage of these medications is determined by the results of the patients' blood work (the TSH blood test, and sometimes the free T3 and free T4 levels; AACE, 2002; Adams, 2008).

Effective treatment of thyroid disease depends upon an accurate diagnosis of hyperthyroidism or hypothyroidism (Cappola & Cooper, 2015; Goolsby & Blackwell, 2004; Heinrich & Grahm, 2003; McDermott & Ridgway, 2001). Regular monitoring of the thyroid patient's symptoms and interpreting blood work are necessary for determining treatment effectiveness. However, as previously mentioned, the TSH blood test, used alone, does not provide the most thorough analysis of thyroid function (Adams, 2008; Beckett & MacKenzie; Dayan, 2001; Rivera et al., 2015). Thus, in cases in which physicians do not use all three main thyroid function tests, thyroid patients often experience chronic or worsening symptoms (Bunevicius & Prange, 2006; Heinrich & Grahm, 2003; McDermott & Ridgway, 2001).

Diagnostic and treatment challenges related to thyroid disease underscore the importance of an effective doctor-patient relationship (Copeland et al., 2003; Houle et al., 2007; Munch, 2004). Female thyroid patients' experiences of treatment and the doctor-patient relationship might be best understood through the lens of social constructivism and feminism, as both worldviews emphasize individuals' experiences in social contexts (Hearn, 2009; Docherty & McColl, 2003).

Conceptual Framework

In this study, data interpretation was guided by social constructionism and feminist theory. Themes related to the culture of the medical profession, diagnostic bias, and gender differences in communication—all of which are discussed later in this chapter—were identified. Emergent themes were also identified. This study expands the research on women's health and adaptation to chronic illness by examining female thyroid patients’ experiences of treatment and the doctor-patient relationship, which have not been studied from a social constructionist/feminist perspective.

Social Constructionism

Lupton (2003) and Martin and Peterson (2009) described the trajectory in medical thought by which social constructionism arose as a response to the biomedical model (p. 579). The biomedical model in health care arose in the 18th century. This model located disease in specific parts of the body and reduced medical concerns to mechanistic processes. In the 1950s, as a response to the biomedical model, Talcott Parsons developed the functionalist perspective, in which the role of a sick individual is seen as a social response to the deviant place in society occupied by persons with poor health (Martin & Peterson, 2009). In the functionalist perspective, patients desire to be accepted by society and therefore seek verification from doctors that they are not malingering (Lupton, 2003). Although Parson’s work is acclaimed for identifying the role of society in understanding illness, the functionalist perspective has been criticized for characterizing patients as passive and grateful, while doctors were portrayed as universally competent and altruistic. In addition, according to Lupton (2003), the functionalist viewpoint did not take into consideration the potential for conflict within the doctor-patient relationship. The social constructionist model emerged in the 1980s in response to these criticisms.

Within the social constructionist model, knowledge and “truth” are not understood as universal, but rather as dependent upon the individual’s subjective interpretation of reality (Lupton, 2003; Patton, 2002). In this perspective, all medical issues, including health, chronic illnesses, and medical care, are socially constructed facts that are subject to varying degrees of consensus and interpretation due to cultural factors and social norms (Docherty & McColl, 2003; Fernandes et al., 2006; Hearn, 2009; Lupton, 2003). In other words, in the management of illness, both the patient and the doctor are influenced by their individual beliefs and experiences and the society in which they live. Thus, the social constructionist perspective is appropriate to the qualitative study of health and disease, which takes as its data the personal experiences, perceptions, observations, and narratives of individuals (Creswell, 2007; Hearn, 2009).

The logical positivist perspective, commonly used in quantitative research, involves an assumption that there are stable, social facts with a single reality, separated from the feelings and beliefs of individuals (Creswell, 2007). In other words, regardless of how an individual perceives an event, only one interpretation of that event is considered to be appropriate or based on “truth” (Patton, 2002). For example, if an individual is diagnosed with a chronic illness and the medical profession contends that such a diagnosis should have a minimal emotional impact on the individual, for him or her to react in any other manner (e.g., fearful, depressed) would be considered abnormal. In contrast, social constructionism, commonly used in qualitative research, is based on the belief that multiple realities are socially constructed through individual (constructivism) and collective (constructionism) perceptions of the same situation

(Patton, 2002). For example, on the individual (constructivist) level, one person might view a chronic illness diagnosis as manageable, while another person might view that same diagnosis as emotionally devastating. These individual perceptions are influenced by the collective (constructionist) framework (e.g., cultural values and norms) in which one lives. Within the social constructionist perspective, both of these interpretations would be considered valid.

Docherty and McColl (2003) noted that a social constructionist approach takes patients' interpretations of their illness experience into account. These interpretations are relevant because they influence the patients' feelings, reactions, and behaviors. Fernandes et al. (2006) noted that those adopting a social constructionist perspective view the body in light of the ways in which society assigns meaning to it (e.g., "healthy" and "unhealthy," "normal" and "abnormal," and "masculine" and "feminine"). Thus, the female body and bodily illnesses take on certain meanings in a social context, and these meanings influence patients' interpretations of the illness experience (Fernandes et al., 2006). Using a qualitative approach, Fernandes et al. interviewed women living with breast cancer, eating disorders, and infertility and found that these women's illnesses manifested emotionally and socially as loss, anger, emptiness, loneliness, and isolation.

Findlay (1993) also argued that social construction is an important source of knowledge in the fields of science and medicine. However, according to Findlay, the technical nature of scientific and medical knowledge often results in perspectives that neglect the social contexts and construction of this knowledge. More specifically, diagnostic and treatment decisions tend to be based on "objective evidence" of disease (e.g., blood tests), and patients' subjective experiences of illness are largely ignored (Hoffmann & Tarzian, 2001). Furthermore, competing perspectives among pharmaceutical, medical, and insurance companies influence diagnostic and treatment decisions (Hearn, 2009). In order to underscore the social and political aspects of medical knowledge and practice, Findlay (1993) argued that biomedicine defines disease as a deviation from a particular standard viewed as biological normalcy. This standard, though often unquestioned, is socially and culturally determined. The implications of this can be seen, for example, in the way in which physicians treated female fertility issues in the 1950s, which often assumed a specific, socially constructed set of values (Findlay, 1993). Findlay cited descriptions of the hormonal systems of males and females from this period, noting that libido was emphasized in males and reproduction was emphasized in females, and argued that acknowledgment of hormones in females was restricted to those directly related to reproduction.

Feminists contend that women continue to be viewed by the medical profession as being at the mercy of their reproductive hormones (Fernandes et al., 2006; Munch, 2004; Wright & Owen, 2001). This perception could have a significant impact on women with thyroid disease because of the psychological symptoms resulting from the hormone imbalances involved in thyroid dysfunction (Shimabukuro, 2008). According to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (American Psychiatric Association, 2000), several of the most common cognitive, mood, anxiety, and psychotic disorders might be best explained by thyroid dysfunction. Yet, there are pervasive beliefs among physicians that women over-report pain and that vague symptoms are the results of mental, rather than physical, illness (Chrisler, 2001; Hoffmann & Tarzian, 2001). Viewed from a social constructionist perspective, these examples show how socio-cultural constructs, perspectives, and attitudes can influence the field of medicine.

Feminism

Despite efforts to incorporate gender-sensitive practices into the field of medicine, historically-based knowledge and beliefs about women persist (Chrisler, 2001; Hoffmann & Tarzian, 2001; Sherwin, 1999). Thus, the relevance of feminism to the current treatment of women in the medical field might be best understood from a historical review of oppressive practices. In the 19th and early 20th centuries, women's bodies were viewed as unstable and their minds were viewed as fragile (Fernandes et al., 2006). These beliefs resulted from the subordinate position that society assigned to women, who were assumed to be more at the mercy of biological forces than were men (Fernandes et al., 2006). Based upon theories of reproductive physiology, women were expected to maintain specific behaviors and social roles (Bohan, 2002; Cosgrove, 2003; Shields, 2007). For example, women were thought to be naturally passive and nurturing and were advised to remain in the home as wives and mothers, as it was believed that too much social interaction would cause physical and emotional distress (Bohan, 2002). In addition, psychologists asserted that obtaining a higher education would damage a woman's ability to reproduce (Bohan, 2002; Schultz & Schultz, 2004).

In psychology as well as in biomedicine, women were historically viewed as fundamentally different from and inferior to men. In psychological practice, the presence of “feminine” emotion (e.g., fear, anxiety) was deemed problematic for women and abnormal in men (Shields, 2007). Although assertions regarding women’s physical and intellectual inferiority to men appeared to be supported by scientific evidence (e.g., men’s brains are larger than women’s), the attributes assigned to each sex were based on biased research practices (Cosgrove, 2003). More specifically, as women were thought to be emotionally fragile and of “mediocre” intelligence compared to men, they were excluded from scientific study (Bohan, 2002, p. 76; Sherwin, 1999). Public debates about mind-body issues (e.g., the influence of cognitive awareness of physical pain on emotion and behavior) among non-academic writers and readers perpetuated popular notions of women’s nature and gender differences (e.g., that women were naturally passive, as opposed to men who were thought to have an innate drive to achieve and dominate; Shields, 2007).

Feminism arose as a response to and rejection of such beliefs (Shildrick, 1997). By the 1970s, feminists claimed that the relationship between selves and bodies, along with perceptions of them, is socially constructed. Feminism attempts to redefine this relationship such that the body is more than simply a reproductive object (Bohan, 2002; Cosgrove, 2003; Fernandes et al., 2006). Bohan (2002) described three distinct phases in the development of feminist psychology. The first phase was characterized by adopting therapeutic techniques that fit into feminist philosophy with the intention of empowering women. The second phase involved integrating feminist philosophy into psychological theories. The final and continuing phase consists of trying to develop a unique and comprehensive theory that explains the common experiences of women.

With regard to the medical field, feminist theory presents a response and challenge to the functionalist model, which asserts that physicians must adopt a position of authority in order to assure patients' recovery, and that patients must accept these roles and trust physicians (Lupton, 2003; Munch, 2004). Feminists argue that patients are the experts of their own medical conditions (Chrisler, 2001; Hoffmann & Tarzian, 2001) and contend that medical knowledge is largely socially constructed—that is, health, chronic illnesses, and medical care are influenced by cultural factors and social norms (Fernandes et al., 2006; Lupton, 2003). Thus, a feminist approach to medicine encourages patients and physicians to question concepts of "normal" and "healthy" and for physicians to consider patients' subjective interpretations of their own illness (Hoffmann & Tarzian, 2001; Wright & Owen, 2001).

According to Verdonk, Benschop, de Haes, and Lagro-Janssen (2008), in the 1990s, studies on women's health began to include women's interpretations of their illness experiences. Such studies continue to be conducted and have expanded to include the influence of gender relations. Nevertheless, medical knowledge is historically based on research in which women were significantly underrepresented (Findlay, 1993; Sherwin, 1999) and the inclusion of female participants in current medical research continues to fall short of male participants. In their paper written on behalf of the Endocrine Society, Alexander-Bridges and Doan (2007) reported that no mandate currently exists to include women and other minorities in industry-sponsored drug trials. Furthermore, despite the Food and Drug Administration's (FDA) 1993 *Guideline for the Study and Evaluation of Sex Differences in Clinical Evaluation of Drugs*, women continue to be unrepresented in clinical trials for the testing of drugs before marketing (Mastroianni, Faden, & Federman, 1999). According to a study by Yang et al. (2009), in clinical trials for 67 new drugs approved by the FDA between 2000 and 2002, women were significantly underrepresented in early phase trials and certain areas including cardiovascular, renal, and gastroenterology, and psychiatry products.

Sherwin (1999) argued that the process by which research is conducted may maintain and promote medical practices that oppress women. These research and medical practices could have a significant impact on women with thyroid disease, particularly with those that are autoimmune in nature (i.e., Hashimoto's and Grave's disease), as autoimmune diseases are the third-most common diseases in the United States, preceded by heart disease and cancer (Committee on Women's Health Research, 2010). According to the Committee on Women's Health Research (2010), although progress has been made over the past couple decades in knowledge about the pathophysiology of autoimmune diseases in women, research has not yet led to effective treatments beyond managing the symptoms.

Adopting a feminist approach to qualitative research involves accepting the narratives about the history of psychology, philosophy, and medicine that feminism proposes. Female patients' illness experiences can be interpreted in light of this narrative. Alongside social constructionism, a feminist approach suggests that female patients' interpretations of their experiences are influenced by social constructs related to the female body, gender issues, and the experience of being a woman (Hearn, 2009).

The Doctor-Patient Relationship

According to Dr. Francis Peabody (1927), proper diagnosis and treatment are dependent upon the quality of the relationship between doctor and patient. Despite this widely-acknowledged importance, traditional doctor-patient relationships have been characterized by authoritarian, paternalistic, doctor-centered approaches, and physicians have historically behaved in ways that marginalize women (Ehrenreich & English, 2005; Vanderford et al., 2001). In contrast, research has shown that doctor-patient relationships that are collaborative, respecting of patient autonomy, and non-sexist have a positive impact on treatment outcomes (Chrisler & Parrett, 1995; Dugdale et al., 2008; Fox & Chesla, 2008; Houle et al., 2007; Peck & Connor, 2011). I am not implying that physicians who work in a traditional relational-style deliberately intend to marginalize or oppress women. Rather, as oppressive practices are systemically ingrained in society by historically-based knowledge and beliefs, "conscious and persistent effort [is required] to resist complicity in [the] patterns" of such practices (Sherwin, 1999, p. 11). The characteristics of traditional doctor-patient relationships are discussed in the following paragraphs.

Traditional Doctor-Patient Relationships

Authoritarianism and paternalism. Authoritarian doctor-patient interactions are characterized by a hierarchical relationship wherein the doctor is in a position of authority over the patient. A paternalistic doctor-patient relationship combines this authority with a concern for the patient's well-being (Kittay, 2007). According to Berger (2002) and Paterson (2000), authoritarian and paternalistic attitudes in medicine stem from the moral authority afforded to doctors upon taking the Hippocratic Oath. In other words, doctors are expected to improve their patients' lives and avoid causing harm, and hence, the doctor acts as a father-like guide for the patient (Berger, 2002). However, doctor-patient relationships based on authoritarianism and paternalism discourage respect for patients' autonomy (Kittay, 2007).

Historically, doctors have possessed specialized knowledge and medical expertise inaccessible to the public. Although this is still the case, today's public has greater access to medical information (Hearn, 2009). Nevertheless, the hierarchy between patients and physicians persists. According to Hearn (2006), physicians feel that their traditional, paternalistic roles are threatened by well-informed patients. McGuire, McCullough, Weller, and Whitney (2005) conducted a qualitative, cross-sectional survey of physicians. The results indicated that, although most physicians have a positive view of patient involvement in medical decision making, physicians view their role as that of an expert whose duty is to educate patients and make recommendations for treatment. In this type of relationship, the physician has decisional priority (i.e., suggests the plan of action) and the patient has decisional authority (i.e., accepts or rejects the plan). McGuire et al. described this one-dimensional model of shared decision making as "ethically inadequate" because it does not account for the variability among patients regarding desire for information and involvement (p. 466).

Based on their study of patient autonomy level and preferred doctor communication style, Kaplan, Schneiderhan, Harrown, and Omens (2002) suggested that physicians should base their approach to information sharing and decision making on their patients’ individual levels of autonomy. Kaplan et al.’s research indicated that for female participants, the higher their level of autonomy, the stronger their preference was for doctors who had an informative versus a paternalistic communication style. Whereas a paternalistic communication style is directive, an informative communication style is participative and encourages patients to make informed treatment decisions. Like female participants, male participants preferred doctors with an informative communication style; however, the male participants’ preferences were not influenced by their autonomy levels.

Similar research by Bradley et al. (2001) revealed that regardless of patient gender, patients were more satisfied with physicians who used a consultative (informative) communication style as opposed to an authoritative (paternalistic) communication style. When physicians used a consultative communication style, levels of satisfaction were highest among young participants (less than 30 years of age) regardless of physician gender, and among older participants (between 30 and 49 years of age) when the doctor was male. When an authoritative communication style was used, levels of satisfaction were lowest among middle-aged participants (50 years of age and older), particularly when the physicians were female. Bradley et al. proposed that these results might reflect conventional gender-role expectations among the middle-aged participants.

Research indicates that authoritarian and paternalistic doctor-patient relationships can have negative consequences for both physicians and patients. Stokes et al. (2006) conducted a study of cases in which general practitioners (GPs) in the UK terminated relationships with patients. Based on accounts of the situations given by both the GPs and the patients, the researchers concluded that the GPs were strategically exercising symbolic power in terminating the relationship (Stokes et al., 2006, p. 613). In the cases considered, this was often due to a conflict between GPs' recommendations and the patients' requests or demands. In such cases, the GPs chose to cease treating the patients rather than adopt a more collaborative approach to healthcare.

According to Risberg, Hamberg, and Johansson (2006), medical knowledge based on biomedical approaches are privileged within the medical field at the top of a hierarchy of research types. This could suggest a tendency among physicians to undervalue patients' knowledge or to undervalue doctor-patient relationships that do not conform to the dominant hierarchies. In fact, patients tend to be viewed by health care professionals as "difficult" when they do not adopt the role expected by the physician (MacDonald, 2003). Risberg et al. (2006) linked this phenomenon to gender bias in the medical field and a resistance to gender awareness. In addition to reinforcing authoritarianism, this state of affairs can result in gender-biased doctor-patient relationships. In their study about the influence of "status characteristics" on doctor-patient interaction, Peck and Connor (2011) interviewed 179 patients regarding their experiences with their physicians. Status characteristics are based on cultural beliefs in which a higher status and level of competence is associated with one group (e.g., men) over another (e.g., women). Results of the study indicated that doctor-patient interactions were more paternalistic and less patient-centered when the doctor was male and the patient was female versus interactions in which the doctor was female and the patient was male or female. Since status beliefs often form and exist at a subconscious level (Rashotte & Webster, 2005), male doctors may be unaware that they are interacting in a more paternalistic fashion with their female patients than their male patients.

Mutter (1999) discussed the paternalistic influence of the dominant “military metaphor” in modern medicine. This view holds that medicine is a war against disease and death. This type of thinking, according to Mutter, encourages physicians to ignore patients’ mental concerns and focus on the physical, emphasizing control over physical forces acting within the patient. This can result in the presumption that the doctor knows more about the patients’ experiences of their bodies than the patients themselves.

In a study of 20 women who had had elective hysterectomies, Lorentzen (2008) discovered that, among negative experiences with doctors, those that were most impactful for the participants were those in which physicians attempted to make false claims about the women’s bodies. The participants found most disturbing those claims that they described as “inaccurate, potentially harmful, demeaning, and as discounting the women’s experiential knowledge of their own bodies” (p. 60). Similarly, female patients in a study by Copeland et al. (2003) complained that doctors did not treat them with respect, did not answer questions without getting impatient, and were judgmental, insensitive, patronizing, and condescending. They explained that they wanted doctors to be sensitive to the whole person, and to express an interest in their feelings, mind, body, and spirit.

Marginalization of women. The marginalization of women by physicians can be viewed as a byproduct of the predominant cultural view, discussed above, of women as physically unstable and mentally fragile (Fernandes et al., 2006). According to Werner and Malterud (2003), at the end of the 19th century, unexplained conditions in women were often seen as attempts to gain power or attention. Consequently, women risked going without treatment if physicians deemed them either overly feminine or overly aggressive and opinionated.

According to Chrisler (2001), the traditional patient role is similar to traditional female gender roles. Both roles encourage passivity, cooperation, dependence, and acceptance. This marginalizes women by making it difficult for them to be assertive or challenge doctors, lest they be labeled bad patients (Chrisler, 2001). Chrisler argued that this could result in misdiagnosis for women in the early stages of autoimmune disorders because their symptoms are often vague.

Marginalization of women can be seen on both individual and societal levels. At the individual level, marginalization of women is also evident in relationships between women and psychologists. According to Wright and Owen (2001), diagnoses of mental illness tend to devalue the female role as perceived by a socially constructed standard. Thus, women who deviate from the normal female role are often seen as mentally ill, and women who conform to the role could also be diagnosed with mental illness because the role is itself marginalized.

At the societal level, medical research and physician reports have also shown a trend of marginalization. According to Findlay (1993), the biological functions of the female reproductive system have historically been viewed in terms of their teleology, rather than strictly descriptively. For example, researchers in the 1950s claimed that changes in the uterine wall during pregnancy were designed to increase space inside the uterus. Findlay argued that the use of this type of language and this conceptual approach to female reproductive processes revealed a mechanistic, objectifying view of women.

Modern Doctor-Patient Relationships

Collaboration. According to Sacks (1987), a neurologist and essayist, “Whereas modern medicine may provide invaluable insights into chemical and biological courses of disease, only patients hold the clues to what their diseases are really like” (p. 40). Sacks’ statement indicates the importance of collaboration between doctors and their patients; doctors cannot gain insight into patients’ experiences unless they actively attempt to understand patients’ points of view.

With the rise of patient-centered care in the last 10 years, there has been a shift in the communication style of many medical practitioners—a more collaborative approach in which patients’ preferences are considered in treatment decisions (Breen et al., 2009; Levinson, Lesser, & Epstein, 2010). In a study by Butalid, Verhaak, Boeije, and Bensing (2012), analogue patients viewed videos of doctor-patient interactions from 1982-1984 and 2000-2001. Analogue patients confirmed a shift from doctor-centered interactions in the earlier videos to patient-centered interactions in the more recent videos, characterized by collaborative, solution-focused communication as opposed to directive, problem-focused communication.

Effective doctor-patient collaboration requires that doctors be willing and able to communicate with patients as individuals. Houle et al. (2007) described the following interpersonal skills as being vital to an effective doctor-patient relationship: (a) understanding, which involves a sincere desire to learn about patients' experiences and results in patients' trust and belief that their doctors know them as individuals; (b) empathy, which is the skill through which doctors express consistent, professional concern for their patients' feelings; and (c) relational versatility, or the ability of the doctor to match his or her interpersonal approach to the varying communication needs of their patients. According to Houle et al., the skill of relational versatility is dependent upon an attitude of respect for and acceptance of others.

Collaboration in doctor-patient relationships also requires trust. Trust, as defined by the female participants in a study by Copeland et al. (2003), is "based on feeling confident and comfortable with the care provided…when the doctor appears sympathetic, cares, and takes time to talk" (p. 41). According to Dugdale et al. (2008), patients trust doctors who provide informed consent, are willing to disclose medical errors, and who keep abreast of the current medical literature. Participants in the Copeland et al. (2003) study expressed feeling reluctant to talk to doctors with whom they do not feel comfortable, and were eager for doctors to know that trust affects their willingness to listen and comply with their doctor's advice. Likewise, the female participants in the Houle et al. (2007) study stated that they are more likely to take a doctor's advice if they believe they can trust the doctor. The participants also indicated that, in order to gain their trust, doctors must show an interest in them, listen attentively, conduct a prompt follow-up, and be available to answer their questions.

Empirical support exists for the importance of collaboration in doctor-patient relationships as opposed to a hierarchical relationship wherein the doctor is in a position of authority over the patient. Doctors' attitudes have been shown to have a direct effect on the quality of care patients receive, as well as patients' ability to make informed decisions about their health (Chrisler & Parrett, 1995). Doctor-centered attitudes are associated with lower patient satisfaction and, according to Krupat (1999), may decrease trust in the doctor-patient relationship.

Recent research suggests that there may be a difference in the level of collaboration encouraged by male and female physicians. In a study conducted by Hall, Roter, Blanch, and Frankel (2009), female medical students more accurately interpreted their patients' non-verbal communication (e.g., facial expressions) than did male medical students. Doctor-patient interactions in which doctors demonstrated sensitivity to their patients' non-verbal cues resulted in decreased distress, longer visits, and higher engagement among analogue patients.

A study conducted by Bloor, Freemantle, and Maynard (2008) found that male medical professionals completed, on average, 160 more medical cases each year than their female counterparts. According to Firth-Cozens (2008b), this disparity may reflect the type of care given by female doctors, in contrast to the care given by male doctors. For example, female physicians may spend more time with each patient, encouraging the patient to speak more and be more active in the decision making process. The increased depth of care and collaboration would result in females completing fewer cases over the same period. Female doctors have indeed been shown to use a more patient-centered approach with their patients than male physicians, as evidenced by longer consultations and a more emotional, psychosocial focus in their discussions (Beach, 2000; Firth

Cozens, 2008b; Hall & Roter, 2002; Hall et al., 2009; Roter & Hall, 2004; Shin et al., 2015).

The more patient-centered approach adopted by most female practitioners may have a significant positive impact for the professionals as well as for the patients. According to a report by the National Clinical Assessment Service (NCAS, 2006), male doctors are involved in more legal and disciplinary action than female doctors. In 2004, 42% of general practitioners were women, but only 13% of doctors referred to the NCAS for discipline were female. According to Firth-Cozens (2008b), this statistic is a direct result of the more sensitive approach taken by female physicians. Better doctor-patient relationships result from female physicians' greater emotional and communication skills, resulting in a decreased likelihood that the doctors will be involved in disputes or complaints.

Patient autonomy. In contrast to the traditional authoritarian and paternalistic relationship between doctors and patients, a more egalitarian approach to healthcare has been shown to benefit treatment outcomes. Doctors who respect patient autonomy allow patients to participate in decisions about their own health and take patients' concerns, opinions, and preferences into consideration. Empirical evidence indicates that physicians are moving toward this ideal.

Physicians in a study by McGuire et al. (2005) expressed consistently positive attitudes towards patient participation in medical decision making. They identified patient autonomy as essential to the doctor-patient relationship and indicated that they were motivated by the fundamental principle of beneficence, as well as their own personal interest in avoiding legal liability. Similar results were found in Rogers' (2002) study of physicians' attitudes toward patient autonomy in treatment for back pain. The majority of physicians interviewed were in favor of patient autonomy regarding the use of complementary therapies (e.g., massage), but desired to maintain control of treatment decisions involving analgesic narcotics due to their potential for addiction.

In the case of autoimmune disorders such as those that cause hyper- and hypothyroidism, respect for patient autonomy is particularly important (Chrisler & Parrett, 1995). Because patients can provide important insight into the experience of their own conditions, patients should be seen as experts on their conditions and respected as such. Considering that the majority of physicians wish to respect patient autonomy while avoiding legal liability (McGuire et al., 2005; Rogers, 2002), a "deliberative model" might be appropriate in decision making. As described by Chin (2002), in the deliberative model, the physician is both a teacher and a friend who assists the patient in evaluating the safety and effectiveness of potential treatment modalities. Chin (2002) posited that such a model is particularly relevant in the "Internet age," in which patients are "flooded with information"—not all of which is reputable (p. 154).

The increased availability of medical information to the public makes patient autonomy a growing concern. Tu and Cohen (2008) reported that, according to an HCS survey, in 2007, 56% of American adults sought information about a health concern, compared to only 38% in 2001. Of those individuals who looked for information about a health concern from sources other than a doctor, over half later spoke with a doctor about that same health concern. This indicates that patients exercise their own autonomy and hope to use the information they discover in conjunction with professional consultation. Additionally, those with chronic health concerns are more likely to seek health information from sources other than doctors. According to Fox (2007), among Internet users with disability or chronic illness such as thyroid disease, 86% have searched online for information. Among those without chronic illness, only 79% have searched for medical information online. Individuals with chronic health concerns also reported that their medical decisions are more frequently affected by information found online.

Fox and Jones (2009) reported on a 2008 Pew Research Center study related to patient autonomy in seeking health information from various sources. The study found that 61% of adults use the Internet to search for health information, and over half of online health queries are made on behalf of someone other than the Internet user. Therefore, in order to establish effective doctor-patient relationships, physicians need to take patient autonomy and outside sources into consideration. In addition to consulting professionals, a majority of adults consult friends or family members, books, and other reference material for medical assistance. Significant percentages of those interviewed claimed that information found online affected health-related decisions they made for themselves or someone in their care (Fox & Jones, 2009). These results underscore the importance of online information for individuals with chronic illness, suggesting that doctors treating such patients should be particularly aware of and sensitive to patient autonomy and knowledge.

Non-sexist. As noted above, traditional doctor-patient relationships have tended to marginalize women by virtue of social perceptions of the female role. In addition to being placed in a position of inferiority due to doctors' medical expertise, female patients in the care of male physicians may conform to traditional, submissive feminine roles (Chrisler, 2001). This undermines female patients' autonomy and makes doctor-patient collaboration unlikely. Thus, it is important for women to feel that their feminine status does not affect the quality of the care they receive.

Despite theoretical and empirical evidence that a more collaborative, less doctor-centered model of healthcare promotes positive healthcare outcomes (Houle et al., 2007; Munch, 2004), the traditional forms of doctor-patient relationships persist. Factors that contribute to the persistence of the traditional model include sexism in healthcare, the medical education system, economics, the culture of the medical profession, and women's communication patterns.

Sexism in Health Care

Abundant research and theoretical literature indicates that sexism exists in the medical profession and results in a number of problems, including under-treatment and misdiagnosis of women's medical issues. According to Secker (1999), male-dominated philosophical, theological, literary, and scientific traditions have characterized women (as opposed to men) as emotional, irrational, pathological, unintelligent, incompetent, dishonest, passive, and childlike (p. 301). Applying these traditions in the medical profession has resulted in a diagnostic bias whereby women's health complaints tend to be viewed as psychosomatic in origin (Hamberg et al., 2004; Hoffmann & Tarzian, 2001; Richman, Jason, Taylor, & Jahn, 2000).

Hoffman and Tarzian (2001) purported that women's complaints are often not taken seriously by medical professionals because women are viewed as overly emotional and likely to exaggerate their pain. According to Cheney and Ashcraft (2007), in the medical profession, there is "a tendency to privilege the rational over the emotional" (p. 153). Furthermore, some illnesses (e.g., depression) are perceived to primarily affect women or are associated with femininity, further indicating a pervasive sexism within the medical profession (Hoffman, & Tarazian, 2001).

Empirical research supports these theoretical arguments, indicating that physicians tend to interpret men's symptoms as biological and women's as psychosomatic (Hamberg et al., 2004; Hoffmann & Tarzian, 2001). When women report pain, they are less likely than are men to be taken seriously and less likely to receive adequate treatment (Miaskowski, 1999). Additionally, research has shown that, for patients with diffuse symptoms, doctors give advice regarding lifestyle more often to women than they do to men, and that they prescribe sedatives more often to women than to men (Hamberg et al., 2004). The same study indicated that male physicians prescribe sedatives to women more often than female physicians do, indicating that traditional gender roles continue to play a part in doctor-patient relationships.

Munch (2004) performed a meta-analysis of the literature on physicians' diagnosing of women's medical complaints. The analysis revealed that physicians tend to misdiagnose women's complaints as psychosomatic or non-serious due to gender bias. This is particularly true in cases when the physiological cause of the condition is unknown. Munch's analysis also revealed that doctors are less aggressive in treating coronary disease in women than in men, and that hospitalized women receive fewer therapeutic and diagnostic procedures than men. In a study of patients with chest pain, Elderkin-Thompson and Waitzkin (1999) found that men were more likely than women to be admitted to the hospital. Women who were hospitalized were just as likely as men to receive a stress test. However, women who were not hospitalized were less likely to have received a stress test at follow-up. This could indicate that the nature of sexism in healthcare requires women to prove that their complaints are as valid as those of their male counterparts.

The necessity for women to prove the validity of their complaints is particularly striking in light of evidence reported by Addis and Mahalik (2003) indicating that, compared to women, men are less likely to seek care for nearly all mental and physical health problems. The authors noted that traditional masculine gender socialization plays a role in discouraging men from seeking treatment. According to the social constructionist perspective, men are traditionally constructed as better able to cope physically and emotionally with health problems than women.

In the past decade, significant progress has been made in the understanding of sex differences in health and illness (Verdonk, 2009). In 2004, the American Heart Association published evidence-based guidelines for the prevention of heart disease in women. These guidelines were updated in 2007 (Mosca et al., 2007). Also in 2007, the World Health Assembly passed resolution WHA60.25, which introduced the practice of integrating gender analysis into the work of the World Health Organization (WHO, 2013). Nevertheless, gender bias in the diagnosis and treatment of illness remains ingrained in the medical field as a result of the biomedical focus in medical training (Celik, Lagro-Janssen, van der Weijden, & Widdershoven, 2009). Celik et al. argued that the incorporation of gender sensitive issues into clinical practice guidelines is insufficient for changing medical practice, as adherence to such guidelines is not mandatory. The authors suggested that in order to successfully address the problem of gender bias in medicine, gender sensitive issues should become a fundamental part of medical education.

Medical Education

The biomedical focus in medical training contributes to the perpetuation of traditional doctor-patient relationships (Celik et al., 2009). In the Western medical profession, health-care practitioners are taught that diagnostic and treatment decisions should be based on objective evidence of disease, such as blood tests (Hoffmann & Tarzian, 2001). This system encourages practitioners to disregard patients' subjective illness experiences, making them unlikely to treat patients as equals in a collaborative relationship (Hoffmann & Tarzian, 2001; McGuire et al., 2005). Patients' preferences, concerns, and emotions are likewise not taken into account (Haidet et al., 2002). Dyche (2007) asserted that although interpersonal communication skills are recognized as important by some educators, they have received much less attention than task oriented, verbal aspects of communication.

During the first two years of medical school, courses in communication typically utilize actors who are trained to act like patients. However, during the third and fourth years of medical school when students have contact with real patients, the focus of training shifts from communication skills to diagnostic skills and patient management (Levinson, Lesser, & Epstein, 2010). According to Levinson et al. (2010), this non-systematic teaching of communication skills results in practicing physicians who must learn communication on their own. Various medical societies have recognized that effective doctor-patient collaboration requires relational versatility, or the ability of doctors to match their interpersonal approach to the communication needs of their patients (Houle et al., 2007; Levinson et al., 2010), and have therefore developed programs to teach patient-centered communication skills to practicing physicians.

Research into how people categorize other people into groups (social categorization theory) has indicated that practicing physicians and medical students tend to categorize patients as an “out group,” or similar to one another, but different from medical professionals (with whom doctors consider themselves as an “in group”). However, in a study by Clucas (2011), doctors who received communication skills training viewed patients at an “intergroup” level, or dissimilar to one another and medical professionals. In other words, doctors who received communication skills training viewed their patients in a more personal manner. Personalization of care, in turn, leads to collaboration, greater patient satisfaction and adherence to treatment, and fewer malpractice lawsuits (Clucas, 2011; Firth-Cozens, 2008b).

Garden (2008) and Halpern (2007) have stressed the importance of empathy and humility in medical training related to doctor-patient relationships. According to Halpern (2007), in medicine, empathy traditionally refers to a “purely cognitive understanding of patients' emotions—a special professional detached concern” (p. 696). However, emotionally engaged physicians communicate more effectively, suggesting a need for increased training in empathy and emotion.

Haidet et al. (2002) reported that students in later years of medical school exhibit more doctor-centered and paternalistic attitudes than students in earlier years of training. This suggests that the structure of medical education encourages the development of these attitudes even when they did not previously exist. According to Haidet et al. and Clucas (2011), the structure of medical education undermines attempts to encourage patient-centered healthcare and to increase patient satisfaction, as medical students become more disease-focused as they advance through their education. Garden (2008) hypothesized that factors contributing to this issue include long work hours and sleep deprivation among medical students, as well as stress and burnout in medical professionals. Garden also identified the following aspects of medical education that may contribute to an objectification of the patient: cadaver dissection, an emphasis on basic science, and a reliance on medical technology at the expense of listening to the patient's story (p. 122).

The medical education system is also related to gender bias among medical professionals. The educational culture, in which only objective, measurable data are taken into account in diagnosis and treatment decisions, results in a general unwillingness among medical professionals to discuss gender issues (Risberg, Hamberg, & Johansson, 2006). According to Risberg et al., the valuation of the biomedical framework above other perspectives leads to a negative attitude toward gender perspectives, and thereby to gender bias.

Sherwin (1992) asserted that physician training is based on stereotypical views of women as people who are “excessively anxious, devious, and unintelligent; they are taught not to take all women’s complaints seriously” (p. 224). In an analysis of medical training material, including textbooks and examination questions, Reichenbach and Brown (2004) discovered gender stereotypes and patriarchal views. A subsequent study by Dijkstra, Verdonk, and Lagro-Janssen (2008) revealed scarce or absent gender-specific information in medical textbooks on internal medicine, cardiology, pharmacology, and psychiatry. Similarly, in a review of 257 case descriptions written for medical training, only 7% mentioned sex differences (Hamberg & Larsson, 2009).

In their discussion of gender awareness in medicine, Verdonk, Benschop, de Haes, and Lagro-Janssen (2009) suggested a need for a structural embedding of gender into medical education. Similarly, Risberg, Johansson, and Hamberg (2009) recommended that role-playing activities and case discussions involving gender perspectives be incorporated into the training of medical students.

According to Blanch, Hall, Roter, and Frankel (2008), female medical students are more likely to display anxiety and to lack confidence in their skills than male medical students. This is true despite evidence that female medical students perform as well as males in academic competence and better in patient-centered clinical communication. In a study of first-year medical students, Moffat, McConnachie, Ross, and Morrison (2004) reported similar findings. In the study, female students reported experiencing more stress regarding their personal competence, learning the curriculum, and assessment.

Additionally, Cleland, Foster, and Moffat (2005) found that female students were more apprehensive about communication than males.

Greater anxiety during medical education may contribute to issues with later professional confidence. According to Gude et al. (2005), male medical students more strongly identify with the role of doctor than females on completing medical school. The researchers analyzed the factors contributing to this outcome, revealing that only females took confidence in their own knowledge into account when assessing the extent to which they identified with the role of doctor.

Blanch et al. (2008) discussed the reasons that female medical students experience more anxiety and less confidence during their medical educations. The authors suggested that males and females experience medical school differently. Evidence indicates that females are more frequently subjected to gender discrimination and sexual harassment, which could increase their anxiety over time. Additionally, female socialization may include a greater degree of acceptability with regard to expression of feelings, vulnerability, and humility. The latter explanation suggests that females could be as confident as males in their knowledge and abilities, but less readily express this confidence due to a higher value placed on modesty.

Economics

As the biomedical focus in medical training perpetuates traditional doctor-patient relationships (Celik et al., 2009), the structure of the healthcare system introduces economic issues that can act as barriers to collaborative doctor-patient relationships. Physicians who have the ability and interest to communicate effectively with patients may not have time or resources to engage in such communication or to develop patient-centered practices. According to Balsa and McGuire (2001), physicians have less time to spend with patients due to financial and administrative concerns. This can result in a decrease in the quality of healthcare and the perpetuation of traditional, hierarchical relationships between physicians and their patients.

According to Hearn (2006), the economics of modern medicine make it particularly difficult to accommodate informed and active patients. The demands of economic efficiency conflict with a respect for patient autonomy. Informing patients and cooperatively working on a treatment plan is time-consuming, and the informed patient tends to be demanding. Although physicians report supporting patient participation and cooperation, they often behave according to the traditional paternalistic model due to a heavy work load, staff shortages, and practical concerns such as reducing healthcare costs and avoiding malpractice lawsuits (Hearn, 2009; Sherwin, 2000).

Evidence suggests that, on average, female medical consultants complete fewer cases per year than their male counterparts. Firth-Cozens (2008b) has argued that this may be related to the tendency for female doctors to be more patient-centered, spending longer in consultation with each patient than men do. Seeing fewer patients could translate to lower income, increasing the extent to which females experience economic limitations. Additionally, if consultants work in groups, a greater proportion of income could be allocated to the most senior team member, who is more likely to be a male. Firth-Cozens (2008a, 2008b) noted, however, that the increased incidence of discipline and litigation among male doctors could offset these differences with regard to financial concerns.

Although women often excel compared to men in areas related to developing strong doctor-patient relationships (Firth-Cozens, 2008b), this advantage does not necessarily translate to increased value. Nicoletti (2006) reported research indicating that, although patients claim to value strong doctor-patient relationships, they are often unwilling to pay more or drive further to visit doctors with whom they could develop such relationships. Nicoletti noted, however, that the existing research studying doctor-patient relationships from an economic perspective is insufficient.

The Culture of the Medical Profession

Beyond medical education and practical economic concerns, the prevailing culture of the medical profession continues to encourage the attitudes that characterize ineffective communication between physicians and their patients. Research by Vanderford et al. (2001) indicated that the traditional medical culture has encouraged physicians to respond to patients in a paternalistic and authoritative fashion in the face of conflict with patients. In narratives collected by Vanderford et al., medical professionals explained that when patients had differing views of treatment, they attempted to persuade patients to accept their advice. Patients who refused the medical professionals' advice were described as "difficult" and "insistent." These trends can also be seen in the marginalization of women and de-emphasis on chronic illness within the medical world.

Marginalization of Women

As previously noted, the traditional doctor-patient relationship involves a marginalization of women, which is partly a result of the historical view of women as overly emotional. In addition, it has been argued that the medical profession encourages a normative, gendered view of illness, which results in a perceived need for women to work harder in order to be perceived as credible patients (Werner & Malterud, 2003).

The gendered view of illness is exemplified by Kempner's (2003) discussion of the common perception of migraine as a women's illness, which is due in part to the higher incidence of migraine among females. The author reviewed evidence suggesting that gendering migraine has a significant impact on health and doctor-patient relationships. Diagnosis rates and the perception of the legitimacy of migraine complaints among female and male patients are affected. Munch (2004) noted that many such gender biases in diagnoses were uncovered by second-wave feminist research between 1970 and 1995.

The cultural marginalization of women in healthcare extends not only to female patients, but to female doctors and nurses, as well. Due to women's history of oppression and the nature of medical training, it is not uncommon for women entering medical professions to maintain patriarchal attitudes (Carter, 1994). This phenomenon is particularly evident in nurse-physician relationships. According to Carter, there are "unspoken rules of communication" between nurses, who are primarily female, and physicians (p. 368). These rules require nurses to refrain from disagreeing with physicians and place a low value on nurses' suggestions. However, it is not clear that gender bias accounts for all interactions between nurses and physicians. In a survey-based study of 125 nurses, Rothstein and Hannum (2007) found that nurses had similar perceptions of female and male physicians with whom they interacted, suggesting that professional differences play a role in addition to gender differences.

Kilminster, Downes, Gough, Murdoch-Eaton, and Roberts (2007) pointed out that gender bias in research may contribute to the uncertainty regarding women's place in the medical field and the effect of changes in gender composition within the field. In an extensive review of literature related to women in medicine, the authors found little strong evidence of gender differences in practical areas of healthcare. Instead, gender expectations in education and clinical practice were found to have a larger effect. The researchers concluded that there has been very little research specifically focusing on male doctors. Research practices are already gendered, treating women as the subject to be examined.

Some suggest, in contrast to Kilminster et al. (2007), that gender-aware research practices are positive. For example, Munch (2004) conducted a review of literature related to second-wave feminist approaches to diagnoses from 1970 to 1995. The review revealed that feminist perspectives were instrumental in uncovering a number of areas where gender bias problematically affects women's healthcare. Gender awareness in research, therefore, may be important in uncovering areas in which the culture of the medical profession marginalizes women.

Treatment of Chronic Illness

Another cultural factor contributing to problematic doctor-patient relationships relates specifically to patients with chronic illnesses. According to Chrisler (2001), the culture of the medical profession is not supportive of chronic illness, as evidenced by the belief among physicians that, for example, women over-report pain, and that vague symptoms are unworthy of serious consideration. Instead of crediting patients' reports about their conditions, medical professionals tend to focus on acute conditions and verifiable complaints.

Martin and Peterson (2009) defined chronic illness as "a state or passage of care for long-term pain and suffering that may not be cured" (p. 579). These authors discussed the social context of chronic illness from a constructionist perspective. Perhaps more than other medical complaints, chronic illnesses require a highly personal process of meaning construction. According to the authors, proper management of illness involves active interpretation, not "simple biomedical labeling" (p. 580). Although doctors may provide interpretations of chronic illness, biomedical interpretations cannot help patients understand and experience the illness and long-term treatment. Additionally, the culture of the medical profession may encourage patients to withhold details of their experiences of chronic illness from physicians in order to avoid being judged as complaining.

Even when medical professionals do take patients' experiences into account, there is evidence suggesting that they interpret experiences according to rigid models. Telford, Kralik, and Koch (2006) conducted a review of literature related to the view of patients with chronic illness as understood through the terms *acceptance* and *denial*. The researchers found that medical professionals tend to place patient experiences within this framework, even when the experiences do not fit the framework. According to the authors, this tendency may affect patients' understanding of their own experiences and cause them to internalize predefined labels in their self-understanding. This suggests that preconceptions and biases related to chronic illness may have a significant effect on learning to cope with chronic illness.

The medical profession's inability to address chronic illness in a meaningful way and to place little importance on chronic pain may interact with the marginalization of women, placing female patients with chronic illness and disability at risk of receiving inadequate treatment (Thomas, 2001). Fernandes et al. (2006) suggested that understanding and constructing meaning for chronic illness may be particularly important for women because issues related to the body are instrumental in the formation of female self-identity. This underscores the impact that gender has in every area of the medical profession and its culture.

Gender Differences in Communication

With regard to conversation during medical consultations, evidence suggests that there is a significant disparity between the communication styles preferred by patients and those preferred by physicians. Platt (2008) reported some of this evidence, noting that doctors commonly complain about verbose patients who tell long stories when doctors ask questions. Additionally, Platt noted that doctors use their authority to encourage patients to communicate in the doctors' preferred styles, resulting in patient dissatisfaction. Doctor-patient relationships are affected by communication, and gender differences in communication styles could amplify these effects.

Women's communication patterns may be ill-suited to the logical structure of the diagnostic tree used by physicians. Research indicates that men and women communicate differently. These differences in communication may present a persistent obstacle to effective communication between doctors and female patients. For example, Tannen's (2007) study revealed that women use conversation to generate intimacy, whereas men use conversation to create or maintain their status in a group. These differences may influence how physicians and patients interact within a professional setting. For example, a meta-analytical review conducted by Roter et al. (2002) revealed that female doctors, as opposed to male doctors, are more patient-centered, have longer consultations, show more partnership behaviors, engage in more positive and emotionally focused talk, ask more psychosocial questions and counsel more psychosocially, and encourage their patients to speak more. A second review conducted by Roter and Hall (2004) reinforced this notion.

Hamberg et al. (2004) argued that gender differences in medical treatment can be partially explained by gender differences in communication. For example, whereas men tend to describe their symptoms in a frank and confident manner, women often give generalized descriptions of their symptoms. In addition, according to research by Hoffmann and Tarzian (2001), women use contextual information (e.g., impact on personal relationships) in their symptom reports, while men's reports focus on objective descriptions of physical symptoms. According to Hoffmann and Tarzian, these differences may be due to differences in socialization experiences. Similarly, Stewart et al. (2003) noted that appropriate communication guidelines for men and women are learned during the cultural socialization process. Women's style of communication, therefore, may not be compatible with the traditional medical interview model utilized by most physicians (Hoffmann & Tarzian, 2001).

These issues may be ameliorated, however, when female patients are treated by female physicians. In a study by Copeland et al. (2003), female health providers were perceived as listening more and as being easier to talk to about a wider range of topics. Female patient participants expressed the belief that it is harder to explain health concerns to a man than to a woman, and that it is unlikely that men would understand their concerns. Participants indicated that women providers were preferred primarily because they were perceived as listening more and as being easier to talk to about a wider range of topics.

Research examining gender-related communication differences in medical students has revealed that female medical students perform better on measures of interpersonal skills and communication performance than males (Bienstock, Martin, Tzou, & Fox, 2002; Laidlaw et al., 2006; Wiskin, Allan, & Skelton, 2004; Yudkowsky, Downing, & Ommert, 2006). These findings are consistent with findings related to female practitioners, suggesting that women have stronger communication skills throughout their medical careers.

Although gender differences in communication have positive implications for female physicians, female patients may be at a disadvantage. According to Ivy and

Backlund (2008), women have been shown to be more tentative and less confident in their communication than men. The authors suggested that this could make females seem uncertain and incompetent in their speech. For female patients, this could increase the likelihood that their medical complaints will not be taken seriously.

As an example of the tentative communication style, Ivy and Backlund (2008) discussed tag questions such as in the sentence, “This is a really beautiful day, don’t you think?” According to the authors, such questions are primarily intended to elicit agreement from the listener. Lakoff (1975) described tag questions as a form of “apology for making an assertion at all” (p. 54) and argued that they represent a lack of assertiveness more indicative of the female communication style. In addition to tag questions, Ivy and Backlund (2008) described a number of other communication devices stereotypically associated with women. This indicates that the female communication style, in addition to systemic gender bias, may contribute to the tendency for medical professionals to devalue women’s complaints, particularly when those complaints are vague or difficult to describe or diagnose.

Diffuse Complaints and Difficult-to-Diagnose Conditions

As noted above, the traditional gender-biased culture of the medical field results in a tendency for doctors to assume that women’s reports of pain are exaggerated or psychosomatic (Hamberg et al., 2004; Hoffmann & Tarzian, 2001). This often results in misdiagnosis or lack of appropriate treatment (e.g., Elderkin-Thompson & Waitzkin, 1999). Consequently, women with diffuse and persistent complaints due to a chronic or difficult to diagnose illness may experience difficulties in their relationship with their doctors and with their treatment experience. This is supported by extensive research on chronic illnesses such as lupus, fibromyalgia, and chronic fatigue–all of which share similarities with thyroid disease (Darer et al., 2004; Kralik et al., 2005; Martin & Peterson, 2009; Richman & Jason, 2001; Telford et al., 2006).

According to Werner and Malterud (2003), doctors report having difficulty in managing consultations involving uncertainty and unexplained conditions. As a result, patients, particularly female patients, report feeling ignored, belittled, and rejected in such consultations. Similarly, Hartman, Borghuis, Lucassen, Laar, and Speckens (2009) found that physicians find it difficult to communicate medically unexplained symptoms to patients, so they use metaphors and nonspecific language, which can have a negative effect on doctor-patient relationships. Martin and Peterson (2009) stated, "the role of the doctor is to take undifferentiated or unorganized illness and to arrive at an organized illness (more latterly a diagnosis)" (p. 581). However, evidence indicates that doctors often have difficulty accomplishing this task.

Lupus. Chrisler and Parrett (1995) have noted that Systemic Lupus Erythematosus has been found in the last 40 years to be fairly common, that women are 5 to 10 times more likely than men to be diagnosed with the disease, and that women of color are disproportionately affected. Because the disease can arise at any time and can affect any of a number of internal systems, it is often difficult to diagnose. Lupus resembles many other diseases, and has as a result been called "the great impostor" (Chrisler & Parrett, 1995). Diagnoses are often uncertain, and there is no definitive test to determine the presence of lupus. Unsuccessful treatment is also common, and lupus patients have been found to experience a number of psychosocial consequences, including elevated levels of depression, lowered self-esteem, changes in sexual function, and lowered body-image. These issues can be particularly troublesome for women, who have complained that doctors focus on their ability to be reproductively active (Chrisler & Parrett, 1995). Psychosocial factors such as support from others and physician help with coping strategies may help patients deal with the disease.

In a study of women living with lupus, the factors most frequently cited as contributing to the struggle with the disease were uncertainty, an altered sense of identity, and managing the financial burden (Mendelson, 2006). This suggests that, in addition to biomedical issues, effective care for individuals with lupus could include mental and emotional support.

Fibromyalgia. Female patients with fibromyalgia have consistently reported being questioned by doctors as to the legitimacy of their symptoms. Patients report that physicians judge their symptoms to be psychosomatic. As a result, patients employ strategies to make doctors take them seriously (Werner & Malterud, 2003). This can have negative effects on doctor-patient relationships, particularly when patients become wary of honestly discussing their symptoms and the psychosocial effects of those symptoms (Peters et al., 2008).

In an analysis of the experiences of 10 women with chronic pain, Werner and Malterud (2005) sought to examine issues related to patient empowerment and how doctors can help patients deal with their difficult to diagnose symptoms. Ultimately, many of the women in the study were diagnosed with fibromyalgia. The researchers discussed the feelings of helplessness doctors experience when faced with patients who have conditions about which little is understood. Additionally, the authors noted that the way in which women are encountered and their symptoms addressed can have an effect on their level of empowerment in coping with their medical issues. Even in cases where diagnoses are uncertain, physicians who take women's complaints seriously can help the patients overcome feelings of vulnerability that exacerbate their difficulties.

Chronic fatigue syndrome. Chronic fatigue syndrome (CFS) is an autoimmune disorder that affects women in much greater proportion than it does men (Richman & Jason, 2001). The primary symptoms of CFS include impairment in short-term memory or concentration, unrefreshing sleep, sore throat, new headaches, and muscle pain, making the condition particularly difficult to diagnose as a result of the diffuse and uncertain nature of these symptoms. As is the case with lupus and fibromyalgia, there are no standard diagnostic criteria and the treatments developed to date have limited success.

According to Richman and Jason (2001), CFS involves a number of psychological consequences for patients. These include placing an exaggerated importance on rest and mistakenly assuming that they are more impaired than they are. The authors noted that, from the perspective of the medical profession, CFS is often viewed as a psychogenic illness wherein patients adopt the role of a sick individual in order to avoid accepted social roles and responsibilities. As a result, according to Johnson (1996), the medical profession has tended to trivialize CFS. In one case, male physicians to whom female patients with CFS had been referred claimed that the referring internist had been performing "million dollar workups on neurotic women" (p. 3). As with lupus and fibromyalgia, CFS patients are at risk of feeling “humiliated and ashamed instead of empowered and understood” by physicians (Allan, 1995, p. 17).

Richman and Jason (2001) addressed CFS from a feminist social constructionist perspective. The authors drew attention to the role of gender dynamics in explaining the differences between physicians’ and patients’ perceptions of the disease. Literature related to CFS from the perspective of the medical profession has focused on describing the disease as primarily psychosomatic and stress-related, whereas patients have emphasized the physical nature of the condition. The researchers concluded that an increased focus among practitioners on the biomedical side of CFS could result in identifying biological indicators, which could lead to a less dismissive attitude toward patients with CFS.

Review of Literature Related to Methodology

Quantitative Research

Although it can be difficult to quantify issues like gender bias and doctor-patient relationships as they pertain to chronic illness, a good deal of quantitative research literature exists on these topics. Existing quantitative studies can generally be placed into one of three common categories.

The majority of quantitative studies are descriptive or correlational in nature, employing self-report surveys to measure specific variables and examining whether relationships exist between them (e.g., Auerbach et al., 2002; Krupat et al., 2000). One such study was conducted by Krupat et al. (2000). The researchers used the Patient-Practitioner Orientation Scale (PPOS), which is designed to measure patient role orientations by assessing patients’ attitudes regarding doctor-patient relationships and doctors’ interaction styles. The results indicated that patient-centered approaches resulted in higher patient satisfaction with the doctor-patient relationship. The researchers argued that, because this was the expected result, the PPOS was shown to be a useful tool for predicting patient satisfaction. In general, results from such studies are strongly conclusive and provide the clearest direction for future research. The Krupat et al. (2000) study, however, has a significant weakness in that the participants responded to researcher-developed scenarios related to doctor-patient relationships, and these scenarios may have been structured or worded such that respondents were influenced to prefer the patient-centered scenarios. This indicates that, although survey-based quantitative studies can yield strong data, careful analysis of research design is necessary.

Another common method uses survey instruments in conjunction with coding of recorded observations, such as physician visits (e.g., Street et al., 2007; Zandbelt et al., 2006). For example, Zandbelt et al. (2006) videotaped 323 patients visiting 30 physicians at an internal medicine clinic in the Netherlands in order to determine factors influencing patient-centered behavior. The doctors’ behaviors during the visits were coded according to a predesigned instrument and analyzed alongside data from surveys completed by both the patients and the doctors. The researchers noted that, although they found significant correlations, physicians may have behaved differently in consultations knowing that they were being recorded. This is an issue that affects studies with similar designs; findings from such studies can be difficult to interpret due to the quasi-experimental nature of recording research environments.

Finally, some quantitative studies reviewed employed descriptive designs wherein narrative or open-ended data were coded by researchers and the resulting data subjected to various statistical analyses. For example, Hamberg et al. (2004) conducted a study to determine whether difference existed in the way male physicians treat irritable bowel syndrome (IBS) as compared to female physicians. The researchers coded open-ended treatment plans created for a hypothetical case of IBS. Coded variables included those related to lifestyle advice, colon X-rays, proposed diagnoses, and others. The results showed that there existed significant gender differences in the treatment plans. Although this research design has the potential to reveal novel and unexpected aspects of the research topic, quantitatively coding and analyzing open-ended narrative data can be complicated and controversial (Hamberg et al., 2004), calling the validity and usefulness of results into question.

One of the primary strengths of quantitative research is its ability to accommodate large sample sizes. The quantitative studies reviewed for this chapter had sample sizes ranging from 30 to 387 participants. By contrast, qualitative studies reviewed had sample sizes as small as four participants. Most quantitative methods do not require researchers to spend much time with each participant, and participants can self-administer surveys simultaneously, allowing researchers to gather and analyze a large amount of data. This also allows study samples to be more diverse, contributing to the generalizability of data. For example, the study conducted by Hamberg et al. (2004) incorporated a nationwide sample of Swedish physicians, all of whom had to take the national exam of which the study measure was a part.

A further benefit of quantitative research is that quantitative meta-analyses of smaller studies can be conducted to discover general trends. One such meta-analysis was conducted by Roter et al. (2002). The researchers synthesized a number of small studies related to gender effects in medical communication. By gathering data from smaller studies, the researchers were able to discover a broad tendency for female physicians to spend more time in communication with patients. This method allows researchers to draw more generalizable conclusions from existing data.

Although quantitative studies like those reviewed above can be useful in determining general trends and providing information about the effectiveness of general practices understood broadly, quantitative research methods do not yield rich narrative data (Creswell, 2007). Qualitative research methods, on the other hand, produce the rich narrative data necessary for discovering information related to complex interactions between individuals and complex associations between illness and psychosocial factors. As mentioned previously, from a social constructionist perspective, concepts of health and illness are socially constructed and subject to varying degrees of consensus and interpretation based on cultural factors and social norms (Hearn, 2009; Lupton, 2003). In addition, patients' interpretations of their illness influence their feelings, reactions, and behaviors (Docherty & McColl, 2003; Fernandes et al., 2006). Thus, a qualitative research approach is most appropriate for exploring the treatment experiences of women with thyroid disease. Such an understanding could prove helpful in better determining the needs of female thyroid patients and therefore lead to prompt, accurate diagnosis and effective treatment.

Qualitative Research

Among research studies adopting a social constructionist perspective, qualitative methods are much more common (Creswell, 2007). One reason for the prevalence of qualitative methods in research related to chronic illness and therapeutic experience is the ability of qualitative studies to yield descriptive, narrative data that includes nuances and complexities of individual situations. Docherty and McColl (2003) conducted a study examining the use of narrative as a way to understand chronic illness. The study used a phenomenological methodology, eliciting descriptions of experiences from the participants and interpreting them under a social constructionist framework. The researchers identified issues that commonly arose in patients' narrative accounts of their illness: emotional reactions to diagnoses, impact of stress, views of death, and the meaning of the illness. Such themes often do not arise in quantitative research, but can be instrumental to understanding the disease experience among people with chronic illnesses such as thyroid disease.

A number of qualitative studies related to female patients' experiences with chronic illness have been conducted (e.g., Copeland et al., 2003; Kralik et al., 2004; Kralik et al., 2005; Werner & Malterud, 2003). Qualitative methods have also been used frequently to study doctor-patient relationships and women's healthcare experiences (e.g., Houle et al., 2007; Werner & Malterud, 2005).

Of the qualitative methods used in literature reviewed for this chapter, phenomenology is the most common by a wide margin. Because phenomenology is used to study individuals' personal experiences, this is a logical choice for research related to doctor-patient relationships, a topic that is closely connected with how those involved experience their interactions. Furthermore, much research related to chronic illness adopts the specific goal of understanding how patients experience illness in order to improve treatment. Thus, the lack of non-phenomenological qualitative methodologies (i.e., narrative, case study, ethnography, and grounded theory) in the existing literature does not necessarily indicate that the literature is methodologically impoverished.

Within the phenomenological research reviewed, several specific approaches were used. The most common type of design employed structured, semi-structured, or open-ended interviews (Docherty & McColl, 2003; Kralik et al., 2004; Werner & Malterud, 2003, 2005). Interviews allow participants to share their views about the research topic directly with researchers and allow researchers to be flexible in the specific aspects of the topic that they address, probing each participant in order to reveal complex information. One example is a study conducted by Docherty and McColl (2003). The researchers interviewed four persons with chronic illness. Two participants were male, three were Caucasian, and they ranged in age from 29 to 74. The purpose of the study was to explore patients' experiences of chronic illness. From the interviews, the researchers identified four themes relevant to understanding the experience of people with chronic illness. Although these themes contribute to a robust understanding of the research topic, the small participant pool and qualitative nature of the findings make studies like this difficult to apply to future research and practice.

In addition to interviews, focus groups are common among studies examining doctor-patient relationships and chronic illness (Copeland et al., 2003; Houle et al., 2007;

Kralik et al., 2004; Kralik et al., 2005). These guided discussions allow multiple participants to describe their experiences at once in dialogue with one another. Although focus groups are typically conducted in person at a scheduled time, researchers have also used e-mail discussion groups. Kralik et al. (2005) conducted a study related to women's experience of chronic fatigue in order to fill a gap in qualitative understanding of the topic. Thirty women whose ages ranged from 21 to 65 participated in an e-mail discussion group with the researchers. The researchers noted that the primary strength of this design was that it allowed participants to be more reflective and go into more detail in their responses than face-to-face focus groups would have allowed. Additionally, participants were free to contribute at their leisure and were not constrained by a specific meeting time. Although participants' responses were revealing, the researchers did not present a list of themes that arose during the discussion. In general, however, focus groups can be useful because participants may collectively emphasize particularly important aspects of the topic of discussion.

In one study conducted by Kralik et al. (2004), data were collected through interviews, focus groups, and solicited autobiographies. The sample consisted of nine people with arthritis who volunteered for the study in response to a newspaper advertisement. The researchers asked the participants to create autobiographies in which they described their experiences as persons with chronic illness. These open-ended texts allowed participants the freedom to express their experiences in any way they chose and in detail. The autobiographies became the basis for phone interviews and a discussion group. This study clearly underscores the strengths of qualitative research; using three types of data allowed the researchers to identify themes and meanings on multiple levels, and participants validated the researchers’ interpretations during the discussion group. However, because participants self-selected, they could have been already eager to share negative healthcare experiences, whereas more satisfied patients might not have been interested in participating. Because qualitative research is not widely held to be generalizable to broader populations, participant selection becomes extremely important in generating useful findings.

Despite the number of qualitative studies related to doctor-patient relationships and chronic illness, there exist no studies in this area related to women with thyroid disease specifically, and even in studies that mention chronic illness generally, thyroid disease is rarely mentioned. In addition, these qualitative studies often have small sample sizes. One study sampled only four participants (Docherty & McColl, 2003), and the other studies ranged in sample size from nine to 50. Small samples make it difficult to generalize results, particularly since the narrative nature of data relates intimately to participants’ individual experiences.

Due to the limited complexity of quantitative data and to the gap in qualitative research related to women and thyroid disease, a qualitative approach was appropriate for this study.

Data Collection Methods

Several methods of data collection were considered in the design of this study. In addition to traditional face-to-face interviews, the options included interviews by telephone or Webcam and voice-over-internet-protocol (VOIP), synchronous online interviews, and asynchronous online interviews. When synchronous methods are used, researcher and participant(s) interact in real time (Ayling & Mewse, 2009). Telephone interviews and conferences, chat using Webcam, and Internet text-based chat are synchronous methods, as are traditional face-to-face interviews. Most asynchronous online research employs e-mail, in which the researcher sends a group of questions to the respondent, who replies when it is convenient to do so and sends the answers back to the researcher, follows up in a subsequent e-mail, and continues to do so until all questions have been answered. Asynchronous group discussions can use a similar approach by making use of mailing lists, bulletin boards, and Internet forums (Ayling & Mewse, 2009).

There are a number of advantages and disadvantages to using any format for data collection. Compared to online interviews, face-to-face interviews provide the researcher with the opportunity to build a personal rapport with the participants, encouraging them to talk freely about their experiences. Face-to-face interviews also enable the researcher to validate the truthfulness of responses by observing body language and tone of voice (Arksey & Knight, 1999; Bianco & Carr-Chellman, 2002). A disadvantage of in-person face-to-face interviews is that limitations on the researcher's ability to travel to the interview site may result in a skewed or insufficient sample; this limitation does not apply in the case of telephone and VOIP interviews. In contrast to asynchronous interview methods, moreover, synchronous interviews of all types allow the researcher to seek immediate clarification of points or additional information from participants if necessary (Arksey & Knight, 1999). Online qualitative methods can be particularly advantageous in accessing hard-to-reach groups such as the elderly, disabled, housebound, or geographically distant (Bianco & Carr-Chellman, 2002), as well as individuals and groups who might not be forthcoming in other settings (Ayling & Mewse, 2009). Another advantage to online methods is reduced travel and transcription costs, although researchers should not choose an approach to data collection based on cost alone, but should "allow our research question to drive the choice" of methods (Bianco & Carr-Chellman, 2002, p. 253).

Disadvantages of online interview methods, both synchronous and asynchronous, include the possibility that relationships between researcher and participants may be tenuous at best and that, except for Webcam chat, the opportunity to observe facial and body language of the participants will be lost (Bianco & Carr-Chellman, 2002). Lack of ability to observe the participant may become an issue particularly when discussing sensitive topics (Davis, Bolding, Hart, Sherr, & Elford, 2004); however, researchers who are at home in the online environment may be able to discern participants' feelings from other cues, such as terse responses in an otherwise forthcoming interviewee (Ayling & Mewse, 2009). Another concern is for participants' confidentiality, which may be endangered if encrypted software is not employed (Ayling & Mewse, 2009; Crompvoets, 2010). However, this limitation can be controlled in the case of synchronous chat if participants are advised to use fictitious screen names and anonymous e-mail accounts to protect their identities (Ayling & Mewse, 2009). In the case of asynchronous forums or bulletin boards, it is very difficult to find a platform that is controlled by the researcher; as Crompvoets (2010) noted, "Finding the right tool was far from problematic [sic] as many that are freely offered, Google groups, for example, remain public property and others, while potentially more secure, require an e-mail address from the participant to register" (p. 206). The potential loss of confidentiality arising from the need for an e-mail address can be controlled in the case of online forums and chat programs by having participants use a fictitious name and e-mail address. Further, the anonymity of Internet research, which may reduce the problem of socially desirable responding, may also encourage individuals to participate more than once, especially if incentives are offered (Bowen, Williams, & Baird, 2008). However, the problem of repeat responding is most likely in online survey research that has a monetary incentive, as individuals can easily fill out an online survey more than once; in one study that specifically examined the problem, repeat responding did not occur in the non-incentivized arm of the study (Bowen et al., 2008). In contrast to face-to-face interviews, online chat interviews can be very time-consuming to conduct (Hinchcliffe & Gavin, 2009), although this disadvantage may be compensated by the time saved by not having to transcribe the interview.

One of the chief goals of qualitative research is to collect rich data from which emergent themes can be derived (Creswell, 2008). Thus, it has been speculated that one of the potential limitations of using online chat, which involves typing questions and answers, could be that abbreviated responses might be forthcoming that do not lend themselves to in-depth analysis (Bianco & Carr-Chellman, 2002). Actual findings contradict this concern. Ayling and Mewes (2009) reported that despite the relative slowness of typing,

> Several participants were able to provide large amounts of text with minimal prompting by the researcher; one notable interview continued for 3 hours, producing 359 lines of transcribed text. Although this volume is considerably less than for spoken interviews, transcripts had a particularly "condensed" feel about them, and often one line of text contained two or more emergent themes….(p. 570)

On the other hand, participants who become uncomfortable or otherwise disengaged can more easily end the interview (Barratt, 2011), which may necessitate a larger potential sample to account for attrition. A concern with using an online forum, in which the participation of more than one individual is the norm, is that too much data, or data of the wrong sort, may be gathered (Crompvoets, 2010). This can be the case because of the disinhibition that can occur in the online environment (Bowen et al., 2008), and may lead to extraneous data.

Another concern that must be addressed in using Internet data collection methods is that of sampling bias as a result of convenience sampling (Bianco & Carr-Chellman, 2002; Crompvoets, 2010). However, convenience sampling is a limitation in any study in which random sampling of a large population is not possible, and in qualitative studies, which do not seek to achieve generalizable results, it is perhaps less of an issue than in statistical studies (Creswell, 2008). In qualitative research, the problem of a skewed sample can be addressed, in part, by noting and discussing themes that are discrepant from the main pattern of findings. Such an approach can enable the expression of dissenting voices and divergent experiences (Ely, Vince, Downing, & Anzul, 1997).

With the exception of archival designs, confidentiality and participants' rights are a major concern in all human subjects research, regardless of data collection method. Online forums, as noted by Crompvoets (2010), pose a significant problem if the researcher cannot establish ownership of the data. On the other hand, online chat software such as X-IM software (see http://www.x-im.net/) makes possible encrypted, one-on-one typed communication, and was used by Ayling and Mewes (2009) in their study of risky sexual practices among gay men. Further, as noted by these authors, participants can be advised to use anonymous e-mail accounts in order to log in to the software, thereby enabling participants to remain anonymous.

To summarize, in judging which data collection method to use for the study, my primary concerns were for the privacy and convenience of participants and for the ability to collect rich and reliable data. Given that members of The Thyroid Support Group (including myself) are accustomed to communicating in an online environment, as well as the immediacy of online chat as an interviewing tool (Ayling & Mewes, 2009; Gaiser & Schreiner, 2009), this method had great appeal. In addition, the ability of chat software to transcribe the interview as well as the absence of hesitations and inaudible statements characteristic of audiotaped interviews (Gaiser & Schreiner, 2009), led me to favor this approach over other interview methods. Further, the potentially greater security of chat software (Ayling & Mewes, 2009) made it superior to online forums and bulletin boards (Crompvoets, 2010). The final concern, convenience, related to participants' ability to access a program and administrative rights for installing it on their computer (Gaiser & Schreiner, 2009) did not seem insurmountable. For these reasons, I chose to use X-IM software to conduct individual, online, synchronous interviews with the participants in my study.

Summary

This chapter was a review of the existing empirical and theoretical literature related to the research topic. A description of the literature search strategy and an overview of thyroid disease were followed by descriptions of the conceptual frameworks for the study. This was followed by a thorough review of the literature on the doctor-patient relationship, the culture of the medical profession, gender differences in communication, and diagnostic bias.

Thyroid disorders are often characterized by vague, diffuse symptoms that can be difficult to diagnose. This presents a problem for patients seeking treatment within the prevalent culture of the medical profession. These problems are particularly troublesome for female patients, who are often met with sexism and marginalization in traditional doctor-patient relationships. Although there is empirical evidence suggesting that a more collaborative, nonsexist approach to individual healthcare is beneficial for both patients and doctors, the traditional system persists for a number of historical, cultural, and economic reasons.

This study expands upon the research on women's health and adaptation to chronic illness by looking at female thyroid patients' experience of treatment and doctor-patient relationship, which has not been studied from a social constructionist/feminist perspective. The social constructionist/feminist approach was chosen for the study because it can take patients' subjective illness experiences into account, and because it assumes that patients are experts on the phenomenological aspects of their conditions. This contrasts with the traditional culture of biomedical education, practice, and research, which overvalues verifiable, objective symptoms and conditions and undervalues patients' subjective reports (Hoffmann & Tarzian, 2001).

Regarding patient competence, Secker (1999) argued that, given the premium placed on reasonableness, rationality, and understanding, and given the nature of stereotypical views of women as emotional, irrational, and unintelligent, it is highly likely that such views influence perceptions of women's competence to make health-related decisions (p. 302).

The issue of patient competence is particularly important in cases related to autoimmune disorders such as those that commonly cause hypo- and hyperthyroidism. Such conditions can often be difficult to diagnose, and if physicians dismiss women's complaints due to sexism or traditional views of patient competence, misdiagnoses or delayed diagnosis could result (Chrisler & Parrett, 1995). Indeed, women experiencing vague and unexplained conditions have repeatedly reported feeling ignored and disrespected by medical professionals. In order to contribute to the understanding of these phenomena, their causes, and their potential solutions, the study will investigate the doctor-patient relationships experienced by female thyroid patients. The following chapter outlines the methodological approach and research design including a description of the participants, instrumentation, and procedure.

Chapter 3: Research Method

Introduction

As can be seen from the previous review of literature, no studies exist in the chronic illness literature that are related to women with thyroid disease specifically; and even in studies that discuss chronic illness generally, thyroid disease is rarely mentioned, despite its pervasiveness in women. Thus, a gap in the literature exists regarding the treatment experiences of women diagnosed with thyroid disease, and particularly their experiences of the doctor-patient relationship. To address this gap, in this qualitative, phenomenological study I examined female thyroid patients' experiences of treatment and the doctor-patient relationship and sought to answer the following research questions: "What are the treatment experiences of women with thyroid disease?"; "How does the doctor-patient relationship affect their experiences?"; and "Do their experiences differ based on the doctor's gender?"

The present chapter of this study contains an in-depth explanation of the research approach, rationale, and design; participants; context of the study; role of the researcher; research questions; data collection and instrumentation; data analysis; ethical protection of participants; qualitative trustworthiness; and dissemination of findings. The chapter is organized accordingly and concludes with a summary.

Research Approach, Rationale, and Design

Research Approach

Whereas quantitative research involves deductive reasoning, qualitative research is inductive in that the researcher builds abstractions and concepts based upon the data collected (Creswell, 2007). The research questions in this study were best addressed via qualitative methodology because the purpose of the study was to explore female thyroid patients' experiences of treatment and the doctor-patient relationship. According to Marshall and Rossman (2006), human behavior cannot be fully understood without knowledge of the framework within which people interpret their thoughts, feelings, and actions (p. 53). Thus, the use of open-ended questions via individual online interviews was an appropriate method for capturing the experience of the phenomenon (e.g., thyroid disease; Creswell, 2007).

Creswell (2007) identified narrative, phenomenology, case study, grounded theory, and ethnography as the five most commonly used qualitative research approaches. The narrative approach provides a description of an event or events in a chronological manner and is best used when the researcher wishes to focus on the experience of a single individual or small group (Creswell, 2007). The narrative approach was ruled out in favor of phenomenology because of my interest in exploring the experiences of unrelated individuals involved in a common phenomenon or experience. Because phenomenology involves several individuals rather than one individual or a small group and focuses on the experiences of the participant and the meaning of those experiences (Creswell, 2007), it was deemed more appropriate than the narrative approach. Grounded theory was also considered, but because of its sociological focus on generating theory that is based on the interactions of groups of people (Creswell, 2007), it was deemed inappropriate for this study, in which I was not seeking to generate a theory and did not focus on group interactions.

As in grounded theory, ethnography involves examining individuals who share the same process, action, or interaction (Creswell, 2007). In ethnographic research, these shared patterns are examined within one cultural group. Neither grounded theory nor ethnography were appropriate for the study, as unrelated individuals were examined across cultures in order to learn about their individual experiences; not learned and shared patterns of values, behaviors, beliefs, and language (Creswell, 2007, p. 68). Finally, case study (one or more cases in a particular setting or context) was not broad enough for this research because of its focus on in-depth examination of multiple data sources regarding a single individual or site (Creswell, 2007). The participants in this study did not share a common boundary in time or physical space and therefore cannot be considered a "case" (Creswell, 2007). Because of the foregoing rationale, phenomenology was the chosen method for the study.

Rationale

The phenomenological research approach was used because it involves examining the meaning of experiences about a particular phenomenon (e.g., thyroid disease) across several individuals who have experienced it (Creswell, 2007). The phenomenological method originated in the philosophy of Husserl (1931). Phenomenological research is not simply description and is not focused solely on themes or concepts (Van Manen, 1997). It also can be inspirational, bringing the researcher to moments of insight. I chose to use the Stevick/Colaizzi/Keen approach as modified by Moustakas (1994), a form of phenomenological research that explicitly uses the experience of the researcher as a part of the research and in which participants are regarded as coresearchers. The

Stevick/Colaizzi/Keen approach is further described in the section entitled "Data Analysis."

According to Creswell (2007), in qualitative research, the researcher is the instrument; therefore, regardless of the method chosen, I would be a part of the research. In Moustakas's (1994) view of phenomenology, research is guided by four major processes: epoche, phenomenological reduction, imaginative variation, and synthesis. *Epoche* is a Greek word meaning "to refrain from judgment" and was first introduced in the qualitative research literature by Husserl (1931) to describe the suspension of "everyday understandings, judgments, and knowings" regarding the phenomenon being studied (Moustakas, 1994, p. 33). By achieving a state of epoche prior to, during, and following participant interviews, the researcher eliminates any of his or her preconceptions regarding the phenomenon, thus allowing the phenomenon to be examined in its purest form (Creswell, 2007; Moustakas, 1994).

Phenomenological reduction involves creating a textural description of what one observes, both external and internal, regarding the phenomenon and its relationship to the self (Moustakas, 1994). The lived experiences of the researcher and the participants are vividly portrayed as individual depictions written by the researcher. Phenomenological reduction is "called 'phenomenological' because it transforms the world into mere phenomena. It is called 'reduction' because it leads us back (Lat. *reducere*) to the source of the meaning and existence of the experienced world" (Schmitt, 1967, p. 61). In order to fully comprehend the essence of the phenomenon, the researcher sets aside any assumptions regarding the participants' experiences (i.e., bracketing) and creates a list of all significant statements gathered during the interviews (i.e., horizonalizing; Creswell, 2007). All statements are initially given equal value and are organized into themes; irrelevant or overlapping statements are later deleted (Moustakas, 1994).

Following phenomenological reduction, the researcher writes a structural description of the phenomenon to represent how the phenomenon was experienced by the entire group of participants (Creswell, 2007). This process, referred to as *imaginative variation*, involves identifying underlying structural themes that account for the phenomenon. By "approaching the phenomenon from divergent perspectives, different positions, roles, or functions," the researcher seeks to understand the "precipitating factors that account for what is being experienced" (Moustakas, 1994, p. 97). *Synthesis* is the final step, in which the researcher combines the textural and structural descriptions into a composite depiction of the essence of the phenomenon (Moustakas, 1994). According to Polkinghorne (1989), the synthesis should provide the reader with an understanding of "what it is like for someone to experience [the phenomenon]" (p. 46).

In addition to Moustakas's (1994) view of phenomenology, my understanding of phenomenology has been enriched by Van Manen (1997), who developed five principles that contribute to good phenomenological research: lived thoroughness, evocativeness, intensity, tone, and epiphany. *Lived thoroughness* means that the phenomenon of interest is concretely situated in the real world such that those reading the research document recognize it as being rooted in true experience (Van Manen, 1997). *Evocativeness* refers to language that enables the reader to understand the phenomenon through the senses, so that it is part of their own experience. This is valuable because it gives the reader the feeling of being close to the research participants and helps bring them to life (Van Manen, 1997). *Intensity* refers to an emphasis on key terms or expressions within the research document. Intensity makes it possible for the reader to trace how the research participant creates meaning out of the phenomenon. *Intensification* is the use of repetition, but it also involves the use of evocative language to communicate fully (Van Manen, 1997). *Tone* is the way a statement sounds, such as serious, funny, and so on (Van Manen, 1997).

Van Manen's approach (1997) is consistent with the university's mission to effect positive social change, as it emphasizes understanding lived experience in order to change practice, whether in health care or teaching. Research and reflection focus on the improvement of professional practice, so that change is built on reflectivity and is a product of reflective engagement with the world. Thus, the nature of the researcher-participant relationship gives rise to an improved doctor-patient relationship, in which the doctor reflectively deals with patients, rather than treating them automatically or prejudicially.

Research Design

Using online chat, I individually interviewed 16 female thyroid patients (including myself) who were members of The Thyroid Support Group, an international online support group for individuals with thyroid disorders. The recommended sample size of a minimum of 10 participants for phenomenological research corresponds to the traditional quantitative research designs based on statistical power analyses conducted by Onwuegbuzie and Johnson (2004).

Participants

The sample included 16 females aged 18 years and older, with a diagnosis of thyroid disease, who were members of The Thyroid Support Group. The recommended sample size of a minimum of 10 participants for phenomenological research corresponds to the traditional quantitative research designs based on statistical power analyses conducted by Onwuegbuzie and Johnson (2004). By aiming for at least 10 participants, I was able to interview until data saturation occurred. Data are considered saturated when interviewees introduce no new information or perspectives on the topic being examined (Moustakas, 1994).

Selection of Participants

Criterion sampling was used in this study, as all participants were required to meet specific criteria to be eligible for participation. According to Creswell (2007), criterion sampling works well with phenomenological studies and helps with quality assurance. The criteria for inclusion were as follows: (a) female, (b) age 18 years and older, (c) with a self-proclaimed diagnosis of thyroid disease, and (d) a member of The Thyroid Support Group. Since the prevalence of thyroid disease is much higher in women than men (Canaris et al., 2000; Cassidy et al., 2002) and the purpose of this study was to explore women’s treatment experiences, male group members were excluded from the study. Due to the vulnerable nature of children, individuals who were under 18 years of age were also excluded. Non-members of The Thyroid Support Group (e.g., spouse of member) were excluded as well.

Vulnerable participants. A number of participants considered vulnerable by the university's IRB may have been included, but were not targeted, in this study. The following are descriptions of vulnerable populations and explanations for their potential inclusion in this study: (a) Elderly individuals: Because the prevalence of thyroid disease in women increases with age (about 20% in women over age 60; Godfrey, 2007), eliminating participants over age 60 would have precluded those individuals who experienced thyroid disease late in life due to an age-related decline in thyroid hormones. (b) Pregnant women: Because thyroid disease is common in pregnant and postpartum women, the experiences of these women are important for a detailed understanding of the treatment experiences of women with thyroid disease; (c) Residents of a mental health facility: Determining whether or not an individual is a resident of a mental health facility would have required asking invasive questions unrelated to the study. In addition, verification was impossible due to the nature of the Internet; (d) Mentally/emotionally disabled individuals: Affective disorders commonly co-occur with thyroid disease. The experience of an affective disorder in conjunction with thyroid disease is vital to understanding the overall treatment experiences of women with thyroid disease; (e) Individuals who might be less than fluent in English: The online support group from which participants were obtained is international. Obtaining information from women who have thyroid disease from various parts of the world may help to provide a universal understanding of women with thyroid disease. However, because I do not speak any languages other than English, the interviews were conducted in English. Therefore, individuals who are not fluent in English were not included in the study; (f) Traumatized individuals: Determining whether or not an individual is traumatized would have required asking invasive questions unrelated to the study; and (g) Economically disadvantaged individuals: Some of the individuals in the online support group are low income and/or have poor health insurance coverage. As such, some group members obtain much of their treatment advice, medications, or both via the Internet. These individuals may help to provide a more thorough understanding of women's treatment experiences.

Recruitment of Participants

Although I utilized the services of a colleague in data analysis and interpretation (as discussed in the section “Qualitative Trustworthiness”), I was the only person to recruit and interact with the group owner, group members, and study participants. Permission was sought and obtained from the group owner-moderator of The Thyroid Support Group via a letter of cooperation (see Appendix B), after which members of The Thyroid Support Group were invited via an on-list e-mail to participate in the study (see Appendix C). If more than 16 equally qualified individuals had offered to volunteer, I would have selected the participants in the order in which their off-list e-mails were received. However, more than 16 participants did not offer to volunteer for participation. All participants were informed that they had the right to leave the study at any time for any reason, without explanation.

Context of the Study

Data were obtained via individual interviews with members of The Thyroid Support Group, an international online support group for individuals with thyroid disorders (see http://health.groups.yahoo.com/group/The_Thyroid_Support_Group/), using the encrypted online chat software X-IM (see http://www.x-im.net/ for program specifications). Per the requirements of the university's IRB regarding conducting research in an organization, a letter of cooperation (see Appendix B) was obtained from the group owner-moderator to solicit group members for participation. Although permission to solicit group members to participate in research was not required from the group owner-moderator, I believed that requesting permission was perceived by the owner-moderator as a gesture of respect and good will.

Role of the Researcher

I was the sole researcher involved with the recruiting, selecting, and interviewing of participants, with entering transcripts into the ATLAS.ti software and saving the data, and with the dissemination of the findings of the study. To help ensure data trustworthiness and quality, I utilized the services of a colleague (on a voluntary basis) to assist me with data analysis and interpretation. My colleague's qualifications included a PhD in English Literature, a Master's degree in Counseling Psychology, and two decades of teaching. She is also a technical editor and published author.

As the sole interviewer, I gathered data as a participant-observer, that is, as someone who already held a position in the community before acting as an observer (Creswell, 2007). As mentioned previously, the method of this study was phenomenological because the research was inspired by my personal interest in and experience with the phenomenon. Thus, my consciousness was the primary data analysis tool (Creswell, 2007; Moustakas, 1994; Willig & Rogers, 2008). Because of my role as designer of the study and collector and interpreter of data, it behooved me to discuss my role as the researcher in the study and to state any latent biases that might have affected the study's process and results.

The researcher's self-examination process, termed *reflexivity*, involves "confronting, and often challenging your own assumptions, and recognizing the extent to which your thoughts, actions and decisions shape how you research and what you see" (Mason, 2002, p. 5). Reflexivity allowed me, as a researcher, to discern and clarify how my position shaped the research process and its interpretations (Willig & Rogers, 2008). Willig and Rogers (2008) distinguished between personal and epistemological reflexivity. Personal reflexivity has to do with the researcher's own principles, beliefs, and social roles that have an impact on the research. Epistemological reflexivity refers to the way decisions and assumptions about the nature of knowledge have shaped the research, and foregrounds the framing of the research question and how that places limits on what can be learned about the phenomenon of interest (Willig & Rogers, 2008).

This section includes a personal reflexive account in which I considered my social identity, principles and beliefs, technical ability, and research background as these related to the research. I looked at three major features of Willig and Rogers' (2008) definition of personal reflexivity: (a) my identity as a person, (b) how I was related to the research topic, and (c) my identity as a researcher.

My identity as a person. I am a Caucasian female and an American citizen, and have lived in the United States all my life.

My relationship to the research project. As a student in psychology, I have learned much about mental illness, its diagnosis, and manifestations. While employed by the Social Security Administration (SSA), I worked directly with individuals applying for disability benefits—some due to mental illness, others due to physical disability, and in some cases, both. Many of my clients expressed frustration with their experiences, not only with maintaining employment, but also with the impact of the illness on their relationships with coworkers, friends, and family members. More specifically, my clients shared that others perceived them as “lazy” for not maintaining a job. I personally experienced judgment by others for similar difficulties brought about by consistent, debilitating fatigue, inability to concentrate, anxiety, and depressed mood. In 2004, I was diagnosed with Hashimoto’s disease, an autoimmune form of thyroid disease.

I initially felt empowered by my diagnosis and understood my symptoms to be a result of the disease. However, in the first three years of my experience as a thyroid patient, I felt disempowered as endocrinologists consistently told me that my fatigue, mood changes, and weight gain were not due to thyroid disease. Rather, I was informed that I simply needed to diet, exercise, obtain treatment for premenstrual syndrome, and “just relax.” I sought support and information from The Thyroid Support Group and learned that there were many other women diagnosed with thyroid disease who were also dissatisfied with their treatment experiences. My shared experiences with these other women and the lack of information in the literature about thyroid patients’ experience of treatment and doctor-patient relationship inspired me to conduct this research.

My identity as a researcher. I graduated in 2003 with a Master’s Degree in Education, with a focus on Community Counseling. After receiving my degree, I was employed initially as an editor and research consultant with a private writing, research, and editing firm and then became employed by the SSA. I currently work as an adjunct instructor of psychology at a proprietary higher education institution.

My influence on the research. As a woman with thyroid disease, I realize that this research is both inspired and limited by my views, life experiences, technical skill, and academic experience. That I have a disorder the same as or similar to those of the research participants and am a member of The Thyroid Support Group may have increased the willingness of potential participants to share their perceptions and experiences with me. However, that shared background may have also limited my ability to identify the influence of my assumptions on my interpretations and may lead to over-identification with the research topic or participants. The fact that I am American, female, and White and that participants were female may also have influenced the way we interacted and the way I interpreted their statements, as would the fact that some participants were non-White and could have been from countries other than the United States. I discuss the steps taken to limit researcher bias and ensure data trustworthiness and quality in the section entitled “Qualitative Trustworthiness.”

Research Questions

As noted previously, the research questions used to guide this study were:

RQ1. What are the treatment experiences of women with thyroid disease?

RQ 2. How does the doctor-patient relationship affect their experiences?

RQ 3. Do their experiences differ based on the doctor’s gender?

Data Collection and Instrumentation

Data Collection

As discussed in Chapter 2 under “Data Collection Methods,” data were gathered via individual interviews via online chat using X-IM encrypted software to establish and record communication with participants. According to Creswell (2007), the use of open-ended questions is most appropriate for phenomenological research, as they gather information on the everyday lived experiences of individuals, from which the researcher can identify themes. Therefore, as the sole interviewer, I collected data via open-ended questions in online chat with the participants regarding their experiences with thyroid disease, including their physical and emotional experiences, perceptions of physicians’ attitudes, satisfaction with treatment (e.g., medications), and lifestyle changes due to thyroid disease. For example, participants were asked to answer, “Please tell me, what has been your experience in seeking treatment for thyroid disease?” and “How do you feel about the treatments you are receiving for thyroid disease?” (see Table 1 and Appendix A). Demographic data collected at the beginning of the interview included age, ethnicity, education level, thyroid disease diagnosis, number of years since diagnoses, treatment (e.g., medications), and gender of physician(s).

In order to triangulate data gathered from the interviews, participants were asked to provide copies of their electronic journals or diaries, if available and only if the participants wished to provide them. Data triangulation and additional steps taken to ensure data trustworthiness and quality are further discussed in the section entitled “Qualitative Trustworthiness.” At the end of each interview, I asked the participant if she would like to review her individual interview transcript for accuracy, as well as if she would like me to contact her via off-list email to share the findings of the research.

Instrumentation

An interview guide I created (see Appendix A) was used to gather data. An external panel of three experts in qualitative methods was consulted regarding the accuracy of the interview guide. In order to enhance the reliability and validity of the interview guide, feedback from the expert panel regarding the wording and order of the interview questions was incorporated into the final version of the guide. The research questions are coded as RQ1, RQ2, and RQ3 respectively, and are listed next to their corresponding interview questions in the interview guide (see Appendix A). The research question matrix shown in Table 1 depicts the relationship between the nine interview questions and the research questions.

Table 1

Interview Questions as They Relate to the Research Questions

Interview Question	Research Question
1. Please tell me, what has been your experience in seeking treatment for thyroid disease? - Possible probe: How did you come to be diagnosed? - Possible probe: How long have you been being treated?	1. What are the treatment experiences of women with thyroid disease?
2. How would you describe your current relationship with the doctor who treats you for thyroid disease?	1. What are the treatment experiences of women with thyroid disease? 2. How does the doctor-patient relationship affect their experiences?
3. How do you feel about the treatments you are receiving for thyroid disease?	1. What are the treatment experiences of women with thyroid disease? 2. How does the doctor-patient relationship affect their experiences?
4. How clearly do you believe your doctor explains things to you? - Possible probe: What do you believe your doctor could do to make his or her communication clearer?	2. How does the doctor-patient relationship affect their experiences?
5. Do you think it matters whether your doctor is a man or a woman? Why or why not?	3. Do their experiences differ based on the doctor's gender?
6. How does being a woman, as opposed to being a man, influence your relationship with your doctor?	1. What are the treatment experiences of women with thyroid disease? 2. How does the doctor-patient relationship affect their experiences? 3. Do their experiences differ based on the doctor's gender?
7. How comfortable do you feel in talking with your doctor about symptoms or medical issues you have experienced that you believe might be related to thyroid disease?	1. What are the treatment experiences of women with thyroid disease? 2. How does the doctor-patient relationship affect their experiences?
8. What do you believe might help you to feel more comfortable in sharing your experience of these symptoms with your doctor?	2. How does the doctor-patient relationship affect their experiences? 3. Do their experiences differ based on the doctor's gender?
9. Is there anything else you would like to add?	

Data Management

Interview data collected via X-IM software consisted of automatically transcribed, typed transcripts with each participant. After each interview, I personally copied and pasted each transcript verbatim onto a password-protected thumb drive. The drive is stored in a locked cabinet in my office.

Data Analysis

To help ensure data trustworthiness and quality, I utilized the services of a colleague (on a voluntary basis) to assist me with data interpretation. Before any data analysis and interpretation began, my colleague and I signed a confidentiality agreement (see Appendix E). I uploaded the confidentiality agreement to ShareFile.com for her to sign. Sharefile.com offers a paid service through which files can be shared securely via encryption and password-protection. My colleague returned the Confidentiality Agreement to me via the same website.

After I personally organized the interviews, I followed the Stevick/Colaizzi/Keen method as modified by Moustakas (1994) for each source. This method involved the following steps:

1. Begin by describing the researcher’s own personal experience with the phenomenon in order to disclose and attempt to set aside biases.
2. Examine the interview transcripts or other data, looking for significant statements about how the participants experience the phenomenon, in order to develop a comprehensive list of non-overlapping statements.
3. Group these statements into categories or themes.

4. Write a description of *what* ("textural description") the participants experienced with the phenomenon, including verbatim examples.
5. Write a description of *how* ("structural description") the experience occurred.
6. Combine the textural and structural descriptions into a composite depiction of the essence of the experience.

I personally entered the interview transcripts into the ATLAS.ti software, which allowed me to code, annotate, and compare segments of information (Creswell, 2007). Both *a priori* coding and emergent coding was used. The latter allows "opening up the codes to reflect the views of the participants in a traditional qualitative way" (Creswell, 2007, p. 152). I identified significant statements and themes based on the theoretical perspectives of feminism and social constructivism (*a priori* coding). More specifically, statements and themes related to the issues of (a) communication (gender differences; see Cheney & Ashcraft, 2007; Tannen, 2007), (b) culture (medical profession and education; see Kaiser, 2002; Thomas, 2001), and (c) diagnostic bias (see Hamberg et al., 2004; Hoffmann & Tarzian, 2001; Munch, 2004).

Once I identified patterns and themes in participants' experiences using the ATLAS.ti software, I interpreted the findings based on feminist theory and social constructionism, as well as existing literature. While it is known that the prevalence of thyroid disease is much higher in women than men across cultures (Canaris et al., 2000; Cassidy et al., 2002), and that many women continue to experience symptoms even when they are receiving treatment (Dayan, 2001), the treatment experiences of women diagnosed with thyroid disease remain unexplored. Based upon my communications with members of The Thyroid Support Group and current feminist literature, I had anticipated that themes will emerge in the following areas: (a) gender differences in communication (see Cheney & Ashcraft, 2007; Tannen, 2007), (b) culture of the medical profession (see Kaiser, 2002; Thomas, 2001), and (c) gender in diagnostic bias (see Hamberg et al., 2004; Hoffmann & Tarzian, 2001; Munch, 2004). In addition, as the support group was international, it was possible that various patterns could emerge based on the participants' culture, ethnicity, or both. In order to help validate the findings, I asked the participants to review the findings for accuracy and thoroughness.

I uploaded the interview transcripts along with my interpretations to ShareFile.com for my colleague to download. My colleague saved the participants' interview transcripts and my interpretations onto a password-protected thumb drive. My colleague reviewed my interpretations of the data and provided me with feedback. After sending me her feedback via ShareFile.com, my colleague destroyed all data related to my study. I used my colleague's feedback as a "reality check" to guard against my subjectivity as an individual with thyroid disease.

Ethical Protection of Participants

Permission to conduct the study was sought and obtained from the university's IRB (approval #12-19-13-0055511). Permission was also sought and obtained from the group owner-moderator of The Thyroid Support Group via a letter of cooperation (see Appendix B), after which members of The Thyroid Support Group were invited via an *on-list* e-mail to participate in the study (see Appendix C). Through the invitation, per the guidance of Ayling and Mewes (2009), I instructed interested members to create a free email account using a fictitious name and to respond to my invitation via *off-list*, individual email with their new email account and fictitious name.

I responded to the first 15 volunteers (not including myself) via *off-list*, individual emails and sent them a Consent Form (see Appendix D) explaining that they were chosen for the study because they are women with a thyroid disease diagnosis. Please note that I used *implied*, rather than informed, consent to safeguard participant anonymity. I instructed each volunteer to review the consent form and to respond to my email *off-list* using her new email account and fictitious name to set up a date and time for her individual interview if she was still interested in participating. The consent form informed prospective participants about the procedures and time commitments of the study, potential risks and benefits, limits to confidentiality, their right to withdraw from the study at any time without penalty, and contact information for myself and my advisor. The consent form also explained that by emailing me to establish a date and time for an individual interview, their consent to participate in the study was implied. Upon receiving implied consent via *off-list*, individual emails from volunteers, I individually emailed each participant to establish a date and time for her individual online interview.

Each participant was asked to not respond to my e-mails from her workplace, as employers may have legal access to her e-mail (Keller & Lee, 2003). I instructed participants to use their new e-mail account using a fictitious name in order to log in to the X-IM software for the interview. For additional security, I encouraged participants to engage in the interview in a private, non-public area (Kraut et al., 2004). As noted under “Data Management,” I copied and pasted each interview transcript onto a password-protected thumb drive, which I will store in a locked cabinet in my office for a period of five years, after which the drive(s) will be destroyed. As my colleague had access to the data, she was asked to sign a confidentiality agreement (see Appendix E) before any data analysis or interpretation began. My colleague saved the participants' interview transcripts, electronic journals/diaries, and my interpretations onto a password-protected thumb drive and destroyed all data related to my study after sending me her feedback via ShareFile.com.

Qualitative Trustworthiness

Data trustworthiness and quality was verified through use of the following techniques: prolonged engagement, triangulation, member checking, and reflexive journaling.

Prolonged Engagement

Prolonged engagement involves an understanding of the culture one plans to investigate, as well as building trust with one's participants (Creswell, 2007; Schensul & LeCompte, 1999). Because I have been a member of The Thyroid Support Group since 2004, trust had been established with the group owner-moderator and potential participants. In addition, as a member, I have a comprehensive understanding of the context and phenomena under study.

Triangulation

Triangulation includes the use of different sources, theories, and investigators in an attempt to substantiate evidence (Creswell, 2007, 2008; Schensul & LeCompte, 1999). I collected data from an interview guide and had planned to collect personal electronic journals or diaries. However, no electronic journals or diaries were available. Triangulation was achieved by using more than one theoretical position (feminism and social constructionism) to interpret the data (theoretical triangulation; Denzin, 1970). I also used the services (on a voluntary basis) of a colleague for data interpretation (consensual validation; Eisner, 1991).

Member Checking

Member checking involves seeking and including participants' feedback in assessing the credibility of the study's findings (Creswell, 2007; Schensul & LeCompte, 1999). At the end of each interview, participants reviewed their individual interview transcript for accuracy. I also asked the participants to review the findings of the research for accuracy and thoroughness.

Reflexive Journaling

Reflexive journaling involves acknowledging and keeping a record of one's personal thoughts and feelings while conducting research in an attempt to eliminate researcher bias (Creswell, 2007; Moustakas, 1994). I maintained a record of personal thoughts and feelings that occurred throughout the research process.

Dissemination of Findings

I will be the sole researcher involved in the dissemination of the findings. Findings of this study will be disseminated in several ways. First, results will be shared with participants who indicated an interest in reading the study. Second, I plan to publish a condensed form of the study in a scholarly journal so that healthcare professionals can utilize the information in practice and future research. Third, I will condense the study to the scope of a conference paper with the intention of presenting the study and its results at appropriate conferences.

Summary

This qualitative, phenomenological study explored the lived experiences of a sample of 16 women diagnosed with thyroid disease in order to answer questions regarding their treatment experiences and the effect of gender on their relationships with their doctors. Using the phenomenological approach of Stevick/Colaizzi/Keen as modified by Moustakas (1994) and enriched by Van Manen (1997), I identified common themes as well as discordant information among the participants. Two approaches to understanding participants' experiences, social constructionism and feminism, were used in data interpretation. Results of this study may, consistent with Van Manen's five principles and the university's mission to effect positive social change, result in improvements in medical practice with female patients with thyroid disease.

Chapter 4 presents the findings of this phenomenological study. In Chapter 5, the findings are interpreted and discussed along with implications for social change and recommendations for further research.

Chapter 4: Results

Introduction

The purpose of this study was to explore treatment experiences and doctor-patient relationships among female thyroid patients. A phenomenological approach was used in order to examine the meaning of the experience of thyroid disease treatment as described by women who had experienced treatment for thyroid disease. Based upon the theories of social constructivism and feminism, the following research questions were answered: “What are the treatment experiences of women with thyroid disease?”; “How does the doctor-patient relationship affect their experiences?”; and “Do their experiences differ based on the doctor’s gender?” This chapter presents the results. I discuss the setting, participant demographics, data collection and management, data analysis, evidence of trustworthiness, and the major themes and subthemes that emerged during data analysis.

Setting

Data were collected via individual online chat interviews with members of The Thyroid Support Group. Before each interview, participants were informed that they had the right to leave the study at any time for any reason, without explanation. Participants were provided with free, international crisis hotline telephone numbers in case they felt upset as a result of their interviews (see Appendix D, Consent Form). To my knowledge, none of the participants became upset due to their interviews. It is not known if any of the participants used the crisis hotline telephone numbers provided. No unexpected events occurred that might have influenced my interpretation of the data.

Participant Demographics

In order to participate in the study, all volunteers were required to meet the following criteria: (a) female, (b) aged 18 years and older, (c) with a self-proclaimed thyroid disease diagnosis, and (d) member of The Thyroid Support Group. Demographic information for all 16 participants is listed in Tables 2 and 3. Please note that the participants' names are pseudonyms. More specifically, the participants' names are the fictitious names created by the participants in order to log in to the X-IM software for their individual interviews.

The sample of 16 participants had an average age of 55 years. The median age was 54 years, with the youngest participant at 32 years old and the oldest participant at 82 years old. The sample was mostly Caucasian (14 out of 16 participants), with one participant identifying as Hispanic and another participant identifying as Czech Polish. The majority of the participants (15 out of 16) reported having education beyond high school. More specifically, three participants reported having "some college," two had associate's degrees, seven had bachelor's degrees, and three had master's degrees. Eight of the participants reported having male doctors, six reported having female doctors, and two reported having both male and female doctors. The majority of the participants' doctors were Caucasian (13 out of 18 total doctors), two were Middle Eastern, one was Asian, one was East Indian, and one was Nigerian (see Table 2).

All 16 participants reported having a diagnosis of hypothyroidism. Eight participants specified Hashimoto's disease diagnoses, and one participant specified having a diagnosis of Grave's disease. Half of the participants (eight out of 16) reported taking natural thyroid medication alone as treatment for thyroid disease. More specifically, five reported taking Armour thyroid, two reported taking Nature-throid, and one reported taking compounded porcine thyroid. Three participants reported taking a combination of natural thyroid and synthetic thyroid medications. More specifically, one participant reported taking Armour thyroid and Tirosint, one participant reported taking desiccated porcine thyroid and levothyroxine, and one participant reported taking NP thyroid and Cytomel. Five of the 16 participants reported taking synthetic thyroid medication only. More specifically, three participants reported taking levothyroxine, one reported taking a combination of Synthroid and Cytomel, and one reported taking Tirosint and Cytomel. Additional diagnoses reported by the participants included hypertension (four out of 16), osteopenia (three out of 16), diabetes (two out of 16), high cholesterol (two out of 16), and breast cancer (two out of 16). All reported additional diagnoses are listed in Table 3.

Table 2

Participant Demographics

Participant	Age	Ethnicity	Highest education level completed	Doctor(s)' gender	Doctor(s)' ethnicity
1: Alicia	46	Caucasian	Bachelor's degree	Male	Caucasian
2: Anne	52	Caucasian	Bachelor's degree	Female	Caucasian
3: April	34	Caucasian	Bachelor's degree	Male	Caucasian
4: Autumn	48	Caucasian	Associate's degree	Male	Middle Eastern
5: Carla	56	Caucasian	High School	Female	Nigerian
6: Diane	41	Hispanic	Business Associate's degree	Male	East Indian
7: Emily	52	Caucasian	Master's degree	Female	Caucasian
8: Jenna	48	Caucasian	Some college	Male	Caucasian
9: Jessica	58	Czech-Polish	Bachelor's degree	Male Female	Caucasian Middle Eastern
10: Karen	64	Caucasian	Some college	Female	Caucasian
11: Kari	78	Caucasian	Bachelor's degree	Female	Caucasian
12: Kim	82	Caucasian	Bachelor's degree	Female	Caucasian
13: Leanne	37	Caucasian	Master's degree	Male	Caucasian
14:Michelle	61	Caucasian	Bachelor's degree	Male	Caucasian
15: Sarah	66	Caucasian	Some college	Female Male	Asian Caucasian
16: Shawna	59	Caucasian	Master's degree	Male	Caucasian

Table 3

Participant Demographics: Diagnoses and Treatments

Participant	Thyroid disease diagnoses	Treatment	Other medical diagnoses
1: Alicia	Hypothyroidism	Levothyroxine	Breast cancer
2: Anne	Hypothyroidism	Compounded porcine- thyroid	None
3: April	Hypothyroidism	Armour thyroid	Cancer
4: Autumn	Hypothyroidism	Armour thyroid	None
5: Carla	Hypothyroidism	Desiccated porcine- thyroid Levothyroxine	Diabetes High cholesterol Mobility-impaired
6: Diane	Hashimoto's disease Hypothyroidism	Armour thyroid Tirosont	None
7: Emily	Hashimoto's disease Hypothyroidism	Cytomel Synthroid	Breast cancer Gastroesophageal reflux-disease Irritable bowel syndrome
8: Jenna	Hypothyroidism	Levothyroxine	Rosacea Seizure disorder
9: Jessica	Hashimoto's disease Hypothyroidism	Naturethroid	Allergies
10: Karen	Grave's disease Hypothyroidism	Armour thyroid	Arthritis Polymyalgia
11: Kari	Hypothyroidism	Armour thyroid	Diabetes
12: Kim	Hashimoto's disease Hypothyroidism	Cytomel NP thyroid	Chronic obstructive-pulmonary disease Hypertension Osteoarthritis Osteopenia
13: Leanne	Hashimoto's disease Hypothyroidism	Armour thyroid	Fibromyalgia Osteopenia
14:Michelle	Hashimoto's disease Hypothyroidism	Cytomel Tirosint	High cholesterol Hypertension
15: Sarah	Hashimoto's disease Hypothyroidism	Naturethroid	Hypertension
16: Shawna	Hashimoto's disease Hypothyroidism	Levothyroxine	Hypertension Osteopenia

Participant Profiles

Using the Stevick/Colaizzi/Keen approach as modified by Moustakas (1994; see Chapter 3), I constructed a textural-structural description for each participant (see Appendix G). Because Moustakas's method is a form of phenomenological research that explicitly uses the experience of the researcher as a part of the research, my own textural-structural description is included as well. In order for the reader to fully understand the essence of the participants' experiences with thyroid disease treatment and the doctor-patient relationship (Polkinghorne, 1989), I provided narratives in the participants' own words where necessary.

Data Collection and Management

For the study, I conducted 15 interviews (see Appendix A) via individual interviews via online chat using X-IM encrypted software over a period of approximately three weeks (between January 12, 2014 and February 5, 2014). Each interview lasted between half an hour to one hour each, depending upon how much each participant chose to share. After each interview, participants were asked to review their interview transcript for accuracy and thoroughness. I copied and pasted each automatically-transcribed interview onto a password-protected thumb drive. The thumb drive is stored in a locked cabinet in my office.

In an attempt to triangulate data gathered from the interviews, I asked participants to provide copies of their electronic journals or diaries. However, no electronic journals or diaries were available because none of the participants had electronic journals or diaries to share.

According to Moustakas's (1994) method, the researcher is to provide a description of his or her own experience of the phenomenon being explored (p. 122). As such, I responded to the interview questions, which resulted in a total of 16 interviews. My own demographic information is also included in Tables 2 and 3.

Data Analysis

After completing each interview, I followed the Stevick/Colaizzi/Keen method as modified by Moustakas (1994). I wrote a textural-structural description for each participant's experience, including my own, based on her responses to the interview questions (see Appendix G). A member check validated the details of the textural-structural descriptions. Each participant reviewed her individual textural-structural description for accuracy and thoroughness.

After all interviews were completed and textural-structural descriptions were written, I entered the interview transcripts into the ATLAS.ti software and used a priori coding to help identify comments and themes relevant to the theoretical perspectives of feminism and social constructivism. The following themes were identified: (a) doctor-patient relationship, (b) patient self-advocacy, (c) doctor-patient communication, (d) and culture of the medical profession (see Appendix H).

I conducted a second review of the interview transcripts in ATLAS.ti and used emergent coding in order to identify and group similar ideas by conceptual theme. For example, statements related to traditional doctor-patient relationships and collaborative doctor-patient relationships became subthemes under the theme Doctor-Patient Relationship. Appendix H presents the full list of themes and subthemes.

While reviewing the interview transcripts along with their corresponding textural-structural descriptions, I recognized some additional noteworthy findings that were relevant for some participants, but did not represent the experience of the group as a whole. In considering desire of all participants for their doctors to be open to their unique experiences [e.g., “Listen to someone that is ‘living it’ and throw away the Synthroid book” (Carla) and “[My doctor] does not understand that there is not one size fits all” (Anne)], I have chosen to refer to these data as “additional findings” rather than refer to this as “discrepant data.”

Statements that were irrelevant to the discussion and did not represent the participants’ experiences with thyroid disease treatment and the doctor-patient relationship were excluded from analysis. For example, “I now work on a volunteer basis with families all over the world to help them to advocate for the best possible treatment for their terminally ill children” (Alicia); and “I see patients all the time myself as a speech-language pathologist and some of them have been not treated/diagnosed correctly” (Shawna).

Evidence of Trustworthiness

Data trustworthiness was verified during the process of data collection and analysis through the use of the following techniques: prolonged engagement, reflexive journaling, member checking, and triangulation (see Chapter 3). Prolonged engagement was achieved, as I had established trust with the group owner-moderator and participants. During data collection and analysis, I utilized reflexive journaling. More specifically, when personal thoughts and feelings surfaced as I read the participants’ interviews and wrote their textural-structural descriptions, I made note of my thoughts and feelings in a journal and then set the journal aside to return to the participants' experiences. I address these thoughts and feelings in the discussion of the results in Chapter 5.

At the end of each interview, participants reviewed their individual interview transcript for accuracy. In addition, participants were asked to review their individual textural-structural descriptions for accuracy and thoroughness. I had planned to collect personal electronic journals or diaries in addition to the data gathered from the interview guide. However, no electronic journals or diaries were available. Nevertheless, triangulation was achieved by interpreting the data from two theoretical positions (feminism and social constructionism). I also used the services (on a voluntary basis) of a colleague for data interpretation. I discuss my colleague's feedback and its impact on data interpretation in Chapter 5.

Results

In this study, I explored female thyroid patients' experiences of treatment and the doctor-patient relationship. The interview questions created for the study reflected upon the following research questions: "What are the treatment experiences of women with thyroid disease?"; "How does the doctor-patient relationship affect their experiences?"; "Do their experiences differ based on the doctor's gender?"

Numerous factors influenced each participant's experience with thyroid disease treatment. While the majority of participants expressed some type of dissatisfaction with their treatment experiences, some participants conveyed only positive comments about their experiences. Many of the participants who were dissatisfied with their treatment experiences switched doctors and were ultimately satisfied with their treatment. Some participants remained dissatisfied despite having seen more than one doctor. The participants' stories provide a comprehensive review of treatment experiences surrounding the doctor-patient relationship, doctor-patient communication, and the culture of the medical profession. Appendix G presents detailed descriptions of each participant's story. In order to provide a thorough examination of the participants' experiences, the following review of themes and subthemes includes quotes from each participant, as applicable. All participant quotes were collected during the interviews.

Theme 1: Doctor-Patient Relationship

Each interview began with asking participants to describe their experience with seeking treatment for thyroid disease. The participants' responses revealed two types of doctor-patient relationships: traditional and collaborative.

Subtheme 1: Traditional relationships. Eleven of the 16 total participants (Anne, April, Carla, Diane, Jenna, Jessica, Karen, Kim, Leanne, Sarah, and Shawna) experienced traditional doctor-patient relationships. Among these participants, 8 felt unheard by their doctors, 10 felt invalidated by their doctors, 8 felt dismissed by their doctors, 4 experienced a lack of empathy from their doctors, and 3 felt disrespected by their doctors.

Feeling unheard. Eight of the 11 participants who experienced a traditional doctor-patient relationship (April, Carla, Diane, Jenna, Jessica, Leanne, Sarah, and Shawna) indicated that they felt unheard by their doctors.

"The [doctor] flat out told me to 'trust her, she had control of the situation' [but] she worked by my levels NOT by my feelings and how I was living life…[and she had] a negative and controlling attitude…[I wish she would] LISTEN." (April)

"I felt that my dose [of thyroid medicine] was wrong, I was getting worse and worse each year. Every time I talked to a doc about it I was demeaned and/or ignored." (Carla)

"As I aged, I experienced illnesses that showed me I had a compromised immune system and something wasn't right, but no doctor would further investigate." (Diane)

"He doesn't listen…When I tried to explain to him my hair was falling out and I was tired ALL the time he just blew it off as not being related…[I wish he would] LISTEN instead of being pushy." (Jenna)

"I am tiered [sic] of doctors thinking that we are just anxious…and will not believe us. They want to put us on antidepressants instead of helping us. This causes more anxiety and is very sad." (Jessica)

"[My] doctor poo-pawed anything I would bring up…questioning whether it was…a symptom of the hypothyroidism instead of some new disease she wanted to prescribe more medication for." (Sarah)

"I start to explain [my] history…but he interrupts me at the point I say the Naturopath put me on levo and launches into a tirade about how I don't have a thyroid problem and should never have been put on meds and they will cause palpitations…hair loss and high BP etc…ignoring I have been on them 9 months with none of those problems…" (Shawna)

Feeling invalidated. Ten of the 11 participants who experienced a traditional doctor-patient relationship (Anne, April, Carla, Diane, Jenna, Jessica, Kim, Leanne, Sarah, and Shawna) indicated that they felt invalidated by their doctors.

“I do tend to get emotional which I think makes doctors (and anyone) give less credence to my depiction of my symptoms.” (Anne)

“I went [to my appointments] with knowledge and she told me to get off google...[and] when I asked her to test my reverse T3, she refused saying it was no more important than the type of blood I had.” (April)

“I felt that my dose [of thyroid medicine] was wrong, I was getting worse and worse each year. Every time I talked to a doc about it I was demeaned and/or ignored.” (Carla)

“As I aged, I experienced illnesses that showed me I had a compromised immune system and something wasn't right, but no doctor would further investigate.” (Diane)

“When I tried to explain to him my hair was falling out and I was tired ALL the time he just blew it off as not being related.” (Jenna)

“I am tiered [sic] of doctors thinking that we are just anxious…and will not believe us. They want to put us on antidepressants instead of helping us. This causes more anxiety and is very sad.” (Jessica)

“[I complained] about a lump in my throat and a choking sensation. That doctor found nothing wrong. I think he felt it was my imagination.” (Kim)

"[My] doctor poo-pawed anything I would bring up…questioning whether it was…a symptom of the hypothyroidism instead of some new disease she wanted to prescribe more medication for." (Sarah)

"I start to explain [my] history…but he interrupts me at the point I say the Naturopath put me on levo and launches into a tirade about how I don't have a thyroid problem and should never have been put on meds and they will cause palpitations…hair loss and high BP etc…ignoring I have been on them 9 months with none of those problems…" (Shawna)

Feeling dismissed. Eight of the 11 participants who experienced traditional a doctor-patient relationship (Anne, April, Carla, Diane, Jenna, Leanne, Sarah, and Shawna) indicated that they felt dismissed by their doctors.

"Last February, at my last appointment with him, he said I seemed to be doing fine [and] gave me a year's prescription for the compounded thyroid and wished me well. I didn't occur to me that he had fired me until I was telling someone else about this appointment. Out of curiosity, I requested my records. In his notes from our last appointment, he said it appeared I was treating myself. This surprised me quite a bit because he had always seemed to appreciate that I was a somewhat informed patient." (Anne)

"I went [to my appointments] with knowledge and she told me to get off google...[and] when I asked her to test my reverse T3, she refused saying it was no more important than the type of blood I had." (April)

“I went in for a BMI and my level was 21. I had no weight to lose...yet I'd lost 40 pounds...Headed in to see a doc... he told me that I was ‘too fat to be sick’ went on to tell me to leave, there were others that really needed him.” (Carla)

“As I aged, I experienced illnesses that showed me I had a compromised immune system and something wasn't right, but no doctor would further investigate.” (Diane)

“When I tried to explain to him my hair was falling out and I was tired ALL the time he just blew it off as not being related.” (Jenna)

“[My] doctor poo-pawed anything I would bring up…questioning whether it was…a symptom of the hypothyroidism instead of some new disease she wanted to prescribe more medication for.” (Sarah)

“I had taken my labs to the primary doc’s office when I went in for a tick bite, and asked him to get back with me about what he thought and whether I could switch from the compounded to something [that would] be covered by insurance, but he never got back to me. I work at a hospital and lots of people think he has gotten less caring over the years.” (Shawna)

Experienced a lack of empathy. Four of the 12 participants who experienced a traditional doctor-patient relationship (Emily, Jessica, Leanne, and Shawna) indicated that they experienced a lack of empathy from their doctors.

“Sometimes I think men doctors don’t take some female symptoms seriously, but then I’ve had women doctors that also didn’t seem to be sympathetic to a formally [sic] skinny patient who quickly put on 20 pounds.” (Emily)

“[I wish doctors would] just let me know they care and take more time to figure stuff out and explain things.” (Jessica)

“I had taken my labs to the primary doc’s office when I went in for a tick bite, and asked him to get back with me about what he thought and whether I could switch from the compounded to something [that would] be covered by insurance, but he never got back to me. I work at a hospital and lots of people think he has gotten less caring over the years.” (Shawna)

Feeling disrespected. Three of the 12 participants who experienced a traditional doctor-patient relationship (Carla, Leanne, and Shawna) indicated that they felt disrespected by their doctors.

“I felt that my dose [of thyroid medicine] was wrong, I was getting worse and worse each year. Every time I talked to a doc about it I was demeaned and/or ignored…[the doctor] said that I was a 'smart ass' and to stay on the same dose…then hung up on me.” (Carla)

“I start to explain [my] history…but he interrupts me at the point I say the Naturopath put me on levo and launches into a tirade about how I don’t have a thyroid problem and should never have been put on meds and they will cause palpitations…hair loss and high BP etc…ignoring I have been on them 9 months with none of those problems…” (Shawna)

Subtheme 2: Collaborative relationships. Thirteen of the 16 total participants (Alicia, April, Autumn, Carla, Diane, Emily, Jenna, Karen, Kari, Kim, Leanne, Michelle, and Shawna) experienced collaborative doctor-patient relationships. Among these participants, 10 felt heard by their doctors, eight felt validated by their doctors, four felt unrushed by their doctors, and 12 participated in shared decision making with their doctors.

Feeling heard. Ten of the 13 participants who experienced a collaborative doctor-patient relationship (Alicia, April, Autumn, Diane, Emily, Karen, Kari, Kim, Leanne, and Michelle) indicated that they felt heard by their doctors.

"I have chosen to stay with the physician because I believe he will listen to me. I research, bring my research to him and we discuss what to do with it." (Alicia)

"[My doctor] wants to know what I know…[he] confirms I am not stupid and if need be, he will correct or add more info to what I already know." (April)

"I was very comfortable [sharing my symptoms] with [my previous doctor, but] have no clue about the new one." (Autumn)

"[My doctor] does take into consideration what I'm saying to him, and gives me feedback. I appreciate that." (Diane)

"I had written all my issues out before seeing the endocrinologist and she still went through the whole list of possible symptoms to see which I was experiencing and to what extent. She was very thorough." (Emily)

"We discuss things clearly and she listens well and makes adjustments based on my response." (Karen)

"My Dr. is easy to talk to…she takes her time and the main thing [is that] she does listen." (Kari)

"I figured out the dose equivalent to my 75 mcg of T4 and my 25 mcg of T3, and the new doctor agreed my calculations were correct and prescribed 2 grains of Armour and an additional 5 or 10 mcg of Cytomel." (Kim)

"He has made clear that he is a good listener and has my best interest at heart." (Michelle)

Feeling validated. Eight of the 13 participants who experienced a collaborative doctor-patient relationship (Alicia, April, Diane, Emily, Karen, Kim, Leanne, and Michelle) indicated that they felt validated by their doctors.

"I think my doctor understands that I am not the person I used to be—that I know how to do the research and that I know what is reasonable." (Alicia)

"[My doctor] wants to know what I know…[he] confirms I am not stupid and if need be, he will correct or add more info to what I already know." (April)

"[My doctor] does take into consideration what I'm saying to him, and gives me feedback. I appreciate that." (Diane)

"I had written all my issues out before seeing the endocrinologist and she still went through the whole list of possible symptoms to see which I was experiencing and to what extent. She was very thorough." (Emily)

"We discuss things clearly and she listens well and makes adjustments based on my response." (Karen)

"I figured out the dose equivalent to my 75 mcg of T4 and my 25 mcg of T3, and the new doctor agreed my calculations were correct and prescribed 2 grains of Armour and an additional 5 or 10 mcg of Cytomel." (Kim)

“He has learned that my body reacts differently than others termed “normal” and is very interested in working with me to “optimize” my thyroid hormone needs.” (Michelle)

Feeling unrushed. Four of the 13 participants who experienced a collaborative doctor-patient relationship (Emily, Kari, Leanne, Shawna) indicated that they felt unrushed by their doctors.

“I had written all my issues out before seeing the endocrinologist and she still went through the whole list of possible symptoms to see which I was experiencing and to what extent. She was very thorough.” (Emily)

“My Dr. is easy to talk to…she takes her time and the main thing [is that] she does listen.” (Kari)

“I like the new D.O. …he seems to be on the right track and he spends a lot of time with you.” (Shawna)

Shared decision making. Twelve of the 13 participants who experienced a collaborative doctor-patient relationship (Alicia, April, Carla, Diane, Emily, Jenna, Karen, Kari, Kim, Leanne, Michelle, and Shawna) indicated that they participated in shared decision making with their doctors.

“I feel that we are carefully working toward finding the best way to treat me….We have a good working relationship. While he tends to be satisfied if my numbers are within the normal range, he does listen when I tell him how I am feeling and that we need to continue working on treatment (adjusting medication dosages and testing) until I am thriving.” (Alicia)

"[My doctor] wants to know what I know…[he] confirms I am not stupid and if need be, he will correct or add more info to what I already know." (April)

"I don't have a lot of trust in her anymore…but I will admit that she is now talking with me more…and we are working on compromises." (Carla)

"[My doctor] does take into consideration what I'm saying to him, and gives me feedback. I appreciate that…We're working on seeing if I have any issues with my adrenal glands." (Diane)

"I appreciate that my endo is open to trying natural hormone if necessary as my PCP seems to think Synthroid is the only option." (Emily)

"[My doctor] has been decent about letting me raise my dosage…he DOES test free t3 and free t4 because I asked him to." (Jenna)

"We discuss things clearly and she listens well and makes adjustments based on my response." (Karen)

"[I] educate [my doctor] from what I learned reading Mary Shomon's newsletters and book." (Kari)

"I figured out the dose equivalent to my 75 mcg of T4 and my 25 mcg of T3, and the new doctor agreed my calculations were correct and prescribed 2 grains of Armour and an additional 5 or 10 mcg of Cytomel." (Kim)

"He has learned that my body reacts differently than others termed "normal" and is very interested in working with me to "optimize" my thyroid hormone needs." (Michelle)

“[My doctor] orders the thyroid tests but forgets the antibodies. I call her up and she says ‘just put Thyro Pero on that order and also whatever you want’ [so] I add Ferritin and B12 based on my internet research.” (Shawna)

Theme 2: Patient Self-Advocacy

In describing their experiences with thyroid disease treatment, 15 of the 16 total participants (Alicia, Anne, April, Carla, Diane, Emily, Jenna, Jessica, Karen, Kari, Kim, Leanne, Michelle, and Shawna) described participation in some form of self-advocacy, including health information-seeking and switching doctors. Two of these participants (Karen and Kim) made statements that indicated a personal belief that “doctor knows best.”

Subtheme 1: Health information-seeking. Twelve of the 15 participants who participated in some form of self-advocacy (Alicia, Anne, April, Carla, Diane, Emily, Jenna, Karen, Kari, Kim, Leanne, and Shawna) conducted health information-seeking.

“I think my doctor understands that I am not the person I used to be—that I know how to do the research and that I know what is reasonable.” (Alicia)

“By this time I had joined the on-line support group and done some research on-line I did finally find a doctor who agreed to include free t3 and t4 in the blood tests and she prescribed Armour.” (Anne)

“I went [to my appointments] with knowledge and she told me to get off google.” (April)

“I'd been online learning…had heard of whole gland desiccated…found a place to buy it…borrowed the money and waited for it to come.” (Carla)

"I have searched for over 30 years as to what was the cause of my rapid weight gain, and constant fatigue." (Diane)

"The endocrinologist seems well versed in my diagnosis, but I only know that because of extensive research I've done on my own." (Emily)

"I think there's a lot that is overlooked…he REALLY pushes for me to do RAI which based on MY research, I don't feel is needed." (Jenna)

"I learned a bank of knowledge that helped me whittle thru all the mediocre docs and find the right one. It took over a year but it was worth it." (Karen)

"[I] educate [my doctor] from what I learned reading Mary Shomon's newsletters and book." (Kari)

"I know enough about thyroid function and my thyroid problem and what works best for me that I am in a position to explain to the doctor what I need, not the other way around!" (Kim)

"I feel that if I hadn't been aggressive in all my research I would have just been kept being told that my [levels were] 'normal' when they were clearly not." (Shawna)

Subtheme 2: Switching doctors. Nine of the 15 participants who participated in some form of self-advocacy (Anne, April, Diane, Jessica, Karen, Kim, Leanne, Michelle, and Shawna) switched doctors.

"I began looking for a Dr. who would do more than t4 replacement… This was an awful time. I went to at least 4 doctors seeking help. This was especially difficult because with each new appointment, I would get my hopes up that this doctor was the ONE who would help me. The letdown after each appointment was devastating." (Anne)

"I hesitated leaving [my doctor] when I got pregnant, [but] she promised she would get me through my pregnancy and she did…As soon as we moved (baby was 2 weeks old) I felt more secure [in switching doctors]." (April)

"I saw several doctors and were [sic] prescribed anti dizziness medication, depression pills, etc. All doctors said my blood work came back fine, including thyroid. However, I was still bedridden and in danger of losing my job." (Diane)

"[My experience has been] very frustrating. Been through three endo's in five months. The last one is really trying to work with me, but the other two got frustrated and abusive with me because I was not tolerating the thyroid meds well." (Jessica)

"When I was younger I did not argue with my doctor because I always thought they knew best. But after years of mistreatment I finally took the bull by the horns…I went through 5 Endos before I found one who knew what she was doing." (Karen)

"I think I may be a little more comfortable with a man. I'm more likely to argue with a female doctor if I think her approach is wrong. If I feel a male doctor's approach to thyroid care is wrong for me, I simply don't go back to him and begin looking for another doctor." (Kim)

"I felt better not taking anything compared to taking Synthroid. It took me another 2 years before I found an Internal Medicine Dr. who would prescribe me something other than Synthroid." (Michelle)

"I am asking around at the hospital where I work and hear that the newer doctor that started in 2013 is one who will get to the bottom of things and spend a lot of time." (Shawna)

Subtheme 3: Belief that "doctor knows best." Two of the 15 participants who participated in some form of self-advocacy (Karen and Kim) made statements that indicated a personal belief that "doctor knows best."

"When I was younger I did not argue with my doctor because I always thought they knew best." (Karen)

"I'm more likely to argue with a female doctor if I think her approach is wrong. If I feel a male doctor's approach to thyroid care is wrong for me, I simply don't go back to him and begin looking for another doctor." (Kim)

Theme 3: Doctor-Patient Communication

Participants' responses to interview questions regarding communication indicated that their experiences with thyroid disease treatment were impacted by their ability to communicate with their doctors. Doctor-patient communication appeared to be influenced by the participant's desire to be informed, the participant's level of trust in her doctor, and by being female.

Subtheme 1: Desire to be informed. Six of the 16 total participants (Anne, April, Emily, Kim, Leanne, and Michelle) expressed a desire for their doctors to inform them about the results of lab work and treatment options.

"I have some work to do to figure out how I can either get her to make me understand where she is coming from…or if I can get her to understand that I am backsliding again…" (Anne)

"I will tell them what I know, what I want to know and [learn] what their opinion is and their thoughts." (April)

“She doesn’t come forward with all she’s thinking unless I push the conversation.” (Emily)

“I need to get the testing done to see where my frees are on the new product.” (Kim)

“She was a teaching Dr. and taught me how to read the numbers on all the appropriate tests---not just TSH, but also FT3 & FT4.” (Michelle)

Subtheme 2: Role of trust. In responding to interview questions regarding communication, nine out of the 16 total participants (Anne, April, Carla, Jenna, Kim, Leanne, Michelle, Sarah, and Shawna) indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors. Four of these nine participants explicitly expressed distrusting their doctors, six refused treatment, three engaged in secret-keeping, and six engaged in self-treatment.

Lack of trust. Four out of the nine participants (Carla, Leanne, Sarah, and Shawna) who indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors explicitly expressed distrusting their doctors.

“[I am] guarded…I don't have a lot of trust in her anymore.” (Carla)

“My distrust is at such a high level after being misdiagnosed for over half of my life that it will be hard to share [with a doctor] in the future.” (Sarah)

“I am keeping a folder of my labs now. I have learned to get copies of them and not believe what the doctor’s office tells me.” (Shawna)

Treatment refusal. Six out of the nine participants (Anne, April, Jenna, Leanne, Michelle, and Sarah) who indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors explained that they had refused treatment.

"…this doctor knew of nothing else to do but go back to Synthroid and did not understand when I was upset at that suggestion." (Anne)

"I will not always go with their recommendations (I have refused RAI 3 times now, twice with the first dr, once with the second…" (April)

"I've rejected several drugs offered to me since the Diabetes diagnosis…and no longer open a bottle till I know what it will do." (Carla)

"I made it CLEAR I was not doing RAI." (Jenna)

"I finally had to go off of Synthroid (on my own) after a year because I felt so bad on it. I felt better not taking anything compared to taking Synthroid." (Michelle)

"[I] gradually tapered off most unnecessary prescriptions over a two-year period [and] then left the Doctor I'd had for over 23 years…" (Sarah)

Secret-keeping. Three out of the nine participants (Kim, Leanne, and Sarah) who indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors explained that they had kept secrets from their doctors.

"My other doctor, whom I'd kept as my primary for everything but thyroid, kept ordering TSH and I simply refused the test when I got to the lab. I just told him I was seeing another doctor for my thyroid treatment…We sometimes have to resort to trickery!" (Kim)

"After knowing I would die if I continued this way, I started taking charge of my own health…added supplements, and gradually tapered off most unnecessary prescriptions over a two-year period [and] then left the Doctor I'd had for over 23 years…" (Sarah)

Self-treatment. Six out of the nine participants (Carla, Jenna, Leanne, Michelle, Sarah, and Shawna) who indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors explained that they had engaged in self-treatment.

"I started self-treating in July of 2002 and pretty much consider myself to still be self-treating [and] the current doc/insurance just run my labs." (Carla)

"A friend who has thyroid issues got me on a multivitamin and 10k units of vitamin D3. Our local herbalist gave me a supplement which offered thyroid and adrenal support." (Jenna)

"I finally had to go off of Synthroid (on my own) after a year because I felt so bad on it. I felt better not taking anything compared to taking Synthroid." (Michelle)

"[I] added supplements, and gradually tapered off most unnecessary prescriptions over a two-year period [and] then left the Doctor I'd had for over 23 years and started self-treating with Thyroid replacement ordered online, treating adrenals, plus additional vitamins and supplements gradually added." (Sarah)

"I thought since the doctors kept saying my thyroid was okay, maybe I just needed something natural as a boost, not really having a lot of information. I also was clicking on ads on the internet and read some doctor that insisted we are all iodine deficient and promoting his pills. I ordered them and took them [for] 1 month…" (Shawna)

Subtheme 3: Role of gender. The majority of participants' responses to questions regarding the potential influence of gender on treatment experiences revealed that the doctors' gender had little influence on doctor-patient communication. However, participant responses indicated that being female influenced doctor-patient communication, particularly regarding the participants' perceptions of being taken seriously and when the participants expressed emotion.

No preference for specific doctor gender. Thirteen of the 16 total participants (Alicia, Anne, April, Autumn, Diane, Emily, Jessica, Karen, Kim, Leanne, Michelle, Sarah, and Shawna) indicated no preference for a male or female doctor.

"I'm not sure. I wonder if a woman might be more understanding, but I feel that my [male] physician is very understanding." (Alicia)

"No…It seems that both men and women doctors are TSH driven." (Anne)

"I had a female [doctor] who hated me…I now have a man who allows me to control my health. HUGE difference." (April)

"I don't think [the doctor's gender] matters much…most of them are just in and out doing as little as they possibly have to do." (Autumn)

"If they have a thorough understanding of the female body, then there shouldn't be difference [between male and female doctors]." (Diane)

"I would probably feel comfortable with either [male or female] if they seem sympathetic to my concerns and serious about continually working on a plan to get my body back to normal." (Emily)

"I think a woman doctor can relate better to her female patient having the same functioning system and emotional background caused by hormones; [however], my first endo was a woman…and she was brutal." (Jessica)

"It's not the sex of the doctor but the compassion and caring of the doctor that makes one good." (Karen)

"It doesn't matter to me [if my doctor is male or female]. My previous thyroid doctor who died was a man, and he was an internal medicine doc whose special interest was in hormone treatment (of all kinds, not just thyroid). He was excellent for thyroid care. I've had female doctors who would only prescribe Synthroid." (Kim)

"No----have been treated by both [male and female doctors]. Dr./Patient relationship is most important." (Michelle)

"I've been pleased with both genders, it really depends on the individual." (Sarah)

"No. I just care about their competence." (Shawna)

Preference for female doctor. Three of the 16 total participants indicated a preference for female doctors.

"Every woman doctor I have had, all of 3, [have] been far more empathetic and able to listen." (Carla)

"I think a woman might be a little more compassionate and understanding." (Jenna)

“I like woman Dr.'s better. Men are too arrogant about their education.” (Kari)

Being taken seriously. Nine out of the 16 total participants (Alicia, Anne, April, Carla, Diane, Emily, Jenna, Leanne, and Sarah) indicated that being taken seriously influenced their ability to communicate with their doctors.

“Knowing that he takes me seriously helps me to feel comfortable sharing my symptoms with my doctor.” (Alicia)

“…my opinion is that doctors, both men and women, take men more seriously. I do tend to get emotional which I think makes doctors give less credence to my depiction of my symptoms.” (Anne)

“[I would feel more comfortable sharing my symptoms] if my dr took my research serious and didn’t just humor me.” (April)

“She is certain that the only test needed for thyroid is TSH and it's an inside joke that I will allow her to run TSH as long as she also runs Free T4 and Free T3 for me.” (Carla)

“It makes me feel confident that he takes me a little more seriously than most of the other doctors who poo-pooed me.” (Diane)

“Sometimes I think men doctors don’t take some female symptoms seriously, but then I’ve had women doctors that also didn’t seem to be sympathetic to a formally [sic] skinny patient who quickly put on 20 pounds.” (Emily)

“[I would feel more comfortable sharing my symptoms] if he would LISTEN and take me seriously and not think it’s all in my head.” (Jenna)

“[My] previous Doctor poo-pawed anything I would bring up and questioning whether it was thyroid related.” (Sarah)

Presence of emotion. Three out of the 16 total participants (Alicia, Anne, and Leanne) indicated that showing emotion influenced communication with their doctors.

“It was not until I broke down in tears with my radiation oncologist that he suggested metabolic testing…[and to] follow this up with my primary care physician.” (Alicia)

“I do tend to get emotional which I think makes doctors give less credence to my depiction of my symptoms.” (Anne)

Theme 4: Culture of the Medical Profession

Participant responses to interview questions indicated that their experiences with thyroid disease treatment were influenced by the culture of the medical profession. More specifically, participants’ treatment experiences were influenced by diagnostic bias, their doctors’ medical knowledge, and economics.

Subtheme 1: Diagnostic bias. Eight of the 16 total participants (Alicia, Anne, Carla, Diane, Jenna, Jessica, Kim, and Leanne) whose treatment experiences were influenced by the culture of the medical profession encountered diagnostic bias. More specifically, seven participants’ doctors considered their symptoms to be psychosomatic and three participants were told by their doctors that their symptoms were due to their lifestyle.

Symptoms considered psychosomatic. Seven of the 15 participants (Alicia, Anne, Diane, Jenna, Jessica, Kim, and Leanne) who experienced diagnostic bias had doctors who considered their symptoms to be psychosomatic.

"I knew something was wrong following my treatment for breast cancer and recovery. I kept mentioning that something was not right to my oncologist and radiation oncologist. I think they attributed my symptoms to recovery from treatment and grief due to the death of my 8 year old son to cancer. It was not until I broke down in tears with my radiation oncologist that he suggested metabolic testing." (Alicia)

"…my opinion is that doctors, both men and women, take men more seriously. I do tend to get emotional which I think makes doctors give less credence to my depiction of my symptoms." (Anne)

"[I had an] inability to swallow pills that started about 10 years ago (doctors thought it was in my head)…[and when] I could no longer drive and could barely walk, I saw several doctors and were [sic] prescribed anti dizziness medication, depression pills, etc." (Diane)

"[I would feel more comfortable sharing my symptoms] if he would LISTEN and take me seriously and not think it's all in my head." (Jenna)

"I am tiered [sic] of doctors thinking that we are just anxious…and will not believe us. They want to put us on antidepressants instead of helping us. This causes more anxiety and is very sad." (Jessica)

“I had been taken to a doctor because of complaining about a lump in my throat and a choking sensation. That doctor found nothing wrong. I think he felt it was my imagination.” (Kim)

Symptoms attributed to lifestyle. Three of the 15 participants (Carla, Jenna, and Leanne) who experienced diagnostic bias had doctors who attributed their symptoms to their lifestyle.

“[the doctor] told me that I was ‘too fat to be sick’…[and] with each job change I got new insurance and new docs and they were all the same. Weight gain is from being a lazy slob [because] I laid around eating bon bons all day long. Didn't matter that I was a body builder before all this, didn't matter that I used to have physical jobs before all this... I was just a lazy, fat, stupid... slob.” (Carla)

“I had complained to the doc about not being able to lose weight but he said it was my diet, not enough exercise etc… how i wish i had only known that it was something wrong with me physically instead of ‘I'm fat’, ‘I'm out of shape’…” (Jenna)

Subtheme 2: Medical knowledge. The treatment experiences of 15 of the 16 total participants (Anne, April, Autumn, Carla, Diane, Emily, Jenna, Jessica, Karen, Kari, Kim, Leanne, Michelle, Sarah, and Shawna) who were affected by the culture of the medical profession appeared to be specifically influenced by their doctors’ medical knowledge. More specifically, 9 participants’ treatment experiences were affected by the use of the TSH blood test alone to determine thyroid function, and 10 participants’ treatment experiences were affected by the use of synthetic medication as the only treatment option for thyroid disease. In addition, according to 15 participants, continuing education for doctors about thyroid disease is needed.

TSH testing is standard. Nine out of the 15 total participants (Anne, Carla, Diane, Jenna, Karen, Kim, Michelle, Sarah, and Shawna) whose treatment experiences were influenced by their doctors' medical knowledge appeared to be specifically affected by the use of the TSH blood test alone as the standard for determining thyroid function.

"It seems that both men and women doctors are TSH driven…Even the doctors I have seen that are okay with [natural medication] still put much more weight on TSH than symptoms or the frees. It is enough to make one feel hopeless at times." (Anne)

"[My doctor] is certain that the only test needed for thyroid is TSH and it's an inside joke that I will allow her to run TSH as long as she also runs Free T4 and Free T3 for me." (Carla)

"I have searched for over 30 years as to what was the cause of my rapid weight gain, and constant fatigue. Each time, my thyroid would be tested and I was told everything was fine. Meanwhile, I struggled daily for energy, and experienced numerous illnesses over the years that puzzled me." (Diane)

"My doctor's] MAIN concern is my TSH getting below .5, [though] he DOES test free t3 and free t4 because I asked him to." (Jenna)

"I do honestly believe that only being treated with Synthroid and only a TSH test being run each year it actually caused me to go through early menopause at the age of 34." (Karen)

“When I was tested at the end of that year, my TSH (the only thyroid test that doctor used) was .01, and he wanted me to discontinue Synthroid because I had ‘gone hyper’. I reminded him I’d been taking thyroid replacement since I was 16 or 17 and I was quite certain I needed it. So he compromised and let me drop the Synthroid to 50 mcg.” (Kim)

“I was ‘finally’ diagnosed after many years of begging [doctors] to be diagnosed (numbers were ‘normal’), [then] it took me another 2 years before I found an Internal Medicine Dr. who would…test not only TSH, but also FT3 & FT4.” (Michelle)

“[My doctor] totally ignored my symptoms, any thyroid numbers but TSH, and this resulted in [many] diagnoses…and [I was] heavily medicated for each of them, on as many as twelve different prescriptions in any given day.” (Sarah)

“I don’t like that he is not open to natural thyroid and isn’t testing my T3 and antibodies.” (Shawna)

Synthetic medication is standard. Ten out of the 15 total participants (Anne, Carla, Emily, Jessica, Karen, Kim, Leanne, Michelle, Sarah, and Shawna) whose treatment experiences were influenced by their doctors’ medical knowledge appeared to be specifically affected by the use of synthetic medication as the only treatment option for thyroid disease.

“[When] the armour shortage hit [my] doctor knew of nothing else to do but go back to synthroid and did not understand when I was upset at that suggestion…The thought of having to settle for synthroid again honestly scared me.” (Anne)

“I was started on Synthroid…it made me sick…they tried levothyroxine, it made me sick…then tried levothroid, it made me sick…Nauseous, headache...” (Carla)

“I appreciate that my endo is open to trying natural hormone if necessary as my PCP seems to think Synthroid is the only option.” (Emily)

“[My doctors] got frustrated and abusive with me because I was not tolerating the [synthetic] thyroid meds well…[synthetic thyroid] meds gave me severe reactions, altered my mental state, and made me feel worse.” (Jessica)

“I was treated with Synthroid for 38 years [and] getting worse and worse every year…It took 38 years for someone to realize I am a very poor converter and my system was not converting the synthetic thyroid down as it should be.” (Karen)

“[I had] no problems until I changed to Synthroid. When I found it didn’t work as well and I wanted to change back to Armour I could not find a doctor who would permit the change. They all said Armour was outmoded and Synthroid was better.” (Kim)

“When I kept saying the Synthroid was making me feel bad, I was told “that’s all we can prescribe”!!” (Michelle)

“Started treatment in 2006 and then left on Synthroid for five years, same low dose. After knowing I would die if I continued this way, I started taking charge of my own health…” (Sarah)

“I don’t like that he is not open to natural thyroid and isn’t testing my T3 and antibodies.” (Shawna)

Continuing education is needed. According to all 15 of the participants (Anne, April, Autumn, Carla, Diane, Emily, Jenna, Jessica, Karen, Kari, Kim, Leanne, Michelle, Sarah, and Shawna) whose treatment experiences were influenced by their doctors' medical knowledge, continuing education for doctors about thyroid disease is needed.

"[My treatment] is being managed by someone who does not understand that there is not 'one size fits all'." (Anne)

"…when I asked her to test my reverse T3, she refused saying it was no more important than the type of blood I had." (April)

"[Doctors] could actually find out how to really treat thyroid [disease…] but even when I thought this place did […] still nope!" (Autumn)

"Listen to someone that is 'living it' and throw away the Synthroid book…maybe it will click in [my doctor's] brain that the stuff that was shoved down her throat does not apply to all folks with thyroid disorders." (Carla)

"It is scary how little doctors actually know about [thyroid] disease, let alone Hashimoto's [disease]…it seems that I am more knowledgeable about some areas of Hashimoto's than he is." (Diane)

"[My PCP is] not aware that many of my symptoms could be caused by low thyroid and she tries to treat them individually – quickly stockpiling my medicine cabinet." (Emily)

"I think [my doctor] could be a little more up to date but again, going through a free clinic I am limited." (Jenna)

"Doctors are not explaining things clearly. I have heard more I dont [sic] knows these past few months that it is unbelieveable [sic]." (Jessica)

“It helped that my regular doc took extra courses to learn more about thyroid dieses after I explained to her the problems I had with each rejected endo she sent me to. I was not her only patient with thyroid problems so she was eager to learn more.” (Karen)

“[It has been] difficult to find a Dr. who knows anything about Thyroid problems…I am explaining more to her then [sic] she to me [about thyroid disease].” (Kari)

“Sometimes I have to teach [doctors] what some of the recognized symptoms [of thyroid disease] are!” (Kim)

“When I was finally diagnosed in 2005 after many years of begging [doctors] to be diagnosed (numbers were “normal”), I found a female PCP to diagnose me. She was a teaching Dr. and taught me how to read the numbers on all the appropriate tests---not just TSH, but also FT3 & FT4.” (Michelle)

“I would love to see in the future that Doctors would pay more attention to the FT3's and FT4's than the stupid TSH levels. I have a Doctor I see for bioidentical hormones and she is the very first one who has said we'll skip the TSH. I see hope with her and may at some point trust her to treat my thyroid.” (Sarah)

“[The doctor] says the Hashi’s antibodies ‘just mean that someday your thyroid might completely stop working. We don’t treat you unless you get a goiter. We don’t treat people as they age unless their TSH is 10 or even 20.’” (Shawna)

Subtheme 3: Economics. The treatment experiences of 11 out of the 16 total participants (Anne, April, Autumn, Carla, Jenna, Karen, Kari, Kim, Leanne, Michelle, and Shawna) who were affected by the culture of the medical profession appeared to be specifically influenced by economics. More specifically, three participants reported feeling rushed by their doctors, eight participants had difficulty with accessing a doctor, and six participants had difficulty with accessing thyroid medication.

Feeling rushed. Three out of the 11 total participants (Autumn, Jessica, and Leanne) whose treatment experiences were influenced by economics reported feeling rushed by their doctors.

"Most [doctors] are just in and out doing as little as they possibly have to do…It would help if they weren't so rushed." (Autumn)

"[I wish doctors would] take more time to figure stuff out and explain things." (Jessica)

Access to doctor. Eight out of the 11 total participants (Autumn, Carla, Jenna, Kim, Leanne, Michelle, Sarah, and Shawna) whose treatment experiences were influenced by economics had difficulty with accessing a doctor.

"I was very comfortable with Angela [the doctor who quit]…have no clue about the new one." (Autumn)

"I got bad sick…and no insurance…couldn't go see a doc…[then, finally] for the first time in 15 years I had access to a doc again [when I] became eligible for a few things, including medical care…" (Carla)

"I think [my doctor] could be a little more up to date but again, going through a free clinic I am limited." (Jenna)

“[My relationship with my doctor is] not ideal, but the best I can have here…There is not Endo around for at least 150 miles and I can't make these long trips.” (Kari)

“This doctor was the first one ever to test my frees and also the first and only to test me for Hashi’s antibodies. He has recently passed away, so I’ve had to find a new doctor again.” (Kim)

“When I was finally diagnosed in 2005 after many years of begging [doctors] to be diagnosed (numbers were “normal”), I found a female PCP to diagnose me. She was a teaching Dr. and taught me how to read the numbers on all the appropriate tests---not just TSH, but also FT3 & FT4. Followup PCP Drs continued to test TSH only & when I kept saying the Synthroid was making me feel bad, I was told “that’s all we can prescribe”!!” (Michelle)

“[My Naturopath] cancelled my August recheck because she was too busy as a school nurse. Said to wait until Nov since I was doing fine.” (Shawna)

Access to medication. Six out of the 11 total participants (Anne, April, Carla, Karen, Kim, and Shawna) whose treatment experiences were influenced by economics had difficulty with accessing thyroid medication.

“I was happy until the Armour shortage hit. When that happened, this doctor knew of nothing else to do but go back to synthroid and did not understand when I was upset at that suggestion.” (Anne)

“I used Synthroid 150 and Cytomel for almost 3 years but it was costing $60+ a month. I recently switched to Armour and it is less than $8 a month.” (April)

“[My doctor] allowed me to stay on the replacements that I've been taking when we found that my state assistance insurance only covers synthetic T4 and I have a very poor body response to that.” (Carla)

“I was happy but now that the FDA no longer approves Armour as a medication I will have to start all over again trying to find a natural product my system can work with. I have a very sensitive system so it is hard to find a good treatment.” (Karen)

“[I had] no problems until I changed to Synthroid. When I found it didn’t work as well and I wanted to change back to Armour I could not find a doctor who would permit the change. They all said Armour was outmoded and Synthroid was better.” (Kim)

“I had taken my labs to the primary doc’s office when I went in for a tick bite, and asked him to get back with me about what he thought and whether I could switch from the compounded to something [that would] be covered by insurance, but he never got back to me.” (Shawna)

Additional Findings

As previously mentioned, I recognized some additional findings that were meaningful to some participants. Although these findings do not represent the treatment experiences of the participants as a whole, these data are nevertheless poignant examples of the phenomenon from individuals who have lived the phenomenon. Additional findings include the belief that the public is misinformed about thyroid disease (Diane), the experience of grief (Carla), the experience of empathy from one’s doctor (Michelle), and the experience of respect from one’s doctor (Michelle).

Public is misinformed. Diane reported a belief that the public is misinformed about thyroid disease.

"[I] think the public is grossly misinformed. Their impression is that you just take a little pill and all is well. This is far from the truth, as it can be very complicated."

Experience of grief. In sharing her thyroid disease treatment experience, one of Carla's comments was indicative of grief.

"I got to watch my iodine uptake...I had such a perfect gland...It was just twice normal size. I have two half siblings with the same genetic defect I have. Both got proper care in a timely manner. Both are doing fine. Healthy weight, good jobs, real lives."

Experience of empathy. Michelle indicated that she experienced empathy from her doctor.

"[My doctor] is very caring and listens to my needs…he has made clear that he is a good listener and has my best interest at heart."

Experience of respect. Michelle indicated that she experienced respect from her doctor.

"I think [my doctor] is so respectful of his patients that it does not matter if [it is a] male or female patient."

Composite Description

According to Moustakas (1994), integrating participants' textural-structural descriptions into one composite description provides the reader with a deeper understanding of the phenomenon being studied. Based on the themes identified from the individual participant interviews, the following composite description provides answers to the research questions: “What are the treatment experiences of women with thyroid disease?”; “How does the doctor-patient relationship affect their experiences?”; “Do their experiences differ based on the doctor’s gender?” and represents the experience of the group as a whole with thyroid disease treatment and the doctor-patient relationship.

Women who develop thyroid disease experience a number of disturbing physical and emotional symptoms, sometimes years before obtaining a diagnosis. When reported to their doctors, symptoms are often considered to be “normal” aspects of aging, particularly when test results indicate no thyroid dysfunction. Nevertheless, many of the women in this study continued to report a feeling that “something is wrong” (Alicia). Whether they chose to believe that “doctor knows best” (Karen) or to pursue further information or a second opinion, these women sought support from others with similar experiences. Due to its convenience and wealth of information, the Internet is a popular medium for individuals seeking information or interaction with other people. Online support groups enable their members to interact anonymously, thus providing members with a safe and supportive environment in which to share their experiences, information, and resources. The women in this study found The Thyroid Support Group to be a reliable source for support and information about thyroid disease symptoms, treatment approaches, testing for thyroid disease, how to interpret such tests, and the names of recommended doctors.

For the women in this study, dissatisfaction with one’s doctor seemed to result from feeling unheard and invalidated by one’s doctor, more so than misdiagnosis in general. When these women shared their concerns with their doctors, they trusted that they would be listened to and taken seriously. When these women brought information to their doctors, they expected their doctors to review the information and to include their thoughts and concerns in the diagnostic and treatment planning processes. The women in this study felt disrespected when their doctors rushed or interrupted them. Feelings of distrust in doctors developed when these women felt dismissed or as if their doctors did not care about them—when their doctors seemed to view them and their experiences by "the numbers" (Michelle) rather than as people. For some of the women in this study, their dissatisfaction with their doctors lead to feelings of hopelessness.

Feeling heard and validated by one's doctor, on the other hand, engenders trust. When the thoughts and concerns of the women in this study were considered—when they were taken seriously—they felt hopeful that they would someday feel well instead of constantly feeling tired, "foggy," anxious, and depressed. According to the women in this study, not rushing or interrupting one's patient demonstrates respect for the patient, which in turn, leads to respect for one's doctor. In addition, including women with thyroid disease in the diagnostic and treatment planning processes encourages authentic communication and patient satisfaction.

Many of the women in this study who did not feel heard or taken seriously by their doctors advocated for themselves—conducted research, sought new doctors, refused treatment, self-treated, and kept secrets if they believed it is necessary—including individuals who believed (at least at one point) that "doctor knows best." The majority of the women interviewed expressed no preference for their doctors to be female or male. They simply wished to be heard and taken seriously. Some of these women in this study feared not being taken seriously because they tend to show emotion as they describe their symptoms and share their experiences. They feared being viewed as weak and unintelligent by their doctors.

The general culture of the medical profession seemed to devalue the experiences of the women in this study—labeling their symptoms as psychosomatic, as solely related to diet and exercise, or due to “women’s problems” for which there are clear treatment guidelines. When these women questioned their diagnosis or did not feel better after following their doctor’s orders, they were labeled as difficult—and sometimes even “fired” by their doctors (Anne). Based on what they learned in medical school, both male and female doctors tend to value the TSH blood test above all other tests available for thyroid disease—despite the fact that a “full thyroid panel” offers the most thorough analysis of thyroid function. The women in this study who were aware of this discrepancy and brought it to the attention of their doctors because they were still not feeling well were often dismissed.

Similarly, although synthetic thyroid medication is standard in treating hypothyroidism, it does not work for everyone. Some of the women in this study actually felt worse on synthetic thyroid medication than on no medication at all. The women who learned about natural thyroid treatments and who brought information about this option to the attention of their doctors were often told that such treatments are outdated or ineffective. Even the women who had taken natural thyroid medication in the past and felt better were told that natural thyroid medication was not a treatment option. But these women knew otherwise—they had learned from their own experiences or from others like them that doctors who prescribe natural thyroid medication *do* exist. Through sharing with other women with thyroid disease, they had learned that it *is* possible that they might feel better taking natural thyroid medication.

For some of the women in this study, financial difficulties, limited health insurance benefits, and geographic location sometimes interfered with finding a good doctor or the medication needed for thyroid disease. In addition, many of the women in this study had the impression that they were more knowledgeable about thyroid disease than their doctors. For the women whose doctors were receptive to a collaborative relationship, treatment planning ensued with shared information, respect for experience, patience, and the understanding that medication would be adjusted until the patients felt well. Some of the women with doctors who functioned in a more paternalistic manner were told to “get off Google” (April). Regardless of their relationship style, it seems that doctors (and their patients, in turn) might benefit from continuing education on thyroid disease—particularly considering its prevalence. Likewise, it seems prudent that research be conducted on the use of natural thyroid medication because of the many women in this study did not feel better while taking synthetic thyroid medication.

Doctors who diagnose and treat women with thyroid disease are in a position to empower their patients (“I have chosen to stay with the physician because I believe he will listen to me. I research, bring my research to him and we discuss what to do with it [and we will] continue working on treatment until I am thriving”; Alicia) or to respond in a manner that elicits feelings of hopelessness and devastation: “It is enough to make one feel hopeless at times…I would get my hopes up that this doctor was the ONE who would help me. The letdown after each appointment was devastating" (Anne). Based on the experiences of the women in this study, it seems that women with thyroid disease grieve their health and long to feel well again. They desperately wish for their experiences to be known and understood" "Listen to someone that is 'living it' and throw away the Synthroid book" (Carla).

Summary

In Chapter 4, I described the findings from this phenomenological study of female thyroid patients' experiences of treatment and the doctor-patient relationship. Upon analyzing the participants' interview transcripts, four themes emerged: (a) doctor-patient relationship, (b) patient self-advocacy, (c) doctor-patient communication, (d) and culture of the medical profession (see Appendix H). Within the main themes, 11 subthemes emerged. Appendix H presents the full list of themes and subthemes. An interpretation of findings follows in Chapter 5.

Chapter 5: Summary and Recommendations

Introduction

The purpose of this chapter is to summarize and discuss the findings presented in Chapter 4 about the treatment experiences of a sample of women with thyroid disease. A review of the research literature in Chapter 2 revealed a significant gap specifically concerning the treatment experiences of women with thyroid disease diagnoses and the doctor-patient relationship. An understanding of how women with thyroid disease experience treatment and the doctor-patient relationship can enhance doctors' knowledge of women's health and chronic illness and can help to determine factors related to positive treatment outcomes. Between January 12, 2014 and February 5, 2014, I individually interviewed via online chat 16 female thyroid patients who were members of The Thyroid Support Group. This phenomenological study resulted in a rich description of the participants' experiences with thyroid disease treatment and the doctor-patient relationship.

Criterion sampling was used to recruit 16 participants who were female, who were aged 18 years and older, who had self-proclaimed thyroid disease diagnoses, and who were members of The Thyroid Support Group. Data were collected using an interview guide that I created, which was validated by an external panel of three experts in qualitative methods (see Appendix A). The data analysis revealed four themes and 11 subthemes. The four themes consisted of experiences surrounding (a) the doctor-patient relationship, (b) patient self-advocacy, (c) doctor-patient communication, (d) and the culture of the medical profession. Appendix H presents the full list of themes and subthemes that emerged from the data analysis.

Exploration of the manner in which people assign meaning to their thoughts, feelings, and actions is required for understanding human behavior (Marshall & Rossman, 2006, p. 53). Thus, the participants' experiences with thyroid disease treatment and the doctor-patient relationship were formed into textural-structural descriptions (see Appendix G) within the conceptual frameworks introduced in Chapters 1 and 2: phenomenology, social constructionism, and feminism. Both social constructionism and feminism emphasize individuals' experiences in social contexts (Docherty & McColl, 2003; Fernandes et al., 2006; Hearn, 2009), and together, they suggest that social constructs associated with gender issues and the female body have an effect on female patients' interpretations of their experiences (Hearn, 2009). In the sample interviewed, participants shared their thoughts and experiences regarding the influence of gender, autonomy, knowledge, and communication on their perceptions of thyroid disease treatment and doctor-patient relationships.

The remainder of the chapter presents an interpretation of findings by major themes and subthemes, a discussion of the limitations of the study, recommendations for future research, implications for social change, and conclusions.

Interpretation of Findings

The textural-structural descriptions of a sample of 16 women with thyroid disease provide information with which one might begin to understand the treatment experiences of women with thyroid disease and their relationships with their doctors. Numerous factors influenced each participant's experience with thyroid disease treatment. The following four themes were identified: (a) doctor-patient relationship, (b) patient self-advocacy, (c) doctor-patient communication, (d) and culture of the medical profession. Within these four main themes, 11 subthemes emerged (see Table 4 and Appendix H). In the following sections, the themes and subthemes are discussed in detail through the lenses of social constructionism and feminism.

Table 4

Themes and Subthemes

Themes	Subthemes	Sub-subthemes
Doctor-patient relationship	Traditional relationships	Feeling unheard Feeling invalidated Feeling dismissed Experienced a lack of empathy Feeling disrespected Feeling heard
	Collaborative relationships	Feeling validated Feeling unrushed Shared decision making
Patient self-advocacy	Health information seeking	None
	Switching doctors	None
	Belief that “doctor knows best”	None
Doctor-patient communication	Desire to be informed	None
	Role of trust	Lack of trust in doctor Treatment refusal Secret keeping Self-treatment
	Role of gender	No preference for specific doctor gender Preference for female doctor Being taken seriously Presence of emotion
Culture of the medical profession	Diagnostic bias	Symptoms considered psychosomatic Symptoms attributed to lifestyle
	Medical knowledge	TSH testing is standard Synthetic medication is standard Continuing education may be needed
	Economics	Feeling rushed Access to doctor Access to medication

Note. Additional findings included the following: public is misinformed, experience of grief, experience of empathy, and experience of respect.

Theme 1: Doctor-Patient Relationship

Research indicates that the nature of the doctor-patient relationship has the potential to determine positive or negative treatment outcomes (Copeland et al., 2003; Houle et al., 2007; Munch, 2004; Stokes et al., 2006). Participant interviews revealed experiences with two types of doctor-patient relationships: traditional and collaborative. The two subthemes within Theme 1: Doctor-Patient Relationship are Subtheme 1: Traditional Relationships (feeling unheard, feeling invalidated, feeling dismissed, experienced a lack of empathy, and feeling disrespected) and Subtheme 2: Collaborative Relationships (feeling heard, feeling validated, feeling unrushed, and shared decision making).

Subtheme 1: Traditional relationships. As discussed in Chapter 2, traditional doctor-patient relationships are hierarchical in nature, with the doctor in a position of authority over the patient (Berger, 2002). In traditional doctor-patient relationships, the doctor controls the discussion, makes a diagnosis, and chooses the treatment plan without the patient’s input (Bradley et al., 2001; Ehrenreich & English, 2005; McGuire et al., 2005; Vanderford et al., 2001). The majority of the participants interviewed in this study (11 out of 16) reported experiencing this type of relationship with their doctors. Within Subtheme 1: Traditional Doctor-Patient Relationships are the following subthemes: feeling unheard, feeling invalidated, feeling dismissed, experienced a lack of empathy, and feeling disrespected.

Feeling unheard. With their doctors controlling the discussions, eight of the 11 participants who experienced a traditional doctor-patient relationship felt unheard.

According to Hedberg and Lynoe (2013), doctors who listen to their patients without interrupting are demonstrating that they are interested in what their patients have to say and are committed to understanding the patient's perspective. When attempting to describe her medical history, Shawna's doctor interrupted her and "launch[ed] into a tirade about how I don't have a thyroid problem and should never have been put on meds." Similarly, Jenna expressed a desire for her doctor to "LISTEN instead of being pushy," explaining that when she shared that her hair was falling out and she was "tired ALL the time," the doctor "just blew it off as not being related [to thyroid disease]." Because there is a positive correlation between physician listening and patients' perceptions that their physician cares for their well-being (Jagosh, Boudreau, Steinert, MacDonald, & Ingram, 2011), feeling unheard by one's doctor has the potential to lead patients to feeling that their doctors are disinterested and do not care about them as patients.

In addition to feeling unheard, April felt invalidated, explaining that her doctor maintained a "negative and controlling attitude" and that when she tried to describe how she was feeling, her doctor told her "to 'trust her, she had control of the situation'." April's experience is reminiscent of Mutter's (1999) "military metaphor" in healthcare, which purports that medicine is a war against disease and death. In following this rationale, doctors tend to focus on and attempt to take control of the patient's physical processes while ignoring mental and emotional concerns. According to Mutter, this type of thinking can give patients the impression that the doctors believe they know more about their patients' experiences than the patients themselves. In contrast, doctors can facilitate their patients’ ability to manage the emotions associated with their illnesses by listening attentively, showing an interest in what their patients are saying, and validating their patients’ feelings (Street, Makoul, Aurora, & Epstein, 2009).

Feeling invalidated. All eight of the participants who felt unheard by their doctors also felt invalidated by their doctors. Two additional participants (Kim and Anne) felt invalidated, for a total of 10 participants to report feeling invalidated by their doctors. Kim felt invalidated because her doctor believed that the choking sensation she felt was “in [her] imagination.” She did *not* report feeling unheard, however, because her doctor offered to investigate her symptoms. Although Anne did not mention feeling heard or unheard, she reported feeling invalidated in that her doctor did not give “credence to [her] depiction of [her] symptoms” because she becomes “emotional” when she discusses her symptoms. If Anne’s doctor had validated her perspective and demonstrated empathy, her experience of negative emotions (i.e., hopelessness and frustration) may have been reduced (Street et al., 2009, p. 297).

According to Malterud and Ulriksen (2010), all experiences are valid—even those that seem to be distorted by emotion—because they are subjective (p. 208). Thus, attempting to understand a patient’s illness experience from her perspective is vital to validating the patient. Diane reported feeling invalidated by her doctors because “no doctor would further investigate” her symptoms when she informed them that “something wasn’t right.” Similarly, when Carla repeatedly expressed to her doctor that she believed her dose of thyroid medicine was incorrect because she did not feel well, she was “demeaned and/or ignored.” Jessica expressed frustration that doctors would “not believe

[her]" and insisted in prescribing antidepressants instead of further investigating her symptoms. A study by Epstein et al. (2007b) revealed that unnecessary prescribing of medications is reduced when doctors use "inquiry, openness, empathy, and validation, rather than cutoffs and assertion of [their own] agenda." (p. 26).

Feeling dismissed. All eight of the participants who felt invalidated by their doctors also felt dismissed by their doctors. Carla's doctor told her that she "…was 'too fat to be sick' and "went on to tell [her] to leave, there were others that really needed him." Carla's experience is reminiscent of the female participants in Copeland et al.'s (2003) study who indicated that their doctors and were insensitive, patronizing, condescending, impatient, and disrespectful. The most frequently expressed desire by participants in Copeland and colleagues' study was for their doctors to allow them to express their concerns without interrupting (p. 40). The type of interruption that Carla experienced would be referred to by Florian and Al-Roubaie (2008) as "non-supportive" and "power driven" as opposed to "supportive," or "clarifying," and "relationship driven" (pp. 648-651). Non-supportive, power driven interruptions by the doctor are a "violation of a speaker's rights," are intimidating for patients (Florian & Al-Roubaie, 2008, p. 651), and have the potential to reduce a patient's trust in their doctor (Skirbekk, Middelthon, Hjortdahl, & Finset, 2011).

While Carla was *actively* dismissed by her doctor, other participants were *passively* dismissed by their doctors. For example, Anne—an individual who becomes emotional when she discusses her symptoms—was "fired" by her doctor without any warning:

> Last February, at my last appointment with him, he said I seemed to be doing fine [and] gave me a year's prescription for the compounded thyroid and wished me well. I didn't occur to me that he had fired me until I was telling someone else about this appointment. Out of curiosity, I requested my records. In his notes from our last appointment, he said it appeared I was treating myself. This surprised me quite a bit because he had always seemed to appreciate that I was a somewhat informed patient.

Based on the results of their study, Stokes et al. (2006) argued that general practitioners who terminated their relationships with their patients were exercising symbolic power—and that the doctors' decisions appeared to be based upon their refusal to adopt a collaborative approach to healthcare. According to Stokes et al., being "fired" by one's doctor is experienced by patients as an "overtly violent" symbolic act (p. 613). Particularly considering that patients tend to be reluctant to share psychosocial aspects of their illness due to fear of dismissal by their doctors (Shattock, Williamson, Caldwell, Anderson, & Peters, 2013), if patients choose to disclose their suffering, doctors have an ethical obligation to relieve their suffering by responding with empathy and compassion (Gelhaus, 2012a, 2012b), not dismissal.

In Shawna's experience, her doctor simply never responded to her inquiry:

> [I] asked him to get back with me about what he thought and whether I could switch from the compounded to something [that would] be covered by insurance, but he never got back to me.

The actual cause of Shawna's doctor not following up with her is unknown. Nevertheless, because Shawna already felt unheard and invalidated by her doctor, the added feeling of dismissal prompted her to seek a new doctor (discussed in section "Theme 2: Patient Self-Advocacy").

Experienced a lack of empathy. Four of the 11 participants who experienced a traditional doctor-patient relationship specifically expressed experiencing a lack of empathy from their doctors. Empathy, as demonstrated by a physician, is an understanding of the patient's "feelings, sensations (e.g., pain)…hopes and fears about the disease and of the role and options of the physician and the therapy" (Gelhaus, 2012a, pp. 105-106). Research has indicated that empathy is a vital component to an effective doctor-patient relationship and positive health outcomes (Houle et al., 2007; Neumann et al., 2009; Pollak et al., 2011; Rakel et al., 2011). According to Gelhaus (2012a), one of the most important aspects of physician empathy is "…taking seriously the patient as a complete, distinct, unique human being, not only as a carrier of diseases and symptoms to treat" (p. 112). For a patient to *not* experience empathy in the clinical encounter has the potential to cause the patient to feel misunderstood and unaccepted (Neumann et al., 2009).

Shawna explained that one of her doctors had become "less caring over the years" and that in her search to find a doctor, she has come to no longer trust doctors (discussed in section "Theme 3: Doctor-Patient Communication"). In addition to wanting to feel heard and validated by her doctors, Jessica expressed a desire for her doctors to "just let [her] know they care." Similarly, in conjunction with not being taken seriously by her doctors (discussed in section “Theme 3: Doctor-Patient Communication”), Emily described a lack of empathy from her doctors regarding her thyroid disease-related weight gain: “Sometimes I think men doctors don’t take some female symptoms seriously, but then I’ve had women doctors that also didn’t seem to be sympathetic to a formally [sic] skinny patient who quickly put on 20 pounds.”

Kim and Karen did not describe experiencing a lack of empathy from their doctors. However, they acknowledged the importance of empathy in the doctor-patient relationship. For Kim, a “doctor’s accepting attitude and understanding, empathetic approach helps” her to feel comfortable with sharing her symptoms. When asked whether the gender of her doctor is important to her, Karen responded, “It’s not the sex of the doctor but the compassion and caring of the doctor that makes one good” (discussed in section “Theme 3: Doctor-Patient Communication”). Michelle is the only participant to express having experienced empathy from her doctor: “He is very caring and listens to my needs…he has made clear that he is a good listener and has my best interest at heart.” Michelle’s experience of empathy from her doctor is discussed in the “Additional Findings” section.

Even though the majority of participants did not specifically state that they did not receive empathy from their doctors, considering Gelhaus’ (2012a) assertion that physician empathy involves “…taking seriously the patient as a complete, distinct, unique human being…” (p. 112), many of the participants’ experiences are indicative of doctors who seem to struggle with demonstrating empathy. For example, Carla’s doctor told her that she was ‘too fat to be sick’ and asked her to leave his office; Anne’s doctor “fired” her without any discussion or warning; and Jenna’s doctor “blew her off” when she complained that she was losing her hair and felt “tired ALL the time.”

Annas (2012) purported that in medicine, patients are “treated as enemies, as machines whose bodily plumbing becomes coextensive with medical machinery” and contends that only “vigorous enforcement of patient rights” will ensure that patients be viewed by doctors as autonomous individuals deserving of empathy and warmth (pp. 30-31). Considering that the medical profession has a tendency to dehumanize patients and, historically, patients have been expected to be passive and submissive with their doctors (Annas, 2012; Lupton, 2003), it is possible that the participants in this study who experienced a lack of empathy did not specifically describe their experiences as such because they were unaware of their *right* to empathy. Because empathy has the potential to reduce patients’ anxiety (Finset, 2012; Fogarty, Curbow, Wingard, McDonnell, & Somerfield, 1999) and even enhance patients’ immune system response (Rakel et al., 2009; Rakel et al., 2011), additional training in empathic communication may be warranted (Gelhaus, 2012a, 2012b; Pollak et al., 2011).

Feeling disrespected. Three of the 11 participants who experienced a traditional doctor-patient relationship indicated that they felt disrespected by their doctors. All three of these participants also reported feeling unheard, invalidated, and dismissed by their doctors. According to research by Wessel et al. (2012), feeling respected is associated with doctors who listen to their patients, answer their questions, and take seriously what their patients are sharing. Similarly, participants in Salt et al.’s (2012) study described effective physician communication as respectful when physicians demonstrated empathy, concern, and patience. However, doctors have reported struggling with consultations with patients who have unexplained symptoms (Werner & Malterud, 2003), who tell long stories (Platt, 2008), and who do not adopt a passive role in their treatment (MacDonald, 2003).

Shawna reported that when she attempted to describe her medical history, her doctor interrupted her and “launch[ed] into a tirade about how [she didn’t] have a thyroid problem and should never have been put on meds.” Carla explained that she had repeatedly told her doctor she believed her “dose [of thyroid medicine] was wrong” because she was feeling worse each year. During one such discussion on the telephone, Carla’s doctor called her “a 'smart ass' and [told her] to stay on the same dose…then hung up on [her].” Shawna’s and Carla’s experiences of disrespectful responses from their doctors might be related to their attempts to be active participants in their treatment. In a study by Frosch, May, Rendle, Tietbohl, and Elwyn (2012), participants who attempted to participate in shared decision making with their doctors reported feeling unheard and disrespected by their doctors. Frosch et al. asserted that doctors may lack the skills needed to create an environment conducive to open communication and shared decision making. According to Chin (2002), doctors have a responsibility to work collaboratively with their patients in creating treatment plans that include not only the doctors’ recommendations, but also considers the patients’ ideas, concerns, and expectations.

Subtheme 2: Collaborative relationships. The majority of the participants interviewed (13 out of 16) also experienced collaborative doctor-patient relationships. At some point in their experiences with treatment for thyroid disease, nine of these 13 participants who experienced a collaborative doctor-patient relationship also had doctors who worked in a traditional paternalistic manner. In other words, only four (Alicia, Autumn, Karen, and Kari) out of the 16 participants interviewed consistently had doctors who did not make them feel unheard, invalidated, dismissed, not empathized with, or disrespected.

As discussed in Chapter 2, in collaborative doctor-patient relationships, doctors tend to listen attentively to their patients, visits tend to be longer, and patients' preferences are considered in treatment decisions (Breen et al., 2009; Hall et al., 2009; Houle et al., 2007; Levinson, Lesser, & Epstein, 2010; Salt et al., 2012; Wessel et al., 2012). In contrast to traditional doctor-patient relationships, collaborative doctor-patient relationships in which patient autonomy is respected help to encourage positive treatment outcomes (Chrisler & Parrett, 1995; Dugdale et al., 2008; Fox & Chesla, 2008; Houle et al., 2007; Peck & Connor, 2011). According to Chin (2002), doctors have a responsibility to work collaboratively with their patients in creating treatment plans that include not only the doctors' recommendations, but also considers the patients' ideas, concerns, and expectations. Within Subtheme 2: Collaborative Relationships are the following subthemes: feeling heard, feeling validated, feeling unrushed, and shared decision making.

Feeling heard. Ten of the 13 participants who experienced a collaborative doctor-patient relationship indicated that they felt heard by their doctors. Research indicates that when patients feel heard by their doctors, they are more likely to be satisfied with their treatment (Levinson, 2011; Peters et al., 2008). Patients are also more likely to trust their doctors if they perceive that their doctors are listening attentively and answer their questions (Houle et al., 2007; King et al., 2015). Alicia explained, “I have chosen to stay with the physician because I believe he will listen to me.” Kari described her doctor as “easy to talk to” and explained that even though her doctor is lacking in knowledge about thyroid disease, “the main thing [is that] she does listen.” Similarly, Diane expressed appreciation that her doctor “take[s] into consideration what [she’s] saying to him, and gives [her] feedback.”

According to Houle et al. (2007) and Jagosh et al. (2011), in conjunction with feeling heard by one’s doctor, patients who believe that their doctors have a genuine interest in their well-being are more likely to trust their doctors. Trust, in turn, tends to result in patients’ willingness to share with their doctors and to consider their advice (Copeland et al., 2003; Peters et al., 2008). After years of trying to find a doctor she felt comfortable with, Michelle found a doctor who “made clear that he is a good listener and has [her] best interest at heart.” Because patients experience their illnesses in the context of their own social worlds, doctors who encourage patients to share their thoughts and concerns from their own perspectives tend to be more effective than doctors who do not actively listen and seek patients’ personal interpretations (Epstein & Street, 2011; Lang, Floyd, & Beine, 2000). When patients feel comfortable sharing their experiences with their doctors, the likelihood of misdiagnosis and delayed treatment is decreased (Lang et al., 2000).

Feeling validated. Eight of the 13 participants who experienced a collaborative doctor-patient relationship indicated that they felt validated by their doctors. All of the participants who reported feeling validated by their doctors had also reported feeling heard. For example, Diane reported appreciating that her doctor “take[s] into consideration what [she shares with] him” when expressing her concerns and discussing treatment options. Although April had reported feeling unheard and invalidated by her previous doctor, she described feeling comfortable sharing her concerns with her new doctor because he “wants to know what [she knows] and confirms that [she is] not stupid.” Alicia explained that her doctor welcomes her thoughts: “I think my doctor understands that I am not the person I used to be [before treatment for breast cancer]—that I know how to do the research and that I know what is reasonable.” Similarly, Michelle expressed that her doctor validates her by understanding that “[her] body reacts differently than others termed ‘normal’ and is very interested in working with [her] to ‘optimize’ [her] thyroid hormone needs.”

Validating one’s patients engenders productive, therapeutic communication because when patients feel safe in sharing their symptoms, doctors can ask relevant questions and may recognize undiagnosed or misdiagnosed illnesses (Dean & Street, 2014; Hedberg & Lynoe, 2013). Shields et al.’s (2013) study of the relationship between doctor-patient communication and the undertreatment of pain revealed that doctors who explored and validated their patients’ experiences conducted more thorough pain assessments than doctors who did not express a curiosity about their patients’ concerns. Research indicates that thorough assessments are more likely to lead to accurate diagnoses and appropriate treatments (Epstein et al., 2007b; Shields et al., 2013).

Furthermore, patients who feel validated by their doctors tend to experience improved psychosocial well-being (e.g., feelings of optimism and self-worth; Street et al., 2009).

Feeling unrushed. Four of the 13 participants who experienced a collaborative doctor-patient relationship indicated that they felt unrushed by their doctors. After leaving the doctor who interrupted her, Shawna found a doctor she liked, stating, "I like the new D.O. …he seems to be on the right track and he spends a lot of time with you." Similarly, Kari described her doctor as "…easy to talk to…she takes her time." Emily was more detailed in her description of how her doctor made her feel unrushed, explaining, "I had written all my issues out before seeing the endocrinologist and she still went through the whole list of possible symptoms to see which I was experiencing and to what extent. She was very thorough."

According to Salt et al.'s (2012) study of individuals with rheumatoid arthritis, having sufficient time to discuss their concerns with their doctors without feeling rushed was a crucial factor in patients' perceived quality of care. In addition to feeling comfortable with and trusting of one's doctor (Copeland et al., 2003; Houle et al., 2007; Sutherns, 2004), research indicates that patients who do not feel rushed by their doctors also feel valued and supported by their doctors (Sutherns, 2004; Swancutt, Greenfield, Luesley, & Wilson, 2011). An additional benefit to feeling unrushed by one's doctor is that patients find it easier to ask questions, which reduces the potential for misunderstanding health information and treatment recommendations (Heinrich & Karner, 2010).

Shared decision making. Twelve of the 13 participants who experienced a collaborative doctor-patient relationship indicated that they participated in shared decision making with their doctors. Alicia explained,

> I feel that we are carefully working toward finding the best way to treat me….We have a good working relationship…he does listen when I tell him how I am feeling and [we will] continue working on treatment (adjusting medication dosages and testing) until I am thriving.

Diane described a similar experience with her doctor, stating, "[My doctor takes] into consideration what I'm saying to him, and gives me feedback…We're [currently] working on seeing if I have any issues with my adrenal glands." Likewise, Michelle reported that her doctor is "very interested in working with [her] to "optimize" [her] thyroid hormone needs." April's experience involves her bringing research to her doctor. She explained, "[My doctor] wants to know what I know…[and] if need be, he will correct or add more info to what I already know."

With the passing of the Affordable Care Act of 2010, shared decision making between patients and doctors became a requirement in the doctor-patient relationship (Frosch et al., 2012). However, traditional doctor-patient relationships in which the doctor makes treatment decisions without the patient's input continue to persist. According to Frosch et al., doctors may lack the skills needed to create an environment conducive to open communication and shared decision making.

Research indicates that most patients desire to be involved in the decision making process (Barry & Edgman-Levitan, 2012; Chin, 2002; Flynn, Smith, & Vanness, 2006;

Quaschning, Korner, & Wirtz, 2012). According to Barry and Edgman-Levitan (2012), shared decision making is the “most important attribute of patient-centered care” (p. 780). Chin (2002) asserted that in order to successfully negotiate a treatment plan with one’s patient, the doctor must be sincere in the shared decision making process. In other words, it is essential that the doctor attempts to understand the patient’s point of view and is open to incorporating the patient’s ideas and concerns into the treatment plan. Shared decision making also requires mutual trust (Chin, 2002; Crooks et al., 2015). In Carla’s experience, her doctor’s willingness to include her in the decision making process is a significant aspect of earning Carla’s trust. Carla explained, “I don't have a lot of trust in her anymore…but I will admit that she is now talking with me more…and we are working on compromises.”

Studies show that involving patients in the decision making process increases patient satisfaction and treatment acceptance (Barry & Edgman-Levitan, 2012; den Ouden, Vos, Reidsma, & Rutten, 2015; Elwyn et al., 2012; Epstein & Street, 2011; Flynn et al., 2006; Quaschning et al., 2012). According to Chin (2002), another benefit of shared decision making is that it can help to ensure that patients are not left alone in a position of evaluating the efficacy of various treatments. Epstein and Street (2011) contend that even if a patient does not initially choose the best treatment option, a worsened condition can be promptly addressed by the doctor due to the mutual trust established via shared-decision making. In addition, the fact that the patient feels understood, respected, and involved in the decision making process might alleviate any resulting distress associated with the patient’s symptoms (Epstein & Street, 2011).

According to McNutt (2004), involving the patient in the decision making process is vital because “only the patient will suffer or enjoy the probabilistic outcomes associated with choosing one option over another” (p. 2516).

Theme 2: Patient Self-Advocacy

In describing their experiences with thyroid disease treatment, 15 of the 16 total participants described participation in some form of self-advocacy, including health information-seeking and switching doctors. The majority of these participants (12 out of 15) experienced a traditional doctor-patient relationship at some point. Two of the 15 participants who participated in a form of self-advocacy (Karen and Kim) made statements that indicated a belief that “doctor knows best” (discussed at end of this section). The subthemes within Theme 2: Patient Self-Advocacy are Subtheme 1: Health Information-Seeking, Subtheme 2: Switching Doctors, and Subtheme 3: Belief that “Doctor Knows Best.”

Subtheme 1: Health information-seeking. Twelve of the 15 participants who participated in some form of self-advocacy conducted health information-seeking. Two of these participants sought health information for use in shared decision making with their doctors. Alicia explained, “[My doctor understands that] I know how to do the research and that I know what is reasonable.” Although Kari described having difficulty with “find[ing] a Dr. who knows anything about Thyroid problems,” she explained that her doctor was receptive when she shared “what [she] learned [from] reading Mary Shomon’s newsletters and book.”

Ten of the 12 participants who sought health-information did so because they continued to feel unwell despite being treated for thyroid disease. Karen reported that after 38 years of not feeling better from treatment for thyroid disease, she sought information online and “learned a bank of knowledge that helped [her] whittle thru all the mediocre docs and find the right one”—a doctor who “listens well and makes adjustments based on [her] response.” In some cases, participants learned that additional blood tests might give a clearer picture of their thyroid function. Shawna explained, “I feel that if I hadn’t been aggressive in all my research I would have just been kept being told that my [levels were] ‘normal’ when they were clearly not.” Anne reported that she “had joined the on-line support group and done some research on-line [and] did finally find a doctor who agreed to include free t3 and t4 [levels] in the blood tests.”

Other participants chose to conduct research in order to make informed decisions regarding their treatment. Jenna explained, “[My doctor] REALLY pushes for me to do RAI which based on MY research, I don’t feel is needed.” Emily described appreciating that her endocrinologist is “open to trying natural hormone” and commented, “[my endocrinologist] seems well versed in my diagnosis, but I only know that because of extensive research I’ve done on my own.” Kim reported that she has been conducting research over the 66 years she has been treated for thyroid disease. She stated, “I know enough about thyroid function and my thyroid problem and what works best for me that I am in a position to explain to the doctor what I need, not the other way around!” Similarly, April explained, “I know my shit and will tell them what I know, what I want to know and what their opinion is and their thoughts. I will not always go with their recommendations (I have refused RAI 3 times now…).” April elaborated on her experience with conducting research to share with her doctor, “I went [to my appointments] with knowledge and she told me to get off google.”

According to Tustin (2010), doctors tend to view patients who bring information from the Internet to their appointments as burdensome. Historically, doctors have had access to medical knowledge unavailable to the public. Although this continues to be true, patients now have greater access to health information (Hearn, 2009). Contributing factors to patients performing their own research include having insufficient time to ask questions at doctor’s appointments (Tustin, 2010), not trusting the doctor’s advice (Frosch et al., 2012; Tustin, 2010), and perceived lack of empathy from one’s doctor (Tustin, 2010). Research indicates that individuals who join online health support groups do so because they desire emotional support in dealing with the anxiety and uncertainty related to their illness (Oh & Cho, 2015; Ye, 2014). Results of a national survey conducted by Fox (2011) for the Pew Research Center revealed that 23% of Internet users with a chronic health condition used the Internet to find others who share their health concerns.

A study by Tustin (2010) indicated that even patients who were satisfied with their treatment tended to conduct online research about their health concerns. However, unlike patients who were dissatisfied with their care, patients who reported being satisfied reported that they relied more on their doctors than on the Internet for health information. Participants in a study by Frosch et al. (2012) expressed a desire to share information with their doctor and to participate in treatment decisions. However, the participants reported hesitation to do so because they feared being labelled by their doctors as “difficult.” Risberg et al. (2006) asserted that doctors have a tendency to undervalue patients’ knowledge. According to MacDonald (2003), because health care professionals have been traditionally thought of as “all knowing,” patients who seem to challenge professionals’ expertise become thought of as “difficult” by professionals.

Research conducted by Amante, Hogan, Pagoto, English, and Lapane (2015) indicated that the likelihood of using the Internet to seek health information increased with education level—particularly among female patients. Similarly, a study by Flynn et al. (2006) revealed that patients who are female and who have a higher educational attainment tend to desire the most active involvement in the decision making process with their doctors. In the current study, 11 of the 12 participants who sought health information acquired education beyond high school (see Table 2 in Chapter 4). Seven of the 12 participants who conducted information-seeking (Anne, April, Diane, Karen, Kim, Leanne, Shawna) also switched doctors.

Subtheme 2: Switching doctors. Nine of the 15 participants who participated in some form of self-advocacy switched doctors. Jessica explained that she had “been through three endo's [sic] in five months [because the first] two got frustrated and abusive with [her] because [she] was not tolerating the thyroid meds well.” Similarly, Michelle reported, “It took me another 2 years before I found an Internal Medicine Dr. who would prescribe me something other than Synthroid.” Anne commented,

> I went to at least 4 doctors seeking help. This was especially difficult because with each new appointment, I would get my hopes up that this doctor was the ONE who would help me. The letdown after each appointment was devastating.

Likewise, Karen reported that she “went through 5 Endos before [she] found one who knew what she was doing.” Diane shared that she “saw several doctors [who] prescribed anti dizziness medication, depression pills, etc.” She elaborated, “All doctors said my blood work came back fine, including thyroid. However, I was still bedridden and in danger of losing my job.” April explained that she “hesitated leaving [her doctor] when [she] got pregnant,” but added that she “felt more secure” and switched doctors once the baby was born.

Research indicates that the most common reasons given by patients for switching doctors include dissatisfaction with and lack of trust in one’s doctor (Berry et al., 2008; Calnan & Rowe, 2008; Liu, Yen, Lo, & Chen, 2014; Platanova, Kennedy, & Shewchuk, 2008; Kessler & Mylod, 2011; Torres, Vasquez-Parraga, & Barra, 2009). A study by Liu et al. (2014) revealed that feeling understood and accepted by one’s doctor is a significant predictor to trusting one’s doctor, and thus, choosing to remain committed to the doctor-patient relationship. According to research by Platanova et al. (2008), a patient’s satisfaction with and trust in one’s doctor are stronger predictors of a patient’s commitment to the doctor-patient relationship than are the monetary costs of switching doctors. In other words, patients who are not satisfied with or do not trust their doctors will switch doctors even if switching results in a greater expense.

Unlike traditional doctor-patient relationships in which patients adopted a passive role in their healthcare, modern patients view themselves as consumers who wish to be informed and to work collaboratively with their doctors (Calnan & Rowe, 2008). A study by Harris (2003) revealed that patients who have had unsatisfactory experiences with doctors are more likely to consult formal sources of information (e.g., patient surveys and websites), as opposed to the opinions of friends and family, in order to find a new doctor. In turn, patients who choose their doctors based on formal information are more likely to switch doctors if they are dissatisfied with their care. In the current study, seven of the nine participants who switched doctors (Anne, April, Diane, Karen, Kim, Leanne, Shawna) had conducted health information-seeking.

Subtheme 3: Belief that "doctor knows best." According to Campbell, Gillet, and Jones (2005), a paternalistic approach in medicine reflects a "rather arrogant assumption that one knows best" (p. 3) and is in direct contrast with patient autonomy. Two of the 15 participants who participated in some form of self-advocacy made statements that indicated a personal belief that "doctor knows best." In other words, during their interviews, Karen (age 64) and Kim (age 82) made comments that suggest they had accepted paternalism and adopted passive (rather than autonomous) roles in their experiences with doctor-patient relationships. Research by Deber, Kraetschmer, Urowitz, and Sharpe (2007) revealed that individuals over age 55 tend to favor a paternalistic approach from their doctors. Benbassat, Pilpel, and Tidhar (1998) argued that older patients may expect a paternalistic type of doctor-patient relationship because it was the cultural norm in the recent past.

During her interview, Karen (age 64) explained that she had accepted a paternalistic approach from her doctors and adopted a passive role as a patient for 38 years. Karen stated, “When I was younger I did not argue with my doctor because I always thought they knew best. But after years of mistreatment I finally took the bull by the horns…I went through 5 Endos before I found one who knew what she was doing.” Kim (age 82), the oldest participant in the current study, reported that she has been treated for thyroid disease for 66 years. Although she adopted a more autonomous role as a patient when her doctor switched her medication from Armour thyroid to Synthroid in 1958, Kim appears to be more tolerant of paternalistic behavior from male doctors than from female doctors. More specifically, Kim stated, “I’m more likely to argue with a female doctor if I think her approach is wrong. If I feel a male doctor’s approach to thyroid care is wrong for me, I simply don’t go back to him and begin looking for another doctor.”

Research indicates that female patients with high levels of autonomy prefer doctors who communicate in an informative rather than paternalistic manner (Flynn et al., 2006; Kaplan et al., 2002). Both Karen and Kim demonstrated autonomous behaviors when they sought health information and eventually switched doctors. However, Kim’s differing reactions to female versus male doctors’ approaches suggest an internalization of status beliefs (culture-based beliefs in which a higher status is associated with one group over another; Peck & Connor, 2011; Rashotte & Webster, 2005). In other words, Kim may be more willing to tolerate a paternalistic approach from a male doctor than from a female doctor because, on a subconscious level, she believes that male doctors are higher in status than female doctors. Research by Bradley et al. (2001) revealed that levels of satisfaction among patients ages 50 and older are significantly lower when female doctors (as opposed to male doctors) use a paternalistic communication style. Bradley et al. (2001) argued that these results might reflect conventional gender-role expectations among middle-aged individuals.

Numerous studies (Benbassat et al., 1998; Briel et al., 2007; Brom et al., 2014; Deber et al., 2007; Kennelly & Bowling, 2001; McKinstry, 2000) suggest that patients ages 55 and older prefer a largely passive role in their care, with their doctors making treatment decisions. In addition, older patients are more likely to accept their doctor's advice without question (Kennelly & Bowling, 2001). However, research also indicates that female patients with a higher educational attainment tend to desire active involvement in the decision making process with their doctors (Flynn et al., 2006). Both Karen and Kim attained education beyond high school. Although Kim is less likely to argue with a male doctor than a female doctor, both Karen and Kim appeared to move from passive to autonomous roles when they sought health information and new doctors when they became dissatisfied with their treatment.

Theme 3: Doctor-Patient Communication

Participants' responses to interview questions regarding communication indicated that their experiences with thyroid disease treatment were impacted by their ability to communicate with their doctors. Doctor-patient communication appeared to be influenced by the participant's desire to be informed, the participant's level of trust in her doctor, and by being female. The subthemes within Theme 3: Doctor-Patient

Communication are Subtheme 1: Desire to Be Informed, Subtheme 2: Role of Trust (lack of trust in doctor, treatment refusal, secret-keeping, and self-treatment), and Subtheme 3: Role of Gender (no preference for specific doctor gender, preference for female doctor, being taken seriously, and presence of emotion).

Subtheme 1: Desire to be informed. Six of the 16 total participants expressed a desire for their doctors to inform them about the results of lab work and treatment options. Research indicates that although the majority of patients seek information about their diagnoses and treatment options from external sources (e.g., the Internet, books), patients continue to refer to their doctors as their primary source for health information (Bernhardt, 2001; Cegala et al., 2008; Cotten & Gupta, 2004; Hassling, Babic, Lonn, & Casimir-Ahn, 2003). April's experience reflects this finding. She stated, "I will tell them what I know, what I want to know and [learn] what their opinion is and their thoughts." Although April conducted research about her diagnosis and treatment options, she did not seek a new doctor. Similarly, Emily conducted her own research but did not seek a new doctor despite expressing frustration that her doctor "doesn't come forward with all she's thinking unless [Emily] push[es] the conversation." Before Michelle's doctor moved to a teaching position, she was comfortable with relying on her doctor for health information. Michelle explained, "She was a teaching Dr. and taught me how to read the numbers on all the appropriate tests---not just TSH, but also FT3 & FT4."

With the shift from paternalistic doctor-patient relationships to patient-centered care, the value of information exchange between doctors and patients has come into focus (Carlsen & Aakvik, 2006; Deber et al., 2007). Research conducted by Flynn et al. (2006)

revealed that even patients who do not want to make treatment decisions desire for their doctors to disclose all treatment options (Flynn et al., 2006). In addition, patients believe that their doctors need to know their entire medical history in order to provide good care (Flynn et al., 2006). According to Cegala et al. (2008), a central outcome of informed patients is their ability to communicate effectively with their doctors by asking important questions and reporting relevant symptoms. Regarding Anne's desire for information exchange with her doctor, she explained, "I have some work to do to figure out how I can either get her to make me understand where she is coming from…or if I can get her to understand that I am backsliding again." Anne's experience is similar to participants in Cegala et al.'s study in which patients became less satisfied with their doctor's communication after receiving treatment for their conditions. Furthermore, almost 40% of the participants felt less informed regarding their treatment options than about diagnostic information.

Research suggests that individuals with chronic illness keep current with information regarding their illness in an attempt to gain control over their health (Leach & Schoenberg, 2008; Mirzaei et al., 2013). Of particular importance to patients with chronic illness is information about recent treatment advances and the potential outcomes and side effects of treatments (Mirzaei et al., 2013). Kim explained that she is in a "wait-and-see mode" regarding how she feels after switching from a synthetic medication to a natural thyroid medication. She stated, "I need to get the testing done to see where my frees are on the new product."

Hassling et al. (2003) suggested that in order to reduce potential feelings of insecurity due to insufficient information, doctors should offer to educate their patients about their illnesses. Murtagh (2006) asserted that doctors demonstrate respect for their patients' autonomy by ensuring that they are fully informed. According to Carlsen and Aakvik's (2006) study, patients prefer doctors who readily offer them health information. As previously mentioned, patient satisfaction and trust in one's doctor are common in patient-centered approaches in which doctors respect patient autonomy, listen attentively, and answer questions (Copeland et al., 2003; Firth Cozens, 2008b; Fuertes, Anand, Haggerty, Kestenbaum, & Rosenblum, 2015; Hall et al., 2009; Houle et al., 2007; Jagosh et al., 2011).

Subtheme 2: Role of trust. In responding to interview questions regarding communication, nine out of the 16 total participants indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors. Four of these nine participants explicitly expressed distrusting their doctors, six refused treatment, three engaged in secret-keeping, and six engaged in self-treatment. Within Subtheme 2: Role of Trust are the following subthemes: lack of trust in doctor, treatment refusal, secret-keeping, and self-treatment.

Lack of trust. Four out of the nine participants who indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors explicitly expressed distrusting their doctors. Carla commented, "[I am] guarded…I don't have a lot of trust in her anymore." She explained,

> During the first visit [my doctor] seemed open minded. She ran the correct tests, she allowed me to stay on the replacements that I've been taking…But by the third visit she was pushing Synthroid, questioning what I have been taking.

Shawna shared that after continually being told by her doctor that her lab work was “normal” and learning otherwise through her own research, she is “keeping a folder of [her] labs now,” explaining, “I have learned to get copies of them and not believe what the doctor’s office tells me.” Similarly, Sarah commented, “My distrust is at such a high level after being misdiagnosed for over half of my life that it will be hard to share [with a doctor] in the future.”

Kraetschmer, Sharpe, Urowitz, and Deber (2004) described trust as “a complex concept, which includes both technical (expertise) and interpersonal (e.g. communication, respect) elements” (p. 318). Research indicates that trust in one’s doctor is necessary for patients to feel comfortable in sharing their symptoms and illness experiences (Copeland et al., 2003; Houle et al., 2007; Lee & Lin, 2010; Peters et al., 2008). Participants in Skirbekk et al.’s (2011) and Houle et al.’s (2007) studies revealed that doctors must show an interest in their patients, listen attentively, and be available to answer their questions in order to gain their patients’ trust. Participants in Skirbekk et al.’s study further added that doctors must demonstrate sensitivity to their emotions. In the current study, all participants who expressed distrusting their doctors had also reported feeling unheard, invalidated, and dismissed by their doctors.

Trust in one’s doctor has been shown to be a predictor of patient adherence to medical advice (Houle et al., 2007; Lee & Lin, 2010; Peters et al., 2008). A study by

Kraetschmer et al. (2004) indicated that even patients who have high levels of autonomy are more willing to follow their doctors' advice if they trust their doctors. Kraetschmer et al.'s study further revealed that patients with low levels of autonomy who tend to prefer a more passive role in their care begin to adopt a more active role as their trust in their doctors declines.

Treatment refusal. Six out of the nine participants who indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors explained that they had refused treatment. Jenna shared that her doctor "doesn't listen" and "blows [her] off a lot" when she attempts to discuss her research. She explained, "He REALLY pushes for me to do RAI which based on MY research, I don't feel is needed…I made it CLEAR I was not doing RAI." Likewise, April shared, she would feel more comfortable with her doctors if they "took [her] research serious and didn't just humor [her]." She added, "I will not always go with their recommendations (I have refused RAI 3 times now, twice with the first dr, once with the second)."

Carla described her experience with treatment refusal,

> I've rejected several drugs offered to me since the Diabetes diagnosis…and no longer open a bottle till I know what it will do. The combo of drugs she put me on to control high blood pressure are KNOWN TRIGGERS for Type 2 [and] I'm still kicking myself for not doing the research before opening the bottles.

According to Anne, her doctor does not take her seriously and "did not understand when [she] was upset" at the doctor's suggestion of taking Synthroid when there was a shortage in Armour thyroid. Similarly, Michelle explained that doctors would not listen when she told them she did not feel well on Synthroid. She stated, “I finally had to go off of Synthroid (on my own) after a year because I felt so bad on it. I felt better not taking anything compared to taking Synthroid.” Like Michelle, Sarah also refused medication and “gradually tapered off most unnecessary prescriptions over a two-year period.” Sarah then “left the Doctor [she] had for over 23 years” because her doctor “poo-pawed” her when she would try to discuss not feeling well.

Numerous studies have revealed that doctors’ ability to communicate with their patients enhances their patients’ level of comfort and trust in the doctors’ treatment recommendations (Copeland et al., 2003; Epstein & Street, 2011; Goff, Mazor, Meterko, Dodd, & Sabin, 2007; Moore et al., 2004; Skirbekk et al., 2011; Vina, Masi, Green, & Utset, 2012). According to research by Goff et al., (2007), poor communication reduces patients’ confidence in their doctors’ treatment recommendations. Participants in Goff et al.’s study explained that before considering their doctors’ treatment recommendations, they must first trust their doctors; and, that in order to trust their doctors, they must feel understood by their doctors. Participants in Epstein and Street’s (2001) study also reported that feeling understood by one’s doctor is a prerequisite to trust. Likewise, patients interviewed by Skirbekk et al. (2011) explained that trusting one’s doctor and considering their doctors’ advice was dependent upon feeling heard and being taken seriously.

Additional reasons given by patients for not trusting and refusing their doctors’ treatment advice is feeling as if they have not received good care from their doctors in the past (Sharf, Stelljes, & Gordon, 2005), and receiving inadequate information from one’s doctor regarding the potential side effects of treatment (Fukaya, 2000). Research by Piette, Heisler, Krein, and Kerr (2005) indicated that the level of trust in one's doctor is a stronger predictor of medication compliance among patients with high out-of-pocket costs than the expense of the medication. According to Lee and Lin (2010), trust in the doctor-patient relationship increases the likelihood of full patient disclosure. Patient disclosure is particularly important in cases in which doctors and patients do not agree on the treatment approach because, with full patient disclosure, doctors might be better equipped to appropriately modify the patient's treatment plan (Lee & Lin, 2010).

Secret-keeping. Three out of the nine participants who indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors explained that they had kept secrets from their doctors. The finding of "secret-keeping" in the current study prompted a perusal of the literature for studies related to the issue of patients withholding information from their doctors. A thorough search of the literature, using the search terms *secret-keeping*, *withholding information*, *lying*, and *disclosure*, in relation to trust resulted in numerous studies related to patients seeking pain medication (e.g., Buchman & Ho, 2014; Maakaron, Manchanda, Hoang, & Steinmetz, 2014; Palmieri & Stern, 2009; Sokol, 2014; Stogner, Sanders, & Miller, 2015; Worley & Thomas, 2014) and doctors utilizing "therapeutic privilege" to withhold information from their patients for the "good of the patient" (e.g., Collis & Sleeman, 2013; Everett et al., 2011; Hodkinson, 2013; Kanaan, 2009; Richard, Lajeunesse, & Lussier, 2010; Matthes & Caples, 2013; Self, 2014; Shahidi, 2010). However, a gap in the literature was discovered regarding the practice of secret-keeping by patients in an attempt to regain control over their own health.

According to Fainzang (2005), the purpose of secret-keeping on the part of the patient is "not the exercise of power but the expression of resistance to the power of [the doctor]" (p. 18). For example, in the current study, Sarah shared that her doctor did not listen to her or take her seriously when she complained that she did not feel well on Synthroid. Sarah explained,

> After knowing I would die if I continued this way, I started taking charge of my own health…added supplements, and gradually tapered off most unnecessary prescriptions over a two-year period [and] then left the Doctor I'd had for over 23 years…

Sarah did not inform her doctor that she was self-treating and seeking a new doctor during this two-year period because her doctor continually "poo-pawed anything [she] would bring up," and added that her "distrust [in her doctor was] at such a high level after being misdiagnosed for over half of [her] life…"

Fainzang (2005) argued that while lying is "justified, even legitimized in doctors [it is] condemned in patients" (p. 6). Through the lenses of feminism and social constructionism, medical knowledge regarding women's bodies is understood as being influenced by cultural factors and social norms (Docherty & McColl, 2003; Fernandes et al., 2006; Lupton, 2003). Concepts of women's health, illness, and methods for managing illness are created and managed by pharmaceutical companies and physicians who maintain positions of authority over patients (Findlay, 1993; Hearn, 2009; Lupton, 2003;

Munch, 2004). However, feminists argue that patients are the experts of their own medical conditions (Chrisler, 2001; Fernandes et al., 2006; Hoffmann & Tarzian, 2001; Wright & Owen, 2001). As such, when an individual experiences a phenomenon that she considers to be abnormal for *her* body and takes action based on *her own* interpretation of the phenomenon, she is reclaiming power and control over her body (Fainzang, 2005, 2015).

Kim is 82 years old and has been receiving treatment for thyroid disease for 66 years. When the doctor who had been treating her for thyroid disease passed away, she had to seek a new doctor—one who would be willing to continue her prescription for Armour thyroid, as well as order a full thyroid panel (not the TSH blood test alone) for her blood work. Kim explained, "My other doctor, whom I'd kept as my primary for everything but thyroid, kept ordering TSH and I simply refused the test when I got to the lab. I just told him I was seeing another doctor for my thyroid treatment…We sometimes have to resort to trickery!" Rather than telling her primary care doctor that she was not satisfied with a TSH-only blood test, Kim chose to tell her doctor that she had already found another doctor to treat her for thyroid disease even though she was still seeking a doctor. As discussed previously in section "Belief that 'Doctor Knows Best,'" Kim seems to be willing to tolerate a paternalistic approach from a male doctor, and this could be due to her age. As such, Kim likely considers her primary care doctor to be an authority figure—an "authority in the face of which one does not dare to openly show resistance or refusal" (Fainzang, 2005, p. 12). According to Fainzang (2005), patients who do not wish to demonstrate “open opposition” to their doctors will sometimes lie in order to “avoid conflict, criticism, or blame” (p. 10).

Nevertheless, while it is considered unacceptable for patients to withhold information from their doctors, for a doctor to withhold information “comes within the framework of permissible lying” (Fainzang, 2005, p. 17). According to Fainzang (2005), “Numerous doctors claim the privilege of knowledge concerning the patient’s body and tend not to disclose information that might enable the patient to make his own choices concerning his being” (p. 17). In addition, patients’ knowledge tends to be undervalued by doctors (Risberg, 2006); and decisions regarding diagnosis and treatment are based on “objective evidence” of disease (e.g., blood tests) while patients’ subjective experiences of illness are largely ignored (Hoffmann & Tarzian, 2001).

Research indicates that patients are more likely to trust doctors who listen to them and show a genuine interest in their well-being (Houle et al., 2007; Jagosh et al., 2011). In turn, trust in one’s doctor increases the likelihood that patients will disclose information to their doctors (Copeland et al., 2003; Peters et al., 2008). Considering that the majority of patients wish to actively participate in their healthcare (Barry & Edgman-Levitan, 2012; Chin, 2002; Flynn et al., 2006; Quaschning et al., 2012) and effective doctor-patient collaboration requires mutual trust (Chin, 2002; Lee & Lin, 2010), it is vital that doctors attempt to understand their patients’ points of view and remain open to their ideas, preferences, and concerns (Barry & Edgman-Levitan, 2012; Chin, 2002; Epstein & Street, 2011; McNutt, 2004; Salt et al., 2012; Wessel et al., 2012).

Self-treatment. Six out of the nine participants who indicated that their ability to communicate with their doctors was influenced by their level of trust in their doctors explained that they had engaged in self-treatment. As with the issue of secret-keeping, the majority of the literature on self-treatment places patients in a subservient position to the doctor and largely focuses on "self-medication" with unauthorized drugs and alcohol (e.g., Larance et al., 2011; Mehuys et al., 2012; Neafsey et al., 2011; Robinson, Sareen, Cox, & Bolton, 2011; Schuman-Olivier et al., 2010). Self-medication is defined by Verma, Mohan, and Pandey (2010) as "the use of medication by a patient on his own initiative or on the advice of a pharmacist or a lay person instead of consulting a medical practitioner" (p. 60). Fainzang (2013) argued that patient self-medication is a form of self-advocacy that involves a thoughtful process of "self-examination, self-diagnosis, and self-prescription" (p. 495) that patients initiate when their doctor "does not agree with [the patient's] interpretation of a phenomenon" (p. 499). Because female patients in particular often need to prove the validity of their complaints (Hoffman & Tarzian, 2001; Munch, 2004) and patients who challenge their doctors tend to be thought of as "difficult" (Frosch et al., 2012; MacDonald, 2003), female patients who self-medicate might be considered as self-advocating by taking control of their health (Fainzang, 2005, 2013, 2015). In the current study, the term "self-treatment" was chosen instead of "self-medication" due to its negative connotation in the majority of the literature.

In the current study, six participants chose to either stop or start taking a medication or supplement without consulting their doctors. For example, Jenna shared that she was struggling with symptoms from thyroid cancer, which remained undiagnosed for approximately four months because her blood work continued to show as "normal." After growths were discovered on Jenna's thyroid, her thyroid was surgically removed. During the fourth month period before her diagnosis, Jenna spoke with a friend "who has thyroid issues [and] got [her] on a multivitamin and 10k units of vitamin D3." Jenna added, "Our local herbalist gave me a supplement which offered thyroid and adrenal support."

Carla reported that her doctor bases her recommendations solely on the results of blood work, ignores her symptoms, pushes her to take Synthroid even though she felt sick taking it, and does not take Carla seriously. As a result, Carla explained, "I started self-treating in July of 2002 and pretty much consider myself to still be self-treating [and] the current doc/insurance just run my labs." Similarly, Michelle stated, "I finally had to go off of Synthroid (on my own) after a year because I felt so bad on it. I felt better not taking anything compared to taking Synthroid." Likewise, Sarah explained,

> [I] added supplements, and gradually tapered off most unnecessary prescriptions over a two-year period [and] then left the Doctor I'd had for over 23 years and started self-treating with Thyroid replacement ordered online, treating adrenals, plus additional vitamins and supplements gradually added.

According to Verma et al. (2010), self-treatment practices among patients are increasing internationally. Research conducted by Holtgräfe and Zentes (2012) revealed a correlation between patient self-treatment and distrust in the opinion of health professionals. In a study of individuals with gastrointestinal disorders, patients with a graduate-level education were more likely to self-treat than those with a secondary education or below (Kua, Ng, Lhode, Kowalski, & Gwee, 2012). Educational attainment is positively correlated with "health literacy," or "the degree to which individuals have the capacity to obtain, process, and understand basic health information to make appropriate health decisions (Lubetkin et al., 2015; White, Osborn, Gebretsadik, Kripalani, & Rothman, 2013, p. 1756). In White et al.'s (2013) study about patients' non-adherence to medication, higher health literacy was associated with lower trust in one's doctor and a greater likelihood of being non-adherent to medication. White and colleagues argued that patients who are highly health literate are less likely to trust their doctors' recommendations without verifying the information and exploring additional options.

Regardless of patients' reasons for self-treatment, there are potential risks to stopping or starting medications and supplements without consulting a doctor. According to Ruiz (2010), potential risks include incorrect self-diagnosis, adverse reactions, and dangerous drug interactions. In Shawna's experience, her choice to self-treat with iodine supplements may have caused a significant spike in her level of thyroid antibodies—which worsens the symptoms of Hashimoto's disease. Shawna explained,

> I thought since the doctors kept saying my thyroid was okay, maybe I just needed something natural as a boost, not really having a lot of information. I also was clicking on ads on the internet and read some doctor that insisted we are all iodine deficient and promoting his pills. I ordered them and took them [for] 1 month.

Having felt unheard, invalidated, dismissed, and disrespected by her doctor, Shawna came to "distrust [her doctor] at such a high level…that it will be hard to share [with a doctor] in the future."

Including patients in the decision making process helps to ensure that they are not left alone in a position of evaluating the efficacy of various treatments (Chin, 2002). Considering that most patients want to be involved in the decision making process (Barry & Edgman-Levitan, 2012; Chin, 2002; Flynn et al., 2006; Quaschning et al., 2012) and shared decision making requires mutual trust (Chin, 2002; Crooks et al., 2015; Epstein & Street, 2011), it is important for doctors to establish trust with their patients. As previously discussed, patients trust doctors who listen to them without interrupting (Hedberg & Lynoe, 2013; Skirbekk et al., 2011) and who take their time (Copeland et al., 2003; Houle et al., 2007), who answer their questions and show a genuine interest in their well-being (Houle et al., 2007; Jagosh et al., 2011; Liu et al., 2014; Skirbekk et al., 2011), who validate them (Epstein et al., 2007b; Malterud & Ulriksen, 2010; Street et al., 2009), and are sensitive to their emotions (Skirbekk et al., 2011).

Subtheme 3: Role of gender. The majority of participants' responses to questions regarding the potential influence of gender on treatment experiences revealed that the doctors' gender had little influence on doctor-patient communication. However, participant responses indicated that being female influenced doctor-patient communication, particularly regarding the participants' perceptions of being taken seriously and when the participants expressed emotion. Within Subtheme 3: Role of

Gender are the following subthemes: no preference for specific doctor gender, preference for female doctor, being taken seriously, and presence of emotion.

No preference for specific doctor gender. When asked if it mattered whether their doctors were male or female, the majority of participants (13 out of 16) indicated no preference for their doctor to be a specific gender. Sarah stated, “I've been pleased with both genders, it really depends on the individual.” According to Karen, “It’s not the sex of the doctor but the compassion and caring of the doctor that makes one good.” Similarly, Emily explained that she would feel comfortable with either a male or female doctor as long as “they seem sympathetic to [her] concerns and [are] serious about continually working on a plan to get [her] body back to normal.” Emily also related the issue of doctor gender to being taken seriously as a female patient (discussed in section “Being Taken Seriously”). Michelle shared that she has been treated by both male and female doctors and she believes that the “Dr./Patient relationship is most important.” Likewise, Shawna reported that she simply “care[s] about their competence.” Diane added, “If they have a thorough understanding of the female body, then there shouldn't be difference [between male and female doctors].”

Autumn’s and Ann’s responses to the interview question regarding gender preference demonstrated a general dissatisfaction with both male and female doctors. Autumn responded, “I don't think [the doctor’s gender] matters much…most of them are just in and out doing as little as they possibly have to do.” Anne replied, “No…It seems that both men and women doctors are TSH driven.” Anne also related the issue of doctor gender to being taken seriously as a female patient (discussed in section “Being Taken

Seriously”). Both of Anne’s and Autumn’s comments are discussed further in section “Subtheme 4: Culture of the Medical Profession,” specifically as they relate to the issues the TSH blood test and economics.

Although Alicia’s and Jessica’s responses suggested an initial preference for a female doctor, they ultimately expressed no preference for their doctor to be a specific gender. When asked if it mattered whether their doctors were male or female, Alicia responded, “I’m not sure. I wonder if a woman might be more understanding, but I feel that my [male] physician is very understanding.” Jessica replied, “I think a woman doctor can relate better to her female patient having the same functioning system and emotional background caused by hormones; [however], my first endo was a woman…and she was brutal.”

The literature regarding patients’ gender preferences for doctors is divided. Although a number of studies indicate that patients prefer doctors of the same gender (e.g., Bonds, Foley, Dugan, Hall, & Extrom, 2004; Fang et al., 2004; Garcia, Paterniti, Romano, & Kravitz, 2003; Godager, 2012), many studies suggest that patients do *not* have a gender preference for their doctors (Bender, 2007; Delgado et al., 2011; Makam, Saroja, & Edwards, 2010; Tempest, Vowler, & Simpson, 2005). Rather, the competence and communication skills of doctors appear to be more important to patients than the doctors’ gender (Bertakis & Azari, 2012; Bourke, 2002; Mavis, Vasilenko, Schnuth, Marshall, & Jeffs, 2005; Tempest et al., 2005; Yuen-man Siu, 2015). This finding is consistent with the results of the current study, with 13 out of 16 participants referring to the importance of their doctors’ competence and communication skills in lieu of their doctors’ gender.

The ability for doctors to communicate effectively with their patients is crucial to meeting their patients’ needs and expectations (Godager, 2012). Numerous studies have revealed that patients prefer doctors who listen attentively, answer their questions, and include them in decision making—practices that are characteristic of patient-centered approaches (Carlsen & Aakvik, 2006; Copeland et al., 2003; Firth Cozens, 2008b; Hall et al., 2009; Houle et al., 2007; Jagosh et al., 2011). Research indicates that female doctors tend to use patient-centered approaches more often than male doctors, as evidenced by longer consultations and a greater psychosocial focus in their discussions (Beach, 2000; Bertakis, 2009; Bertakis & Azari, 2012; Firth Cozens, 2008b; Hall & Roter, 2002; Hall et al., 2009; Roter & Hall, 2004; Sandhu et al., 2009; Shin et al., 2015).

Considering the aforementioned findings regarding patient-centered approaches, it was expected that the participants in the current study would express a preference for female doctors. The fact that the participants in the current study reported no preference for a specific doctor gender might be due to the fact that only four out of the 16 participants interviewed (Alicia, Autumn, Kari, and Karen) consistently had doctors who did not make them feel unheard, invalidated, dismissed, not empathized with, or disrespected (discussed previously in “Subtheme 2: Participant Self-Advocacy”). In other words, during the time of their interviews, the majority of the participants might have still been seeking doctors who use a patient-centered approach. If this is the case, the gender of the doctors ultimately chosen by participants remains unknown because at the time of the interviews, participants were not asked whether or not they were seeking or considering seeking new doctors. Future studies might consider asking participants how many doctors they have had, the gender of those doctors, their reasons for seeking new doctors, and whether or not participants have decided to keep their current doctor.

Preference for female doctor. When asked if it mattered whether their doctors were male or female, three of the 16 total participants indicated a preference for female doctors. Kari, who has a female doctor, explained, “I like woman Dr.'s better. Men are too arrogant about their education.” As previously discussed, patient-centered approaches in which doctors listen to and involve their patients are frequently used by female doctors (Bertakis & Azari, 2012; Firth Cozens, 2008b; Hall et al., 2009; Sandhu et al., 2009). Because Kari reported feeling heard and being involved in the decision making process, it is likely that Kari’s doctor utilized a patient-centered approach. Regarding Kari’s comment about male doctors being “too arrogant in their education,” because Kari is 78 years old, it is likely that she experienced paternalistic doctor-patient relationships in the past. Carla’s doctor is also female. According to Carla, “Every woman doctor [she’s] had, all of 3, [have] been far more empathetic and able to listen.” Although she considers herself to be “guarded” with her current doctor, Carla expressed a particular distrust in male doctors because “it was a male doctor’s prejudice and ignorance that basically cost [Carla her] life.”

Jenna, whose doctor is male, stated, “I think a woman might be a little more compassionate and understanding.” Although Jenna would prefer to have a female doctor, she is “limited in options [because she goes] through a free clinic” (discussed further in section “Theme 4: Culture of the Medical Profession”), and is therefore, unable to seek a new doctor. Jenna had reported feeling unheard, invalidated, and dismissed, as well as shared that she sought health information, refused treatment, and self-treated. Whether or not these experiences are related to her doctor’s gender cannot be determined. Jenna’s assumption that female doctors might be more “compassionate and understanding” could be due to her negative experience with her male doctor or based on a conventional view of women as nurturers (Bertakis & Azari, 2012; Hall, Roter, Blanch-Hartigan, Schmid Mast, & Pitegoff, 2015; Shields, 2007). According to Bertakis and Azari (2012), traditional gender role expectations among both patients and doctors may be unconsciously reinforced by gender differences in communication.

Being taken seriously. Nine out of the 16 total participants indicated that being taken seriously influenced their ability to communicate with their doctors. Of these nine participants, Alicia and Diane were the only individuals who felt like their doctors took them seriously. Alicia explained, “Knowing that he takes me seriously helps me to feel comfortable sharing my symptoms with my doctor.” Similarly, Diane stated, “It makes me feel confident that he takes me a little more seriously than most of the other doctors who poo-pooed me.” When asked what might help her to feel more comfortable in sharing her symptoms with her doctor, Jenna responded, “If he would LISTEN and take me seriously and not think it’s all in my head.” Likewise, April replied, “If my dr took my research serious and didn’t just humor me.”

Emily and Anne related their experiences with not being taken seriously to gender. More specifically, Emily and Anne indicated believing that both male and female doctors are less likely to take women’s complaints as seriously as men’s complaints. Emily explained, “Sometimes I think men doctors don’t take some female symptoms seriously, but then I’ve had women doctors that also didn’t seem to be sympathetic to a formally [sic] skinny patient who quickly put on 20 pounds.” Anne stated, “…my opinion is that doctors, both men and women, take men more seriously. I do tend to get emotional which I think makes doctors give less credence to my depiction of my symptoms.” The presence of emotion in the clinical encounter is discussed in the section, “Presence of Emotion.”

Werner and Malterud (2003) and Hoffmann and Tarzian (2001) contend that the medical profession encourages a normative, gendered view of illness that disregards patients’ subjective illness experiences. As a result, women often need to work harder in order to be perceived as credible patients. According to Soderberg, Olsson, and Skar (2012), it is a “violation of a person’s dignity” to not be taken seriously (p. 145). In a study of 1.5 million individuals regarding their trust and confidence in their doctors, being taken seriously by one’s doctor was found to be the strongest predictor of patient trust and confidence (Croker et al., 2013).

Gensichen et al.’s (2012) study of women being treated for depression revealed that patients felt well-cared for and trusted their doctors because their symptoms were taken seriously. Likewise, in Stenberg, Fjellman-Wiklund, and Ahlgren’s (2012) study of individuals being treated for neck and back pain, patients expressed that being taken seriously by their doctors was essential for feeling comfortable in communicating with their doctors. Participants who did not feel like they were taken seriously reported feeling rejected and ashamed; and this experience was more common among female participants than male participants. Stenberg and colleagues argued that the pain levels of the female participants in their study may have been underestimated, and that this might be due to a stereotypical view of women as overly emotional and complaining. Female participants in Soderberg et al.'s (2012) study reported believing that they were not taken seriously by their doctors because they were female. The authors likened the participants' experiences of not being taken seriously to being disqualified as people (p. 148). The participants indicated that, as a result of not being taken seriously, they felt like that had no influence in their communication with their doctors.

According to Hedberg and Lynoe (2013), doctors who are considered to be competent by their patients listen to their patients, take them seriously, answer their questions, and invite them to participate in their care. In addition to being perceived as competent, doctors are perceived as trustworthy by their patients when they demonstrate sensitivity to their patients' emotions (Skirbekk et al., 2011). By creating an environment in which patients feel safe in communicating about their illness experiences, doctors are better able to ask relevant questions and recognize potentially misdiagnosed or undiagnosed illnesses (Dean & Street, 2014; Hedberg & Lynoe, 2013).

Presence of emotion. Three out of the 16 total participants indicated that showing emotion influenced communication with their doctors. More specifically, in Alicia's experience, the presence of emotion prompted effective communication with her doctor. However, the presence of emotion appeared to be problematic for Anne's and Leanne's attempts to communicate effectively with their doctors. Anne explained, "I do tend to get emotional which I think makes doctors give less credence to my depiction of my symptoms." According to Hoffman and Tarzian (2001) and Connolly (2001), because women tend to be perceived as overly emotional and likely to exaggerate their symptoms, women's complaints are often dismissed by medical professionals. Research indicates that men's symptoms are more likely to be interpreted as biological by doctors, while women's symptoms are construed to be psychosomatic—that is, that women's symptoms are a result of a mental, rather than physical, illness (Chrisler, 2001; Hamberg et al., 2004; Hoffmann & Tarzian, 2001). The issue of women's symptoms being considered psychosomatic is discussed further in section "Theme 4: Culture of the Medical Profession."

Whereas Anne related her emotional communication to her doctor not perceiving her as credible, Alicia explained that her emotional communication roused her doctor's attention. Alicia explained, "It was not until I broke down in tears with my radiation oncologist that he suggested metabolic testing…[and to] follow this up with my primary care physician." In Johansson, Hamberg, Lindgren, and Westman's (1996) study of female patients experiencing pain, participants reported employing various strategies in an attempt to convince their doctors they were "deserving" of medical attention (p. 500). When doctors were not responsive to the women's descriptions of bodily symptoms, the women then referred to authorities outside of themselves (e.g., "I saw on television…"). If this was unproductive, the women eventually "plead" (i.e., cried) with their doctors, usually with success (p. 500). Similar results were found in Werner and Malterud's (2003) study of women who sought to obtain their doctors' validation of their chronic pain through using assertiveness and “surrendering” (i.e., no longer challenging the doctor; p. 1413). According to Werner, Isaksen, and Malterud (2004), female patients need to utilize such strategies in order to fit in with normative, biomedical expectations of illness and be perceived as credible patients.

Although Anne’s and Alicia’s experiences with demonstrating emotion seem to be on opposite ends of the spectrum (i.e., with Anne’s emotion being problematic for communication with her doctor; and Alicia’s emotion encouraging communication with her doctor), their experiences shared the commonality of needing to convince their doctors that their symptoms were deserving of attention. Research indicates that whether patients’ emotional cues are subtle or obvious, doctors often fail to acknowledge and validate their patients’ concerns using empathic communication (Epstein et al., 2007a; Finset, 2012; Hakanson, Sahlberg-Blom, & Ternestedt, 2010; Kennifer et al., 2009). In some cases, patients’ emotions are dismissed by their doctors (Hakanson et al., 2010; Kennifer et al., 2009), and in other cases, doctors respond to their patients’ emotions with biomedical questioning (Epstein et al., 2007a; Finset, 2012).

In Hakanson et al.’s (2010) study of individuals with irritable bowel syndrome, participants reported feeling dismissed when their doctors told them to “calm down” or “stop being hysterical” (p. 1120). Even if it was not their doctors’ intention, the patients felt patronized by their doctors and as if they were being accused of exaggerating their symptoms. Finset (2012) argued that doctors sometimes offer reassurance prematurely in response to their patients’ distress (e.g., “don’t worry). According to Epstein et al. (2007a), simple reassurance may cause patients to feel dismissed unless the reassurance is accompanied by medical explanations based on a genuine understanding of the patients' concerns. As such, incorporating empathy-related communication techniques into medical training programs may help doctors to be better equipped to handle emotions in the clinical encounter (Finset, 2012) and to respond constructively.

Theme 4: Culture of the Medical Profession

Participant responses to interview questions indicated that their experiences with thyroid disease treatment were influenced by the culture of the medical profession. More specifically, participants' treatment experiences were influenced by diagnostic bias, their doctors' medical knowledge, and economics. The subthemes within Theme 4: Culture of the Medical Profession are Subtheme 1: Diagnostic Bias (symptoms considered psychosomatic and symptoms attributed to lifestyle), Subtheme 2: Medical Knowledge (TSH testing is standard, synthetic medication is standard, and continuing education may be needed), and Subtheme 3: Economics (feeling rushed, access to doctor, and access to medication).

Subtheme 1: Diagnostic bias. Eight of the 16 total participants whose treatment experiences were influenced by the culture of the medical profession encountered diagnostic bias, which resulted in diagnostic error. More specifically, eight participants' doctors did not recognize that the participants' symptoms were due to thyroid disease. Seven of the participants' doctors considered their symptoms to be psychosomatic and three participants were told by their doctors that their symptoms were due to their lifestyle. Within Subtheme 1: Diagnostic Bias are the following subthemes: symptoms considered psychosomatic and symptoms attributed to lifestyle.

Alegría and colleagues (2008) defined diagnostic bias as unconscious, systematic errors in the collection or processing of information that may influence the clinician's judgment of patients' illness (p. S26). Gender bias is one of many types of bias (e.g., ethnic, cultural, etc.) and is regarded as an unintended, systematic neglect of either women or men (Hamberg, 2008, p. 237). In the medical field, gender bias occurs as a result of stereotyped preconceptions about a person's health, behavior, experiences, and needs based on their gender (Hamberg, 2008). Based upon the experiences of the eight participants who received inaccurate diagnoses, it appears that their doctors' errors might be explained by gender bias.

Research indicates that the paternalistic nature of the medical profession encourages gender bias. As a result, women's medical problems are often misdiagnosed and undertreated (Connolly, 2001; Chrisler, 2001; Hamberg et al., 2004; Hoffmann & Tarzian, 2001; Richman et al., 2000; Soderberg et al., 2012; Stenberg et al., 2012; Werner & Malterud, 2003; Werner et al., 2004). Secker (1999) asserted that depictions of women as emotional, irrational, and unintelligent are systemically ingrained in the medical profession because philosophical, theological, literary, and scientific traditions have been male-dominated. As such, women's health complaints that are not substantiated by objective evidence (e.g., blood tests) tend to be viewed as psychosomatic, rather than physiological, in origin (Hamberg et al., 2004; Hoffmann & Tarzian, 2001; Richman et al., 2000; Werner et al., 2004).

Symptoms considered psychosomatic. Seven of the 15 participants who experienced diagnostic bias had doctors who considered their symptoms to be psychosomatic. Kim explained, “I had been taken to a doctor because of complaining about a lump in my throat and a choking sensation. That doctor found nothing wrong. I think he felt it was my imagination.” Similarly, Diane reported,

> [I had an] inability to swallow pills that started about 10 years ago (doctors thought it was in my head)…[and when] I could no longer drive and could barely walk, I saw several doctors and were [sic] prescribed anti dizziness medication, depression pills, etc.

Jenna indicated that she would feel more comfortable sharing her symptoms with her doctor “...if he would LISTEN and take [her] seriously and not think it’s all in [her] head.” Likewise, Anne explained, “I do tend to get emotional which I think makes doctors give less credence to my depiction of my symptoms.” Jessica shared, “I am tiered [sic] of doctors thinking that we are just anxious…and will not believe us. They want to put us on antidepressants instead of helping us. This causes more anxiety and is very sad.”

Numerous studies indicate that doctors tend to interpret men’s symptoms as physiological and women’s symptoms as psychosomatic (Bernardes & Lima, 2011; Chrisler, 2001; Elderkin-Thompson & Waitzkin, 1999; Hamberg et al., 2004; Hoffmann & Tarzian, 2001; Lillrank, 2003; Munch, 2004; Newton, Southall, Raphael, Ashford, & LeMarchand, 2010; Mullersdorf & Soderback, 2000; Stenberg et al., 2012; Werner & Malterud, 2004). According to Werner et al. (2004), female patients with chronic pain are often judged by their doctors to be experiencing imaginary illnesses and are given psychiatric diagnoses—and even stereotyped as “crazy, lazy, illness-fixed, or weak” (p.

1043). In Mullersdorf and Soderback's (2000) study of individuals with back pain, men received physiological interventions (e.g., joint manipulation) more often than women, who were mostly treated with psychotropic medication. Werner and Malterud's (2003) study of women with chronic pain revealed that patients felt the need to "work hard" in order to make their symptoms real and visible to their doctors. More specifically, in order to be perceived as credible, patients were cautious to not appear to be too healthy or too sick, too strong or too weak, too assertive or too passive in their interactions with their doctors. In other words, they struggled "to be perceived as somatically ill, whilst simultaneously avoiding appearing mentally unbalanced" (p. 1414).

Research also indicates that women are less likely than men to receive diagnostic testing even when presenting with the same symptoms (Hamberg, 2008; Napoli, Choo, & McGregor, 2014). Newton, Southall, Raphael, Ashford, & LeMarchand, 2010; Mullersdorf & Soderback, 2000; Stenberg et al., 2012; Stålnacke and colleagues' (2014) study of individuals with chronic pain revealed that male patients were significantly more likely than female patients to be referred for physiotherapy and radiological examination even though the female patients reported a greater number of pain sites than male patients. Similarly, a study of patients with acute coronary syndrome revealed that fewer female patients received cardiac catheterizations than male patients, even after adjusting for the patients' presenting complaint, history, diagnosis, and cardiac risk (Chang et al., 2007).

Furthermore, there is a discrepancy in how doctors respond to male and female patients with diffuse symptoms (e.g., as with chronic fatigue syndrome; Werner &

Malterud, 2003). For example, research indicates that when the physiological cause of a patient’s symptoms is unknown, doctors tend to prescribe sedatives and offer advice regarding lifestyle more often to female patients than to male patients (Hamberg et al., 2004; Munch, 2004; Vaccaro & Huffman, 2012).

Symptoms attributed to lifestyle. Three of the 15 participants who experienced diagnostic bias had doctors who attributed their symptoms to their lifestyle. In each case, doctors’ lifestyle advice was related to weight loss. Before being diagnosed with thyroid disease, Jenna’s doctor insisted that her weight gain was due to her diet and not enough exercise. She commented, “how I wish I had only known that it was something wrong with me physically instead of ‘I'm fat’, ‘I'm out of shape’…” Carla reported that her doctors made her feel like her “weight gain [was] from being a lazy slob [because she] laid around eating bon bons all day long.” She further explained, “Didn't matter that I was a body builder before all this, didn't matter that I used to have physical jobs before all this... I was just a lazy, fat, stupid... slob.”

According to Stone (2014), both patients and doctors experience frustration when patients’ symptoms are not explained by objective evidence (e.g., blood tests). While patients feel invalidated and at fault due to lack of “proof” of their illness, doctors experience feelings of helplessness and guilt because they are expected to cure their patients. In Western medicine, symptoms that are not validated by objective evidence are considered to be of the mind, and therefore, related to choice and responsibility (Stone, 2014). Annandale and Clark (2000) contend that health is “marketed as a result of lifestyle choice” (p. 58). In other words, patients are thought to be responsible for their conditions (e.g., people who are obese must lack self-control). As explained by Solomon, Nahas, Segal, and Young (2010), “In medicine we are most comfortable with blaming the pathology (and, when that fails, with blaming the patient)” (p. 516).

Research indicates that doctors offer lifestyle advice more often to women than men (Hamberg et al., 2004; Munch, 2004; Vaccaro & Huffman, 2012). With regard to weight loss as medical advice, a study by Dutton, Perri, Stine, Goble, and Van Vessem (2010) revealed that doctors recommended significantly stricter weight loss goals for obese female patients than obese male patients. Malterud and Ulrikesen (2010) suggested that in cases in which obesity is a concern, doctors should consider endocrine disorders as a potential cause of patients’ weight gain.

Regardless of whether or not laboratory tests support the cause of obesity to be physiological, doctors should use sensitivity when offering lifestyle advice. Because body image is a fundamental aspect of a person’s identity and Western culture views obesity as a symptom of lack of self-control (Malterud & Ulriksen, 2010), it is important that doctors share information in a manner that does cause the patient to feel blamed. In addition, offering emotional support to patients engenders trust, which is vital for establishing and maintaining an effective doctor-patient relationship (Houle et al., 2007; Skirbekk et al., 2011; Stone, 2014).

With regard to diagnostic bias and medical advice, it is important to consider the doctors’ specialties. As noted by Ogdie et al. (2012), doctors are more prone to errors in diagnosis when presented with problems outside of their specialty. The current study did not investigate the specialties of participants’ doctors. It is recommended that the influence of doctors' specialties on choice of diagnostic tests, diagnosis, and medical advice be investigated in future research.

Subtheme 2: Medical knowledge. The treatment experiences of 15 out of the 16 participants who were influenced by the culture of the medical profession appeared to be specifically affected by their doctors' medical knowledge. More specifically, nine participants' treatment experiences were affected by the use of the TSH blood test alone as the standard to determine thyroid function, and 10 participants' treatment experiences were affected by the use of synthetic medication as the only treatment option for thyroid disease. In addition, according to 15 participants, continuing education for doctors about thyroid disease is needed. Within Subtheme 2: Medical Knowledge are the following subthemes: TSH testing is standard, synthetic medication is standard, and continuing education may be needed.

TSH testing is standard. Nine out of the 15 total participants whose treatment experiences were influenced by their doctors' medical knowledge appeared to be specifically affected by the use of the TSH blood test alone as the standard for determining thyroid function. Three of these participants (Diane, Michelle, and Sarah) specifically experienced difficulty with obtaining a diagnosis of thyroid dysfunction due to a "normal" TSH blood test. Diane explained,

> I have searched for over 30 years as to what was the cause of my rapid weight gain, and constant fatigue. Each time, my thyroid would be tested and I was told everything was fine. Meanwhile, I struggled daily for energy, and experienced numerous illnesses over the years that puzzled me.

Sarah reported, "[My doctor] totally ignored my symptoms, any thyroid numbers but TSH, and this resulted in [many] diagnoses…and [I was] heavily medicated for each of them, on as many as twelve different prescriptions in any given day." Michelle shared,

> I was 'finally' diagnosed after many years of begging [doctors] to be diagnosed (numbers were 'normal'), [then] it took me another 2 years before I found an Internal Medicine Dr. who would…test not only TSH, but also FT3 & FT4.

The majority of participants who were affected by the use of the TSH blood test alone specifically reported being undertreated for thyroid dysfunction do to a "normal" TSH blood test. Anne commented,

> It seems that both men and women doctors are TSH driven…Even the doctors I have seen that are okay with [natural medication] still put much more weight on TSH than symptoms or the frees. It is enough to make one feel hopeless at times.

Similarly, Kim, who is 82 years old and has been treated for thyroid disease for 66 years, reported,

> When I was tested at the end of that year, my TSH (the only thyroid test that doctor used) was .01, and he wanted me to discontinue Synthroid because I had 'gone hyper'. I reminded him I'd been taking thyroid replacement since I was 16 or 17 and I was quite certain I needed it. So he compromised and let me drop the Synthroid to 50 mcg.

Three of the participants (Carla, Jenna, and Shawna) who believed they were undertreated for thyroid dysfunction based on the results of the TSH blood test alone (instead of also including the free T3, free T4, and antibodies blood tests) specifically discussed the addition of the following blood tests to the TSH blood test: free T3, free T4, and antibodies. Carla stated, "[My doctor] is certain that the only test needed for thyroid is TSH and it's an inside joke that I will allow her to run TSH as long as she also runs Free T4 and Free T3 for me." Similarly, Jenna explained, "[My doctor's] MAIN concern is my TSH getting below .5, [though] he DOES test free t3 and free t4 because I asked him to." Shawna shared, "I don't like that he is not open to natural thyroid and isn't testing my T3 and antibodies."

The TSH blood test is considered the "gold standard" for determining thyroid function (Adams, 2008, p. 1). However, its efficacy is debatable due to inconsistent data from various studies (Adams, 2008; Beckett & MacKenzie, 2007; Wheatland, 2010). Experts on thyroid function differ in opinion regarding the accuracy of the current range limits for the TSH blood test, as well as whether or not age-specific ranges should be created (Adams, 2008). Referring to the TSH blood test as a "waste of resources," Wheatland (2010) argued that it should not be used for determining thyroid function due to its poor diagnostic accuracy (p. 458). Furthermore, despite evidence that including the free T3 and free T4 blood tests with the TSH blood test produces the most accurate thyroid function analysis, the TSH blood test is most often used exclusively (Beckett & MacKenzie, 2007; Dayan, 2001). When the TSH blood test is used alone, clinically important diagnoses may be missed (Dayan, 2001), and thyroid patients may be undertreated (Baisier, Hertoghe, & Eeckhaut, 2000).

In addition to ordering the TSH, free T3, and free T4 blood tests, doctors should investigate the potential presence of thyroid autoantibodies (i.e., TgAb, TPOAb, and

TRAb) in order to determine if thyroid dysfunction is autoimmune in nature (i.e., caused by Hashimoto's disease or Grave's disease; Bunevicius & Prange, 2006; Dayan, 2001). Furthermore, in cases in which a patient is already receiving treatment and is determined to be euthyroid (i.e., "normal" levels of thyroid hormone are detected in the blood), levels of antibodies can fluctuate and cause psychiatric symptoms (e.g., depression and anxiety; Bunevicius & Prange, 2006). Thus, in conjunction with the patient's reported symptoms, a review of all thyroid function tests provides the most thorough analysis for properly diagnosing and treating thyroid dysfunction (Adams, 2008; Aslan et al., 2005; Bunevicius & Prange, 2006; Canaris et al., 2000; Dayan, 2001; Fassier et al., 2011; Godfrey, 2007; Rivera et al., 2015; Shimabukuro, 2008; Simmons, 2010).

In some cases, despite thyroid tests being "normal," patients continue to report symptoms of hypothyroidism. As such, doctors may decide to treat their patients with thyroid hormone medication or increase their patients' dose of medication. Wheatland (2010) argued that a trial of thyroid hormone medication is the "best method for achieving diagnostic certainty" and ultimately alleviating thyroid patients' symptoms (p. 458). According to Adams (2008), thyroid experts contend that deciding to treat patients based on symptoms should be left to the discretion of the doctor (p. 15).

Synthetic medication is standard. Ten out of the 15 total participants whose treatment experiences were influenced by their doctors' medical knowledge appeared to be specifically affected by the use of synthetic medication as the only treatment option for thyroid disease. More specifically, 10 participants reported having difficulty in convincing their doctors that synthetic thyroid medication caused them to not feel well. In addition, the participants' doctors would not consider prescribing them natural thyroid medication instead of synthetic thyroid medication. Jessica explained, "[My doctors] got frustrated and abusive with me because I was not tolerating the [synthetic] thyroid meds well…[synthetic thyroid] meds gave me severe reactions, altered my mental state, and made me feel worse." Likewise, Carla reported, "I was started on Synthroid…it made me sick…they tried levothyroxine, it made me sick…then tried levothroid, it made me sick…Nauseous, headache..." Michelle shared, "When I kept saying the Synthroid was making me feel bad, I was told "that's all we can prescribe"!!"

According to Anne,

> [When] the Armour shortage hit [my] doctor knew of nothing else to do but go back to Synthroid and did not understand when I was upset at that suggestion…The thought of having to settle for Synthroid again honestly scared me.

Karen shared that she struggled for energy for 38 years and that it took doctors that long to realize that her body was "not converting the synthetic thyroid down as it should be." Emily commented, "I appreciate that my endo is open to trying natural hormone if necessary as my PCP seems to think Synthroid is the only option."

Kim explained,

> [I had] no problems until I changed to Synthroid. When I found it didn't work as well and I wanted to change back to Armour I could not find a doctor who would permit the change. They all said Armour was outmoded and Synthroid was better.

Kim's experience with natural and synthetic thyroid medication warrants extra discussion because she is 82 years old and has been treated for thyroid disease for 66 years. Kim shared that when she was 16 years old, her doctor diagnosed her as hypothyroid based on her symptoms alone and prescribed her Armour thyroid, the standard treatment at the time. According to Kim, "The only test available back then was the basal metabolism…but there was no way I could get to the testing facility without an hour's bus and streetcar rides…So he began treatment without my having been tested." When Synthroid was created in 1958 without undergoing any clinical trials (Tybout & Hennessy, 2013), Kim's doctor began prescribing her Synthroid, the new standard, instead of Armour thyroid. As mentioned previously, Kim "had no problems until [she] changed to Synthroid."

Because today's public has greater access to medical information via the Internet (Hearn, 2009; Tustin, 2010), doctors who oppose the use of natural thyroid medication might argue that patients who don't feel well on Synthroid are experiencing the "nocebo effect." In other words, reading about the potential negative symptoms one might experience from a medication can actually cause a person to experience those symptoms (Wells, 2012). In addition, there is a vast amount of information online about the positive experiences of thyroid patients taking natural thyroid medication—written by the patients themselves (e.g., http://www.stopthethyroidmadness.com; http://thyroid.about.com/bio/Mary-Shomon-350.htm; http://dearthyroid.org; http://www.butterflynationproject.org). Although the nocebo effect is one potential cause for the participants in the current study to not feel well on Synthroid, it is extremely unlikely for Kim because she experienced negative effects from Synthroid when she switched from Armour thyroid in 1958—before the advent of the Internet.

According to Gaby (2004), a medical doctor who prescribes Armour thyroid and Bongiorno (2015), a naturopathic doctor who prescribes Armour thyroid, a significant number of thyroid patients who continue to experience symptoms of hypothyroidism while on Synthroid experience relief of those symptoms on Armour thyroid. Gaby (2004) purported that the negative reaction of the conventional medical community to the use of natural thyroid medication "represents, at least in part, a biased attitude" (p. 168). He continued, "Whatever the reason, it appears that conventional medicine has not made a serious attempt to evaluate the evidence regarding the empirical use of [natural] thyroid hormone" (p. 168). In a study by Goff et al. (2012), patients who did not trust their doctors' recommendations for medication reported concern that their doctors' recommendations were influenced by pharmaceutical companies rather than centered on the patients' needs.

In the Western medical education system, doctors are taught to make diagnostic and treatment decisions in accord with "objective evidence" of disease in lieu of patients' subjective illness experiences (Hoffmann & Tarzian, 2001; Werner & Malterud, 2003). Because the majority of medical textbooks and review articles recommend synthetic medication as the only appropriate treatment for hypothyroidism (Gaby, 2004), it is understandable that doctors are hesitant to prescribe anything else. However, considering the many narratives of patients who report feeling well on natural thyroid medication (e.g., http://www.stopthethyroidmadness.com; http://thyroid.about.com/bio/Mary-

Shomon-350.htm; http://dearthyroid.org; http://www.butterflynationproject.org), it seems that research on natural thyroid medication is warranted (Gaby, 2004). On a personal note, one of my previous doctors was an Endocrinologist who was also a teaching doctor. I liked him; he was pleasant, easy to talk to, and empathic. However, he refused to prescribe natural thyroid medication (I did not feel well on synthetic thyroid medication). At one point, I asked him, "I know you prefer to prescribe synthetic thyroid medication; however, would you consider prescribing me natural thyroid medication?" He responded, "It's not a matter of preference…it's what we're taught."

Because medical professionals have a tendency to undervalue patients' knowledge (Risberg et al., 2006) and doctors have been traditionally thought of as "all knowing," patients who seem to challenge their doctors' expertise become thought of as "difficult" (MacDonald, 2003). Female patients, particularly those with a higher educational attainment, tend to conduct research about their illnesses (Ye, 2014) and desire the most active involvement in the decision making process with their doctors (Flynn et al., 2006). Of the 16 participants in the current study, 15 participants attained an education beyond high school, 12 conducted research about thyroid disease, and 12 desired to actively participate in the decision making process. However, when female patients are perceived to be "complaining too much," they risk having their complaints interpreted as exaggerated or imaginary (Frantsve & Kerns, 2007; Richardson, 2005; Werner et al., 2003).

According to Carla, her doctor's "prejudice and ignorance…cost [Carla her] life." She continued, "I have two half siblings with the same genetic defect I have. Both got proper care in a timely manner. Both are doing fine. Healthy weight, good jobs, real lives." Carla's experience highlights the importance of doctors' mindfulness regarding the potential for diagnostic bias. Left undiagnosed or undertreated, thyroid disease can result in progressive psychological and physiological problems (Bunevicius & Prange, 2006; Gaitonde et al., 2012; Heinrich & Grahm, 2003; McDermott & Ridgway, 2001; Roberts & Ladenson, 2004). Thus, it is imperative that doctors who treat thyroid disease consider thyroid patients' knowledge and subjective illness experiences in conjunction with what they learned in medical school.

Continuing education is needed. According to all 15 of the participants whose treatment experiences were influenced by their doctor's medical knowledge, continuing education for doctors about thyroid disease is needed. In some cases, participants believed they knew more about thyroid disease than their doctors. Kari explained, "[It has been] difficult to find a Dr. who knows anything about Thyroid problems…I am explaining more to her then [sic] she to me [about thyroid disease]." Kim stated, "Sometimes I have to teach [doctors] what some of the recognized symptoms [of thyroid disease] are!" Likewise, Diane commented, "It is scary how little doctors actually know about [thyroid] disease, let alone Hashimoto's [disease]…it seems that I am more knowledgeable about some areas of Hashimoto's than he is." Sarah shared,

> I would love to see in the future that Doctors would pay more attention to the FT3's and FT4's than the stupid TSH levels. I have a Doctor I see for bioidentical hormones and she is the very first one who has said we'll skip the TSH. I see hope with her and may at some point trust her to treat my thyroid.

Other participants expressed frustration that their doctors would not believe their symptoms were a result of following conventional treatment guidelines (e.g., TSH blood test, synthetic medication). For example, Carla commented that she wished her doctor would “listen to someone that is ‘living it’ and throw away the Synthroid book,” continuing, “Maybe it will click in [my doctor’s] brain that the stuff that was shoved down her throat does not apply to all folks with thyroid disorders.” Similarly, Anne reported, “[My treatment] is being managed by someone who does not understand that there is not ‘one size fits all’.”

Karen and Michelle had positive experiences with their doctors’ knowledge of thyroid disease. Karen explained, “It helped that my regular doc took extra courses to learn more about thyroid dieses after I explained to her the problems I had with each rejected endo she sent me to. I was not her only patient with thyroid problems so she was eager to learn more.” Similarly, Michelle shared,

> When I was finally diagnosed in 2005 after many years of begging [doctors] to be diagnosed (numbers were “normal”), I found a female PCP to diagnose me. She was a teaching Dr. and taught me how to read the numbers on all the appropriate tests---not just TSH, but also FT3 & FT4.

As mentioned previously, the majority of patients refer to their doctors as their primary source for health information—including patients who seek information about diagnostic and treatment options from external sources (e.g., the Internet, books; Bernhardt, 2001; Cegala et al., 2008; Cotten & Gupta, 2004; Fox, 2011; Hassling et al., 2003). In fact, Fox’s (2011) study of patients with chronic illness who sought information and peers online revealed that participants did *not* use the Internet to self-diagnose and self-medicate. Rather, participants indicated that they considered the information they gathered as a supplement they wished to share with their doctors. Thus, it is vital that doctors remain current with the literature regarding the illnesses they treat. In addition, responding to information-seeking patients in a manner such as Karen's and Michelle's doctors (i.e., taking extra courses, including the patient) would help to validate patients' concerns and establish trust while demonstrating patient-centered behavior.

With the rise of patient-centered care in the last 10 years, various medical societies have acknowledged that the traditional biomedical focus in medical training perpetuates traditional styles of doctor-patient relationships in which the belief that the "doctor knows best" endures (Campbell et al., 2005; Celik et al., 2009) and patients' preferences, concerns, and emotions are largely disregarded (Haidet et al., 2002; Hoffmann & Tarzian, 2001; McGuire et al., 2005). In addition, scholars and members of the medical community have recognized that medical knowledge is historically based on research in which women were significantly underrepresented (Miller & Bahn, 2013; Findlay, 1993; Sherwin, 1999) and that gender bias persists in modern medical textbooks (Dijkstra et al., 2008; Hamberg & Larsson, 2009; Hochleitnera, Nachtschattb, & Sillervan, 2013; Leerdam, Rietveld, Teunissen, & Lagro-Janssen, 2014). As such, policies that require the inclusion of women in medical research have been created and women's health programs have been implemented (Miller & Bahn, 2013; Pinn, 2013). Furthermore, in response to patient demands for doctors who are able to match their relational approaches to the communication needs of their patients, medical societies have developed training programs to teach patient-centered communication skills to medical students and practicing doctors (Houle et al., 2007; Levinson et al., 2010; Ross & Haidet, 2011).

According to Pinn (2013), although sex and gender differences in healthcare are almost universally recognized by the medical community, further research and education regarding women's specific healthcare needs is crucial. In the current study, Anne commented, "I am not a doctor so there is a lot I do not understand. But it seems to me that the vast majority of endocrinologists have on blinders." The significance of Anne's comment is two-fold: (a) she demonstrated respect for her doctors' knowledge by acknowledging her own shortcomings, and (b) she alluded to her desire for doctors to take her seriously. With regard to knowledge of how to diagnose and treat thyroid disease, as stated previously, it is important to consider the doctors' specialties. However, if doctors choose to treat their patients for medical conditions in which they do not specialize, it is essential that they continually seek the latest information regarding those conditions. Considering the debatable efficacy of the TSH blood test (Adams, 2008; Beckett & MacKenzie, 2007; Wheatland, 2010) and the vast number of patients reporting not feeling well on synthetic thyroid medication (see http://www.stopthethyroidmadness.com; http://thyroid.about.com/bio/Mary-Shomon-350.htm; http://dearthyroid.org; http://www.butterflynationproject.org), it seems that additional research and education is needed on how to meet the unique needs of female thyroid patients.

Subtheme 3: Economics. The treatment experiences of 11 out of the 16 total participants who were affected by the culture of the medical profession appeared to be specifically influenced by economics. More specifically, three participants reported feeling rushed by their doctors, eight participants had difficulty with accessing a doctor, and six participants had difficulty with accessing thyroid medication. Within Subtheme 3: Economics are the following subthemes: feeling rushed, access to doctor, and access to medication.

Feeling rushed. Three out of the 11 participants whose treatment experiences were influenced by economics reported feeling rushed by their doctors. Autumn explained that in her experience, "Most [doctors] are just in and out doing as little as they possibly have to do," and continued, "It would help if they weren't so rushed." Jessica expressed a desire for her doctors to "take more time to figure stuff out and explain things."

Research indicates that having sufficient time to discuss health concerns with one's doctor is a crucial factor in patients' perceived quality of communication and overall satisfaction (Heinrich & Karner, 2010; Salt et al., 2012; Sutherns, 2004; Swancutt et al., 2011). However, the organization of the healthcare system produces economic concerns that can act as obstacles to collaborative doctor-patient relationships. Due to financial and administrative concerns, doctors who are capable of communicating with their patients in a collaborative manner may be impeded by time constraints and limited resources for developing patient-centered practices (Balsa & McGuire, 2001; Dunn, 2003; Greenfield et al., 2014). As a result, the quality of the healthcare suffers and traditional, hierarchical doctor-patient relationships persist (Levinson, 2011; Peters et al., 2008; Swancutt et al., 2011).

According to Hearn (2006), doctors struggle to accommodate informed and active patients due to economic efficiency demands. Even doctors who support patient participation often behave in a paternalistic manner due to a heavy work load, staff shortages, and practical concerns such as reducing healthcare costs and avoiding malpractice lawsuits (Hearn, 2009; Sherwin, 2000). However, Greenfield et al. (2014) argued that, when viewed from both a micro- (patient) and macro- (public health) perspective, longer, patient-centered visits might actually be cost-effective. More specifically, from the micro-perspective, the healthcare system may ultimately reduce costs by allowing doctors to properly address their patients' concerns and to collaboratively choose the most appropriate course of treatment; from the macro-perspective, because chronic illnesses are the primary cause of mortality worldwide and patient-centered approaches are fundamental to high-quality care, utilizing a patient-centered approaches may reduce the need for patients with chronic illness to see multiple providers.

Research indicates that patient satisfaction and trust in one's doctor are stronger predictors of patients' commitment to the doctor-patient relationship than are the monetary costs of switching doctors (Platanova et al., 2008). In other words, patients who are not satisfied with or do not trust their doctors will seek new doctors even if switching results in a greater expense. Nevertheless, not all patients have equal access to the types of doctors they prefer.

Access to doctor. Eight out of the 11 participants whose treatment experiences were influenced by economics had difficulty with accessing a doctor. Kari had hoped to see an endocrinologist for her treatment. An endocrinologist is a doctor that specializes in disorders of the endocrine system, which includes the thyroid (AACE, 2015). However, there were no endocrinologists in Kari's area. She explained, "[My relationship with my doctor is] not ideal, but the best I can have here…There is not Endo around for at least 150 miles and I can't make these long trips." In 2007, the national supply of endocrinologists was at least 15% lower than demand (Anderson, 2007). According to Vigersky et al. (2014), the number of endocrinologists in the United States is insufficient for satisfying current and future demand.

Shawna expressed frustration because her naturopath "cancelled [her] August recheck because [her naturopath] was too busy as a school nurse." Shawna stated, "[She] to wait until Nov since I was doing fine, [so] on my own, I did more reading and added [another supplement]." As discussed previously, Shawna felt dismissed and switched doctors.

Some participants expressed difficulty with accessing a doctor due to financial constraints. In Diane's search for a doctor, the initial cost for seeing the doctor who listened to her and took her seriously was $400. While Diane was able to afford this fee, an out-of-pocket payment of $400 is too expensive for many patients. For example, Jenna shared, "I think [my doctor] could be a little more up to date but again, going through a free clinic I am limited." Similarly, Carla stated, "I got bad sick…and no insurance…couldn't go see a doc…[then, finally] for the first time in 15 years I had access to a doc again [when I] became eligible for a few things, including medical care…” Jenna’s and Carla’s experiences highlight the disparities in healthcare due to socioeconomic status (Comber, Brunsdon, & Radburn, 2011; Piper, Glover, Elder, Baek, & Wilkinson, 2010; Shi, Lebrun, & Tsai, 2010). According to Comber et al. (2011), access to healthcare involves not only having health insurance, but also locating a doctor and obtaining transportation to the facility. In addition to affecting patients’ access to doctor, financial constraints can also prevent patients from accessing their medication.

Access to medication. Six out of the 11 participants whose treatment experiences were influenced by economics had difficulty with accessing thyroid medication. Carla explained that struggled with accessing natural thyroid medication, stating, “[My doctor] allowed me to stay on the replacements that I've been taking when we found that my state assistance insurance only covers synthetic T4 and I have a very poor body response to that.” More specifically, because Carla’s insurance would not cover the type of thyroid medication she needed, Carla ordered non-prescription thyroid supplements online. April reported switching from synthetic thyroid medication to natural thyroid medication in order to save money. She explained, “I used Synthroid 150 and Cytomel for almost 3 years but it was costing $60+ a month. I recently switched to Armour and it is less than $8 a month.”

Other participants struggled with accessing natural thyroid medication due to recalls by the Food and Drug Administration (FDA). Karen explained,

> I was happy but now that the FDA no longer approves Armour as a medication I will have to start all over again trying to find a natural product my system can work with. I have a very sensitive system so it is hard to find a good treatment.

Likewise, Anne shared, “I was happy until the Armour shortage hit. When that happened, this doctor knew of nothing else to do but go back to Synthroid and did not understand when I was upset at that suggestion.”

Since its invention in 1958, synthetic thyroid medication (name brand Synthroid) has been the standard treatment for hypothyroidism (Tybout & Hennessy, 2013). However, as previously mentioned, numerous thyroid patients don’t feel well on synthetic thyroid medication and report feeling better taking natural thyroid medication (Armour thyroid is the most popular brand). Although some doctors prescribe natural thyroid medication, the general consensus of the conventional medical field is that Armour thyroid is outdated and Synthroid is better (Dommisse, 2009; Gaby, 2004). Furthermore, Armour thyroid is periodically removed from the market by the FDA due to issues related to “quality” (Dommisse, 2009), leaving patients who take Armour thyroid without thyroid medication.

According to Gaby (2004), the negative reaction of the conventional medical community to natural thyroid medication “represents, at least in part, a biased attitude” (p. 168). Dommisse (2009) contends that the medical community’s preference for synthetic thyroid medication is based upon biased research in which pharmaceutical companies are involved. Research indicates that diagnostic and treatment decisions are influenced by competing perspectives among pharmaceutical, medical, and insurance companies (Hearn, 2009) and that patients fear their doctors' recommendations for medication are influenced by pharmaceutical companies (Goff et al., 2012). Thus, considering that numerous patients report feeling well on natural thyroid medication, it seems that research on natural thyroid medication is warranted.

Additional Findings

As previously mentioned, I recognized some additional findings that were meaningful to some participants. Although these findings do not represent the treatment experiences of the participants as a whole, these data are nevertheless poignant examples of the phenomenon from individuals who have lived the phenomenon. Additional findings include a belief that the public is misinformed about thyroid disease (Diane), the experience of grief (Carla), the experience of empathy from one's doctor (Michelle), and the experience of respect from one's doctor (Michelle).

Public is misinformed. Diane reported a belief that the public is misinformed about thyroid disease. She commented, "[I] think the public is grossly misinformed. Their impression is that you just take a little pill and all is well. This is far from the truth, as it can be very complicated." Diane's comments mirror the experiences of patients with chronic pain and medically unexplained symptoms. More specifically, individuals with chronic pain and medically unexplained symptoms often report feeling discredited by not only their doctors, but their family and friends as well (Nettleton, 2006; Slade, Molloy, & Keating, 2009; Stenberg et al., 2012). Diane shared that she searched for over 30 years for the cause of her rapid weight gain and chronic fatigue. At one point, her symptoms were so severe that she was "bedridden and in danger of losing [her] job." Lacking a diagnosis for many years, Diane would have had no recourse if she lost her employment. Diane struggled and worked hard for her thyroid-related symptoms to be perceived as legitimate and worthy of attention.

Experience of grief. In sharing her thyroid disease treatment experience, one of Carla's comments was indicative of grief. Carla stated,

> I got to watch my iodine uptake...I had such a perfect gland...It was just twice normal size. I have two half siblings with the same genetic defect I have. Both got proper care in a timely manner. Both are doing fine. Healthy weight, good jobs, real lives.

Research indicates that individuals with chronic illness (e.g., thyroid disease, diabetes, arthritis) experience grief over time as a result of loss of health or functioning (Dysvik, Natvig, & Furnes, 2013; Schulman-Green, Jaser, & Martin, 2012). According to Dysvik et al. (2013), grief also occurs in response to needing to leave jobs and social networks, resulting in feelings of loneliness and despair. In sharing her experience, Carla reported that she used to be a body builder and had a successful career. However, Carla is now mobility impaired as a result of not receiving treatment in time for her "thyroid storm" 20 years ago. She also lost her career and health insurance. Before receiving radioactive iodine treatment for her thyroid storm, the doctor gave her an informed consent form and told her, "Sign it or die." I signed it," Carla said.

Experience of empathy. Michelle indicated that she experienced empathy from her doctor. She stated, "[My doctor] is very caring and listens to my needs…he has made clear that he is a good listener and has my best interest at heart." Michelle further expressed appreciation that her doctor listens to her, takes her seriously, and works with her collaboratively.

Research indicates that empathy is a vital component to an effective doctor-patient relationship and positive health outcomes (Houle et al., 2007; Neumann et al., 2009; Pollak et al., 2011; Rakel et al., 2011). According to Gelhaus (2012a), empathy involves "…taking seriously the patient as a complete, distinct, unique human being…" (p. 112). Although only four of the 16 total participants interviewed in this study specifically expressed experiencing a *lack* of empathy from their doctors, Michelle is the *only* participant to specifically indicate that she experienced empathy from her doctor. Furthermore, considering that nine of the 16 total participants believed their doctors did not take them seriously, it could be argued that at least nine participants had doctors who struggled with demonstrating empathy. Because empathy has the potential to reduce patients' anxiety (Finset, 2012; Fogarty et al., 1999) and even enhance patients' immune system response (Rakel et al., 2009; Rakel et al., 2011), additional training in empathic communication may be warranted (Gelhaus, 2012a, 2012b; Pollak et al., 2011).

Experience of respect. Michelle indicated that she experienced respect from her doctor—the same doctor who provided her with empathy. When asked whether or not the gender of her doctor is important, Michelle responded, "I think he is so respectful of his patients that it does not matter if [it is a] male or female patient."

Only three of the 16 total participants interviewed in this study specifically expressed experiencing *dis*respect. However, Michelle is the *only* participant to specifically indicate feeling respected by her doctor. Feeling respected by one's doctor is associated with feeling heard and taken seriously (King et al., 2015; Wessel et al., 2012), as well as being met with empathy, concern, and patience (Salt et al., 2012)—all of which are components of patient-centered approaches. As previously discussed, patient-centered approaches engender trust in one's doctor (Copeland et al., 2003; Firth Cozens, 2008b; Hall et al., 2009; Houle et al., 2007; Jagosh et al., 2011). Trust, in turn, tends to result in patients' willingness to share with their doctors and to consider their advice (Copeland et al., 2003; Peters et al., 2008). Thus, demonstrating respect to one's patients is a vital component to establishing and maintaining effective doctor-patient relationships.

Limitations of the Study

Although the contributions of the participants add to the literature on the experience of thyroid disease and the doctor-patient relationship, findings should be considered with caution due to limitations of the study. Because this study was conducted via the Internet and I did not meet with the participants face-to-face, the participants' age and gender could not be verified. Likewise, the participants' thyroid disease diagnoses were self-reported. The sample was self-selected from members of The Thyroid Support Group, which means that the sample may vary systematically and therefore may not be representative of most female thyroid patients. Because participants chose to participate in the study, they might have been enthusiastic about sharing their negative healthcare experiences, while patients who were satisfied with their treatment experiences had no interest in participating. In addition, the sample was mostly Caucasian, which reflects the findings of studies that indicate most Internet users tend to be Caucasian and have convenient access to a computer (e.g., Fox & Jones, 2009; Kraut et al., 2004). As such, the results of this study may not be generalizable to non-Caucasian individuals who do not have convenient computer access. The mean age of the participants was 55 years; and the majority of participants reported having an education beyond high school. Therefore, the results of this study may not reflect the experiences of younger thyroid patients who do not have a higher education. The majority of participants' doctors were Caucasian and male. As such, the results of this study may not be generalizable to thyroid patients with non-Caucasian, female doctors. Furthermore, because this study focused on the experiences of female patients with thyroid disease, the findings may not reflect the experiences of male thyroid patients.

Another limitation of this study is the potential for personal bias, as I have a thyroid disease diagnosis and have been a member of The Thyroid Support Group since 2004. In order to control for this limitation, I utilized reflexive journaling during data collection and analysis. More specifically, I maintained a journal about my personal feelings and opinions so they could be separated from the data. As I read and re-read participants' experiences, I recalled having similar experiences and felt the emotions of sadness and anger. Through journaling about my feelings regarding the participants' experiences, I realized that in some instances, I was transferring my own emotions to their statements. In other words, I ultimately made certain that the emotions of the participants discussed in this study were the emotions of the participants and not my own.

A final limitation of this study is that none of the participants had electronic journals to share. I had planned to collect personal electronic journals in addition to the data gathered from the interview guide in order to triangulate the data. Nevertheless, triangulation *was* achieved because more than one theoretical position (feminism and social constructionism) was utilized to interpret the data. In addition, I used the services (on a voluntary basis) of a colleague for data interpretation.

Data Triangulation

In addition to using two theoretical positions (feminism and social constructionism) to interpret the data, utilizing the services of a colleague for data interpretation (on a voluntary basis) helped to triangulate the data in order to ensure data trustworthiness and quality. During the process of data analysis, my colleague reviewed my work regarding the identification of themes and subthemes. After I recognized the theme of “Doctor-Patient Relationship” with the subthemes, “Traditional” and “Collaborative,” I created a section called “Dissatisfaction with Treatment” beneath the “Traditional” subtheme. My colleague suggested that I was underemphasizing *satisfaction* with treatment. I agreed with her analysis and carefully reviewed participants’ comments regarding instances in which they felt heard, validated, and taken seriously by their doctors. In conjunction with reflexive journaling, receiving my colleague’s feedback regarding this issue helped me to realize that I was focusing on the participants’ negative experiences and not giving credence to their positive experiences.

Another issue recognized by colleague was the practice of self-advocacy behaviors among participants, specifically as the behaviors related to doctor-patient communication. I had identified the processes of health information-seeking, seeking new doctors, treatment refusal, and self-treatment as related to the participants’ autonomy and in response to doctors who did not listen to, validate, or take the participants seriously.

Considering my colleague’s feedback, it became evident that being dissatisfied with one’s treatment was not necessarily a prerequisite to participating in self-advocacy behaviors. In other words, even participants who felt heard, validated, and taken seriously by their doctors sought health information, refused treatment, and self-treated.

Recommendations for Future Research

A thorough review of the participants’ interviews and resulting themes revealed a number of issues in need of further research. These issues include: (a) the education levels of female patients who seek health information, (b) patients’ self-advocacy behaviors (i.e., seeking new doctors, self-treatment, and secret-keeping, (c) the role of gender in the doctor-patient relationship, (d) the efficacy of the TSH blood test for diagnosing thyroid dysfunction, (e) doctors’ specialties in relation to diagnostic bias, (f) the use of natural thyroid medication, and (g) grief as it relates to thyroid disease.

Education Level of Female Patients

The research reviewed for this study indicated that female patients—particularly those with a higher educational attainment—tend to conduct research about their illnesses (Ye, 2014), desire the most active involvement in the decision making process with their doctors (Flynn et al., 2006), and are more likely to self-treat (Kua et al., 2012). The results of the current study reinforced these findings: of the 16 participants interviewed, 15 participants attained an education beyond high school (see Table 2 in Chapter 4), 12 conducted research about thyroid disease, 12 desired to actively participate in the decision making process, and seven self-treated. As discussed previously, the majority of patients refer to their doctors as their primary source for health information—even patients who seek information from external sources (Cegala et al., 2008; Cotten & Gupta, 2004; Fox, 2011). Thus, it is recommended that future research examine the relationship between the education level of female patients and the doctor-patient relationship.

Patient Self-Advocacy Behaviors

In the current study, the process of switching doctors was considered a form of self-advocacy. Although the processes of "secret-keeping" and "self-treatment" were previously discussed in relation to trust and doctor-patient communication, I believe they are also self-advocacy behaviors. I will explain in the following sections.

Switching doctors. In my initial search of the literature for information about the process of switching doctors, I came across the term "doctor shopping." The term doctor shopping has a negative connotation and generally refers to patients who are seeking prescription pain killers (e.g., Peirce, Smith, Abate, & Halverson, 2012; Worley, 2012; Worley & Thomas, 2012). While research in the area of preventing abuse of pain killers is valuable, I had difficulty with finding information relevant to patients who switched doctors due to dissatisfaction with their current doctor. A search of the literature using the words "switching doctors" revealed a few studies (e.g., Liu et al., 2014; Platanova et al., 2008; Kessler & Mylod, 2011; Ravichandran, 2015; Torres, Vasquez-Parraga, & Barra, 2009). However, these studies focused on "patient loyalty" and "patient commitment" to the doctor-patient relationship—terms that place the sole responsibility for the doctor-patient relationship onto the patient.

In reading studies about patient-centered care, I stumbled upon the term "disengaging" to describe patients' decisions to switch doctors due to dissatisfaction with their care. However, I only found two such studies (McGowan, Escott, Luker, Creed, & Chew-Graham, 2010; Stone, 2014). Thus, further research is needed on research regarding patients who "disengage" from their current doctor due to dissatisfaction.

Secret keeping. The finding of "secret-keeping" in the current study prompted a search of the literature for studies related to patients withholding information from their doctors. Numerous studies were found in relation to patients seeking pain medication (e.g., Buchman & Ho, 2014; Maakaron et al., 2014; Sokol, 2014; Stogner et al., 2015) and doctors utilizing "therapeutic privilege" to withhold information from their patients for the "good of the patient" (e.g., Collis & Sleeman, 2013; Hodkinson, 2013; Matthes & Caples, 2013; Self, 2014). However, a gap was discovered regarding the practice of secret-keeping by patients as a form of self-advocacy in an attempt to regain control over their own health. As discussed previously, the purpose of secret-keeping by participants in the current study was "not the exercise of power but the expression of resistance to the power of [the doctor]" in which patients attempted to reclaim power and control over their own bodies (Fainzang, 2005; p. 18). Because patients are the experts of their own medical conditions (Chrisler, 2001; Fernandes et al., 2006; Hoffmann & Tarzian, 2001), yet patients fear conflict and criticism from their doctors (Fainzang, 2005, 2015), further research is needed about patients keeping secrets from their doctors as a form of self-advocacy.

Self-treatment. As with the issues of seeking new doctors and secret-keeping, the majority of the literature on self-treatment places patients in a subservient position to the doctor. Searching the literature with the term “self-treatment” resulted in numerous studies related to “self-medication” with unauthorized drugs and alcohol (e.g., Larance et al., 2011; Mehuys et al., 2012; Neafsey et al., 2011; Robinson et al., 2011). However, participants in the current study initiated self-treatment after a thoughtful process of “self-examination [and] self-diagnosis” (Fainzang, 2013, p. 495) in response to doctors who dismissed their complaints that they did not feel well on the medication their doctors prescribed. Because female patients in particular often need to prove the validity of their complaints (Hoffman & Tarzian, 2001; Munch, 2004) and patients who challenge their doctors tend to be thought of as “difficult” (Frosch et al., 2012; MacDonald, 2003), female patients who choose to self-treat might be considered as self-advocating (Fainzang, 2005, 2013, 2015) rather than behaving as “non-compliant” patients. Further research needs to be conducted on the process of self-treating as a form of self-advocacy.

Role of Gender

In the beginning of the study, I anticipated that participants would describe greater satisfaction with female doctors than male doctors due to women’s shared history of social subordination to men (see Bohan, 2002; Cosgrove, 2003; Shields, 2007; Sherwin, 1999). However, the majority of participants’ responses to questions regarding the potential influence of gender on treatment experiences revealed that the doctors’ gender had little impact on their experiences. The literature regarding patients’ gender preferences for doctors is divided. Although a number of studies indicate that patients prefer doctors of the same gender (e.g., Bonds et al., 2004; Fang et al., 2004; Godager, 2012), many studies suggest that patients do *not* have a gender preference for their doctors (e.g., Bender, 2007; Delgado et al., 2011; Makam et al., 2010; Tempest et al., 2005). Studies that focused on doctors' perceived competence and communication skills indicated that patients who perceived their doctors to be competent and easy to talk to had no specific gender preferences for their doctors (Bertakis & Azari, 2012; Bourke, 2002; Mavis et al., 2005; Tempest et al., 2005). These finding are consistent with the results of the current study, with 13 out of 16 participants referring to the importance of their doctors' competence and communication skills in lieu of their doctors' gender. Further research is recommended on the doctor gender preferences of patients being treated for thyroid disease.

Efficacy of the TSH Blood Test

The efficacy of the TSH blood test for determining thyroid function is under debate due to inconsistent data from various studies (Adams, 2008; Beckett & MacKenzie, 2007; Wheatland, 2010). Experts on thyroid function differ in opinion regarding the accuracy of the current range limits and question whether or not age-specific ranges should be created (Adams, 2008). Furthermore, despite evidence that including the free T3 and free T4 blood tests with the TSH blood test produces the most accurate analysis of thyroid function, an unaccompanied TSH blood test tends to be utilized (Beckett & MacKenzie, 2007; Dayan, 2001). As a result, clinically important diagnoses may be missed (Dayan, 2001), and thyroid patients may be undertreated (Baisier et al., 2000). As such, there is a need for further research on the efficacy of the

TSH blood test when used alone and in conjunction with the free T3, free T4, and thyroid antibodies blood tests.

Doctor Specialty and Diagnostic Bias

Half of the participants in the current study reported experiencing diagnostic bias. According to numerous studies (e.g., Bernardes & Lima, 2011; Soderberg et al., 2012; Stenberg et al., 2012), women's medical problems are often misdiagnosed and undertreated. Furthermore, doctors tend to give lifestyle advice more often to women than they do to men (Hamberg et al., 2004; Munch, 2004; Vaccaro & Huffman, 2012); and women are less likely than men to receive diagnostic testing even when presenting with the same symptoms (Hamberg, 2008; Napoli et al., 2014). However, it is important to note that doctors are more prone to diagnostic bias and error when presented with problems outside of their specialty (Ogdie et al., 2012); and the current study did not investigate the specialties of the participants' doctors. As such, it is recommended that future research investigate the influence of doctors' specialties on their choice of diagnostic tests, diagnosis, and medical advice regarding thyroid disease.

Natural Thyroid Medication

As confirmed by the experiences of 10 out of 16 total participants in the current study, synthetic thyroid medication is not an effective treatment for all individuals with thyroid disease. A review of the literature on thyroid medication revealed a dearth of studies related to the efficacy natural thyroid medication. Gaby (2004) argued that the negative reaction of the conventional medical community to the use of natural thyroid medication "represents, at least in part, a biased attitude" (p. 168). Further, Dommisse

(2009) asserted that the medical community's preference for synthetic thyroid medication is based upon biased research in which pharmaceutical companies are involved.

Since its creation in 1958, synthetic thyroid medication (name brand Synthroid) has been the standard treatment for hypothyroidism (Tybout & Hennessy, 2013). According to Reynold and Olsen (1969), although natural thyroid was the standard treatment at the time Synthroid was created, the pharmaceutical industry needed to "learn how to obtain the effect of desiccated thyroid" via synthetic medication because the demand for natural thyroid medication was too high for the available supply of fresh glands (p. 1). Furthermore, because Synthroid preceded the current stringent drug approval process, Synthroid was accepted by the FDA without any clinical trials (Tybout & Hennessy, 2013). Due to the threat of generic medications, when Boots Pharmaceutical purchased Synthroid from Flint Laboratories in 1986, Boots commissioned a pharmacist to conduct a study with the hopes of proving that Synthroid was superior. However, the results indicated that the generic medications were bioequivalent (Tybout & Hennessy, 2013). According to Tybout and Hennessy, Boots suppressed the results of the study for seven years, at which time a lawsuit was filed on behalf of patients who had overpaid for Synthroid based on the false proclamation that it was superior to other synthetic thyroid medications.

I personally believe that the experiences of thyroid patients who do not feel well on synthetic thyroid medication, but are denied an opportunity to try natural thyroid medication, are comparable to the experiences of patients with medically unexplained symptoms. More specifically, as with patients who have medically unexplained symptoms, thyroid patients who require natural thyroid medication to function are often dismissed and do not feel heard, understood, or taken seriously (Peters et al., 2008; Shattock et al., 2013; Stone, 2014; Werner et al., 2003); Like patients with medically unexplained symptoms, these thyroid patients must work hard to be perceived as credible patients with legitimate symptoms (Johansson et al., 1996; Werner & Malterud, 2003; Werner et al., 2004). According to Stenberg et al. (2012), patients who believe their doctors do not take them seriously feel rejected and ashamed. Considering the many narratives of patients who report not feeling well on synthetic thyroid medication, it is strongly recommended that further research be conducted on the efficacy of natural thyroid medication.

Grief and Thyroid Disease

Carla's experience of grief prompted a search of the literature about the relationship between grief and thyroid disease. Although many studies were discovered about the grieving process in relation to other chronic illnesses (e.g., Dysvik et al., 2013; Novak, Costantini, Schneider, & Beanlands, 2013; Schulman-Green et al., 2012), no such studies were found specifically about thyroid disease. Research indicates that individuals with chronic illness experience grief over time as a result of loss of health or functioning (Dysvik et al., 2013; Schulman-Green et al., 2012); and thyroid disease is a chronic illness that affects an estimated 30 million Americans (AACE, 2013) and 200 million people worldwide (Rajoria et al., 2010). As such, further research is recommended regarding the experience of grief in individuals with thyroid disease.

Dissemination of Findings

The findings of this study will be disseminated in several ways. First, the results will be shared via individual emails with participants who indicated an interest in reading the study. Second, I plan to publish a condensed form of this study in a scholarly journal so that healthcare professionals can utilize the information in practice and future research. Third, I will condense this study to the scope of a conference paper with the intention of presenting the study and its results at appropriate conferences. Finally, I will build upon the findings of this study by conducting further research in the areas of the relationship between thyroid patients' education levels and doctor-patient communication, thyroid patient self-advocacy behaviors, and the experience of grief as it relates to thyroid disease.

Implications for Social Change

The results of the current study contribute to positive social change by expanding upon the existing research on women's health and chronic illness to include thyroid disease, thus enabling medical professionals to better determine and meet the unique needs of female patients with thyroid disease. Based on the results of this study, the processes of diagnosing and treating thyroid disease appear to be influenced by a number of factors, including the nature of the doctor-patient relationship, doctor-patient communication, the structure of the healthcare system and medical education, diagnostic and gender bias, and economics. Additional factors that seem to be intricately related to these processes include patients' education levels and self-advocacy behaviors. It is recommended that additional research be conducted in these areas in order to further enhance our understanding of thyroid disease and the doctor-patient relationship and ultimately ensure positive health outcomes.

The results of the current study indicate a need for doctors who treat thyroid patients to learn how to recognize the communication needs of their patients and match their relational approach to those needs (Briel et al., 2007; Houle et al., 2007; Levinson et al., 2010). Flynn et al. (2006) suggested that doctors gather information regarding patients' preferences for involvement on intake forms to assist doctors in tailoring their approach to meet their patients' needs. However, even doctors who wish to work collaboratively with their patients may not have the time or resources to employ patient-centered practices (Celik et al., 2009). In order for doctors to provide patient-centered care, policy makers must develop payment models that encourage efforts toward patient involvement, and with regard to care, a focus on quality rather than quantity (Bernabeo & Holombow, 2013; Epstein & Street, 2011; Kerr & Hayward, 2013).

With regard to knowledge of how to diagnose and treat thyroid disease, as stated previously, it is important to consider the doctors' specialties. However, if doctors choose to treat their patients for medical conditions in which they do not specialize, it is essential that they continually seek the latest information regarding those conditions. Considering the aforementioned issues with the TSH blood test (see Adams, 2008; Beckett & MacKenzie, 2007; Bunevicius & Prange, 2006; Dayan, 2001; Wheatland, 2010) and the reaction of numerous individuals to synthetic thyroid medication (see http://www.stopthethyroidmadness.com; http://thyroid.about.com/bio/Mary-Shomon-350.htm; http://dearthyroid.org; http://www.butterflynationproject.org), in conjunction with the reported experiences of the participants in the current study, it seems that additional research and education is needed on the use of the TSH blood test for determining thyroid function and the use of natural medication for treating thyroid disease.

Conclusions

Although 30 million Americans are affected by thyroid disease, more than half remain undiagnosed (AACE, 2013). Even after beginning treatment for thyroid disease, many women report not feeling well despite taking synthetic thyroid medication (the standard treatment for hypothyroidism) and their TSH blood test results showing as "normal." Because thyroid dysfunction produces symptoms similar to other disorders (e.g., depression, menopause), thyroid disease is often misdiagnosed and left untreated (Canaris et al., 2000; Godfrey, 2007; Pearce, 2015; Simmons, 2010). In addition, the undertreatment of thyroid disease results in numerous distressing physical and emotional symptoms and declining functioning (Cappola & Cooper, 2015; Gaitonde et al., 2012; Heinrich & Grahm, 2003; Roberts & Ladenson, 2004). Despite being considered the "gold standard" for determining thyroid function, the efficacy of the TSH blood test is debatable due to inconsistent data from various studies (Adams, 2008; Beckett & MacKenzie, 2007; Wheatland, 2010); and the TSH blood test tends to be used alone to determine treatment effectiveness even though the full panel (TSH, free T3, free T4, and antibodies tests) provides the most thorough analysis of thyroid function (Beckett & MacKenzie, 2007; Bunevicius & Prange, 2006; Dayan, 2001). Furthermore, as supported by the results of the current study, numerous thyroid patients report not feeling well taking synthetic thyroid medication and describe feeling better with natural thyroid medication. However, the majority of doctors hesitate to prescribe natural thyroid medication because they learn in medical school that synthetic thyroid medication is the only appropriate treatment for hypothyroidism (Dommisse, 2009; Gaby, 2004).

In the face of such challenges, a doctor-patient relationship based on mutual trust and collaboration helps to ensure positive treatment outcomes (Crooks et al., 2015; Houle et al., 2007; Shimabukuro, 2008; Simmons, 2010). Research indicates that patients trust doctors with whom they feel heard, validated, and taken seriously—all of which are positively correlated with the likelihood of considering doctors' recommendations (Houle et al., 2007; Jagosh et al., 2011; Quaschning et al., 2012). Likewise, including patients in the decision making process and responding to patient concerns with empathy encourages authentic communication and patient satisfaction (Barry & Edgman-Levitan, 2012; Gelhaus, 2012a, 2012b; Platanova et al., 2008). Patients who do not feel heard, validated, or taken seriously by their doctors are likely to participate in self-advocacy behaviors (e.g., conduct research, seek a new doctor, refuse treatment, self-treat, and keep secrets; Fainzang, 2005, 2013, 2015; Fox, 2011; Ye, 2014)—particularly female patients with a higher education (Flynn et al., 2006; Kua et al., 2012; Ye, 2014).

Research indicates that patients wish to work *with* their doctors—even patients who seek health information, refuse treatment, and self-treat (Barry & Edgman-Levitan, 2012; McNutt, 2010; Quaschning et al., 2012). However, traditionally, doctors have been taught to adopt a position of authority over their patients in order to ensure their patients' recovery; and patients have been expected to accept a passive role and trust their doctors

(Lupton, 2003; Munch, 2004). According to MacDonald (2003), because society has changed and patients want to be active participants in their care, doctors must be willing to surrender some authority (p. 306). As previously stated, I am not implying that doctors who work in a traditional relational-style deliberately intend to oppress their patients. Rather, because oppressive practices are systemically ingrained in society by historically-based knowledge and beliefs, “conscious and persistent effort [is required] to resist complicity in [the] patterns” of such practices (Sherwin, 1999, p. 11).

Historically oppressive practices in medicine continue to be challenged by patient-centered care initiatives in which doctor-patient collaboration is encouraged (Barry & Edgman-Levitan, 2012; Deber et al., 2007; Miller & Bahn, 2013; Pinn, 2013; Ross & Haidet, 2011). As such, it is important for practicing doctors to work collaboratively with patients who prefer a collaborative relational style (Chin, 2002; Flynn et al., 2006; Houle et al., 2007; Levinson et al., 2010). Furthermore, discussion of gender sensitive issues, sex differences in healthcare needs, and gender bias continues to be integrated into modern medical curriculum (Miller & Bahn, 2013; Pinn, 2013). As discussed previously, gender bias in medicine occurs as a result of stereotyped preconceptions about a person’s health, behavior, experiences, and needs based on their gender (Hamberg, 2008). From a feminist viewpoint, historically-based beliefs in psychology and biomedicine that women are fragile, unintelligent, and inferior to men continue to have a negative impact on both men and women (Chrisler, 2001; Hamberg, 2008; Hoffmann & Tarzian, 2001; Sherwin, 1999). Traditionally, in psychological practice, the presence of “feminine” emotion (e.g., fear, anxiety) is considered problematic for women and abnormal in men (Shields, 2007). In addition, “female disorders” in psychology and biomedicine—or disorders that are typically assigned to women based on stereotypes—are often unrecognized and misdiagnosed in men (Boysena, Ebersolea, Casnera, & Coston, 2014; Field et al., 2014). For example, men are undertreated for osteoporosis and eating disorders as compared to women because these disorders are traditionally thought of as “feminine” (Field et al., 2014; Shingleton, Thompson-Brenner, Thompson, Pratt, & Franko, 2015; Walldorf et al., 2013). Likewise, women are undertreated for back and chest pain as compared to men because these symptoms tend to be thought of as “masculine” (Chang et al., 2007; Hoffmann & Tarzian, 2001; Werner & Malterud, 2003). Thus, it is essential that doctors recognize the potential for gender bias and to remain current with the literature regarding the illnesses they treat (Napoli et al., 2014; Newton et al., 2010; Stenberg et al., 2012).

In conjunction with feminism, a social constructionist perspective of illness asserts that objective views of the human body are socially constructed (Fernandes et al., 2006). In other words, society and its establishments (e.g., medicine) assign meaning to the human body (e.g., “healthy” and “unhealthy,” “normal” and “abnormal,” “masculine” and “feminine”) and disregard individuals’ subjective illness experiences. From a feminist/social constructionist viewpoint, patients’ interpretations of their own illness experiences are valid and patients are considered experts of their own medical conditions (Chrisler, 2001; Docherty & McColl, 2003; Hoffmann & Tarzian, 2001; Lupton, 2003). Adopting a feminist/social constructionist approach to medicine encourages patients and doctors to question concepts of “normal” and “healthy” and for doctors to consider patients' subjective interpretations of their own illness—techniques that are characteristic of patient-centered care (Barry & Edgman-Levitan, 2012; Hoffmann & Tarzian, 2001; Levinson et al., 2010; Miller & Bahn, 2013; Pinn, 2013; Wright & Owen, 2001).

The reported experiences of the women in the current study provide information with which one might begin to understand the treatment experiences of women with thyroid disease and their relationships with their doctors. Overall, the most commonly expressed needs shared by participants were to feel heard and be taken seriously by their doctors—both of which are common in collaborative doctor-patient relationships and patient-centered practices. Doctors who diagnose and treat women with thyroid disease are in a position to empower their patients. Based on the results of the current study, women who have thyroid disease desperately wish to feel well again and for their experiences to be known and understood. Further research on the treatment experiences of women with thyroid disease and the doctor-patient relationship is imperative for better understanding the unique needs of female thyroid patients in order to more accurately diagnose and effectively treat this debilitating and potentially life-threatening disease.

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Appendix A: Interview Guide

Introductory Script

Research has suggested that studies examining the factors that contribute to effective, non-authoritative communication between doctors and patients would help educate physicians about patients' needs.

I am going to ask you a number of questions about your background and experience as a woman with thyroid disease. Please answer them by typing your replies. You may use as much space as you like. If you feel that any of the questions are too personal, you do not have to answer them. If any of the questions are not applicable to you, please tell me. If you begin to feel upset or uncomfortable, please inform me and I will cease the interview. You may withdraw from the study at any time without any penalty.

Remember, all of your information will be kept confidential. Please make sure you are in a public, non-private area. Do not type your name anywhere during this interview.

Because we are using online chat to conduct this interview, a transcript of our conversation will be automatically recorded. This transcript will form the basis of my study data.

Before we begin, do you have any questions?

Here is the first question.

Demographic Information

1. What is your age?

2. What is your ethnicity? (e.g., Caucasian, Black/African, Native American, Asian/Pacific Islander, Hispanic, East Indian, Middle Eastern, Other).

3. What is your highest education level completed? (e.g., High school graduate, GED, Some high school, Associates degree, Bachelor's degree, Some college, Master's degree, Professional degree, Other/please specify).

4. What is your thyroid disease diagnosis? You can type more than one answer (e.g., Grave's disease, Hashimoto's disease, Hyperthyroid, Hypothyroid, Other/please specify).

5. Do you have any other medical diagnoses? You can type more than one answer (e.g., Fibromyalgia, Chronic Fatigue Syndrome, Other/please specify).

6. What treatment(s) are you using for your thyroid disease? You can write more than one answer (e.g., Synthroid, Armour thyroid, Other/please specify).

7. If you take medications, what are the dosages for the medications?

8. What is the gender of your doctor(s)?

9. What is the ethnicity of your doctor(s)? (e.g., Caucasian, Black/African, Native American, Asian/Pacific Islander, Hispanic, East Indian, Middle Eastern, Other/please specify).

<u>Personal Experiences</u>

1. Please tell me, what has been your experience in seeking treatment for thyroid disease? (RQ 1)

- Possible Probe: How did you come to be diagnosed?
- Possible Probe: How long have you been being treated?

2. How would you describe your current relationship with the doctor who treats you for thyroid disease? (RQ 1; RQ 2)

3. How do you feel about the treatments you are receiving for thyroid disease? (RQ 1, RQ 2)

4. How clearly do you believe your doctor explains things to you? (RQ 2)

-Possible probe: What do believe your doctor could do to make his or her communication clearer?

5. Do you think it matters whether your doctor is a man or a woman? Why or why not? (RQ 3)

6. How does being a woman, as opposed to being a man, influence your relationship with your doctor? (RQ 1; RQ 2; RQ 3)

7. How comfortable do you feel in talking with your doctor about symptoms or medical issues you have experienced that you believe might be related to thyroid disease? (RQ 1; RQ 2)

8. What do you believe might help you to feel more comfortable in sharing your experience of these symptoms with your doctor? (RQ 2; RQ 3)

9. Is there anything else you would like to add?

Do you have a journal or diary about your experience with thyroid disease that you would like to share with me? You are not obligated to share. If you would like to share your journal/diary with me, please remove your real name from their journal/diary before emailing it to me.

Would you mind reviewing the transcript of our chat to make sure everything is correct? You are not obligated to review our chat transcript.

Thank you so much for your participation. When I have completed my study, would you like a copy of the results?

Appendix B: Letter of Cooperation from a Community Research Partner

This type of letter must be obtained from any type of organization involved in identifying potential participants or collecting data. Please contact irb@waldenu.edu if you have any questions about the appropriate content for a letter of cooperation. Either letter or e-mail format is acceptable, from the perspective of the Walden University Institutional Review Board (IRB).

__________________, Group Owner-Moderator

October 15, 2013

Dear Ms. McCormick,

Based on my review of your research proposal, I give permission for you to conduct the study entitled “Women and Thyroid Disease: Treatment Experiences and the Doctor-Patient Relationship” within The Thyroid Support Group. As part of this study, I authorize you to invite members of my group to participate in the study as interview subjects. Their participation will be voluntary and at their own discretion. We reserve the right to withdraw from the study at any time if our circumstances change.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,

___________________, Group Owner-Moderator

Appendix C: On-List Group Email Invitation

Hello everyone!

My name is Laura McCormick and I am a doctoral student at Walden University (http://www.WaldenU.Edu).

I obtained permission from the Group Owner and Moderator to seek participants for my study. If you are a woman age 18 or older, have a thyroid disease diagnosis, are a member of this support group, and if you are interested in participating in research about women's experiences with thyroid disease treatment, then I invite you to take part in a research study of women with thyroid disease. I am seeking 10-15 participants on a voluntary basis.

A potential benefit to this study is that it gives participants the opportunity to share their experiences of thyroid disease with professionals and the general public (your real names will not be known or used). If you are interested in participating in my study, please do the following:

1. Establish a free email account (e.g., Yahoo Mail: https://edit.yahoo.com/registration) **using a fictitious name**.
2. Email me **off-list** through my personal email address by January 26, 2014 to express your interest in participating. **Please use your fictitious name at all times.**
3. I will respond to your email and include a consent form in my response. After reading the consent form, if you are still interested in participating, we will communicate via email using your fictitious name and email address to set up a date and time for your individual interview.
4. Once we set a date and time for your interview, please be sure to participate in the interview in a private, non-public location.

I want to assure everyone that you are in no way required to participate in my study. Likewise, if you choose to participate in my study, you may change your mind at any time and withdraw from the study without explanation. I will never know who does and does not participate in this study and I will never know the true identity of any participant.

I will be checking my email frequently. I look forward to hearing from those of you who are interested.

Warm regards,

Laura

Appendix D: Consent Form

You are invited to take part in a research study of women with thyroid disease. You were chosen for the study because you are a woman with a thyroid disease diagnosis and you expressed an interest in this study. Please read this form and ask any questions you have before agreeing to be part of the study.

This study is being conducted by a researcher named Laura J. McCormick, who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to obtain an understanding of the experiences of women with thyroid disease.

Procedures:

If you agree to be in this study, you will be asked to:

- Download and install X-IM chat software, a free, encrypted chat platform (see http://www.x-im.net/ for details) to your computer using your new e-mail account and fictitious name in order to log in to a one-on-one chat session with Laura.

- Before beginning the interview, please have ready a phone number of a counselor that you trust and can call if you feel upset from the interview. If you feel upset from the interview, you may also call the National Suicide Prevention Lifeline: 1-800-273-8255 (1-800-799-4889: TTY - Hearing & Speech Impaired) or the National Hopeline Network: 1-800-784-2433. International Suicide and Crisis Hotlines are available here: http://suicidehotlines.com/international.html

- Complete an interview with Laura using the X-IM encrypted chat software about your experience as a woman with thyroid disease. This will take approximately 1 hour. At the end of the interview, you will be asked if you would like to follow up by e-mailing Laura your journal/diary (see below) and by reviewing your individual chat transcript. Please make sure that you participate in the interview in a private, non-public location, and use your fictitious name at all times.

- E-mail Laura your journal/diary (if you have one, and *only* if you want to) about your experience with thyroid disease. E-mail Laura *not* through the support group, but to her e-mail address and protect the journal with a password. Also, please make sure you remove your name from your journal/diary.

Voluntary Nature of the Study:

Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you want to be in the study. No one in The Thyroid Support Group will know whether you choose to participate and no one will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may withdraw from the study at any time. You may skip any questions that you feel are too personal. You do not have to supply a copy of your journal/diary if you do not want to. You do not have to participate in any follow-up activities such as reviewing the transcript of your interview if you do not want to.

No type of gift or compensation will be offered for participating in this study.

Risks and Benefits of Being in the Study:

A potential risk of participating in this study is the possibility of your e-mail being read by someone other than Laura. In order to prevent access to your e-mails, interview responses, and journal, Laura has password-protected her computer. No one will have access to the login information that you use to join the chat session, so no one will be able to see the transcript of your interview, which will be stored on a password-protected drive.

Another possible risk is that you might feel emotional distress in talking about some aspects of your experience. If this is the case, you are free to end the interview, take a break, or withdraw from the study without consequences.

A potential benefit of this study is to have your "voice" be heard about what it's like to be a woman with thyroid disease.

Confidentiality:

Any information you provide will be kept confidential. Laura will not use your information for any purposes outside of this research project. Also, Laura will not know your real name and will not include anything that could identify you in any reports of the study.

Contacts and Questions:

The researcher's name is Laura J. McCormick. The researcher's faculty advisor is Dr. Ruth Crocker. You may ask any questions you have at any time. You may contact the researcher or the advisor. If you want to talk privately about your rights as a participant, you can call the Director of the Research Center at Walden University.

After reading this consent form, emailing Laura to establish a date and time for your individual interview implies your consent to participate in this study. Again, you may change your mind and withdraw from the study at any time.

You may keep this form for your records.

Appendix E: Confidentiality Agreement

During the course of my activity in analyzing and interpreting data for this research, *Women and Thyroid Disease: Treatment Experiences and the Doctor-Patient Relationship*, I, Mary Ann Cincotta, understand that I will have access to information which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to participants.

By signing this Confidentiality Agreement I acknowledge and agree that:

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

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

Printed Name of Research Assistant	Mary Ann Cincotta

____

Research Assistant's Electronic* Signature	Mary Ann Cincotta
Researcher's Electronic* Signature	Laura J. McCormick

*Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person's typed name, their e-mail address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

Appendix F: On-List Group Email at End of Interviewing

Hello everyone!

Recently, I made a post asking for volunteers for my study about women with thyroid disease. I am writing to inform you that I no longer need volunteers.

I hope everyone has a wonderful day!

Warm regards,

Laura

Appendix G: Participant Textural-Structural Descriptions

Participant 1: Alicia

Alicia has been receiving treatment for thyroid disease for approximately seven years. Following her breast cancer treatments, Alicia felt like something was wrong. She indicated that she informed her oncologist and radiation oncologist of her concerns on more than one occasion. Since Alicia had recently lost her 8-year old son to cancer and was recovering from treatment for breast cancer, she believed that her doctors likely attributed her symptoms to grief. Alicia stated, "It was not until I broke down in tears with my radiation oncologist that he suggested metabolic testing…[and to] follow this up with my primary care physician."

Based on the results of her blood work, Alicia's primary care physician prescribed her levothyroxine. Alicia expressed that she and her doctor have a good working relationship, even if they do not always agree on the course of treatment (which is based on the results of blood work). Alicia stated, "While he tends to be satisfied if my numbers are within the normal range, he does listen when I tell him how I am feeling." She continued, "I feel that we are carefully working toward finding the best way to treat me." Alicia expressed feeling grateful that her doctor listens to her concerns and takes her seriously. As a result, Alicia feels comfortable, validated, and has trust in her doctor. She explained, "Knowing that he takes me seriously helps me to feel comfortable sharing my symptoms with my doctor."

In addition to sharing symptoms with her doctor, Alicia also shares with him research she has conducted about thyroid disease treatment. Alicia explained that, since her son’s passing, she has “…learned to advocate for the best medical treatment possible…” and added, “I think my doctor understands that I am not the person I used to be—that I know how to do the research and that I know what is reasonable.” In fact, based upon Alicia’s research, her doctor is considering prescribing her Cytomel because her “free T3 is not where it should be.” When asked whether or not the gender of her doctor was important, Alicia responded, “I’m not sure. I wonder if a woman might be more understanding, but I feel that my [male] physician is very understanding.” She concluded, “I have chosen to stay with the physician because I believe he will listen to me. I research, bring my research to him and we discuss what to do with it.”

Participant 2: Anne

Anne has been receiving treatment for thyroid disease for approximately seven years and currently takes compounded porcine thyroid. Anne’s doctor told her that she became hypothyroid from the radiation used to treat her throat cancer. However, Anne reported that, based on her own research, she believes she was hypothyroid before receiving the radiation treatment. Anne described her overall treatment experience for thyroid disease as “awful,” explaining that her treatment “…is being managed by someone who does not understand that there is not ‘one size fits all’ [approach in the treatment of thyroid disease].” Anne expressed disappointment and frustration because her doctor bases her treatment decisions on the results of the TSH blood test and gives little importance to the results of free T3 and free T4 blood tests, or to Anne’s symptoms. When asked whether or not she believes her doctor’s gender influences her treatment, Anne responded, “No…It seems that both men and women doctors are TSH driven.”

Anne shared that she believes doctors do not take her seriously. She explained, "…my opinion is that doctors, both men and women, take men more seriously. I do tend to get emotional which I think makes doctors give less credence to my depiction of my symptoms." Anne reported knowing some women who are able to discuss their conditions without expressing emotion, and stated, "…they seem to have better relationships with their doctors than I am able to establish. So it may not be so much the gender of the patient or the doctor but the ability of the patient to express oneself." Anne further expressed that she would feel more comfortable sharing her symptoms and thoughts with her doctor if she believed she would be taken seriously. She stated,

> …it seems to me that the vast majority of endocrinologists have on blinders. Even the doctors I have seen that are okay with [natural medication] still put much more weight on TSH than symptoms or the frees. It is enough to make one feel hopeless at times.

Participant 3: April

April has been receiving treatment for thyroid disease for approximately four years. April reported that she had a lump in her throat for 3 years, during which time her doctor monitored the size. When she decided to have a second baby, April asked her doctor to biopsy the lump. Due to the presence of atypical thyroid cells, April's thyroid was partially removed. Upon further examination by April's doctor, her remaining thyroid tissue was suspected to be cancerous and was totally removed in a second surgery.

For a period of 3 years after her surgeries, April took Synthroid and Cytomel, as ordered by her doctor. However, April was still not feeling well. She expressed feeling extremely dissatisfied and frustrated with this doctor. April explained, “She worked by my levels NOT by my feelings and how I was living life…[and she had] a negative and controlling attitude.” April reported that her doctor did not take her seriously and felt like the doctor “hated” her for being well-informed: “I went [to my appointments] with knowledge and she told me to get off google...[and] when I asked her to test my reverse T3, she refused saying it was no more important than the type of blood I had.”

Recently, April switched to a male doctor who works with her collaboratively. She explained, “[He] wants to know what I know…[he] confirms I am not stupid and if need be, he will correct or add more info to what I already know.” April’s current doctor also prescribes her Armour thyroid instead of Synthroid and Cytomel, which is saving April money. When asked if the gender of her doctor is important to her, April responded, “Not at all,” explaining that she simply wants doctors to take her research seriously and not just humor her.

Participant 4: Autumn

Autumn has been receiving treatment for thyroid disease for approximately seven years. After her sister was diagnosed with thyroid disease, Autumn’s doctor decided to test her as well, and she was found to be hypothyroid. Autumn described her treatment experience as “lackluster.” She explained that she was comfortable talking with her previous doctor, but since the doctor has retired, she is currently unsure of what to expect from her new doctor. Despite finding her previous doctor easy to talk to, Autumn was not completely satisfied with her treatment experience and still does not feel well. She expressed feeling rushed during her appointments, stating, “It would help if they [doctors] weren’t so rushed.”

In addition to feeling rushed during her appointments, Autumn also experienced frustration and loss of hope when her doctor lowered her dose of Armour thyroid medication even though she felt “really good” at that dose: “…they [doctors] could actually find out how to really treat thyroid [disease…] but even when I thought this place did […] still nope!” When asked how the gender of her doctor influences her relationship with the doctor, Autumn shared her belief that female doctors understand female patients better than male doctors do and that her two best doctors were female. However, Autumn also commented, “I don't think it [the doctor’s gender] matters much…most of them are just in and out doing as little as they possibly have to do.”

Participant 5: Carla

Carla has been receiving treatment off and on for thyroid disease for approximately 20 years. She described her treatment experience as “inexcusably poor” and explained that she remained undiagnosed and suffered unnecessarily with hyperthyroid symptoms for a period of 10 months after being dismissed by a doctor. Having been a body builder, Carla was naturally larger than the average woman, and decided to see a doctor when she lost 40 pounds in one month. However, Carla did not receive the treatment she expected. Carla explained, “[the doctor] told me that I was ‘too fat to be sick’ went on to tell me to leave, [and that] there were others that really needed him.” After 10 months had passed, Carla was unable to lift her arms at work and was rushed to another doctor who diagnosed her as being in a “thyroid storm” – a condition that caused her to have tendonitis and made her prone to a heart attack. The doctor told Carla that she needed to have her thyroid ablated by radioactive iodine (RAI) or that she would die. Carla felt fear and a sense of grief during the procedure: “Sign it or die... I signed it [and] I got to watch my iodine uptake... I had such a perfect gland... It was just twice normal size.”

Over a period of 6 months after RAI, Carla was observed by doctors in training while she had blood drawn weekly to determine her thyroid function. Based on her blood work, Carla’s thyroid was determined to be dead. Carla had gained 100 pounds during this period of time. Over the next 2 years, Carla was treated with Synthroid, which she described as making her nauseous and giving her headaches. Despite increases in her dose of Synthroid, Carla continued to gain weight and eventually needed crutches to walk. As a result, she experienced difficulty maintaining a job and health insurance. Carla felt frustrated and hopeless. She stated,

> With each job change I got new insurance and new docs and they were all the same. Weight gain is from being a lazy slob [because] I laid around eating bon bons all day long. Didn't matter that I was a body builder before all this, didn't matter that I used to have physical jobs before all this... I was just a lazy, fat, stupid... slob.

Carla eventually lost her job and her health insurance. Shortly beforehand, she called her doctor and explained that she believed she needed a higher dose of Synthroid in order to gain more energy and lose weight. When Carla’s doctor told her she could increase to 200mcg of Synthroid, she felt unheard and invalidated because she was already taking that dose of Synthroid. When Carla pointed this out to her doctor,

> [The doctor] said that I was a 'smart ass' and to stay on the same dose…then hung up on me. I felt that my dose was wrong, I was getting worse and worse each year. Every time I talked to a doc about it I was demeaned and/or ignored.

With no health insurance, Carla reduced her daily dose of Synthroid to make it last as long as possible. She eventually ran out of Synthroid, lost her home, and moved in with a family member. At this point, experiencing labored breathing and a slow heart rate, Carla decided to conduct some research on the Internet and discovered "natural desiccated thyroid" and "adrenal support" products. Within a year of self-treating with these products, Carla developed more energy, started to exercise, and no longer needed her crutches to walk. However, Carla's source for thyroid and adrenal supplements eventually became unavailable, so she gradually reduced her dose while she searched for a new source. Over a period of two years, Carla relied on friends who shared their supplements and natural thyroid medication prescriptions. Within a few years, Carla developed lymphedema, which she attributes to the RAI, and a cellulitis infection in her leg. As she did not have access to a doctor, Carla's condition worsened and she eventually became mobility-impaired.

Recently, Carla became eligible for medical assistance. Although she is currently seeing a doctor, Carla remains "In a word…guarded [because a] doctor's prejudice and ignorance…basically cost me my life." Carla continued, "I have two half siblings with the same genetic defect I have. Both got proper care in a timely manner. Both are doing fine. Healthy weight, good jobs, real lives." When asked to describe her relationship with her current doctor, Carla explained that she initially seemed open-minded because she allowed her to continue taking natural thyroid and adrenal supplements. However, Carla's doctor eventually recommended Synthroid. Carla explained that she has lost trust in her doctor because she seems to not want to consider Carla's previous negative experiences with Synthroid. Carla expressed a desire for her doctor to "Listen to someone that is 'living it' and throw away the Synthroid book" and, referring to her doctor's medical education, hopes that "maybe it will click in her brain that the stuff that was shoved down her throat does not apply to all folks with thyroid disorders."

Carla shared her belief that her current doctor bases her recommendations solely on the results of blood work, ignores her symptoms, and does not take her seriously: "even though she listens, and we discuss...she still tries really had to talk me into her view point." Carla continued, "she is certain that the only test needed for thyroid is TSH and it's an inside joke that I will allow her to run TSH as long as she also runs Free T4 and Free T3 for me." When asked about the potential influence of her doctor's gender, Carla stated, "Every woman doctor I have had, all of 3, [have] been far more empathetic and able to listen," but continued, "…only 1 of those was truly well trained." Although Carla sees her doctor regularly, she continues to self-treat with natural thyroid and adrenal supplements based on her symptoms. Despite her negative experiences with thyroid treatment, Carla has not lost all hope. She commented, "I have a dream... that one day there will be a shared list of truly good thyroid docs that we will all have access to."

Participant 6: Diane

Diane has been receiving treatment for thyroid disease for approximately four years, but explained that she searched for over 30 years for the cause of her rapid weight gain and chronic fatigue. Diane believed her symptoms could be due to thyroid malfunction, as thyroid disease runs in her family. However, Diane remained undiagnosed:

> Each time my thyroid [was] tested I was told everything was fine. Meanwhile, I struggled daily for energy, and experienced numerous illnesses over the years that puzzled me…As I aged, I experienced illnesses that showed me I had a compromised immune system and something wasn't right, but no doctor would further investigate.

Eventually, Diane's blood work indicated that she was hypothyroid, so her doctor prescribed her levothyroxine. Along with taking levothyroxine, Diane also started on a weight loss plan. Within 3 weeks, Diane began to experience severe dizziness and difficulty breathing, so she stopped the weight loss plan. However, Diane continued to struggle with dizziness, could no longer drive, and was barely able to walk. Diane stated, "I saw several doctors and were [sic] prescribed anti dizziness medication, depression pills, etc. All doctors said my blood work came back fine, including thyroid. However, I was still bedridden and in danger of losing my job."

Diane decided to make an appointment with a reputable Endocrinologist who is known for his research on thyroid disease and is also a thyroid patient. Although the appointment cost her $400, Diane was pleased with the experience, stating,

> …based on his review of my labs (which were all in normal range) and hearing my symptoms, and looking at me, he said that he suspected Hashimoto's [disease]…He said the one test that was missing in all my labs were an [sic] Thyroid Antibody Test…My antibodies were 849. In a normal person they should be less than 9.

The Endocrinologist switched Diane from levothyroxine to Tirosint and Armour thyroid. Diane's dizziness and weakness soon subsided.

Diane's current doctor is an Endocrinologist who conducts research with the Endocrinologist her diagnosed her with Hashimoto's disease. The fact that this Endocrinologist conducts research helps Diane to feel more confident about his advice. In addition, the Endocrinologist listens to her concerns and validates her. Diane explained, "…he takes me a little more seriously than most of the other doctors who poo-pooed me." However, Diane remains concerned that he does not understand Hashimoto's disease to the extent she'd prefer. Diane stated, "…it seems that I am more knowledgeable about some areas of Hashimoto's than he is…But, he does take into consideration what I'm saying to him, and gives me feedback. I appreciate that."

When asked whether or not the gender of one's doctor is important, Diane responded, "If they have a thorough understanding of the female body, then there shouldn't be difference [between male and female doctors]." What Diane believes is important is that her doctor listens to her concerns, takes her seriously, and has a working knowledge of thyroid disease. Diane explained,

> …it is scary how little doctors actually know about [thyroid] disease, let alone Hashimoto's [disease]. I also think the public is grossly misinformed. Their impression is that you just take a little pill and all is well. This is far from the truth, as it can be very complicated.

Participant 7: Emily

Emily has been receiving treatment for thyroid disease for approximately one year. After sharing with her doctor that she had experienced rapid weight gain, loss of eyebrows, and thinning finger nails among other symptoms, Emily's primary care physician (PCP) tested her thyroid. The results of the blood tests indicated that Emily had Hashimoto's disease. Emily reported that she is currently taking Synthroid and Cytomel. She expressed frustration that she continues to not feel well, stating, "…it is a roller coaster. I feel like I'm getting better and then some things start getting worse."

Based on Emily's research, she recognizes that her PCP does not attribute many of her symptoms to thyroid disease. Emily explained, "…she tries to treat [my symptoms] individually – quickly stockpiling my medicine cabinet." Emily expressed a desire for a more collaborative relationship with her PCP; a relationship in which her PCP would share information and explain to Emily what to expect during treatment. However, as Emily explained, her PCP "…doesn't come forward with all she's thinking unless I push the conversation."

Emily recently started to see an Endocrinologist and reported greater satisfaction with the Endocrinologist than her PCP. Emily explained that she believes the Endocrinologist is easy to talk to and appreciates that she is thorough: "I had written all my issues out before seeing the endocrinologist and she still went through the whole list of possible symptoms to see which I was experiencing and to what extent." Emily also reported feeling hopeful that if she continues to not feel well, her Endocrinologist will allow her to try natural hormone. Emily explained that her PCP "…seems to think Synthroid is the only option."

When asked if she believes the gender of her doctor is important, Emily indicated a desire for a doctor who is empathic and willing to work with her collaboratively: "I would probably feel comfortable with either [male or female] if they seem sympathetic to my concerns and serious about continually working on a plan to get my body back to normal." She added, "Sometimes I think men doctors don't take some female symptoms seriously, but then I've had women doctors that also didn't seem to be sympathetic to a formally [sic] skinny patient who quickly put on 20 pounds."

Participant 8: Jenna

Jenna has been receiving treatment for thyroid disease for approximately one year after having a total thyroidectomy due to thyroid cancer. She currently takes levothyroxine. Jenna described her relationship with her doctor as "tolerable," explaining that she is "limited in options" because she goes to a free clinic. Jenna expressed frustration that her doctor seems to be less knowledgeable than she is about thyroid disease: "I think he could be a little more up to date...[he tests my] free T3 and free T4 because I asked him to…[but] I don't feel he listens to MY side too well. He thinks I know too much, I think."

In addition to not feeling heard or taken seriously, Jenna explained that she often feels dismissed by her doctor and that he ignores her symptoms: “…he doesn’t listen…I try [to describe my symptoms] but I feel he blows me off a lot… his MAIN concern is my TSH getting below .5.” She continued, “When I tried to explain to him my hair was falling out and I was tired ALL the time he just blew it off as not being related.”

Jenna expressed a desire for her doctor to listen instead of being “pushy” and commented that she would be more comfortable sharing with her doctor if he would “…not think it’s all in my head.” When asked if the gender of her doctor might have an impact on their relationship, she commented that she believes a woman might be more compassionate and understanding. However, since Jenna receives treatment at a free clinic, she does not have the option of seeking out another doctor.

Participant 9: Jessica

Jessica has been receiving treatment for thyroid disease for approximately one year. Although she was diagnosed with Hashimoto’s disease eight years ago, she decided to wait as long as possible before starting to take medication, stating, “I knew it would be hell to start hormone therapy and hung in without it as long as I could. So far, I was right.” Jessica described her treatment experience as “very frustrating” and commented that she had seen three Endocrinologists in five months. Jessica explained that her most recent Endocrinologist “…is really trying to work with me, but the other two got frustrated and abusive with me because I was not tolerating the [synthetic] thyroid meds well.” Jessica described feeling scared because synthetic thyroid medication “…altered my mental state, and made me feel worse.” She also felt invalidated because her

Endocrinologists did not believe that her symptoms were side effects from the medication.

When asked whether the gender of her doctor is important to her, Jessica indicated a preference for female doctors. She stated, “I think a woman doctor can relate better to her female patient having the same functioning system and emotional background caused by hormones,” but continued, “[however], my first endo was a woman…and she was brutal.” Jessica commented that she hopes her new Endocrinologist will care about how she feels, take her seriously, and “…take more time to figure stuff out and explain things.” Jessica concluded, “I am tiered [sic] of doctors thinking that we are just anxious…and will not believe us. They want to put us on antidepressants instead of helping us. This causes more anxiety and is very sad.”

Participant 10: Karen

Karen has been receiving treatment for thyroid disease for approximately 44 years after having a total thyroidectomy. Karen described her treatment experience as “not favorable,” explaining, “I was treated with Synthroid for 38 years [and] getting worse and worse every year.” She continued, “I do honestly believe that only being treated with Synthroid and only a TSH test being run each year it actually caused me to go through early menopause at the age of 34.” Tired of struggling with symptoms of hypothyroidism, Karen decided to conduct some research on the Internet and learned as much as she could about thyroid disease. Karen stated,

> When I was younger I did not argue with my doctor because I always thought they knew best. But after years of mistreatment I finally took the bull by the

> horns…I went through 5 Endos before I found one who knew what she was doing.

Karen expressed satisfaction with the collaborative-nature of her relationship with her current Endocrinologist: “We discuss things clearly and she listens well and makes adjustments based on my response.” Karen also reported appreciating that her Endocrinologist allows her to take a natural thyroid medication. However, Karen is struggling to find a natural medication that she can afford since, as she explained, Armour thyroid is not FDA approved. When asked whether or not the gender of her doctor is important to her, Karen responded, “It's not the sex of the doctor but the compassion and caring of the doctor that makes one good.”

Participant 11: Kari

Kari has been receiving treatment for thyroid disease for approximately four years. Karen explained that she had been struggling with symptoms of hypothyroidism for a number of years, and since her mother was hypothyroid, she insisted that her doctor test her each year for thyroid dysfunction. Kari expressed a belief that she was hypothyroid long before she was diagnosed because she experienced “problems long before I pushed for more tests” based on what she learned from conducting her own research. Kari explained that, in her experience, it has been “difficult to find a Dr. who knows anything about Thyroid problems,” and continued, “I am explaining more to her then [sic] she to me [about thyroid disease].” However, Kari stated that her doctor is “the best I can get in the area I live” because the closest Endocrinologist is 150 miles from her home.

Despite Kari’s frustration with her treatment experience, she expressed an appreciation that her doctor listens and takes her seriously: “My Dr. is easy to talk to […] she takes time and the main thing [is] she does listen.” When asked whether or not the gender of her doctor is important to her, Kari expressed a preference for female doctors, stating, “I like woman Dr.'s better. Men are too arrogant about their education.”

Participant 12: Kim

Kim has been receiving treatment for thyroid disease for approximately 66 years. As a young girl, Kim complained to her doctor about a lump in her throat and a “choking sensation.” However, Kim explained, “That doctor found nothing wrong. I think he felt it was my imagination.” By the time she was 16, Kim had been experiencing irregular periods for five years, so her mother took her to a “well-reputed clinic.” Kim recalled her experience:

> The doctor I saw there put me on Armour Thyroid and my periods straightened out and become regular from the very first month. The only test available back then was the basal metabolism…but there was no way I could get to the testing facility without an hour’s bus and streetcar rides…So he began treatment without my having been tested.

For years, Kim was treated with Armour thyroid based on her symptoms. Kim explained that she “started on it [Armour thyroid] so young that no one has questioned whether I need it.” However, when Synthroid became the standard of treatment for thyroid disease, Kim’s doctor required that she discontinue the Armour thyroid and start to take Synthroid instead. Kim stated,

> [I had] no problems until I changed to Synthroid. When I found it didn't work as well and I wanted to change back to Armour I could not find a doctor who would permit the change. They all said Armour was outmoded and Synthroid was better.

Kim decided to search for a doctor who would listen to her and consider her symptoms. She eventually found a doctor who prescribed Cytomel in addition to Synthroid. Kim explained that she took this combination of medication for one year and she "felt like a new person by the 3rd day!" However, when she was tested at the end of that year, her "TSH (the only thyroid test that doctor used) was [considered to be too low], and he wanted me to discontinue Synthroid." The doctor compromised with Kim and allowed her to reduce, rather than completely stop, the Synthroid.

Disappointed with her treatment, Kim conducted research to better understand the roles of T3 and T4 and their equivalencies from brand to brand of thyroid medication. She also found a doctor who was willing to prescribe her Armour thyroid. Kim brought her research to the doctor and he agreed that her "calculations were correct." Kim was pleased with this doctor, explaining, "This doctor was the first one ever to test my frees [free T3 and free T4] and also the first and only to test me for Hashi's antibodies." Unfortunately, since this doctor passed away, Kim had to search for another doctor to treat her thyroid disease. In the meantime, Kim explained,

> My other doctor, whom I'd kept as my primary for everything but thyroid, kept ordering TSH and I simply refused the test when I got to the lab. I just told him I was seeing another doctor for my thyroid treatment…We sometimes have to resort to trickery!

Kim expressed a desire for a doctor who is knowledgeable of thyroid disease and treatment, and who she could trust, share with, and feel heard and validated. She explained, “I know enough about thyroid function and my thyroid problem and what works best for me that I am in a position to explain to the doctor what I need, not the other way around!” Kim further explained, “A doctor’s accepting attitude and understanding, empathetic approach helps a lot.”

Kim recently found a new doctor who is willing to prescribe natural thyroid medication. She described the doctor as “very personable [and] seems more well informed than many.” However, Kim is “in wait-and-see mode since I’ve had to switch to a new natural desiccated product.” When asked whether or not the gender of her doctor is important to her, Kim responded,

> I think I may be a little more comfortable with a man. I’m more likely to argue with a female doctor if I think her approach is wrong. If I feel a male doctor’s approach to thyroid care is wrong for me, I simply don’t go back to him and begin looking for another doctor.

Participant 13: Leanne

Leanne has been receiving treatment for thyroid disease for approximately eight years after experiencing a two-year delay in treatment. Leanne explained that she was under a significant amount of stress in 2004 and lost 25 pounds in a month. She also developed a tremor and was sweating an unusual amount. Out of concern, her doctor ordered tests. According to her doctor, Leanne was hyperthyroid and needed to have a procedure called “radioactive iodine” (RAI) in order to kill her thyroid. After conducting research about RAI and learning that there were some serious potential side effects, Leanne refused the treatment. Leanne reported, “My doctor was not happy with me…told me I was being unreasonable, walked out of the room, and slammed the door behind him.” Leanne’s doctor referred her to an Endocrinologist.

Leanne had blood drawn for this Endocrinologist and visited her one time. Leanne reported, “She wondered why I didn’t get RAI and when I told her I refused it, she said there was nothing she could do to help me. I felt really confused and dismissed.” When Leanne told the Endocrinologist that she was experiencing anxiety, sadness, fatigue, and trouble concentrating, the Endocrinologist told her that the way she felt had “nothing to do with [her] thyroid [because her] blood work was normal” and told Leanne to “go see a counselor.” Leanne decided to make an appointment with another Endocrinologist.

Leanne reported that the second Endocrinologist was “nice and seemed more empathic” than the previous Endocrinologist. Leanne commented, “He listened to what I had to share and told me that the way I felt was probably related to my thyroid problem.” The Endocrinologist also explained to Leanne that she had Hashimoto’s disease. However, the Endocrinologist told her that, based on the results of her blood work, there was nothing he could do to help her feel better at the time. Leanne felt disappointed and frustrated and decided to conduct research about Hashimoto’s disease. She also asked her first Endocrinologist for a copy of her lab work.

Leanne reported learning that her first Endocrinologist had circled the Hashimoto’s antibodies result on her lab work. Leanne commented, “This is the same Endo who told me the way I felt had nothing to do with my thyroid. If this was true, why did she circle something on my blood work as if it was significant?" Losing trust in Endocrinologists, Leanne decided to visit a Holistic M.D. Leanne expressed appreciation for this doctor because he listened to her, validated her thoughts and feelings, and demonstrated empathy. The doctor prescribed her Armour thyroid and a corticosteroid for adrenal fatigue. Within a week, Leanne started to feel better and she gained weight. However, over time, Leanne gained too much weight and became concerned that the doctor rarely ordered blood work. She shared, "The previous Endos I had relied too much on the blood work and did not consider my symptoms, but this doc seemed to want to base his decisions on my symptoms alone." She expressed feeling confused because she felt good on some days and terrible on other days. After four years of feeling exhausted much of the time and having difficulty losing weight, Leanne decided to seek the advice of an Endocrinologist again.

Leanne visited the new Endocrinologist one time, reporting disappointment in the Endocrinologist's demeanor. Leanne stated, "She advised me to 'exercise more' and 'eat better' even though I explained I had been exercising and despite the fact that I felt tired and my stamina was poor." The Endocrinologist also informed Leanne that she developed Osteopenia as a result of the corticosteroid she had been taking. Leanne explained that the Endocrinologist told her that she needed to wean off the corticosteroid "…under a doc's care or I could die if I did it wrong." Leanne reported hoping that the Endocrinologist would work with her, but would only prescribe Synthroid. Since Leanne had read online that many women did not feel better on Synthroid, Leanne preferred to stay on natural thyroid medication. Leanne shared,

> …she told me she would not work with me unless I took Synthroid. I felt devastated. I did not want to wean off the corticosteroid AND Armour, particularly when I thought the Armour was helping me. I asked her if she'd consider working with me and let me stay on the Armour. She said "absolutely not" but did not explain why. I didn't even ask because I felt "shut down" and stupid. I paid my co-pay and left…once again feeling like I had no doctor to trust, listen, and help me.

Leanne decided to return to the Holistic M.D. because "…he at least didn't mind me taking the Armour. He also didn't make me feel like everything I was experiencing was in my head." She secretly weaned off the corticosteroid over a period of one year because the doctor insisted she continue to take the medication.

During this time, Leanne continued to search for another doctor and found an Endocrinologist who was willing to prescribe Armour thyroid. Leanne stated, "I called his office and asked [if he prescribed Armour]." Leanne continued, "He was great. He listened to me and I could tell he cared. He was attentive, listened to my thoughts [and] considered what I had to say." According to Leanne, she did not feel as well as she would like to, but she grew to trust him and appreciated the Endocrinologist's collaborative approach. She stated, "I at least felt like I could tell him anything and not hide information from him." Unfortunately, the Endocrinologist retired at the age of 70. Leanne shared, "Once again, I felt hopeless, as I had to start over trying to find someone I could trust and count on."

Once again, Leanne returned to the Holistic M.D. Leanne explained,

> At this point, having had the disease for 8 years and learning a lot about it (through reading and experience), I believed I could treat myself and just use this doc for the Armour script. This went on for about a year. I adjusted my dose on my own and simply reported to the doc. He never questioned my reasons for changing my dose…up and down, depending on how I felt. At first, I felt like I had control over my health. However, tired of the ups and downs, general fatigue, and not having blood work to base my decisions on at all, I decided I should search again for a doc who would look at both blood work AND symptoms. In many ways, I feel like I know more about thyroid disease than most docs.

Leanne reported that she is currently seeing an Endocrinologist who does not prescribe Armour thyroid, but who seems knowledgeable and demonstrates empathy. Since she had never actually tried synthetic thyroid medication like Synthroid, Leanne decided to give a new medication called Tirosint a chance. Leanne explained, "He knew I preferred natural treatments, so asked me if I'd compromise and try this new med. I said yes. I liked it that he considered how I felt." She added, "He is attentive and seems like he really cares about how I feel and what I think…It makes me willing to try whatever he recommends, even if I'm scared about it." However, Leanne also explained that she has not been fully up-front with her Endocrinologist about how fatigued she is feeling: "In the past, with other doctors, it seemed like when I complained, they thought I was over-reacting and taking up their valuable time. So, part of me is hesitant to complain too much."

According to Leanne, within a period of three months, the Tirosint caused her to feel disoriented and gave her headaches. After trying different doses of Tirosint, Leanne asked the Endocrinologist if she could go back to a natural thyroid medication because she “felt better on it than on the synthetic.” Leanne expressed extreme disappointment in the Endocrinologist’s response: “He told me no…that I had already tried natural. He seemed to care that I wasn’t feeling well, but refused to let me go back to something natural even though I felt better on it.” Leanne explained that, as a result, she has secretly stopped taking the Tirosint and started to take a low dose of the Armour thyroid she has left over from the Holistic M.D. she used to visit.

Recently, Leanne conducted more research and made an appointment with a Doctor of Osteopathy (D.O.) who is highly recommended by other women with thyroid disease. However, the D.O. does not have any appointments available for six months from now. Leanne reported feeling nervous about admitting to her current Endocrinologist what she has done and is unsure of whether or not she’ll keep her appointment with him. When asked if she believes the gender of her doctor is important, Leanne replied,

> I used to think it mattered. When I first started to advocate for my own health and tried to find a doc who would listen to me, I assumed that I was being treated poorly because I’m a woman…so it must all be in my head. However, the two most dismissive doctors I’ve had were women… What matters is that they listen, seem to care, and take me seriously.

Participant 14: Michelle

Michelle has been receiving treatment for thyroid disease for approximately nine years. Michelle is hypothyroid due to Hashimoto's disease. She explained, "When I was finally diagnosed in 2005 after many years of begging [doctors] to be diagnosed (numbers were "normal"), I found a female PCP to diagnose me." Michelle was very pleased with the collaborative nature of her relationship with this doctor, explaining, "She was a teaching Dr. and taught me how to read the numbers on all the appropriate tests---not just TSH, but also FT3 & FT4." However, shortly after meeting her, Michelle's doctor moved away due to a teaching position.

Michelle described the next three years as being difficult. More specifically, the doctors who Michelle saw after her doctor moved tested only her TSH level to determine her treatment plan. In addition, when she told the doctors that Synthroid was making her "feel bad," she was told, "that's all we can prescribe!!" Michelle eventually decided to discontinue Synthroid on her own and to search for a doctor who would listen to her. Michelle explained,

> I felt better not taking anything compared to taking Synthroid. It took me another 2 years before I found an Internal Medicine Dr. who would prescribe me something other than Synthroid and would test not only TSH, but also FT3 & FT4.

Michelle commented that she feels very comfortable with her current doctor because "he has made clear that he is a good listener and has my best interest at heart." Michelle expressed that she appreciates that her doctor listens to her, takes her seriously, and works with her collaboratively:

> He is very caring and listens to my needs in spite of what numbers will show at times. He has learned that my body reacts differently than others termed "normal" and is very interested in working with me to "optimize" my thyroid hormone needs.

Due to Michelle's negative experience with Synthroid (fatigue and weight gain), Michelle's doctor recently switched her to Tirosint because it is free of starch, gluten, dyes, and sugar. Michelle explained, "The switch has helped a little, however, we are still experimenting with Tirosint (which is new) to see how my body reacts." When asked whether or not the gender of her doctor is important, Michelle responded, "No----have been treated by both [male and female doctors]. Dr./Patient relationship is most important." Michelle added, "I think he is so respectful of his patients that it [also] does not matter if [the patient is] male or female."

Participant 15: Sarah

Sarah has been receiving treatment for thyroid disease for approximately eight years. Although blood tests indicated Hashimoto's disease in 1989, Sarah's doctor at the time did not believe treatment was warranted. Sarah explained,

> [My doctor] totally ignored my symptoms, any thyroid numbers but TSH, and this resulted in [many] diagnoses…and [I was] heavily medicated for each of them, on as many as twelve different prescriptions in any given day.

After struggling with hypothyroid symptoms for 17 years and developing hypertension, osteoporosis, depression, asthma, a vitamin D deficiency, sleep apnea, and high cholesterol, Sarah's doctor prescribed her a low dose of Synthroid to "reduce her cholesterol [level].” After taking the same low dose of Synthroid for five years and not feeling any better, Sarah decided to leave her doctor, conduct research, and treat herself. She explained,

> After knowing I would die if I continued this way, I started taking charge of my own health, lost over 60 pounds with better nutrition and added supplements, and gradually tapered off most unnecessary prescriptions over a two-year period…started self-treating with Thyroid replacement ordered online, treating adrenals, plus additional vitamins and supplements gradually added.

Sarah further explained, “I'm healthy and feeling good for first time in over 30 years and thrilled to be off all the over prescribed medications and no longer living in a drug induced fog.”

Sarah currently sees a PCP for general health concerns, but continues to self-treat for her thyroid disease. Sarah expressed feeling scared to discuss her thyroid disease with her PCP because her previous doctor did not listen to her or take her seriously. Rather, she “…poo-pawed anything I would bring up and [questioned] whether it was thyroid related…instead of some new disease she wanted to prescribe more medication for.” When asked whether or not she believed the gender of her doctor influenced her relationship, Sarah responded, “I think sometimes a Doctor can take advantage of us because they look at us as the 'weaker' sex,” but added, “…it really depends on the individual.” Sarah concluded, “My distrust is at such a high level after being misdiagnosed for over half of my life that it will be hard to share in the future.”

Participant 16: Shawna

Shawna began to experience symptoms of thyroid disease in 2006, but could not start treatment because, according to her Nurse Practitioner and Gynecologist, the blood tests indicated that her thyroid was “okay.” Shawna went through five doctors before finding one that she considered competent. After experiencing bouts of severe fatigue and hair loss, significant weight gain, and cold intolerance for six years, Shawna began to self-treat. Shawna explained,

> I thought since the doctors kept saying my thyroid was okay, maybe I just needed something natural as a boost, not really having a lot of information. I also was clicking on ads on the internet and read some doctor that insisted we are all iodine deficient and promoting his pills. I ordered them and took them 1 month in January 2013.

After taking the iodine pills for 21 days and not feeling any better, Shawna decided to visit a Naturopath. Based on the blood work ordered by the Naturopath, Shawna’s thyroid peroxidase antibody levels were high, which the Naturopath attributed to the iodine pills. As such, Shawna stopped taking the iodine pills. However, the Naturopath also told Shawna that Hashimoto’s disease was a “possibility.” Following the Naturopath’s instructions, Shawna began to take a low dose of levothyroxine and natural supplements for her adrenal glands. Shawna started to feel better, but lost only three pounds in three months. Therefore, the Naturopath switched Shawna from levothyroxine to compounded T3/T4. Shawna lost ten more pounds in four months.

Although Shawna was feeling better, she suspected that the Naturopath was "…basically there to promote sales at the pharmacy" and did not feel confident in the Naturopath's understanding of thyroid disease. As such, Shawna decided to ask a Primary Care Physician for his opinion:

> I had taken my labs to the primary doc's office when I went in for a tick bite, and asked him to get back with me about what he thought and whether I could switch from the compounded to something [that would] be covered by insurance, but he never got back to me. I work at a hospital and lots of people think he has gotten less caring over the years.

At the same time, the Naturopath cancelled Shawna's next appointment because "she was too busy as a school nurse." So, Shawna decided to see an Endocrinologist. However, as with previous doctors, Shawna was disappointed with the Endocrinologist. Shawna reported that the Endocrinologist was disrespectful to her:

> I start to explain [my] history…but he interrupts me at the point I say the Naturopath put me on levo and launches into a tirade about how I don't have a thyroid problem and should never have been put on meds and they will cause palpitations…hair loss and high BP etc…ignoring I have been on them 9 months with none of those problems except the high BP […] and that was high before I started the levo.

In addition, Shawna was disappointed with the Endocrinologist's understanding of thyroid disease:

> He wants me to stop [the compounded thyroid medicine] cold turkey. He says the Hashi's antibodies "just mean that someday your thyroid might completely stop working. We don't treat you unless you get a goiter. We don't treat people as they age unless their TSH is 10 or even 20."

Due to her negative experience with the Endocrinologist, Shawna reluctantly decided to return to the Naturopath. She explained that she had a plan to "…see her one more time and get more meds then figure out who to go to next." During her visit, the Naturopath recommended melatonin and theanine to Shawna to help her sleep. However, upon conducting research on these supplements, Shawna discovered that theanine can interfere with her blood pressure medication.

Having difficulty finding a doctor she felt like she could trust, Shawna asked for advice from coworkers at the hospital for which she works. Based upon recommendations, Shawna started to see a Doctor of Osteopathy (D.O.). She was pleased that the D.O. recognized and treated her low vitamin D and ferritin levels. In addition, Shawna expressed appreciation that the D.O. "…takes a lot of time" during their visits.

Although Shawna was not pleased that the D.O. switched her from the compounded thyroid medication to levothyroxine, she reported that her lab work for her thyroid has been "… the best to-date." She continued,

> I don't like that he is not open to natural thyroid and isn't testing my T3 and antibodies, but his focus on the iron and d3 seems to be right…[and] if I can do fine on the levo I don't have a problem with that.

Shawna added, “But I feel that if I hadn’t been aggressive in all my research I would have just been kept being told that my [levels were] ‘normal’ when they were clearly not.” When asked whether or not the gender of her doctor is important to her, Shawna replied, “No. I just care about their competence.”

Appendix H: Themes and Subthemes

Themes	Subthemes	Participant Pseudonyms
Doctor-Patient Relationship		
	Traditional Relationships	
	Feeling Unheard	April, Carla, Diane, Jenna, Jessica, Leanne, Sarah, Shawna
	Feeling Invalidated	Anne, April, Carla, Diane, Jenna, Jessica, Kim, Leanne, Sarah, Shawna
	Feeling Dismissed	Anne, April, Carla, Diane, Jenna, Leanne, Sarah, Shawna
	Experienced a Lack of Empathy	Emily, Jessica, Leanne, Shawna
	Feeling Disrespected	Carla, Leanne, Shawna
	Collaborative Relationships	
	Feeling Heard	Alicia, April, Autumn, Diane, Emily, Karen, Kari, Kim, Leanne, Michelle
	Feeling Validated	Alicia, April, Diane, Emily, Karen, Kim, Leanne, Michelle

		Feeling Unrushed	Emily, Kari, Leanne, Shawna
		Shared Decision making	Alicia, April, Carla, Diane, Emily, Jenna, Karen, Kari, Kim, Leanne, Michelle, Shawna
Patient Self-Advocacy			
	Health Information-Seeking		Alicia, Anne, April, Carla, Diane, Emily, Jenna, Karen, Kari, Kim, Leanne, Shawna
	Switching Doctors		Anne, April, Diane, Jessica, Karen, Kim, Leanne, Michelle, Shawna
	Belief that "Doctor Knows Best"		Karen, Kim
Doctor-Patient Communication			
	Desire to be Informed		Anne, April, Emily, Kim, Leanne, Michelle
	Role of Trust		
		Lack of Trust in Doctor	Carla, Leanne, Sarah, Shawna
		Treatment Refusal	Anne, April, Jenna, Leanne, Michelle, Sarah

Secret-Keeping	Kim, Leanne, Sarah
Self-Treatment	Anne, Carla, Jenna, Leanne, Michelle, Sarah, Shawna

Role of Gender

No Preference for Specific Doctor Gender	Alicia, Anne, April, Autumn, Diane, Emily, Jessica, Karen, Kim, Leanne, Michelle, Sarah, Shawna
Preference for Female Doctor	Carla, Jenna, Kari
Being Taken Seriously	Alicia, Anne, April, Carla, Diane, Emily, Jenna, Leanne, Sarah
Presence of Emotion	Alicia, Anne, Leanne

Culture of the Medical Profession

Diagnostic Bias

Symptoms Considered Psychosomatic	Alicia, Anne, Diane, Jenna, Jessica, Kim, Leanne
Symptoms Attributed to Lifestyle	Carla, Jenna, Leanne

Medical Knowledge

TSH Testing is Standard	Anne, Carla, Diane, Jenna, Karen, Kim, Michelle, Sarah, Shawna
Synthetic Medication is Standard	Anne, Carla, Emily, Karen, Jessica, Kim, Leanne, Michelle, Sarah, Shawna
Continuing Education May Be Needed	Anne, April, Autumn, Carla, Diane, Emily, Jenna, Jessica, Karen, Kari, Kim, Leanne, Michelle, Sarah, Shawna

Economics

Feeling Rushed	Autumn, Jessica, Leanne
Access to Doctor	Autumn, Carla, Jenna, Kari, Kim, Leanne, Michelle, Shawna
Access to Medication	Anne, April, Carla, Karen, Kim, Shawna

Additional Findings

Public is Misinformed	Diane
Experience of Grief	Carla
Experience of Empathy	Michelle
Experience of Respect	Michelle