INVESTIGATING FACTORS RELATED TO AUTOIMMUNE THYROID DISEASE (AITD) MANAGEMENT USING SOCIAL NETWORK ANALYSIS

A Dissertation

by

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ABSTRACT

Autoimmune Thyroid Disease (AITD) is a condition that quickly becomes chronic if not diagnosed and addressed promptly. It is one of the most prevalent health problems in the US. However, approximately 60% of those with AITD are unaware of their condition. Such an unawareness may be because many early AITD symptoms are mild and, therefore, are overlooked until the disease becomes acute. At this point, unfortunately, treatment may be too late. This is why early screening and more information on AITD are critical. Consequently, the gaps in the medical training and resources for AITD limit the effectiveness of health education interactions between the provider and patients. This limited effectiveness requires patients often to rely on informal support sources for knowledge about their disease and disease management strategies. Social network analysis (SNA) is both a theoretical framework and measurement approach that the provider can use to examine how the composition and structure of a patient’s social network are associated with their knowledge and management of AITD. By conducting a systematic literature review (SLR) and two SNA studies, I aim to explore individual and sociocultural factors in an AITD patients' personal network in this dissertation as they relate to the knowledge and management skills needed for AITD.

DEDICATION

All Honor and Glory be to God for the completion of this dissertation. He is good, all the time, and all the time He is good. Jeremiah 29:11, For I know the plans I have for you declares the Lord, plans to prosper you, and not to harm you plans to give you hope and a future. Trust in the Lord with all your heart and lean not on your own understanding in all of your ways acknowledge Him and He will make your paths straight (Proverbs 2:5-6). Those who hope in the Lord will renew their strength. They will soar on wings like eagles; they will run and not grow weary they will walk and not faint (Isaiah 40:31).

CONTRIBUTORS AND FUNDING SOURCES

Contributors

This work was supervised by Dr. Nicolaas Deutz and outside members: Dr. Brea Perry and Brandon Burton of Indiana University, Dr. Ledric Sherman, Dr. Beverly Irby, and Dr. Whitney Garney of Health Education and Kinesiology.

Dr. Perry and Brandon Burton contributed to methods and analyses and provided detailed feedback. Paria Tajallipour is the systematic reviews and research services coordinator at Texas A&M University who conducted the initial systematic literature review search. All other work conducted for the dissertation was completed by myself independently.

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CHAPTER I

INTRODUCTION

Autoimmune Thyroid Disease (AITD)

Autoimmune thyroid disease (AITD) is a prevalent health condition among women in the United States; further, it is a significant global pregnancy and childhood health problem (Association, 2020; Taylor et al., 2018). AITD affects an estimated 20 million Americans, with more than 12% of the population getting a thyroid disease at some point in their lives (Association, 2020). AITD is caused by unknown triggers in the immune system that cause antibodies to attack the body's own tissues rather than fight off infections. Some of the symptoms of thyroid disorders include fatigue, weight gain, puffy face, thinning hair, and increased sensitivity to cold (MFMER) . Early detection is critical, as one in eight women will develop a thyroid disorder in their lifetime. This disorder can be coupled with an undiagnosed risk of cardiovascular disorders, endometriosis, infertility, and osteoporosis (Association, 2020).

According to the American Thyroid Association, 60% of those with AITD are unaware of their condition (Association, 2020). One explanation could be that many of the associated symptoms are mild in nature and therefore are overlooked until the disease becomes acute (Beck-Peccoz et al., 2017). Unfortunately, at this point, treatment may be too late. This is why early screening and more information on prevention are critical. In 2015, researchers found substantial benefits to early detection and treatment of asymptomatic persons; however, widespread screening and treatment can also result in overdiagnosis and overtreatment (LeFevre & Force, 2015). The U.S. Preventive Services Task Force (USPSTF) found that the sparse scientific literature on prevention, detection, and training for AITD did not provide sufficient evidence to assess the benefits of pre-screening thyroid dysfunction in nonpregnant asymptomatic adults (Rugge et al., 2015).

Promoting AITD Awareness

Early screening and communication of the value of a healthy lifestyle are ways to promote AITD awareness (Helfand & Crapo, 1990; Lepoutre et al., 2012). However, researchers have shown that physicians are ill-prepared to encourage healthy lifestyles (Patel, 1999; Williams et al., 2000) that can help alleviate the symptoms of AITD in their patients. Much of what medical healthcare professionals learn about AITD comes from either standard textbooks (e.g., Kumar & Clark, 2020) or primary medical care textbooks (Kumar & Clark, 2020; Todd, 2009). Additional online resources are available for independent study on the websites of the government, professional societies, and patient support groups (Boelaert et al., 2010; Todd, 2009) rather than hands-on instruction and training. Scholars have shown that education, particularly regarding prevention and disease management, heavily relies on a combination of conversations with healthcare providers and the written materials that they have designed to strengthen a patient’s self-management capacities (Vassilev et al., 2013; Williams et al., 1998).

Furthermore, it is the medical provider's responsibility to locate and distribute these materials to the patient. Given that most providers' training is through texts and alternative sources, it is doubtful that clinicians are spreading this knowledge to their patients. Though physicians are encouraged to communicate and support healthy lifestyles conducive to AITD prevention and management with their patients, U.S. physicians reported that they encouraged healthy lifestyles in less than 34% of their patient interactions (Lobelo et al., 2009).

The provision of health education to patients is an effective way for practitioners to prevent chronic disease among their patients. Yet, health education often is not used as a tool to reduce the burdens of chronic disease (Birtwhistle et al., 2019; Jacobs et al., 2010). Consequently, the gaps in the medical training and resources for AITD limit the effectiveness of health education interactions between the provider and patients. This limited effectiveness requires patients to often rely on informal support sources for knowledge about their disease and its management strategies (Sillence et al., 2007).

Purposes of this Dissertation

Therefore, the first purpose of this dissertation was to review the current literature to determine how the medical training of health professionals affects early screening for, and detection of, AITD in the United States. In this review, I also assessed what (if any) effective training programs have been reported in the literature. By systematically reviewing the literature, I have described the training characteristics discovered to be beneficial in diagnosing and screening for AITD, such as its audience, delivery style, intervention method, and interdisciplinary training. The second purpose of this dissertation was to assess the relationship between social support within social networks and patients' knowledge and management skills for AITD. This relationship was assessed using the Social Network Analysis (SNA) to determine individual and network-level factors related to the level of knowledge and management skills for AITD that patients possess. Thus, the third purpose of this dissertation was to address this gap and analyze the connections between patients to assess their social support by using an egocentric network analysis based on the SCT.

Social Support and Chronic Disease

Social support is assistance received from an informal (friends, family, and peers) or formal (healthcare professionals and organizations) social network (Bardach et al., 2011). Since social support is an experience that involves both formal and informal relationships with others, it is often broken down into various types (Strom & Egede, 2012), such as emotional support-- the expression of feelings indicating the value and worth that is provided by sources of support (Strom & Egede, 2012); tangible support-- the concept of provisions, such as financial assistance, services, or goods (Strom & Egede, 2012); and informational support-- advice or guidance to others that helps solve problems through information (Strom & Egede, 2012).

Generally, social support is regarded as beneficial to one's health and wellbeing (Siedlecki et al., 2014; Stewart, 1993; Uchino, 2006), especially among chronic disease populations. Social support can provide chronic disease patients with a better quality of life (Sulistyraini & Andriansyah, 2019), increased patient compliance and prescribed therapies (Cohen et al., 2007), and can lead to enhanced motivation and skills for performing healthy behaviors by encouraging the promotion of healthy qualities (Heaney & Israel, 2008). For example, Kong et al., 2019 examined social support as a mediator between depression and quality of life in a population of aging Chinese adults with chronic disease. They found that social support was positively associated with quality of life in older adults, which meant older adults with higher perceived social support were more likely to have better health outcomes (Kong et al., 2019). Green et al (2018) assessed support for online health communities (OHC) for people living with chronic health conditions and found that moderating online content for OHC with high activity appeared to encourage high levels of community participation, information sharing, and mutual aid among their participants. This research is useful because Green et al. (2018) demonstrated the practical significance of online support for chronic disease patients by providing meaningful involvement, support, and information in an easily accessible environment.

Benefits of Social Support

The benefits of social support can vary based on who is providing support and the context of the support (Clark & Gong, 2000). Individuals may react differently to different persons in their network and may seek out different types of support depending on the situation they are in. For example, Gallant (2003) found that concern expressed by friends made individuals with a chronic disease feel singled out, while spousal concern was generally regarded as supportive. She suggests that a person's function within a support network might influence how a patient receives assistance. Furthermore, positive social support can assist an individual in coping with life challenges such as the diagnosis of a chronic disease (Bertera, 2005). Consequently, high levels of social support may lead to improved health, such as a higher quality of life and fewer negative physical and psychological symptoms like despair and stress (Wang et al., 2003). Thus, a better understanding of who is providing various types of support is important and how those support structures might improve patients' knowledge and management of a chronic disease.

Given the nature and complexity of AITD, the health outcomes and wellbeing of patients are contingent on proper disease management (i.e., following specific dietary and activity guidelines; Clark, 2000). Scholars have indicated that ongoing social support plays a significant role in patients’ ability to adopt and adhere to management strategies for their disease (Scannell, 2014). Bustamante et al. (2018) explored the association between social support and chronic disease management among older adults by examining the role of type 2 diabetes treatment, testing, and complications on self-management. Bustamante et al. (2018) found that social support was a strong predictor of improved management of type 2 diabetes among aging adult populations and that older adults were at risk for social isolation (Bustamante et al., 2018). They also saw social support as a key variable for health promotion in a sample of Hispanic patients suffering from rheumatic diseases (Brooks et al., 2014). According to Brooks et al. (2014), the availability of social support, particularly from partners or spouses and friends, should be included when evaluating the burden of disease because the patient may benefit from encouraging other patients to adhere to certain treatment plans for chronic illnesses. While social support and chronic disease research continue to grow, understanding which specific mechanisms and types of support within social networks are most beneficial to self-managing disease is still being developed (Ridder & Schreurs, 1996). Therefore, the second purpose of this dissertation was to assess the relationship between social support within social networks and patients’ knowledge and management skills for AITD. This relationship was assessed using the Social Network Analysis (SNA) to determine individual and network-level factors related to the level of knowledge and management skills for AITD that patients possess.

Social Network Analysis

The Social Network Analysis (SNA) is both a theoretical framework and a measuring method that can be used to investigate how the composition and structure of a patient's social network relate to their understanding and management of AITD (Perry et al., 2018; Sentell et al., 2021). Health researchers have used SNA to evaluate the relationships between a network and the environment in which it exists (Perry et al., 2018; Valente, 2010). Though some researchers have used SNA to investigate people with chronic diseases, they are few. Of the researchers who have used SNA to examine chronic diseases, most have focused on examining the effect of care management (Fattah et al., 2020; Holtrop et al., 2018) prevention and control programs (DeFosset et al., 2020; Dorjee et al., 2013; Marquetoux et al., 2016), mapping collaborative relationships among health organizations (Contandriopoulos et al., 2016; Hoe et al., 2019; Kothari et al., 2014), and friendship and loneliness (Forgeron et al., 2013; Long et al., 2019; Penninx et al., 1999).

There are two primary approaches to conducting an SNA: egocentric (i.e., personal) network research and whole network (i.e., sociometric, sociocentric, census) research (Borgatti et al., 2018). The egocentric approach assesses the network of relations surrounding individuals. It focuses on generalizing features of an ego’s personal network (Borgatti et al., 2018; Perry et al., 2018). Thus, when conducting egocentric network research, the investigator collects information from a sample of egos about themselves and their personal networks. All network information is provided through the ego, making the ego the focal point of the study (Perry et al., 2018). In contrast, the whole network approach focuses on all members that make up a defined network and assesses all the interactions existing within that network (Borgatti et al., 2018; Chung et al., 2005; Perry et al., 2018). In this case, there is no focal ego, but all members and interactions are analyzed that create the opportunity to assess individual, group, and network (i.e., structural) factors relative to health outcomes (Valente, 2010).

Social Cognitive Theory

In the absence of an effective cure for chronic diseases, there is a growing focus on improving patients’ self-management competency (Jang & Yoo, 2012). A goal of medical health professionals is to develop and provide effective interventions that are theory-based to raise patients' self-efficacy (Jang & Yoo, 2012). Theory can provide a framework for conducting health research (Bandura, 2004) and should provide sound hypotheses during the development stage of interventions (Tougas et al., 2015). The Social Cognitive Theory (SCT; Bandura,1996) is one of the most common behavioral theories that public health applies to chronic disease management (Painter et al., 2008). Many behavioral change theories that promote health (e.g., Health Belief Model, Theory of Planned Behavior) focus on behavior initiation without considering their maintenance. By contrast, SCT helps achieve the public health aim of sustaining behaviors through maintenance (Luszczynska & Schwarzer, 2015). Thus, SCT is considered a fundamental resource in many different fields such as clinical, psychological, and educational research (Luszczynska & Schwarzer, 2015). A goal of SCT is to understand how people regulate their behavior through control and reinforcement to achieve goal-directed behaviors that can be maintained over time (Sell et al., 2016). SCT comprises a wide range of traits that affect an individual's ability to change, such as goal formulation, impediments to successful self-management, and attitudes about behavioral change (Sell et al., 2016). The interpersonal theory construct of *reciprocal determinism* looks at the interactions among social, behavioral, and environmental factors to determine how they continuously influence each other (Bandura, 1997; Schunk & Usher, 2019). For instance, the ways in which individuals interpret how the outcome of their actions affects their environment and adjusts their subsequent behavior can be examined through this model. In patient populations, the application of SCT can help further the understanding of the influence of social and environmental variables (e.g., social support) and individual characteristic variables (e.g., self-efficacy, behavioral capabilities, outcome expectations, self-regulation) on disease management (Schunk & Pajares, 2009). Bandura’s SCT (1996) examined *social support*, *self-efficacy, outcome expectations*, and *self-regulation* as they are related to behavior and behavioral change.

Definition of Social Support

Social support is defined as aid from others, such as friends and family, when one is a member of a social network that is either informal (peers) or formal (healthcare professionals and organizations) (Bardach et al., 2011). Researchers have found that patients with chronic disease who perceive support from family and friends saw significant improvement in their self-management (Bustamante et al., 2018; Pamungkas et al., 2017). Additionally, researchers have shown that having a social support system is important to operationalizing self-efficacy. However, social support has yet to be studied with other variables in the context of AITD.

Definition of Self-Efficacy

Self-efficacy is the central construct of SCT and is defined as an individual's belief in their ability to exercise control over challenging demands and their own functioning (Bandura, 1997). With the growing incidence of chronic disease in the United States, patients' confidence in managing their AITD becomes crucial to living a healthy lifestyle. Thus, a patient's confidence in their ability to manage AITD on their own can determine their ability to achieve optimal health outcomes (Bodenheimer et al., 2002; Farrell et al., 2004; Lorig et al., 2001). However, according to Bodenheimer et al. (2002), self-efficacy varies depending on the circumstances surrounding the occurrence of behavior change (Bandura, 2004). Researchers have shown that self-efficacy is associated with improved health outcomes (Bodenheimer et al., 2002; Farrell et al., 2004), so it is important to determine how self-efficacy may vary based on a patient's social support network.

Definition of Outcome Expectations

Outcome expectations are dependent on the patient's self-efficacy about chronic disease management (Bandura, 2004); they are defined as an individual's belief about the possible consequences of their actions (Luszczynska & Schwarzer, 2015). Healthcare interventions that focus on improving the self-management of chronic diseases can produce positive outcomes like better management and monitoring of chronic conditions, reduced health care costs, and improved psychosocial functioning (Clark, 2000). In SCT, outcome expectations are social, physical, and self-evaluative and are dependent on the individual's self-efficacy (Bandura, 1997). These outcome expectations can serve as either an incentive or disincentive to make positive behavioral changes (Reisi et al., 2016). Iannotti and colleagues (2006) found that positive outcome expectations and their interaction with self-efficacy were significantly associated with adhering to the management of diabetes. Consequently, patients with increased confidence will have more positive outcome expectations, resulting in improved adherence to self-care strategies (Reisi et al., 2016). However, gaps still remain in the understanding and improvement of the self-management of AITD beyond the patient's behavior.

Definition of Self-Regulation

Self-regulation is a construct of SCT that focuses on behavioral change through three core components: self-monitoring of behaviors (determinants and effects), self-judgment (individual judgment of one's behavior in relation to environmental and personal circumstances), and self-evaluation (affective self-reactions; Tougas et al., 2015; Bandura, 1991). Self-regulation is a positive framework for developing interventions that address chronic disease management (Clark, 2000) primarily by helping patients improve how well they self-regulate their chronic health condition through self-evaluation, self-monitoring, and self-judgment (Tougas et al., 2015) and is influenced directly by self-efficacy and outcome expectancies (Bandura, 1997). The chronic disease research that explores self-regulation has focused chiefly on asthma (Baptist et al., 2013), arthritis (Kovar et al., 1992), and cardiac rehabilitation (Furber et al., 2010). However, AITD-specific chronic disease self-regulation has received scant attention.

Definition of Behavioral Capability

Behavioral capability is defined as the individual's level of knowledge or skill related to a behavior (Bandura, 2004; Luszczynska & Schwarzer, 2015) and is an important factor influencing self-behavior (Wu et al., 2016). Knowledge of a chronic disease is dependent on the individual’s self-efficacy and serves as a baseline for understanding the chronic disease. Wu et al. (2016) found the relationship between knowledge and self-care was positively correlated with self-efficacy. Their results indicated that knowing about a chronic disease can enhance self-efficacy, increase self-care behaviors, and implement effective disease management (Wu et al., 2016). For instance, if a patient wants to know how to manage their AITD, they must first understand what chronic disease is. This construct is usually put into practice by providing hands-on and informational training to the individual (Bandura, 2004). To assess this construct, it is essential to assess the baseline knowledge of chronic diseases within the patient population and look at the quality and the content of the communication between provider and patient.

Theoretical Framework

To understand more about AITD patients’ knowledge and efficacy for disease management, I integrated the SCT theoretical framework with an SNA approach. The

SCT theoretical framework will be used as a model to explore how and to what extent social support and self-regulation influences self-efficacy about chronic disease management to uncover potential approaches to preventing and managing AITD. Simultaneously, I used SNA to investigate how their personal network supports AITD patients. More concretely, I measured the social environment relative to SCT constructs in the study's sample. Specifically, by accounting for the relationships within a patient's egocentric network and the support provided to the patient through their network connections, I determined network patterns and structures related to their knowledge and management of disease (Patterson & Goodson, 2019). Although the application of SNA gives researchers the ability to empirically evaluate the social context of relationships (Valente, 2010), it has not yet been used in combination with SCT to examine chronic disease management. Thus, the third purpose of this dissertation was to address this gap and analyze the connections between patients to assess their social support by using an egocentric network analysis based on the SCT.

Objectives of this Dissertation

In sum, given the importance of social networks to patients acquiring knowledge, coupled with the limited AITD health education provided through the doctor-patient relationship, an examination of patients' social networks has the potential to uncover key relationships or connection points that are critical to a patient's ability to acquire knowledge about and to manage their AITD. To address these aims, the objectives of this dissertation are: (a) to systematically review the current state of the literature on what (if any) effective training of medical health professionals exists that is dedicated to early detection and screening of AITD in the United States and to add a phase 2 review that explores social support from the perspective of chronic disease; (b) to integrate the SCT theoretical framework into the application of egocentric network analysis to determine individual- and network-level factors that are related to patients' knowledge and management skills for AITD; and (c) to integrate the SCT theoretical framework into the application of an egocentric network analysis to examine and understand the relationships within the social networks that provide social support that is important to the acquisition of knowledge and the management of disease by patients.

Research Questions

Therefore, I sought to answer the following research questions:

1. How does the training of medical health professionals affect the early screening for and detection of AITD in the United States?
2. What (if any) effective training has the literature reported?
3. What individual-level factors informed by the Social Cognitive Theory, such as self-regulation, are related to a patient's self-efficacy about the management of AITD?
4. Do egocentric network variables, such as network composition, homophily, and structure, explain the variance in the self-efficacy to manage AITD among a patient population beyond individual-level factors, such as demographic variables and SCT variables?
5. What factors are related to an AITD patient connecting with someone who provides more social support?

6. Are there differences in the factors associated with providing tangible, emotional, and informational support in AITD patients' networks?

Dissertation Format

This dissertation consists of five chapters with three individual manuscripts. Chapter one's manuscript reviews the literature on what (if any) effective training of medical health professionals exists that is dedicated to early detection and screening of AITD, and chapter one explores support from a social network perspective of chronic disease. The second and third manuscripts include empirical studies of patient social networks relative to the knowledge and management of AITD. The three manuscripts represent independent chapters in the dissertation and, when coupled with introduction and conclusion chapters, fulfill the requirements of a traditional five-chapter dissertation.

The following is a description of each chapter:

- Chapter 1 is an introduction and overview of the effect of multiple ecological factors (i.e., training medical health professionals, health education, social support) that affect early screening and detection of AITD, the SCT theoretical framework, an introduction to the SNA as a theory and set of methods, and a description of the purpose and significance of this dissertation.
- Chapter 2 comprises a systematic review of the current state of the literature on what (if any) effective training of medical health professionals exists that is dedicated to early detection and screening of

AITD and explore support from a social network perspective of chronic disease. This chapter serves as the first journal article.

- Chapter 3 included the SCT theoretical framework with the SNA to document the findings of an egocentric network analysis conducted on a sample of AITD patients. This study investigates individual- and network-level factors related to the knowledge and management skills of patients for AITD. This chapter serves as the second journal article.
- In Chapter 4, I used the SCT theoretical framework with the SNA to present findings drawn from the same egocentric network analysis as in Chapter 3. However, I shifted the analytical focus from factors related to knowledge and management skills to social network relationships. Specifically, in this chapter, I examined how people with AITD are supported by their social ties. This chapter serves as the third journal article.
- Chapter 5 provides a summary of the findings from Chapters 2 through 4. Future research and practical implications are discussed.

CHAPTER II

INVESTIGATING FACTORS RELATED TO MANAGING AUTOIMMUNE THYROID DISEASE: A REVIEW

Part 1: Investigating Factors Related to Autoimmune Thyroid Disease (AITD) Management Literature Review (Training)

Introduction

Autoimmune Thyroid Disease (AITD) is a condition that quickly becomes chronic if not diagnosed and addressed promptly and is considered one of the most widespread health problems in the United States. However, approximately 60% of those with AITD are unaware of their condition (American Thyroid Association, 2020; Taylor et al., 2018). AITD affects an estimated 20 million Americans, with over 12% of the population getting a thyroid disease at some point in their lives (American Thyroid Association, 2020). AITD is caused by unknown immune system triggers resulting in antibodies attacking the body's tissues. Some of the symptoms of thyroid disorders include but are not limited to fatigue, weight gain, puffy face, thinning hair, and increased sensitivity to cold (MFMER) .

Researchers have attributed this lack of awareness to the fact that many of the symptoms are mild in nature and, therefore, are overlooked until the disease becomes acute (Beck-Peccoz et al., 2017). Physicians frequently miss thyroid dysfunction due to a lack of monitoring (Chander et al., 2020; Hueston, 2001), which is unfortunate because treatment may be too late when such cases are discovered. This is why early detection, additional knowledge, and research integration into AITD-related medical practice are crucial. LeFerve and Force (2015) found substantial benefits to early detection and treatment of asymptomatic persons with AITD and reported that widespread screening and treatment for AITD can result in overdiagnosis and overtreatment (LeFevre & Force, 2015). Early screening and communication of the value of a healthy lifestyle are ways to promote AITD awareness (Helfand & Crapo, 1990; Lepoutre et al., 2012). Nonetheless, Patel (1999) and Williams et al. (2000) showed that physicians are ill-prepared to encourage healthy lifestyles that can help alleviate the symptoms of AITD in their patients.

AITD-related health education and medical training are essential. They encourage physicians to communicate and support healthy lifestyles with their patients. However, U.S. physicians have reported encouraging healthy lifestyles in less than 34% of medical visits (Lobelo et al., 2009). Numerous factors can contribute to this deficit. According to a study by Hivert and colleagues (2016), significant factors are a lack of knowledge about various processes that affect medical conditions and a deficit in the competencies that physicians need to effectively disseminate AITD knowledge. Even though scientific evidence supports prevention and management strategies, communication of this knowledge during medical training is marginal at best (Hauer et al., 2012; Hivert et al., 2016). Thus, regarding medical training and health education, I hypothesize that some physicians feel ill-prepared and therefore lack the confidence to effectively communicate healthy lifestyles and promote early screening for AITD to patients.

Training Medical Health Professionals

Medical health professionals receive training from universities (medical schools, residencies, fellowships) within their own specialty (Burgess et al., 2020). In addition, universities have begun to add new training programs to strengthen medical health professionals' communication skills with patients (Burgess et al., 2020; Ross et al., 2020). However, Okumura et al. (2010) shows that a lack of training and resources are barriers to treating patients with chronic diseases. Consequently, there is a need for professional development in areas of teaching, facilitation, interpersonal teamwork, and assessment in the training of medical health professionals (Burgess et al., 2020). Despite this need, the literature shows that many of these programs for medical health professionals offer very little formal training regarding disease-specific factors (Bickel-Swenson, 2007; Okumura et al., 2010) and that the information that they teach is usually not well integrated into the curriculum (Burgess et al., 2020; Bickel-Swenson, 2007).

Even though some studies address the effect of early screening and detection of AITD (Hopkins et al., 2018; Okuda et al., 2009), the current state of training for medical health professionals focuses specifically on the early diagnosis and detection of AITD is poorly understood. Thus, I have conducted a systematic review to determine how the training of medical health professionals affects the early screening for and detection of AITD in the United States. This review also assesses what (if any) effective training programs have been reported in the literature. I hypothesize that medical health professionals' training and health education play integral roles in the early screening and detection of AITD.

Methods

This review aims to examine the research literature that investigates how the training of medical health professionals affects the early screening and detection of AITD in the United States. Systematic reviews are important essential contributions to research, especially for medical and health professionals, as they synthesize and assess all work related to a research question over a particular period (Bennett & Assefi, 2005; Forbes & McCarron, 2005; Patterson & Goodson, 2019). This synthesis permits the reader to better understand the breadth of research on a specific topic by gaining knowledge of existing published research (Okoli & Schabram, 2010; Patterson & Goodson, 2019). Additionally, systematic literature reviews benefit the field of health education by identifying significant new objectives for future research with the potential to generate new knowledge to facilitate evidence-based decision-making (Ng & de Colombani, 2015; Patterson & Goodson, 2019). By completing this systematic review, I will assess the literature on the training of medical health professionals and its effect on early screening and detection of AITD while also identifying critical gaps in the current body of literature. This systematic review was conducted according to the Preferred Reporting for Systematic Review and Meta-Analysis (PRISMA) (Moher et al., 2009). Reviewers have systematically surveyed the peer-reviewed literature describing educational interventions for medical health professionals and AITD. A Cochrane technology platform (Jordan et al., 2016) was used to manage the review process (Veritas Health Innovation, 2017).

Search strategy and selection criteria

A systematic literature search was conducted by a research librarian using the Ovid-MEDLINE, CINAHL, EMBASE, and Central databases between September 16 and November 17, 2020 (see Appendix A). Screening and eligibility assessments were conducted by two independent reviewers using the following criteria: physician or nurse populations that use training and education on AITD (including hypothyroidism or hyperthyroidism) as an intervention. The keywords used for the search are “autoimmune thyroid disease or AITD or Graves disease or Hashimoto’s disease or autoimmune thyroiditis,” “physician or doctor or nurse,” “medical or nursing,” and “continuing or professional education or curriculum” (See Appendix A). As this study examines medical health professionals in the United States, articles describing studies not conducted in the United States or published in English were excluded. This decision was based on the steady rise of the prevalence of autoimmune disease in Westernized societies, with the United States being third on the list of highest frequencies (Lerner et al., 2015). Uncertainties that arose during the eligibility assessment of the included studies were discussed among the authors until a consensus was reached.

Data collection process

A data extraction **table** (see Appendix B) was developed and pilot tested by the review group and refined by the research librarian. Each study was then assessed, and two reviewers extracted data from each study using the Covidence software (Veritas Health Innovation, 2017). The variables chosen to be extracted were title, citation/author information, year of publication, and the healthcare setting or the setting in which the training was provided (i.e., clinic, university). Further, I used the type, location, modality (i.e., dissemination modality), intervention strategy, and length of practitioner intervention. Another variable was whether interdisciplinary training (integrated education training and collaboration across multiple medical specialties) and key findings were used (yes or no).

Assessment of Risk of Bias

The content of the included studies was analyzed using the methodological risk of bias domains from the *Cochrane Handbook for Systematic Reviews of Intervention* (Higgins et al., 2019). All studies were assessed for risk of bias, and any discrepancies found were resolved through discussion. The studies were categorized as included or excluded based on the application of the inclusion or exclusion criteria during the overall quality assessment of the studies.

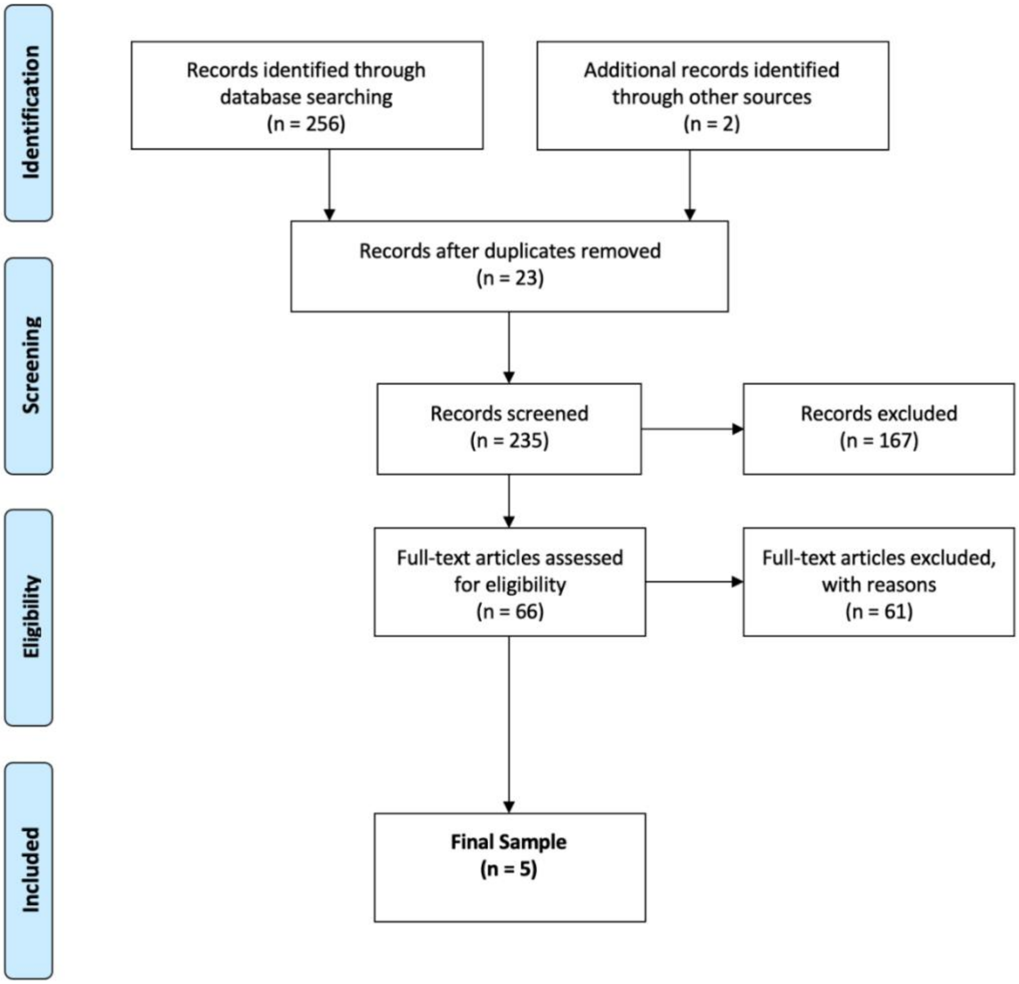
Findings

Search results and selection of studies

The initial literature search returned 256 studies that met the inclusion criteria based solely on examining titles. Twenty-six duplicate studies were removed, and 233 titles and abstracts were screened for inclusion. After screening, 167 studies were considered irrelevant as thyroid disease training and education were not examined. Sixty-six studies were chosen for a full-text review. An additional 61 studies were excluded because of either (a) the study was not specific to medical training or medical curricula; (b) the study was not a U.S.-based study; (c) the study was about patient education; not training health professionals; or (d) the study was published as an abstract, meta-analysis, narrative, or literature review. Thus, the present review is based on the results of five research articles. **Figure 2.1** illustrates the PRISMA flow diagram (Stovold et al., 2014) that resulted in our final sample of studies.

Figure 2.1

PRISMA flow diagram of studies examining the effect of training medical health professionals on early screening and detection for AITD



Study settings

The remaining five studies took place in the following healthcare settings: hospital (n=2), clinic (n=1), university (n=1), and conference (n=1). The type of practitioners were physicians (n=4) and emergency personnel, physician assistants, and residents (n=1). Information extracted from each study can be found in Appendix B.

Intervention strategy, modality, and interdisciplinary training

I extracted any methods cited as an effective intervention strategy for early AITD detection and diagnosis. Regarding dissemination modality, two studies used lectures (learning session; n=2; Dunnington et al., 1987; Houck et al., 2002) in which the participants received a training session before being evaluated. Two studies used evidence-based support tools and management toolkit guidelines (n=2; Allen et al., 1998; Haymart et al., 2010). The remaining study used medical simulation (n=1; Leviter et al., 2020).

Three studies identified interdisciplinary training as a part of their intervention strategy. They found that knowledge could be disseminated among medical health professionals across disciplines (Haymart et al., 2010, Allen et al., 1998; Leviter et al., 2020). The two remaining studies did not use interdisciplinary training.

Outcomes of training

Interdisciplinary training was useful in teaching skills needed to treat patients with thyroid disorders in three studies (n=3; Allen et al., 1998; Haymart et al., 2010; Leviter et al., 2020). Allen et al. (1998) reported that early creation of proper hypotheses improved doctors', residents,' and students' ability to index and use enough evidence to diagnose thyroid disorders; according to the authors, methods for resolving contradictory evidence varied depending on medical competence Additionally, one study focused on guidelines for managing thyroid dysfunction during pregnancy and postpartum (Haymart et al., 2010). Haymart et al. (2010) found that the number of thyroid surgeries performed was related to the number of surgeons aware of the guidelines and found that these surgeons were more likely to inform patients about the necessity for greater LT4 doses (levothyroxine, LT4) during pregnancy. Lastly, a simulation activity over thyrotoxicosis (excess thyroid hormone) was implemented for emergency medicine providers (Leviter et al., 2020). Medical providers who participated in the simulation thought it helpful in teaching the skills needed to care for postpartum AITD patients with respiratory distress or impaired mental status (Leviter et al., 2020).

Further, one study that compared the teaching effectiveness of didactic lectures and problem-oriented small groups sessions (POSGS) disseminated medical information about thyroid disease to a group of third-year medical students (Dunnington et al., 1987). They found that the POSGS had a significant edge over the didactic learner (DL) students due to the instructional teaching method of thyroid disease (Dunnington et al., 1987). They concluded that regardless of topic or evaluation technique, students in POSGS performed better on the multiple-choice exam questions than DLs (Dunnington et al., 1987). Last, Houck et al. (2002) examined a multimodality intervention for internal medicine residents between an intervention and control group. The intervention group of first-year residents received an educational session on how to examine a normal and goitrous thyroid from an evidence-based handout by an endocrinologist; the control group received no specific intervention (Houck et al., 2002). They reported a significant difference between the intervention group and the control group. They concluded that the capacity of first-year residents to recognize thyroid problems improved after a one-hour multimodality learning session (Houck et al., 2002).

Discussion

In this study, I aimed to review the literature investigating the effect of training medical health professionals on early screening and detection of AITD in the United States. For asymptomatic patients, early detection of thyroid dysfunction is essential for preventing long-term morbidity and mortality (LeFevre & Force, 2015). Consequently, widespread screening can be problematic due to labeling, false-positive results, and overdiagnosis and treatment (LeFevre & Force, 2015). Thus, health professionals must be trained adequately to detect the disease and make management recommendations.

Therefore, I examined the relevant literature on the effect of interventions to educate health professionals on the early detection and diagnosis of AITD. How this education was provided was found to be essential to ensuring that health professionals had the knowledge and tools needed for an accurate diagnosis. Furthermore, training in management strategies was also helpful for advising patients on managing symptoms and improving their quality of life.

Throughout this systematic literature review, I compiled a list of intervention strategies used to study the effects of training on AITD screening and detection. The most commonly used tools were evidence-based support tools and lecture learning sessions (Allen et al., 1998; Dunnington et al., 1987; Haymart et al., 2010; Houck et al., 2002). Evidence-based support tools provided physicians with the essential current evidence they needed to make safe and accurate management and diagnosis decisions by helping them efficiently filter large quantities of information (Allen et al., 1998). researchers have shown that evidence-based support tools such as handheld computers or protocols are useful in decision-making and can better facilitate change in expertise and attitudes when compared to teaching alone (Crabtree et al., 2017; Craig et al., 2001; Leung et al., 2003). Zinski et al. (2017) reported that evidence-based support tools positively improved medical students' educational experience with evidence-based medicine (Leung et al., 2003). Lecture-based learning was still found to be effective among medical professionals and, in some cases, preferred. Medical simulation was the intervention strategy the remaining study used. In this strategy, learners reported they were effectively taught the skills necessary for patient care (Leviter et al., 2020).

Specifically, in medical education, evidence-based medicine emerged as a solution to the challenge of screening and the incorporation of scientific evidence into medical education and decision-making (Allen et al., 1998). While medical simulation is a tool that allows medical health professionals to develop the skills and knowledge for managing acutely ill patients, it also was effective in teaching thyroid management skills by recognizing and identifying a thyroid storm in postpartum patients (Leviter et al., 2020). Although most of the literature generally speaks of the benefits of traditional training, Dunnington et al. (1987) compared didactic lectures and problem-oriented small group sessions (POSGS). They concluded that POSGS training was considerably more effective than a didactic lecture. Consequently, POSGS was effective in teaching clinical problem solving and improved communication skills (Dunnington et al., 1987), which was useful in provider-initiated patient education (Haymart et al., 2010) about thyroid detection and screening.

Lecture-based learning was discovered to be the most common intervention strategy for training health professionals in AITD diagnosis and management in this sample of studies. Some evidence indicated that lecture-based learning was effective in changing physicians' performance and the health outcomes of patients (Smits et al., 2003). It can be assumed that better performance can lead to effective prevention of AITD by better communicating diagnoses. While there has been a movement towards problem-based learning or “flipped classroom” methodologies, medical students preferred lecture-based learning (Ramnanan & Pound, 2017; Tsang & Harris, 2016). Furthermore, lecture-based instruction typically translates into acquired knowledge (i.e., passive learning) rather than active learning or skill application (Tsang & Harris, 2016). Not surprisingly, simulation-based learning, an active teaching methodology, was described as the most effective learning method by medical students and faculty members (Harris et al., 2012; Tsang & Harris, 2016). This strategy allowed students to think deeply and construct mental models, equipping them with the skills needed to make accurate diagnoses and treatment recommendations (Tsang & Harris, 2016).

Additionally, Haymart et al. (2010) found that surgeons who read the Endocrine Society guidelines on managing thyroid dysfunction were significantly more likely to inform patients about the thyroid (Haymart et al., 2010). This finding emphasized the importance of provider-initiated patient education on thyroid prevention and screening. Throughout much of the literature, interdisciplinary training is a modality associated with positive outcomes for nurses, doctors, physician assistants, or any medical health professional (Allen et al., 1998; Haymart et al., 2010; Leviter et al., 2020). Further, the studies that focused on particular modalities such as evidence-based support tools, management toolkit guidelines, and medical simulation found that interdisciplinary training using these modalities were the most effective in training medical health professionals (Allen et al., 1998; Haymart et al., 2010; Leviter et al., 2020).

This review indicated a split regarding interdisciplinary regarding training: just more than half used an interdisciplinary approach, while the other two training programs did not. The goal of training for interdisciplinary thyroid disorders is to train health professionals across all backgrounds who possess minimal knowledge and few skills in this area (Gilkey & Earp, 2006; Henrich et al., 2003). In clinical training, “significant interest has been given to conditions that reflect the overlap between areas of disciplines, which often identify gaps in education and training” (Henrich et al., 2003, p. 879). As such, interdisciplinary training, a strategy associated with positive patient outcomes, was used in three of the five studies in this review (Allen et al., 1998; Haymart et al., 2010; Leviter et al., 2020). In particular, AITD management that included lifestyle modifications achieved through a multidisciplinary approach produced a higher patient adherence rate to lifestyle changes while improving the overall health-related quality of life among patients with Hashimoto’s Thyroiditis, the most common autoimmune thyroid condition (Abbott et al., 2019). Additionally, these studies cited community pharmacists as critical partners in managing chronic disease who can serve as promoters of better medication adherence (Mossialos et al., 2015). Incorporating multiple healthcare disciplines into AITD-related training has the potential to provide a more holistic care team for patients.

Limitations

As no previous systematic reviews are available discussing the prevention and knowledge training of medical health professionals for AITD in the United States, I anticipated that this review will encourage early screening and prevention of AITD. However, some limitations did exist for this study. Although I followed the best practices for a systematic review to ensure thoroughness, I might have missed and not indexed some studies in the searched databases. To improve the comprehensiveness of the systematic review, I used strategies such as the involvement of a systematic review librarian in the development of search terms, having two researchers participate in the screening, and a cross-referencing process.

Implications for Future Research and Practice

In this study, I have examined the research literature on the training of health professionals for diagnosing and managing AITD. The review showed that the current literature was extremely limited and produced only five studies on these topics. Given the limited nature of this research on this topic, continued research on the medical training on the prevention and management of AITD is critically needed. As research on educating health professionals was limited, future research should examine the efficacy of interdisciplinary simulation-based training that includes lifestyle medicine strategies for physicians and other health professionals. (Leviter et al., 2020). Specifically, observational evaluations of training effectiveness have the potential to provide the data needed to determine which instructional modality is most effective for patients and providers. For example, evaluating the number of early diagnoses among patients post-intervention compared to pre-intervention would indicate if early detection resulted from the program.

The importance of developing trust and respect between medical health professionals and patients cannot be overstated. As AITD is seen as a complex health condition, a collaborative approach between provider and patient to help address control efforts is beneficial. The partnership between medical health professionals and patients aims to create an environment where patients possess the tools to successfully self-manage their chronic disease (Heisler et al., 2003; Montori et al., 2006). Furthermore, Tattersall (2002) has stressed the importance of patient education as a way to improve compliance and has suggested that medical health professionals need to fully understand the value of patients self-managing chronic disease. Therefore, I hypothesize that in addition to more effective training and education for providers, establishing a partnership that fosters respect and trust between patients and medical health professionals could be a key to improving the management and early detection of AITD.

Education on managing chronic disease plays a vital role in improving patient self-management (Bodenheimer et al., 2002). Though this subject was outside the scope of the current review, providing patient prevention and education on early disease detection has significant potential to improve disease self-management (Finkelstein, 2002; Jordan & Osborne, 2007). As indicated in this study, the education on detecting, screening, and diagnosing AITD has the potential to improve patients' ability to manage their chronic disease (Association, 2020; Lorig et al., 2001; Tattersall, 2002). Future training programs and studies should highlight the important concepts that patients need to understand to facilitate high-quality patient-provider communication and the adoption of effective early detection and management strategies.

Furthermore, I observed that medical training application varies across the literature. It is important to consider that these studies used surveys for data gathering focused on individual- and organizational-level interventions and that these surveys often elicited self-reflection from medical health professionals. Consequently, when examining intervention strategies at the organizational level, it would be beneficial to consider the medical school's culture as any type of intervention designed based on the results of these studies would necessarily involve curricular, policy, or programmatic changes (Cottingham et al., 2008).

The gaps in knowledge surrounding education and training protocols and knowledge dissemination between providers provide a rationale for more closely examining where and how patients are receiving information and support for their AITD. Specifically, the gaps in medical training and resources on AITD limits the interactions focused on health education between provider and patients. Therefore, patients often rely on informal support sources for knowledge about their disease and management strategies (Sillence et al., 2007). Furthermore, research shows that patients’ social networks are a primary way to disseminate information about chronic diseases (Bodenheimer et al., 2002). However, factors specifically related to patients’ knowledge and management of AITD and how this knowledge might trace social networks are less understood. Thus, social network analysis (SNA) could be an appropriate next step in AITD-related health education research. SNA could identify the interactions between patients and their social contacts in connection to the knowledge and management of a disease. This understanding may help improve the dissemination of early screening and prevention knowledge on AITD.

Conclusion

This review provides important information for medical health professionals to better meet the needs of their patients and peers. However, due to deficits in the rigor of medical training curricula, many medical professionals feel inadequately trained in the basics of clinical knowledge, specifically regarding management and diagnosis (Okuda et al., 2009). Due to this disconnect, it is critical to investigate interventions with the potential to diminish this educational gap since "effective clinical leadership has been shown to improve performance" (Hopkins et al., 2018, p. 293). Medical health professionals must be equipped with practical medical training supported during graduate education and beyond. High-quality, comprehensive training and education of medical health professionals are critical to ensuring that the appropriate patients receive early screening and detection of AITD. Overall, although the literature is limited, this study finds that the training of medical health professionals can facilitate early detection and screening of AITD through increased knowledge and skills. Thus, the prevalence of AITD in the United States and the dearth of research on this topic warrants further examination of the relationship between training and the early detection and management of AITD. Increased efforts to incorporate new training for medical health professionals are needed to evaluate the efficacy of different training modalities used to increase the early detection of AITD.

Summary of Part 1

Part 1 of this review summarizes the literature on the training of medical health professionals and health education's integral role in early screening and detection of AITD. The second part builds on this review to examine the effect of social support on the AITD population while also focusing on differences and similarities in the effect of social support on AITD. This focus leads to a summary of the literature on social support and AITD, particularly from a patient's point of view. Finally, areas for further research are highlighted.

Part 2: Investigating Factors Related to Autoimmune Thyroid Disease (AITD) Management Literature Review (Social Support)

Introduction

Autoimmune Thyroid Disease (AITD), a condition that quickly becomes chronic if not diagnosed and addressed in a timely manner, can be considered one of the most frequently occurring health problems in the United States. However, approximately 60% of those with AITD are unaware of their condition (American Thyroid Association, 2020; Taylor et al., 2018). The disease affects an estimated 20 million Americans, with more than12% of the U.S. population developing some form of thyroid condition in their lifetime (American Thyroid Association, 2020). AITD is caused by unknown triggers in the immune system, where antibodies attack the body's own tissues rather than fighting off infections. Some of the symptoms of thyroid disorders are fatigue, weight gain, puffy face, thinning hair, and increased sensitivity to cold (MFMER). AITD can take on many forms, namely, thyroid disorders or cancers, Hashimoto’s Disease, Graves’ Disease, hyperthyroidism, and hypothyroidism that lead to complications such as heart conditions, congenital defects, and enlargements of the thyroid gland (Boelaert et al., 2010). The literature (Heaney & Israel, 2008) underlines the significant relevance of social ties on health by indicating that high-quality communication can improve care, clinical results, and patient behaviors (Sustersic et al., 2018). However, the effect of patients' social networks on the dissemination and acquisition of AITD knowledge is uncertain. Given the etiology of AITD's intricacy, more measurable methodologies are required to highlight interacting elements such as social support and AITD management.

Social support is defined as assistance received from people such as friends and family, where one is a part of an informal (e.g., peers) or formal (e.g., healthcare professional and organizations) social network (Bardach et al., 2011). Social support helps provide communication and support that can serve informational, emotional, and tangible needs (Edwards et al., 2015; Lee et al., 2004). There are many types of social support, but three types are instrumental for understanding the social network of those with AITD: 1) emotional support, 2) tangible support, and 3) informational support. Emotional support promotes feelings of belonging and worth (Ford et al., 1998). Financial support, services, and material things are all examples of tangible support, and they are all linked to higher physical functioning (Strom & Egede, 2012). Finally, informational support refers to the use of data to assist others, such as providing counsel or direction to address an issue (Strom & Egede, 2012). Having access to various services can lead to improved health outcomes and self-efficacy about managing chronic disease (Taal et al., 1993; Uchino, 2006).

Some researchers have found a direct association between social support, personal relationships, and patients' quality of life (House et al., 1988). It has been discovered that people who receive emotional support feel more connected and appreciated, leading to more positive self-evaluations and self-efficacy (Cohen & McKay, 1984). In addition, a lack of genuine aid is associated with sadness and low morale (Schaefer et al., 1981). Lastly, Helgeson and Sheldon (1996) have shown that receiving information from health professionals is more beneficial than peer discussion among family and friends. Many patients, however, obtain the majority of their informational, material, and emotional support from informal sources rather than formal sources (Lee et al., 2017; Wu & Lu, 2017).

Even though researchers have studied the effect of social support on chronic disease (De Maria et al., 2018; Penninx et al., 1999; Singer & Lord, 2020), the literature that assesses the specific relationship between social support and AITD is scant. Thus, I conducted this systematic review to examine the effect of social support on AITD. In this literature review, I address the following question: Are there differences and similarities in the effect of social support on all forms of AITD?

Methods

In this review, I aim to examine the effect of social support on AITD. Systematic reviews are important contributions to research as they synthesize and assess all work related to a research question over a particular period (Bennett & Assefi, 2005; Forbes & McCarron, 2005). This systematic review was conducted according to the Preferred Reporting for Systematic Review and Meta-Analysis (PRISMA) (Moher et al., 2009). Reviewers have systematically surveyed the peer-reviewed literature to examine social support and AITD. A Cochrane technology platform was used to manage the review process (Veritas Health Innovation, 2017).

Search strategy and selection criteria

A systematic literature search was conducted by a research librarian using the following databases: Ovid-MEDLINE, CINAHL, EMBASE, and PsycINFO (EBSCO) between August 8 and August 25, 2021 (see Appendix A for specific search terms). Screening and eligibility assessments were conducted by two Texas A&M independent reviewers using the following criteria: “explores social support (tangible, informational, emotional, belonging) and autoimmune thyroid disease, which includes any thyroid disorders or cancers, Hashimoto’s, Graves Disease, hyperthyroidism, and hypothyroidism.” The keywords used for the search are “autoimmune thyroid disease,” “AITD,” “Graves disease,” “Hashimoto's disease,” “autoimmune thyroiditis,” “hyperthyroidism,” “hypothyroidism.” Additional terms are “social or emotional or tangible or instrumental or informational or belonging,” “support, psychosocial,” “social support,” “emotional support,” “tangible support,” “informational support,” and “belonging support” (See Appendix A). As I examined social support and AITD, studies not published in English and those focused on social networks (Twitter, Facebook, etc.)

were excluded. Uncertainties that arose during the eligibility assessment of included studies were discussed among the reviewers until a consensus was reached.

Data collection process

A data extraction table (see Appendix C) was developed and pilot tested by the review group and refined by the research librarian. Each study was then assessed, and two reviewers extracted data from each one using Covidence software (Veritas Health Innovation, 2017). The variables chosen to be extracted were citation/author information, year of publication, type of AITD (thyroid disorders or cancers, Hashimoto's, Graves Disease, hyperthyroidism, and hypothyroidism), type of social support (informational, tangible, emotional, belonging, instrumental), perceived adequacy of social support, subjects' experience of social support, and key findings.

Assessment of Risk of Bias

The content of the included studies was analyzed using the methodological risk of bias domains from the *Cochrane Handbook for Systematic Reviews of Intervention* (Higgins et al., 2019). All studies were assessed for risk of bias, and any discrepancies found were resolved through discussion. The studies were categorized as included or excluded based on applying the inclusion and exclusion criteria during the overall quality assessment of the studies.

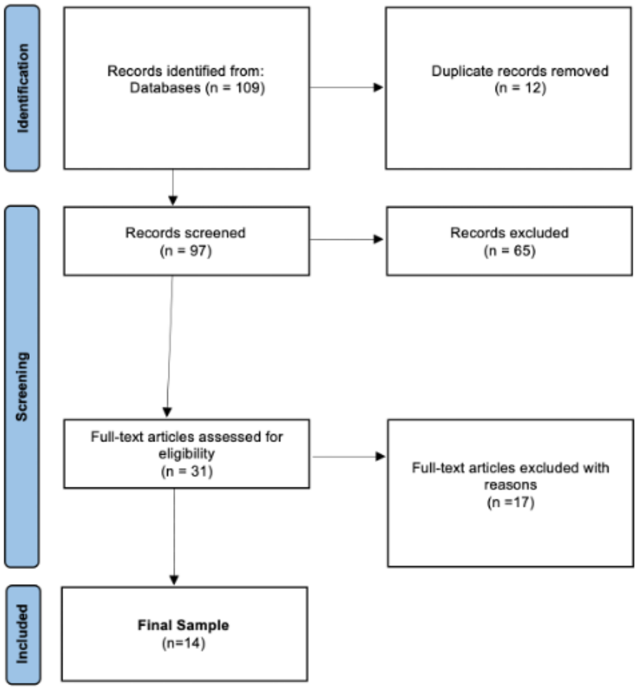
Findings

Search results and selection of studies

The initial literature search returned 109 studies that met the inclusion criteria based solely on examining titles. Twelve duplicate studies were removed, and 97 titles and abstracts were screened by title and abstract. After screening, 65 studies were considered irrelevant as social support was not examined for those with AITD and resulted in 31 studies for a full-text review. An additional 17 studies were excluded because of either (a) no association between social support, and thyroid disorder was discussed, (b) the study was not in English, (c) the study's assessment of social support was inadequate, or (d) the reviewers did not have access. Thus, the present review is based on the results of 14 studies. **Figure 2.2** illustrates the PRISMA flow diagram (Stovold et al., 2014) that resulted in our final sample of studies.

Figure 2.2

PRISMA flow diagram of studies examining social support and AITD



Autoimmune thyroid disease

Approximately 70% of studies that looked at the effect of social support on the course of AITD focused on thyroid cancer (10 out of 14). Two focused on Graves' Disease (n=2), one focused on thyroid disorder (n=1), and the last one focused on hyperthyroidism (n=1). The following sections describe the studies' findings that link social support to a type of AITD.

Thyroid cancer

Ten studies were concerned with social support and thyroid cancer. Banach and colleagues (2013) examined a broad group of thyroid cancer survivors from throughout the world to (a) analyze the effects of thyroid cancer on their lives, (b) define modern thyroid cancer care in various nations, and (c) highlight areas for improvement in thyroid cancer care. It was determined that thyroid survivors appeared to have unmet informational and emotional support needs (Banach et al., 2013; Bender et al., 2016; Pitt et al., 2019). Banach et al. (2013) also looked at the effects of psychosocial and informational support at the time of diagnosis in this study cohort. Patients indicated that they did not receive support from medical professionals at the time of their diagnosis, nor did they obtain clear written information about their treatment (Banach, 2013). However, the amount of social support received was not found to be a predictor of death from thyroid cancer.

In a study investigating feelings of disenfranchisement and support needs, they concluded that healthcare professionals did not meet thyroid cancer patients' psychosocial/emotional needs. Fear and anxiety about cancer spreading and surgical risks prompted an increased need for healthcare providers to provide emotional and psychological support (Henry et al., 2018). Further, a systematic review was conducted to examine the unmet psychosocial support needs of adults diagnosed with thyroid cancer (Hyun et al., 2016). According to this review, unmet information needs were found to be a characteristic connected with disease, particularly when it came to aftercare, and psychological needs were found to be incompletely met (Hyun et al., 2016). A qualitative study analyzing the preoperative needs of patients with thyroid cancer concluded that patients with thyroid cancer require a strong patient-surgeon relationship distinguished by informational and emotional support and respect for the individual (Pitt et al., 2019). Mirsa et al. (2013) came to a similar conclusion after studying patient experiences with local-regional thyroid cancer recurrence. The ability to cope with disease recurrence was aided by trust in healthcare providers and psychosocial support from family or social relationships (Misra et al., 2013). Lastly, nurses may improve the quality of life of thyroid cancer patients by improving social support and teaching them how to cope with troublesome symptoms on their own (Huang et al., 2004; Schultz, 2002).

The social ties of the participants were not determined in any of the ten trials. In addition, the 10 research studies found that informational, emotional, and psychological assistance were the most essential. However, there was no direct link between information support and distress that indicates this may be contingent on affecting illness perceptions (Wiener et al., 2019). Finally, a positive view of support from family and friends presaged an increase in quality-of-life scores for thyroid cancer patients (Huang et al., 2004). Lack of knowledge and inadequate advice from medical health professionals, on the other hand, was linked to poor emotional support (Roberts et al., 2008). In summary, there appears to be a constant, favorable influence on positive social support and psychosocial outcomes for thyroid cancer patients.

Graves' disease

In a Chinese population, Chen et al. (2012) investigated the association between mental health status and social factors that influence Graves' Disease (GD) patients before and after antithyroid medication treatment (ATD). The researchers discovered a substantial difference in social support and thyroid volume between patients in remission and those not in remission at the start of the study. The most plausible reason could be that the patients who were not in remission had larger thyroid glands, greater depression levels, fewer positive coping methods, and less social support before ATD (Chen et al., 2012). Social support, positive occurrences, and a good coping style were indicated to be protective factors that predicted remission after ATD treatment and protected against mental health deterioration in this study (Chen et al., 2012). As a result, Chen et al. (2012) discovered that social support and the development of positive coping skills were significant in enhancing mental health in GD patients. In a similar study, Yoshiuchi and colleagues (1998) investigated the association between the short-term outcome of GD (assessed 12 months after ATD) and psychosocial factors such as coping skills and social support. They found that psychological stress was associated with the course of GD in women. However, they did not provide direct evidence for a causal effect of social support on GD occurrence was provided.

Consequently, these two studies (i.e., Chen et al., 2012; Yoshiuchi et al., 1998) included selected populations of newly diagnosed GD or GD that were in remission. Chen and colleagues (2012) discovered that the perceived adequacy of social support and psychological components of social support have positive benefits (Chen et al., 2012). Patients who received more social support had a better prognosis without compromising their employment performance or social standing (Chen et al., 2012). Lastly, receiving social support from families and organizations improved mental health, and increased social support had the potential to enhance the remission rate among GD patients taking ATD (Chen et al., 2012; Yoshiuchi et al., 1998).

Thyroid disorder

Shiue (2015) was the only researcher who focused on thyroid disorders. Shiue looked at the prevalence of unmet emotional support in the United States to determine if there were a link between environmental variables and thyroid disorders. Data from 6,733 American adults were retrieved from the U.S. National Health and Nutrition Examination Survey to evaluate the incidence of unmet emotional support in America and see if there is a link between environmental factors (2005-2008). Of this group, 1,273 Americans reported needing more emotional support in the past year (Shiue, 2015). Female Mexican Americans between the ages of 40 and 60 showed the most significant need for emotional support. However, people with thyroid disorders were also among those who reported they needed more emotional support than they had received in the past year (Shiue, 2015). Shiue (2015) found that adults who needed emotional support for their health conditions appeared to account for 5-22% of the population attributable risk (PAR).

Further, Shiue (2015) found that the primary indicators of emotional support appeared to be the rate of the disease occurrence and demographic factors. Shiue (2015) hypothesized that persons diagnosed with a chronic illness, such as diabetes or thyroid disease would require more emotional support than usual to maintain their existing lifestyle. The effect of social network characteristics on the occurrence of thyroid disease appeared to be stronger in middle-aged women. There was no direct evidence for the perceived adequacy of social support. They concluded that persons with a history of thyroid disorders could benefit from removing environmental contaminants and better health care that included emotional support (Shiue, 2015).

Subclinical hypothyroid

According to the sole study of subclinical hypothyroid patients, having more information about their disease improved their ability to self-manage their condition (Zdanowska et al., 2010). It found a correlation between the request for information about hypothyroid, treatment, and emotional support (Zdanowska et al., 2010). Patients with thyroid disease who reported obtaining information were concerned about emotional support, explanation, and reassurance (Zdanowska et al., 2010). Patients with hypothyroidism were also anxious about investigation and therapy that indicated a lack of message and emotional support in providing patients with tailored information (Zdanowska et al., 2010). According to their findings, a definite correlation exists between the information patients receive and their emotional condition (Zdanowska et al., 2010).

Discussion

The purpose was to explore support from a social network perspective of chronic disease in the peer-reviewed literature. Seven articles looked at informational support (n=7), three that looked at emotional support (n=3), two that looked at two types of social support (informational and emotional; (n=2)), and two that looked at four types of social support (informational, emotional, tangible, and belonging; n=2). In 9 of the 14 investigations, I discovered that perceived social support was the most essential element in accounting for the favorable benefits of social support. Positive social support was found to have the greatest impact on the course of the disease in eight out of fourteen studies (n=8), independent of the kind of AITD. There was enough data to support a positive effect on subjective health indicators such as quality of life (n=7), mental health (n=5), and cure rates (n=3). Improved mental health and a better prognosis were linked to functional measures of the amount of support and a more favorable course in the AITD disease. This could be partly because these patients may be able to alter the course of their illness by leading healthier lives and practicing better self-care.

A scope of autoimmune thyroid disease

To determine any differences and similarities between the various AITD disorders, I examined the scope of AITD disorders stated above. In terms of its effect on AITD progression, I conclude that social support accounted for a wide range of outcomes. The subjective emotions of social support were more relevant than social support measures. Lastly, the perceived adequacy of social support was consistently linked to a better prognosis of the illness, regardless of the type of AITD.

Perceived adequacy of social support

Positive social support was consistently linked to better outcomes in thyroid cancer patients. Regardless of the numerous types of AITD diseases, there was strong evidence that social support improves subjective health markers, such as quality of life, mental health, and cure rates (Chen et al., 2012, Huang et al., 2004). Furthermore, perceived social support positively affected more objective health metrics measurements among patients with Graves' Disease (Chen et al., 2012). According to the findings of this study, poor social support has a broad yet particular effect on the progression of AITD. The perceived adequacy of social support appears to be influenced by specific elements relating to disease features such as prognosis or newly diagnosed patients (Zdanowska et al., 2010). This influence could be attributed to newly diagnosed patients having fewer positive coping strategies, less social support from family and friends, and insufficient information about diagnosis and treatment options (Chen et al., 2012; Zdanowska et al., 2010). Chen et at., (2012) found that social support, negative events, and positive coping styles were protective factors that predicted a cure after ATD treatment. Finally, AITD patients who received greater social support had a better ability to self-manage, which could improve their disease prognosis.

Social support and disease progression

Objective evaluations of the quantity of emotional, psychological, and informational assistance were used to gauge social support. Graves' Disease had the only general influence on disease progression (Chen et al., 2012; Yoshiuchi et al., 1998). Patients who received more social support had improved mental health and improved patient prognosis (Chen et al., 2012; Yoshiuchi et al., 1998). However, in thyroid cancer, subclinical hypothyroid, and thyroid disorder, unmet emotional and informational supports were characteristics connected with the prognosis of the disease (Hyun et al., 2016; Henry et al., 2018). This connection could be linked to the psychological typology of AITD, which is usually consistent following diagnosis (Shiue, 2015; Chen et al., 2012). Patients with these illnesses feel they live in an “information age.” Yet, they do not always understand the information provided to them about their particular disorder (Schultz, 2002). At the time of diagnosis, patients reported that they did not receive adequate information about their disease or clear written information about their treatment and that healthcare practitioners did not meet their psychosocial and emotional needs (Banach, 2013; Henry et al., 2018; Hyun et al., 2016). However, misunderstandings and a subjective lack of knowledge, on the other hand, may result from a different limitation in perception, particularly when thyroid disease is present (Zdanowska et al., 2010). In conclusion, Graves’ Disease had the sole overall influence on disease progress that could be partly related to the disease going into remission following ATD treatment, leading to improved adherence and self-management (Chen et al., 2012; Yoshiuchi et al., 1998).

Limitations

I believe that our study will draw greater attention to the problem and emphasize the need for future research in this area because there have been no prior systematic evaluations assessing the influence of social support on AITD. This study does, however, have significant drawbacks. Although I followed recommended procedures for conducting a systematic review to guarantee accuracy, I may have overlooked certain papers not indexed in the databases I searched. I employed approaches such as having a systematic review librarian help select search keywords, having two researchers engage in each step of the review process, and cross-referencing to increase the comprehensiveness of the systematic review. The limited number of publications accessible for each form of AITD is another possible and inevitable disadvantage (apart from cancer). This restricts the ability to draw conclusions that can be applied to a wide range of AITDs. Finally, it was challenging to acquire a comprehensive picture of social support in many AITD illnesses since many of the studies in our review focused on just one kind of AITD, thyroid cancer.

Future Research

To date, published research from investigators has focused on social support in the chronic disease population; however, studies are scarce on the social support among AITD patients. Future research should look at all the types of social support (tangible, informational, emotional, belonging) suggested in this review to quantify social support among distinct populations of people with AITDs. The studies reviewed here did not provide much insight into different sorts of social support at different times. As a result, future researcher should concentrated on this topic. Finally, scholars could compare the effect of social support on various AITD disorders. It was difficult to gain a broad picture of social support in diverse conditions of AITD because most of the researchers in this review focused on just one type of AITD, thyroid cancer. More importantly, the varied effects of social support in relation to disease characteristics are essential to fully understand the influence of disease characteristics.

CHAPTER III

EGOCENTRIC NETWORK ANALYSIS ASSESSING FACTORS RELATED TO A PATIENT HAVING HIGHER KNOWLEDGE AND SELF-EFFICACY ABOUT MANAGEMENT SKILLS RELATED TO AITD

Introduction

Autoimmune Thyroid Disease (AITD) is a prevalent chronic disease that targets the immune system and is estimated to be present in 5% of the world's population (Antonelli et al., 2015). It affects approximately 20 million Americans (American Thyroid Association, 2020; Fairweather & Rose, 2004) and is caused by genetic and environmental triggers in the immune system, where antibodies attack the body's own tissues rather than fighting off infections (Yoo & Chung, 2016). However, up to 60% of those with AITD disease go undiagnosed (American Thyroid Association, 2020). One explanation could be that many of the symptoms are mild and overlooked until the disease becomes acute (Beck-Peccoz et al., 2017). Thus, it is vital to investigate factors related to the knowledge and self-efficacy about managing AITD.

Self-management support, or the help given to those who have a chronic disease (Support), is one strategy that helps patients identify and solve challenges associated with their own chronic disease (Grady & Gough, 2014). Self-management support has been most successful when focused on individually centered behavioral change outcomes (Vassilev et al., 2013), such as increased activity and exercise, good nutrition, and stress management. For example, a systematic review of self-management support interventions in chronic disease patients found that patient-centered activities (e.g., enhancing physical activity) effectively reduced complications or reactivation of diseases that could shorten the quality of life and cause mortality (Massimi et al., 2017). This is consistent with research studies that have emphasized the provision of competent self-management and knowledge to decrease chronic disease-related distress and self-management behaviors (Audulv et al., 2012; McEwen et al., 2010). In addition, the management of chronic AITD is fundamentally different from acute care as it comprises early detection of thyroid dysfunction and timely referral of clients to specialists, a combination of pharmacological and psychosocial intervention, as well as regular monitoring and adherence to treatment (Beaglehole et al., 2008; Birtwhistle et al., 2019).

The literature has shown that patient education, particularly regarding prevention and disease management, heavily relies on a combination of conversations with healthcare providers and written materials designed to strengthen a patient’s capacities to self-manage (Vassilev et al., 2013; Williams et al., 1998). However, researchers have also shown that training on prevention and management strategies during medical education is minimal at best (Hauer et al., 2012; Hivert et al., 2016). This limitation creates a gap between the provider's knowledge and communicating with a patient. In fact, while medical health professionals are encouraged to communicate and support healthy lifestyles and be a source of information to their patients, physicians practicing in the United States reported encouraging healthy lifestyles in less than 34% of their patient contacts (Lobelo et al., 2009). Organizations such as the American Thyroid Association (ATA) continue to provide information on the treatment, management, and prevention of AITD (Orloff et al., 2018) as a component of continued efforts to support the patient, but support from a provider is a critical link missing for the patient. Thus, patients often seek further health information from outside the healthcare system by looking to family members and friends for further explanation and support (Ayers & Kronenfeld, 2007; Carlsson, 2000; Rosland et al., 2013).

Social Support and Social Network Analysis

Social support is defined as the assistance that patients receive from other people such as friends and family, where one is informal (peers) and the other is a formal (healthcare professional and organizations) social network (Bardach et al., 2011). Social support can positively affect health outcomes for those with chronic disease through many different mechanisms, such as patients' increased perception of quality of life, increased access to health care, and increased compliance with prescribed therapies (Cohen et al., 2007). For example, positive social support can help an individual cope with life transitions (Beretta et al., 2005), such as chronic disease diagnosis. Additionally, social support provides individuals with social needs such as emotional understanding, affection, and acceptance (Beretta et al., 2005). High levels of social support may create a more positive health status, including a better quality of life with less negative physical and psychological symptoms such as depression and stress (Wang et al., 2003). Lastly, social support can mediate self-management practices and health outcomes (Strom & Egede, 2012).

Categorical types of social support are emotional, tangible, and informational. Emotional support fosters an experience of belonging and being valued (Ford et al., 1998). It is important for AITD patients because recent research has shown that emotional support can decrease mortality rates among those with chronic disease illness (Reblin & Uchino, 2008) and improve symptom management (Kowitt et al., 2015). Tangible support is the concept of provisions, such as financial support, services, and material goods. It is associated with better physical functioning (Strom & Egede, 2012) and directly links a patient to necessary resources. Tangible support is associated with increased self-esteem and increased optimism on social support (Symister & Friend, 2003) and increased psychological well-being (Coffman, 2008). Lastly, informational support describes the use of information to help others, such as giving advice or guidance to solve a particular problem (Strom & Egede, 2012), that is often received from both formal (e.g., health care provider) and informal (e.g., friend or family member) sources of support. Given the health implications of AITD, it is important to study all three types of social support to understand the role each type plays for those with AITD. Furthermore, there is a widely recognized need for further investigation into the mechanisms that support self-management and whether these relationships vary based on certain factors (e.g., types of support; (Gallant, 2003)). One particular method that can be used in such an investigation is the Social Network Analysis (SNA). SNA is a methodological tool that studies have used to examine the role of social support in various clinical populations (Wasserman & Galaskiewicz, 1994), such as people with diabetes (DeFosset et al., 2020; Raghavan et al., 2016), coronary heart disease (Berkman, 1982), stroke (Nagayoshi et al., 2014), and cancer (Koehly et al., 2003;

Luque et al., 2010). Given the importance of social support, it is essential to look at factors related to a patient’s social network.

The SNA is a methodological technique that measures the structures of a patient’s social relationships when formed between individuals and groups (Scott, 2017; Valente, 2010). Specifically, a *social network* is defined as a set of socially relevant members (i.e., nodes) connected by one or more relations (Marin & Wellman, 2011; Patterson & Goodson, 2019). Studies have used the SNA to explore a variety of public health topics, such as diabetes (Ostovari et al., 2019), sobriety (Patterson et al., 2020), and care management (Holtrop et al., 2018). SNA is traditionally comprised of two analytical approaches: egocentric and whole network research (Valente, 2010). The egocentric approach is particular to the perspective of the individual (patient) or ego. This approach is used to understand the ego’s social environment that consists of their closest and most personal ties (i.e., alters; (Scott, 2017). To gain an in-depth understanding of the ego and its personal network, the ego may be asked to name alter egos it feels most close to and characteristics about each alter ego they nominate (e.g., relation to the ego; gender). The ego may then be asked to report on their own behaviors, and the behaviors of their nominated alter egos. Whole network research is an approach that attempts to account for an entire, defined network that comprises all relationships between individuals within a given environment (e.g., patient clinic, college sorority) (Valente, 2010). In the whole network research, each member of the network may be asked to describe their connections and behaviors to any of the other individuals located within the whole network and report on their own behaviors (Valente, 2010).

Studies have used egocentric and whole network research to demonstrate the importance of social contacts within a chronic disease patient's network and how important health behaviors and outcomes, including management skills, can be influenced by or transferred across social ties. For example, Vassilev and colleagues (2013) used a social network approach to explore self-management support within peoples' social networks. Three hundred people with a chronic illness were randomly selected from economically deprived areas and asked to map social network members in response to the question, "Who do you think is most important to you in relation to managing your condition?" The study results indicated partners and close family members made the most significant contributions to self-management support in these patients' networks. However, there was evidence of input from an extensive range of relationships, such as distant family members and friends. They also found that those who did not have a partner relied on others to contribute to management support more than those with a partner (Vassilev et al., 2013). Lastly, they concluded that the level and type of input given by individuals might change based on circumstances (Vassilev et al., 2013), such as an extraordinary crisis or being sick for a short amount of time which required temporary short-term assistance from others (Vassilev et al., 2013).

Furthermore, care managers and other healthcare professionals are becoming more prevalent in primary care practices (i.e., primary care networks; (Holtrop et al., 2018). Holtrop and colleagues' (2018) analyzed if care managers play a key role in chronic disease management within the practice network. They examined communication about chronic disease management within 24 practices in Colorado and

Michigan. Survey questions were designed to evaluate the communication dynamics on chronic disease care within a practice. The survey questions also assessed the culture and quality of care of each practice. The results indicated that when a care manager is located within a patients' provider network, they are more likely to be the center of communication for patients (Holtrop et al., 2018). Meaning care managers co-located in a practice are more likely to be part of the communication network than those not centrally located. These findings support the assertion that care managers have the capacity to serve as the hub of communication within a patient's network that streamlines and simplifies the information for patients (Holtrop et al., 2018) and demonstrates the utility of the SNA in the design of future care delivery models.

Last, the Los Angeles Diabetes Prevention Coalition has used the SNA as a guide to planning diabetes prevention strategies (DeFosset et al., 2020). By examining network structures and positions of organizations within the coalition and how organizations were perceived by others within the network (DeFosset et al., 2020), researchers were able to create an informed plan for the coalition. They identified several coalition-building actions, reviewed the quality and quantity of partnerships, and analyzed interorganizational connections to optimize the prevention programming strategies implemented by the coalition (DeFosset et al., 2020).

As mentioned earlier, because medical training on educating patients on disease management is limited, patients likely use their social network for support and information related to their illness (Boelaert et al., 2010; Hauer et al., 2012; Hivert et al., 2016; Todd, 2009). Furthermore, studies have shown the importance of network members in providing social support for a person with a chronic disease (Gallant, 2003; Strom & Egede, 2012). As such, it is important to explore AITD management from a network perspective. Network measures like homophily entail forming bonds with others similar to you (Perry, 2010). Findings suggest there are strong effects for homophily in health behavior (Centola, 2011), which is especially true in social networks of older adults (Flatt, Agimi, & Alber, 2016). While the SNA has been successfully applied to the study of chronic disease management generally, the research on the factors present in AITD patients' personal networks, particularly as they relate to the knowledge and management of the disease, is limited.

Research Questions

Thus, the purpose of this study is to examine the patient and network-level factors related to having higher levels of knowledge and self-efficacy about the management of AITD. I aim to answer the following research questions:

1. What individual-level factors informed by the Social Cognitive Theory, including self-regulation, are related to a patient's self-efficacy about the management of AITD?
2. Do egocentric network variables, including network composition, homophily, and structure, explain the variance in the self-efficacy about the management of AITD among a patient population beyond individual-level factors, including demographic variables and Social Cognitive Theory variables?

Methods

Participants and Procedures

A survey was issued in August 2021 to explore patient and network-level characteristics connected to a patient having a greater level of knowledge and self-efficacy about AITD care. This survey was given to patients at the Aspire Health Clinic in Kansas City, Missouri. This clinic was recognized as one of the few in Kansas City specializing solely in AITD. Many of the patients who come to this clinic have been diagnosed with a thyroid disease and have a close relationship with their primary care physician. After assessing the *Qualtrics* link, patients reviewed the details concerning the study's purpose. Once consent was given, the survey participants were asked about their demographic, personal health attributes (i.e., self-regulation, knowledge of chronic disease), and egocentric network information. The primary physician and graduate student who conducted this research communicated this survey to potential participants. The primary physician and owner of Aspire Health Clinic was chosen due to her specialization in autoimmune thyroid disease. The survey was communicated via word of mouth, mass email distribution, and flyers posted on social media pages. The sampling approach was convenience sampling of AITD patients at Aspire Health Clinic to investigate elements prevalent in AITD patients' personal networks, particularly related to AITD knowledge and management. Patients who took part in the study were not reimbursed after completing the survey. Through this investigation, the following research topics were addressed:

What individual-level factors informed by the Social Cognitive Theory, including self-regulation, are related to a patient's self-efficacy about the management of AITD?

Do egocentric network variables, including network composition, homophily, and structure, explain the variance in the self-efficacy about the management of AITD among a patient population beyond individual-level factors, including demographic variables and Social Cognitive Theory variables?

The Texas A&M University Institutional Review Board approved the protocol and materials before data collection. All data were collected were anonymous, and the survey instrument did not ask for identifying information. Once data had been cleaned and checked, data were kept in a password-protected folder only accessible by the research team and is stored for a minimum of three years post completion of the research.

Inclusion criteria

Participants were requested to participate in the study provided they met certain inclusion requirements, including being above 18 years of age and having Autoimmune Thyroid Disease, which covers any thyroid condition, Hashimoto's, Graves Disease, hyperthyroidism, and hypothyroidism. Participants were excluded if they were under the age of 18 and did not have Autoimmune Thyroid Disease, which was defined as any of the preceding symptoms.

Network Survey Design

The survey contained a series of questions about AITD knowledge and management within a patient's social network to assess a patient's self-efficacy for AITD management. It was completed at a time and place convenient for the participant. The poll was conducted online between August and October 2021 using Qualtrics Software. The primary physician originally sent the survey to clinic participants via email and social media, encouraging them to participate and complete the survey. This type of survey, known as an “egocentric network survey,” includes demographic data and asks participants about person health attributes (i.e., self-regulation, knowledge of chronic disease) and their egocentric network information.

At the start of the survey, participants were provided with details concerning the study’s purpose and were required to indicate consent to participate before advancing to the survey questions. A 26-question survey was asked to elicit knowledge related to risk factors leading to chronic disease (e.g., the following blood pressure is considered to be high: 140/90). The Self-Efficacy for Management of Chronic Conditions survey asked participants about their confidence in managing their chronic disease. These questions were answered on a scale of one to ten, with one being "not at all confident" and ten meaning "completely confident." The responses revealed the participant's personal self-efficacy in dealing with their AITD. To measure the self-regulation of participants with AITD, participants indicated on a 5-point Likert scale how much they agreed or disagreed with a statement (e.g., I have a hard time setting goals for myself). Participants provided information about their ability to control their behavior to achieve their self-management goal of AITD. It was assumed that if participants reported high self-regulation scores, their self-efficacy for managing AITD would be higher (Wilson et al., 2020). In other words, strong self-regulation scores are associated with self-efficacy to improve adherence to chronic illness treatment (Wilson et al., 2020).

Data Collection

A flyer was posted to Aspire Health Clinic’s social media pages on August 9, 2021. The flyer included a link to the survey and a brief description of the purpose of the survey. The initial email inviting participants from Aspire Health Clinic to participate in the survey was sent on 17 August 2021. The email included the purpose of the survey, instructions on how to complete the survey, and the survey link. Every third day, a survey flyer was placed on the clinic's social media for three months. Follow-up posts were issued to the social media pages on August 25, 2021, to remind people to complete the survey. A live video was released to social media on September 15, 2021, encouraging patients to participate in the survey. The study's primary physician and graduate student planned an interactive webinar on September 30, 2021, to encourage participants who had not yet completed the survey to do so. Because many participants suffered from the coronavirus-19 (COVID-19) epidemic, data collection was prolonged until October. On October 5, 2021, the participants received a reminder email. On October 14th, the lead physician posted the last social media post, and the survey ended later that day. Ninety-nine participants took part in the study.

Data Analysis

Data from the survey were extracted from Qualtrics© software in a Microsoft Excel© file. The file contained raw data of the current survey response. Two files were created from the responses extracted. The files contained individual data and network-level data for each participant. All analyses were carried out using R software and relevant R packages (R Core TeamAnalysis). Table 3.1 describes the study's key network measurements, separated by variables.

Measures

Demographics

Respondents were asked to report their age, gender, race/ethnicity, and relationship status (e.g., married, dating, engaged, single).

Knowledge of Chronic Disease

The Chronic Disease Knowledge (CDK) Questionnaire was used to assess the patient's knowledge of lifestyle-related risk factors of AITD (Frantz, 2008). The CDK is a 26-question survey instrument eliciting knowledge related to risk factors leading to chronic disease (e.g., the following blood pressure is considered to be high: 140/90). Response choices on the knowledge scale are 1= yes, 2= no, and 3 = I do not know. Each statement is scored so that higher values reflect more complete knowledge. Other studies have reported a Cronbach's alpha coefficient of 0.8 that indicates a valid and reliable instrument to assess knowledge of chronic disease risk factors (Agarwal et al., 2019; Biraguma et al., 2019; Frantz, 2008).

Management of Chronic Disease

The Self-Efficacy for Managing Chronic Diseases 6-Item Scale (SES6G) was used to assess a patient's confidence in doing certain activities (Obeid et al., 2013). Scoring on the SES6G ranges from 1=not at all confident to 10=totally confident. The total score of the scale is the mean of the six item scores. The mean allows for a maximum of two missing item responses. A higher number indicates higher levels of self-efficacy. Studies have reported that the SES6G effectively assesses patients' self-efficacy about managing chronic disease (Freund et al., 2013; Gruber-Baldini et al., 2017; Hu et al., 2013). The SES6G demonstrated good convergent construct validity and high internal consistency with Cronbach's alpha at 0.930 (Freund et al., 2013).

Short Form Self-Regulation Questionnaire

The Self-Regulation Questionnaire (SSRQ) is a 31-item self-report test of one's ability to control behavior to attain one's goals (Neal & Carey, 2005). The scale uses a 5-point Likert scale, and the participants rated how much they agree with each item: 1 (Strongly Disagree), 2 (Disagree), 3 (Uncertain or Unsure), 4 (Agree), and 5 (Strongly Agree). The total SSRQ score is the sum with higher scores representing high (intact) self-regulation capacity (≥ 120), middle scores representing an intermediate capacity to self-regulate (107-119), and low scores representing a low capacity to self-regulate (≤ 106). The SSRQ is considered a reliable and accurate way to measure self-regulation and has high internal consistency, as shown by the Cronbach's alpha coefficient of 0.87 (Carey et al., 2004; Šebeňa et al., 2018).

Medical Outcomes Study Social Support Survey

The Medical Outcomes Study Social Support Survey (MOS-SSS) was used to measure various dimensions of social support (Sherbourne & Stewart, 1991). MOS-SSS is a 19-item multidimensional, self-administered instrument developed for patients in the Medical Outcomes Study (MOS). A modified 13-item survey assessed emotional, informational, and tangible social support. The scale is a 5-point Likert scale (e.g., 1= None of the time, 5 = All of the time). The mean item response was obtained for each scale to obtain a score for each subscale. The average score for all 13 items was calculated to obtain the overall support index. The scale scores were then transformed to a 0-100 scale, with higher scores indicating more support (Sherbourne & Stewart, 1991). The MOS-SSS yielded reliable and accurate data and had a high internal consistency, as shown by a Cronbach's alpha coefficient of 0.94 (Dafaalla et al., 2016; Griep et al., 2005; Zucoloto et al., 2019).

Egocentric Network Data

Two types of questions were asked to assess egocentric networks: 1) name generator and 2) name interpreter questions. Name generators asked the ego to list the initials of up to five network members with whom they discuss important health matters (Perry & Pescolido, 2010). Name interpreter questions asked the ego to provide information about and qualify the relationship with each alter ego (e.g., gender, length, and type of relationship). Through the name interpreter questions, egos reported their relationship with each alter ego (e.g., friend, parent); each alter ego's gender; frequency of communication with each alter ego (7=everyday, 6=3-6x/week, 5=1-2x/week, 4=1-

2x/month, 3=1-2x/year, 1=less than once/year, 0=Never).; most common method of communication (e.g., in-person); if the alter ego has AITD (yes, no, unknown); and if the alter ego is supportive of the ego’s health goals (0=Never, 1=Rarely, 2=Sometimes, 3=Most of the time, 4=Always).

Analytic Strategy

Ego-Network Analysis (E-Net) software (Borgatti, 2006) was used to calculate the standard egocentric network measures: homophily, heterogeneity, network composition, and structural holes. In our investigation, I was interested in which individual (e.g., age, race/ethnicity, knowledge) and network level (e.g., network density; network composition of AITD patients) factors were related to an ego having higher levels of AITD knowledge about and belief in self-efficacy about chronic disease management.

Descriptive statistics and ordinary least squares regression for continuous outcomes that predict self-efficacy about chronic disease management were calculated using Stata. Ordinary least squares regression models were assessed in three blocks. The first block of variables consisted of all ego-level factors: gender, age, race and ethnicity, relationship status. The second block added knowledge of the chronic disease and self-regulation scores. The third block assessed network-level variables, including network compositional variables. Tests for multicollinearity were computed on all independent variables with variance inflation factors ranging between 1.030 and 1.304 that indicated no issues with multicollinearity in these models.

Results

Descriptive Statistics

In the final sample of 99 patients, 15% (n=12) were not dating, 1% (n=1) were dating several people, 19% (n=19) were dating one person exclusively, 1% (n=1) were engaged, 43% (n=43) were married, 1% (n=1) were married but separated, 13% (n=13) were divorced, and 9% (n=9) were widowed; the sample had an average age of 58.2 years old (SD=16.15). A large majority, 76.8% (n=76), of our sample were female and 23.2% (n=23) were male. Nearly 85.9% (n=85) were White, 6.0% (n=6) were Black, 3.0% (n=3) were Asian, 4% (n=4) were Biracial or Multiracial, and 1.1% (n=1) was American Indian. All the patients (n=99) had AITD, which was required to participate in the study. Knowledge of chronic disease scores ranged from 2 to 23 with an average of 16.9 (SD=4.02); 39% (n=39) had good knowledge, 46% (n=45) adequate knowledge, and 15% (n=15) had poor knowledge. The average self-efficacy score was 6.3 (SD=2.11, range 1-10), which falls within the mildly confident range (from 4-7). The sample registered a mean self-regulation score of 109.6 (SD=20.82). The following ranges for interpreting self-regulation total scores was ≥120 High (intact) self-regulation capacity, 107-119 intermediate (moderate) self-regulation score, and ≤low (impaired) self-regulation capacity. These samples had 37% (n=37) with high (intact) self-regulation capacity, 22% (n=22) with intermediate (moderate) self-regulation capacity, and 41% (n=40) with low (impaired) self-regulation capacity. Lastly, 61.8% of the network is the same gender as the ego (female), and 45.8% of the network communicates with their nominated alter egos in person. The average size of the network was 3.2, meaning that the egos nominated on average 3 people. See Table 3.1 for the descriptive statistics.

Table 3.1

Descriptive Characteristics of the Sample

Variable	N	%	M	SD
Age			58.23	16.15
Gender				
Male	23	23.2		
Female	76	76.8		
Relationship Status				
Not Dating	12	12.1		
Dating Several People	1	1.0		
Dating One Person Exclusively	19	19.1		
Engaged	1	1.0		
Married	43	43.6		
Married But Separated	1	1.0		
Divorced	13	13.1		
Widowed	9	9.1		
Race/Ethnicity				
White	85	85.9		
Black or African American	6	6.0		
American Indian or Native American	1	1.1		
Asian	3	3.0		
Biracial or Multiracial	4	4.0		
Knowledge of Chronic Disease Score (CKD)	39	39.3	16.93	4.02
Good Knowledge	45	45.5		
Adequate Knowledge	15	15.2		
Poor Knowledge				

Self-Regulation Score (SRQ)			109.56	20.82
High (intact) self-regulation capacity	37	37.3		
Intermediate (moderate) self-regulation capacity	22	22.2		
Low (impaired) self-regulation capacity	40	40.5		
Self-Efficacy Score			6.30	2.10
Autoimmune Thyroid Disease				
Yes	99	100		
No	0	0.0		
Network Composition				
Health Network Size			3.2	1.19
Percent Female	197	61.76		
Percent who primarily communicates in person	146	45.8		

Note. M=mean; SD=standard deviation

Each ego (n=99) was given the opportunity to name up to five alter egos, which resulted in 317 nominees. Of the percentage of alter egos nominated by the ego, 47% (n=150) were kin; 22% (n=69) were friends; 17% (n=55) were spouses, significant others, or partners; and 14% were identified as “other” (n=43). A vast majority of egos’ nominees (73%; n=231) did not have the AITD disorder, while 46 (15%) had AITD and 40 egos (13%) identified the AITD status of their nominated alter egos as unknown. Thirty-one of the egos (n=99) named an alter ego with AITD. The average size of a health network was 3.2 (SD = 1.19), which meant egos nominated an average of three alter egos.

Ordinary Square Least Squares Regression

The first analysis, including demographic variables, yielded a statistically significant model (Nagelkerke R^2 = .201, p<.01), with race being one of the individual level factors that significantly inversely influences self-efficacy for chronic disease management (B=-1.196, p<0.01). Age was the other individual level factor associated with self-efficacy for chronic disease management. As age increases, self-efficacy for chronic disease management increases by .014 standard deviation (B=.014, p<0.05). With the health-related attribute variables added to the model, the R^2 increased to 0.24 (Nagelkerke R^2 =0.248, p<0.01). Race was significantly and inversely related to predicting self-efficacy about chronic disease management; white patients on average had a lower self-efficacy score than patients of color (B=-1.201, p<0.01). Age was associated with self-efficacy for chronic disease management at .012 standard deviation (B=.012, p<0.05). The self-regulation score was significantly related to self-efficacy about chronic disease management. Each standard deviation increase in the self-efficacy scale increased the self-efficacy about chronic disease management by .266 (B=.266, p<0.05). The final 3-nested OLS model that predicts self-efficacy within this sample of patients was significant (Nagelkerke R^2 = 0.388, p<0.1) and explained 13.8% (Nagelkerke R^2 = 0.138) of the overall variance (see Table 3.2 for regression results). Age was associated with self-efficacy for chronic disease management at .018 standard deviation (B=.014, p<0.05). Race was significantly and inversely related to predicting self-efficacy about chronic disease management; white patients on average had a lower self-efficacy score than patients of color (B=-1.073, p<0.01). The self-regulation score was significantly related to self-efficacy about chronic disease management. Each standard deviation increase in the self-efficacy scale increased the self-efficacy about chronic disease management by .276 (B=.276, p<0.05). Further, the egocentric network variables explained an additional 13.8% (Nagelkerke R^2 = 0.138) of the variance in the self-efficacy about chronic disease management above the individual-level factors in this sample. A higher proportion of ties to female alters was associated with reduced self-efficacy about chronic disease management (B=-.012, $p<0.01$). Egos with more ties (B=.307, $p<0.01$) and denser networks (B=1.219, $p<0.05$) have more self-efficacy for managing chronic disease.

Table 3.2

Three Regression Models Predicting Self-Efficacy about Chronic Disease Management Among a Patient Population

Predictors	Model 1 $R^2=0.201$		Model 2 $R^2=0.242$ Δ $R^2=0.041$		Model 3 $R^2=0.388$ Δ $R^2=0.138$	
	B	S.E.	B	S.E.	B	S.E.
Age	0.014**	0.006	0.012**	0.006	0.018**	0.006
Race (ref= Nonwhite)	-1.196***	0.280	-1.201***	0.280	-1.073***	0.292
Gender (ref=Male)	0.273	0.222	0.244	0.219	-0.021	0.224
Relationship (ref=Unmarried)	0.042	0.187	0.006	0.194	-0.301	0.221
Knowledge of Chronic Disease			-0.033	0.112	0.098	0.115
Self-Regulation Score			0.266**	0.121	0.276**	0.133
Network Composition						
Percent with AITD					-0.049	0.043
Percent Female					-0.121***	0.039
Percent Kin					0.032	0.031
Social Support						
Informational					-1.469	2.391

Emotional					-1.469	2.391
Tangible					-0.641	1.038
Communication						
Percent In Person					-0.026	0.030
Density					1.219**	0.466
Degree					0.307***	0.112
Constant	0.067		0.164		-0.374	
F	5.727***		4.738***		3.307***	
Adjusted R^2	0.116		0.191		0.267	

Note. *p<0.1; **p<0.05; ***p<0.01, Standardized coefficients are reported.

Discussion

The literature on AITD patients and their disease self-management is scarce, with only a few studies that focus on chronic disease (Cameron et al., 2018; Ebrahimi Belil et al., 2018; Farrell et al., 2004). In this study, I have aimed to (1) assess individual-level factors related to a patient's self-efficacy about the management of AITD and (2) to identify egocentric network variables that explain additional variance in the self-efficacy among a patient population. The ordinary least square regression analysis results demonstrated that age, race, and self-regulation were related to an ego's self-efficacy about the management of AITD. After controlling for individual-level variables, I found that egocentric network variables, like network composition such as density (interconnectedness) and network degree (number of alters nominated), explained an additional 13.8% of the variance in a patient's self-efficacy about the management of AITD. The findings support prior research showing that knowing how many individuals are in a network and how linked they are might help build relationships (Provan et al., 2004). This study adds to the body of knowledge by examining AITD in particular and identifying various individual and interpersonal variables associated with AITD in the patient group.

Individual-Level Factors

In this study, I found that age, race, and self-regulation were related to an ego's self-efficacy about the management of AITD. Age was found to be significantly associated with self-efficacy for chronic disease management. As age increased, the self-efficacy for management increased as well. This could be because thyroid disease is often diagnosed during the fourth through sixth decades of life (Manji et al., 2006), and the median age of this sample size was about 58 years old, which could explain why there was a strong relationship between self-efficacy and age in this study. Another theory is that self-efficacy is a behavior-specific phenomenon (Hu, Li, & Ga, 2013). Patients may believe they are exceptionally competent in controlling their AITD because they are older.

Race was significantly inversely related to the self-efficacy about chronic disease treatment, with white patients scoring lower on average than patients of color. However, the majority of our sample was made up of white females. Consequently, thyroid disease is found in approximately 40% of white females and 20% of white males in the United States (Rayman, 2019). Many patients are undiagnosed (American Thyroid Association, 2020) because the symptoms are mild. In African Americans and Japanese, the incidence of AITD was less than half that of whites (Rayman, 2019). A crucial component could be the community's common AITD experience. Many patients with a chronic disease believed they were well-informed about the condition and their personal behaviors because they had lived with their disease for so long (Willis, 2016). However, other research has shown that effective self-efficacy has often been challenging to achieve (Savoli et al., 2020), with some clinicians believing that patients do not have the capacity to self-manage their disease (Phillips et al., 2014). Some research has found disparities in the general self-efficacy between whites and persons of color in the United States that may have health implications (Assari, 2017). In particular, one study that looked at the relationship between baseline self-efficacy and long-term risk of all-cause mortality in whites and African Americans found that the effects of race and baseline general self-efficacy about mortality risk were greater in whites than in African Americans over a 25-year period (Assari, 2017). Therefore, it is vital to evaluate specific populations to improve health outcomes.

In addition, self-regulation was significantly related to self-efficacy about chronic disease management. Self-regulation is the ability to manage one's actions, emotions, and thoughts to achieve long-term goals (Vohs & Baumeister, 2004). The findings of this study showed that by using self-regulation to monitor and manage their AITD health behaviors, patients can greatly boost their self-efficacy. Researchers have shown that improvements in self-regulation can enhance adherence to chronic disease treatment (Wilson et al., 2020) and enable behavior change in patients (Gawande et al., 2019). Further, Kubzansky and colleagues (2011) have found that higher levels of self-regulation reduced the risk of developing chronic diseases such as coronary heart disease. Consequently, since self-regulation is predictive of important outcomes from disease management, it is understandable that self-regulation would increase the self-efficacy of patients with AITD.

Network-Level Factors

The final regression model showed that egocentric network composition variables significantly explained the variance in the self-efficacy among a patient population after controlling for individual-level variables. This regression refers to research on health-related social networks and social support (emotional, tangible, informational) that largely focuses on the AITD patient population. The network concept of homophily (i.e., the tendency for someone to connect with others similar to them on a given characteristic; (Valente, 2010) emerged as an important factor in explaining the self-efficacy about chronic disease management. In our study, a higher proportion of ties to female alters was associated with reduced self-efficacy about chronic disease management. This is similar to other health-related network findings that demonstrate the concept of homophily related to patients who prefer the same heritage and gender when it comes to chronic disease management (Sentell et al., 2021). However, given that self-efficacy decreased, one reason could be that the patient's relationship with the female alters does not contribute to increased self-efficacy for managing chronic disease. Relationships may be both a facilitator and an inhibitor to self-management (Taleghani et al., 2014). The relationship's influence on the patient may negatively affect a patient's health behavior (Martire & Helgeson, 2017).

Lastly, network density and degree were found to be significant factors of the ego's self-efficacy for managing chronic disease. Density, which is a measure of interconnectedness, reflects the number of connections present in a network. The number of connections an ego has is measured by its network degree (Valente, 2010). Egos with high scores mean they are well connected within the network. In this study, the number of nominated alters and the degree to which they were connected predicted the ego having more self-efficacy for chronic illness management. Meaning that egos who had more ties that knew each other had more self-efficacy for chronic disease management than egos with sparse networks.

Social Network Analysis as an Intervention

In recent years SNA has been applied throughout health-related studies. Given the results of this dissertation found that both individual and network level factors were found to be significant in the knowledge and management of AITD, it seems relevant to highlight the importance of using SNA as an intervention. As a result, a system-level change perspective may be utilized to identify, synthesize, and map the current information and evidence concerning SNA used in this study. As a result, to improve understanding of chronic disease management, organizational health care professionals must look beyond devising treatments for symptoms; they must address patient access to health information, culture, and how chronic disease information is disseminated. At the patient level, a patient-centered strategy (i.e., digital health) is needed to aid in the greater knowledge of clinical and health aspects of chronic disease development, focusing on a novel intervention that includes preventative measures. Finally, SNA supplied the study's methodological features, emphasizing the significance of health-related social and relationship components.

Limitations

This study was distinctive in that it focused on how both individual and interpersonal-level variables influence the self-efficacy about chronic illness management in an AITD patient population. The study comprised a convenient sample of patients from a single clinic in the United States. As a result, I must consider selection bias when interpreting my findings. Second, most of the sample population was white and female. This is most likely attributable to convenience sampling and because the study was done in a clinic where most of the patients were white. As a result, the generalizability of our findings is restricted, and future research should concentrate on a more diverse patient group. Third, this data was collected during the COVID-19 pandemic, which may have affected the findings.

Implications for Future Research and Practice

Because the data is cross-sectional, I can only examine the connection between relationships; I cannot identify the timeframe of the correlations. As a result, further longitudinal research is needed to study the effect of network structure on self-efficacy about AITD management. Most crucially, egocentric network composition factors based on an ego's assessment of a nominated alter's social support contributed to a deeper comprehension of AITD and the ego's self-efficacy and management of AITD. Regarding future practice, health professionals and practitioners should be aware of the methods or models on the self-efficacy about chronic disease management to disseminate this knowledge to patients with AITD. Specifically, I found that self-regulation is predictive of important disease management outcomes. Mola (2013) showed that many patients with chronic disease broaden their health-related knowledge in various ways to choose the best treatment option to manage it . Thus, educating patients about the self-management of chronic disease strategies could help reinforce positive strategies for changing health behavior that can be used throughout their self-treatment.

Conclusion

This study demonstrates an individual-level and network level approach to see what influences self-efficacy about managing chronic disease. I also wanted to specifically examine an AITD patient population since research on this topic remains scarce. This is the first to explore AITD inside social networks within a patient population to the best of my knowledge. Overall, this research supports Bandura's (1991) Social Cognitive Theory Model, which emphasizes the role of self-regulation in health-related behavior.

Due to the dearth of knowledge on AITD, predictors of and influences on AITD must be investigated and better understood. The AITD population is of particular concern because of many undiagnosed individuals. This study adds to the body of knowledge by describing the influence of individual and interpersonal variables on a patient's self-efficacy about the management of AITD. The results show that age, race, and self-regulation are related to an ego’s self-efficacy about the management of AITD. Additionally, being in a community with those who are the same gender can lower self-efficacy. An egocentric social network analysis added to standard methodologies by showing the influence of self-efficacy on AITD management. As a result, these findings can serve as a foundation for future AITD research since they used both egocentric and sociocentric social network analysis to better understand the self-efficacy of AITD management.

CHAPTER IV

EGOCENTRIC NETWORK AND SOCIAL SUPPORT AMONGST A PATIENT POPULATION: A MULTILEVEL MODELING ANALYSIS

Introduction

Autoimmune Thyroid Disease (AITD) is one of the most widespread health problems in the United States and globally (American Thyroid Association, 2020; Fairweather & Rose, 2004). According to the American Thyroid Association (ATA), 60% of those with AITD are unaware of their condition (American Thyroid Association, 2019). AITD is caused by unknown triggers in the immune system, where antibodies attack the body's own tissues rather than fight off infections (American Thyroid Association, 2019). The disease affects an estimated 20 million Americans, meaning more than 12% of the U.S. population develops some form of thyroid condition in their lifetime (American Thyroid Association, 2020). More concerning is that 5-20% of the AITD population are women of child-bearing age (Fairweather & Rose, 2004; ATA, 2021). Studies have focused on the strong influence of social relationships on health (Heaney & Israel, 2008) by showing that high-quality communication can improve care, clinical outcomes, and patient behaviors (Sustersic et al., 2018). However, how patients' social networks affect the dissemination and acquisition of AITD knowledge remains unstudied. Given the complexity of the etiology related to AITD, more quantifiable approaches are necessary to consider the interacting factors related to social support and disease management.

Social support is defined as assistance received from people, such as friends and family, in an informal (e.g., peers) or formal (e.g., healthcare professional and organizations) social network (Badach, Tarasenko, & Schoenberg, 2011). Social support helps provide communication and support that can serve informational, emotional, and tangible needs (Edwards et al., 2015; Lee et al., 2004). There are many types of social support, but three types are instrumental for understanding the social network of those with AITD: 1) emotional support, 2) tangible support, and 3) informational support. Emotional support fosters an experience of belonging and being valued (Ford et al., 1998). Tangible support is the concept of provisions, such as financial support, services, and materials goods. It is associated with better physical functioning (Strom & Egede, 2012) (Woloshin et al., 1990).

Informational support is the use of information to help others, such as giving advice or guidance to solve a particular problem (Strom & Egede, 2012). Accessing different types of support can equate to better health outcomes (Uchino, 2006) and self-efficacy about managing chronic disease (Taal et al., 1993). House et al. (1988) demonstrated a direct link between social support, personal relationships, and a patient's quality of life. It has shown that those who receive emotional support experience an enhanced sense of belonging. Cohen et al. (2007).found that being valued results in increases in positive self-evaluations and higher levels of self-efficacy

Furthermore, low tangible support is most consistently related to depression and negative morale (Schaefer et al., 1981). Consequently, receiving informational support from health professionals can be more effective than discussions among family and friends (Helgeson & Cohen, 1996). However, research has shown that many patients receive the majority of their support, informational, tangible, and emotional, from informal sources of support as opposed to formal sources (Lee et al., 2017; Wu & Lu, 2017); this support warrants more research on how social networks provide AITD patients support relative to their knowledge and management of the disease.

Social Network Analysis

Bodenheimer et al. (2002) noted that patients' social networks are a primary way to disseminate information about chronic disease. However, how social networks support the factors related explicitly to patients' knowledge and management of AITD is less understood. To understand how a patient's social network influences AITD management, it is important to look at a patient's social network structure. The Social Network Analysis (SNA) is a methodological tool that offers a unique approach for measuring and understanding a patient's social network. Researchers have frequently used SNA to examine the role of social support in specific populations (Wasserman & Galaskiewicz, 1994), such as diabetes patients (DeFosset et al., 2020; Raghavan et al., 2016), coronary heart disease patients (Berkman, 1982), stroke (Nagayoshi et al., 2014), and cancer patients (Koehly et al., 2003; Luque et al., 2010). It has also used the SNA to investigate self-management and support in chronic disease populations (Pérez-Aldana et al., 2021; Song et al., 2017).

The primary purpose of the SNA is to measure and assess the structures of a patient's social relationships and how one's social network might affect important health outcomes (Valente, 2010; Scott, 2017). Specifically, a *social network* is defined as a set of socially relevant members (i.e., nodes) connected by one or more relationships (Patterson & Goodson, 2019; Yousefi Nooraie et al., 2020). SNA comprises two analytical approaches: egocentric and whole network research (Valente, 2010). *Whole network research* is an approach that attempts to account for all relationships within a defined group of individuals in a given environment (e.g., patient clinic, college sorority; Valente, 2010). By contrast, an egocentric network approach focuses on a sample of individuals and their closest social ties. In the case of this approach, the measured network is specific to an individual respondent rather than a predetermined, defined group of people. This approach is used to understand the ego's social environment that consists of their closest and most personal ties (i.e., alters; (Scott, 2017). To gain an in-depth understanding of the ego and their personal network, the ego may be asked to name alter egos who they feel most close to and characteristics about each alter ego they nominate (e.g., relation to the ego; gender). The ego is then asked to report on their own behaviors and the behaviors of their nominated alter egos.

The egocentric network analysis facilitates the calculation of network variables such as homophily, heterogeneity, composition, and structural holes. *Homophily* measures the extent to which an ego is similar to their alter egos on a specific variable (Perry, 2018). For example, if a female ego is connected to two female alter egos and two male alter egos, her network would return a homophily score of 0.50 based on sex because 50% of her network is the same sex as the ego. *Heterogeneity* measures the degree of difference between an ego's alter egos on a specific characteristic (e.g., race and age; Borgatti et al., 2013). The more alter egos differ from one another on a given variable, the larger an ego's heterogeneity score will be. *Network composition* represents a proportion of an egocentric network that possesses a specific characteristic (e.g., the proportion of the network that is male) for a categorical variable, and the average network score on a given characteristic is calculated for continuous variables (Borgatti et al., 2018). For example, if an ego's network was composed of all family members, they would receive a composition score of 100% based on family ties. S*tructural holes* are missing links between alter egos (Burt, 1992). Structural holes indicate that alter egos within an egocentric network do not interact closely but may be aware of one another (Borgatti et al., 2013; Perry et al., 2018).

Three types of structure variables help explain structural holes: effective size, constraint, and hierarchy. Effective size determines the information the ego has access to within the network by measuring the non-redundant alters to whom an ego is connected (Russell et al., 2020; Burt, 1992). Constraint is the assessment of the connectivity of the ego to others who are connected (Burt, 1992). The higher an ego's constraint score, the more its ties influence the ego (Russell et al., 2020). Hierarchy quantifies the degree to which an egocentric network is restricted by a single alter ego (Burt, 1992; Patterson et al., 2020).

Social Network Analysis and Social Support

The use of an SNA offers a unique approach for understanding social support within a patient's social network. The SNA has the capacity to examine how the composition and structure of a patient's social network influence their knowledge and management of AITD. Using SNA could allow for examining social connections present within patient’s networks and how they relate to providing support that enhances our understanding of the role of social support in AITD management (Borgatti et al., 2018; Felsher et al., 2020; Valente, 2010).

Much of the current SNA research emphasizes the importance of identifying meaning and patterns within a relationship (Felsher et al., 2020; Kadushin, 2012). The literature has focused on the strong influence that social relationships have on health and how effective interventions can promote health (Heaney & Israel, 2008). One study found great potential in interventions that enhanced motivation and skills for performing health behaviors while also enhancing social networks’ health-promoting qualities (Heaney & Israel, 2008). In the study, the authors explored the effect of social relationships on health status, behaviors, and health decision-making (Heaney & Israel, 2008). They concluded that social relationships were key to a person’s health, and they stressed the importance of tailoring social network interventions to the needs of the participants. For example, encouraging more informal social interactions between individuals and the people who support them creates better health outcomes for individuals (Pinto, 2006). This study suggests a need for a continued understanding of the extent to which social support influences the structure and function of social networks relative to health (Heaney & Israel, 2008).

Research has also shown that good communication can improve care, clinical outcomes, and patient behaviors (Sustesrsic et al., 2018). Felsher et al. (2020) used the SNA to explore the pre-exposure prophylaxis (PrEP) motivation related to communications among female intravenous drug users. Felsher et al. (2021) investigated the reasoning for initiating or refusing PrEP in a real setting. They found that individuals were embedded in a cluster of relationships associated with their use of PrEP. Specifically, they found that network interventions that facilitated PrEP conversations (i.e., encouraging members of network clusters to discuss PrEP use) may increase PrEP uptake and adherence among women who inject drugs

Further, one study presents the usefulness of the SNA by exploring social support for people suffering from chronic pain (Fernandez-Pena, Moline, & Valero 2018). The data of 30 individuals with chronic pain were collected to measure a personal support network. Fernandez-Pena, Moline, and Valero (2018) used a mixed-methods approach and applied both the SNA and semi-structured interviews to study social support in the context of chronic pain. They revealed characteristics that explained the various sorts of assistance provided by social networks and received by patients. These factors were mainly influenced by the structure and composition of social networks. Consequently, they found that the varied social and relational environments of those with chronic pain must be considered, specifically when informal support is insufficient in supplementing the existing formal resources (e.g., provider support) at the community level (Fernandez-Pena et al., 2018). The study results showed the importance of non-kin social support and the significant role of non-providers in the personal networks of people with chronic pain.

Research Questions

Given evidence that communication and support within social networks influence health behaviors (Felsher et al., 2020; Hendricks et al., 2014) and that social support is essential for health, especially within the chronically diseased population (Heaney & Israel, 2008; Sustersic et al., 2018), more research to determine the factors related to support provision is warranted. Therefore, this study examines the relationships within AITD patient networks that provide them with social support. Specifically, this study investigates individual-, dyadic-, and network-level factors related to patients connecting with people who provide emotional, tangible, and informational support. This study aims to answer the following research questions:

1. What factors are related to an AITD patient connecting with someone who provides more social support?
2. Are there differences in the factors associated with tangible, emotional, and informational support provision within AITD patients' networks?

Methods

Egocentric Network Analysis

This study used an egocentric network analysis to examine what factors are related to patients connecting with people who provide emotional, tangible, and informational support. In sum, egocentric networks were assessed from a sample of respondents (i.e., egos) who provided information about themselves and a set of important social connections in their life (i.e., alter egos). Egocentric network analysis is a type of social network analysis that focuses on a person's (i.e., ego) immediate network and how their connections affect them (i.e., alter egos; Paxton et al., 1999). Therefore, this study explored a sample of egos and their personal networks that included what factors might associate with an ego connecting with someone who provides more social support.

Participants and Procedures

The ninety-nine patients who participated in this study nominated 317 total alter egos. All patients were between the ages of 19-80. A Qualtrics online survey link was sent via mass email to patients at Aspire Health Clinic in Kansas City, Missouri. A flyer with the survey link was also posted on the clinic's social media pages. After assessing the Qualtrics link, patients reviewed details concerning the study's purpose. Once consent was given, the survey participants were asked about their demographic, personal health attributes (i.e., self-regulation, knowledge of chronic disease), and egocentric network information. The study was approved by the institutional review board before data collection.

Measures

Demographics

Respondents were asked to report their age, gender, race, and relationship status (e.g., married, dating, engaged, single).

Knowledge of chronic disease

For CDK, The Chronic Disease Knowledge Questionnaire (CDK) was used to assess the patient's knowledge of lifestyle-related AITD risk factors (Frantz, 2008). CDK is a 26-question survey instrument that elicits knowledge related to risk factors that lead to chronic disease (e.g., the following blood pressure is considered to be high: 140/90). Response choices on the knowledge scale are 1= yes, 2= no, and 3 = I don't know. Each statement is scored so that higher values reflect more complete knowledge. Other studies have reported Cronbach's alpha coefficients of 0.8 that indicate a valid and reliable instrument to assess knowledge of the risk factors for chronic disease (Agarwal et al., 2019; Biraguma et al., 2019; Frantz, 2008).

Management of chronic disease

The Self-Efficacy for Managing Chronic Diseases 6-Item Scale (SES6G) was used to assess a patient's confidence in doing certain activities (Obeid et al., 2013). Scoring on the SES6G ranges from 1=not at all confident to 10=totally confident. The total score of the scale is the mean of the six item scores. This mean allows for a maximum of two missing item responses. A higher number indicates higher levels of self-efficacy. Studies have reported that the SES6G effectively assesses patient self-efficacy about managing chronic disease (Freund et al., 2013; Gruber-Baldini et al., 2017; Hu et al., 2013). The SES6G demonstrated a good convergent construct validity and a high internal consistency with Cronbach's alpha of 0.930 (Freund et al., 2013).

Short Form Self-Regulation Questionnaire

The Self-Regulation Questionnaire (SSRQ) is a 31-item self-report test of one's ability to control behavior to attain one's goals (Carey et al., 2004). The scale uses a 5-point Likert scale, and the participants rated how much they agree with each item: 1 (Strongly Disagree), 2 (Disagree), 3 (Uncertain or Unsure), 4 (Agree), and 5 (Strongly Agree). To obtain the total SSRQ score, the items are totaled to create a sum score with higher scores representing high (intact) (≥ 120), middle scores representing intermediate (107-119), and low scores representing low (≤ 106) self-regulation capacities. The SSRQ is considered a reliable and accurate way to measure self-regulation and has a high internal consistency, with a Cronbach's alpha coefficient reported at 0.87 (Carey et al., 2004; Šebeňa et al., 2018).

Medical outcomes study social support survey

The Medical Outcomes Study Social Support Survey (MOS-SSS) was used to measure various dimensions of social support (Sherbourne & Stewart, 1991). The MOS-SSS is a 19-item multidimensional, self-administered instrument developed for patients in the Medical Outcomes Study (MOS). A modified 13-item survey assessed emotional, informational, and tangible social support. The scale uses a 5-point Likert scale (e.g., 1= None of the time, 5 = All of the time). To obtain a score for each subscale, the mean item response was obtained for each scale. To obtain the overall support index, the average scores for all 13 items were calculated. The scale scores were then transformed to a 0-100 scale, with higher scores indicating more support (Sherbourne & Stewart, 1991). The MOS-SSS yields reliable and accurate data and has high internal consistency, with a reported Cronbach's alpha coefficient of 0.94 (Dafaalla et al., 2016; Griep et al., 2005; Zucoloto et al., 2019).

Egocentric network data

Two types of questions were asked to assess egocentric networks: 1) name generator and 2) name interpreter questions. Name generators asked the ego to list the initials of up to five network members with whom they discuss important health matters (Valente, 2010). Name interpreter questions asked the ego to provide information about each alter ego (e.g., gender, length of the relationship to the alter, type of relationship to the alter) and qualify the ego's relationship with that alter ego. Through name interpreter questions, egos reported their relationship to each alter ego (e.g., friend, parent), each alter ego's gender, frequency of communication with each alter ego (7=everyday, 6=3-6x/week, 5=1-2x/week, 4=1-2x/month, 3=1-2x/year, 1=less than once/year, 0=Never), the most common method of communication (e.g., in-person) if the alter ego has AITD (yes, no, unknown), and if the alter ego is supportive of the ego's health goals (0=Never, 1=Rarely, 2=Sometimes, 3=Most of the time, 4=Always).

Name interpreter questions derived from egocentric network questions were used to assess the three types of support being measured (i.e., informational, tangible, and emotional). The MOS-SSS (Stewart, 1993) measured informational, tangible, and emotional social support received from each nominated alter ego. The ego was asked to think about the people they nominated and identify the following kinds of support they received from each of the nominated alter egos using the 5-point Likert scale described above. Each question began with, "Is this person someone who":

1. you can count on to listen to you when you need to talk.
2. gives you good advice about a crisis.
3. gives you information to help you understand a situation.
4. you can confide in or talk to about yourself or your problems.
5. whose advice you really want.
6. who you share your most private worries and fears with.
7. you to turn for suggestions about how to deal with a personal problem.
8. understands your problems.

9. takes you to the doctor if you needed it.
10. prepares your meals if you are unable to do it yourself.
11. helps with daily chores if you are sick.
12. does things to help you get your mind off things,
13. helps you if you are confined to bed.

Multilevel Models

Multilevel modeling has been used throughout social network research to analyze egocentric networks (Perry et al., 2018). Multi-level modeling shows a clear multi-level structure of lower-level units of alter egos or ties between egos and alter egos grouped within higher-level units of ego networks (Perry et al., 2018). Multi-level modeling, in particular, is frequently employed in analytical approaches to account for dependency in observational research (Van den Noortgate et al., 2013). Four multi-level models are conducted in this study: one that predicts general social support an ego receives from their alter egos and three distinct models that assess the three distinct types of social support. Model 2 predicts the informational support an ego receives from their alter egos, Model 3 predicts the tangible support an ego receives from their alter egos, and Model 4 predicts the emotional support an ego receives from their alter egos.

In these models, two levels of variables are assessed. Level 1 variables, the lowest level, represent alter ego-level variables such as relationship or support between the ego and alter ego and characteristics about the alter ego (e.g., gender). All Level 1 variables represent alter ego/dyadic level information derived from the name interpreter questions referenced earlier (Valente, 2010). The level 2 variables represent ego- and network-level scores such as attribute information (e.g., if an ego has AITD, ego's management self-efficacy scores) and egocentric network structural variables (e.g., network composition based on AITD diagnosis, Valente., 2010).

Level 1 variables: alter egos and ties

The Level 1 variables are the alter egos' characteristics such as gender, relationship to the ego, and communication frequency with the ego. The degree of the social support offered by the alter ego to the ego was measured at this level in terms of tangible, informational, and emotional support.

Level 2 variables: egos and network

To understand whether the characteristics of the ego are related to the types of support the ego perceives within their network, I measured the ego's self-efficacy score about managing chronic disease, type of communication, and total network characteristics. The measures of the total network characteristics are the percent of the network with AITD, the percent of the network that is female, and the average network size. Level 2 network variables, including compositional and structural variables, were computed using E-Net statistical software (Borgatti, 2006).

Analytic Strategy

To assess the likelihood an ego connects with an alter ego that provides social support, I conducted four multilevel models computed using the multi-level package (Bliese, 2016) with R programming language and software (Core Team, 2017). The first multi-level model assesses the likelihood that an ego connects with an alter ego who provides total social support. Model 2 predicts the informational support an ego receives from their alter egos. Model 3 predicts the tangible support an ego receives from their alter egos. Model 4 predicts the emotional support an ego receives from their alter egos.

Intraclass correlation coefficients (ICC) were obtained before undertaking the multi-level analysis that indicates a multi-level method was statistically suitable. As a result, random-intercept models were developed that assign a unique intercept to each ego that depends on their networks and allows for assessing ego, alter ego, and network-level effects (Perry et al., 2018). Therefore, Model 1 assesses the factors associated with an ego being connected to alter egos who provide social support (social support, Model 1). Model 2 assesses the emotional support an ego receives from their alter egos (emotional, Model 2). Model 3 assesses the tangible support an ego receives from their alter egos (tangible, Model 3). And Model 4 assesses the informational support an ego receives from their alter egos (informational, Model 4). Independent variables present in each model are 1) individual-level variables of the ego's knowledge of chronic disease score, ego's management of chronic disease score, ego's self-regulation score, ego's AITD status, and ego's demographic variables; 2) dyadic-level variables are the alter egos' gender, alter egos' AITD status, alter egos' relation to the ego, frequency of communication between ego and alter ego, and the level of support between ego and alter ego; and 3) network-level variables are the proportion of the network that has AITD, the proportion of the network that is female, and the average network size.

Results

Level 1: Alter and Ties

Participants (n=99) nominated 317 total alter egos. A majority of those nominated were white females (77%, n=244; 62%, n=197); 47.3% were family (kin), 22% (n=69) were friends; 17% (n=55) were spouses, significant others, or partners; and 14% (n=43) were other. Alter egos registered an average general support score of 3.5 (SD=0.48) that indicated egos "usually" felt their alter egos supported them in their management of AITD. Egos reported they "usually" rely on their alter egos for emotional support (Mean=3.6; SD=0.46) and also "usually" rely on their alter egos for informational support (Mean=3.6; SD=0.46). Alter egos registered an average tangible support score of 3.2 (SD=0.69) that indicates egos "usually" felt their alter ego financially supported them. Regarding AITD status, more than half of the alter egos did not have AITD (72.4%; n=231) that indicates egos "usually" felt supported by their alter egos regardless of AITD status. The main type of communication among alter egos was in person (46%; n=146) and by phone call (31%; n=98). Lastly, egos reported they communicated with their alter egos on average three to six times per week (38%; n=123). See Table 4.1 below for all the descriptive statistics.

Table 4.1

Descriptive Characteristics of Level 1 Variables: Nominated Alter egos and Ties

Variable	N	%	M	SD
Gender				
Male	112	35.1		
Female	197	61.8		
Other	8	3.1		
Race				
White	244	76.9		
Non-White	73	23.1		
Relationship to Ego				
Parent	39	10.2		
Sibling	37	9.7		
Extended Family	24	6.3		
Friend	69	18.0		
Daughter/Son	50	13.1		
Spouse	55	14.4		
Mentor	6	1.6		
Other	8	0.3		
Healthcare Provider	29	8.1		
Overall General Social Support (5-point Scale, 1-5)			3.51	.48
Emotional Social Support (5-point Scale, 1-5)			3.67	.46
Tangible Social Support (5-point Scale, 1-5)			3.17	.69
Informational Social Support (5-point Scale, 1-5)			3.67	.46
Type of Communication				
In Person	146	46.1		
Text Message	62	19.6		
Phone Call	98	30.8		
Social Media	11	3.5		
Communication Frequency				
Everyday	0	0.0		
3-6 times per week	123			

1-2 times per week	110	38.4
1-2 times per month	47	34.4
1-2 times per year	31	14.7
Less than once per year	6	9.7
		2.8
AITD Status of Alter egos		
Unknown	40	12.6
Yes	46	14.5
No	231	72.9

Note. M=mean; SD=standard deviation

Level 2: Egos and Networks

In this sample, all egos reported AITD as a diagnosis (100%; n=99). Eighty-five percent (n=85) of egos were white, with the average age being 58.2 (SD=16.01). A large majority, 76.8% (n=76), of our sample was female. The average self-efficacy score was 6.3 (SD=2.11, range 1-10), which falls within the mildly confident range (from 4-7). The sample registered a mean self-regulation score of 109.6 (SD=20.9) which means they scored themselves to have high (intact) self-regulation. Knowledge of Chronic Disease scores ranged from 2 to 23 and averaged 16.9 (SD=4.02), which means patients had adequate knowledge of the chronic disease. The average health network size was 3.2 (SD = 1.19), which meant that egos nominated an average of three alter egos. More than half of the ego’s total network comprised women (alters; 61.8%, n=197), and 12% ego’s alter network was reported to have AITD. See Table 4.2 below for all ego and network descriptive statistics.

Table 4.2

Descriptive Characteristics of Level 2 Variables: Egos and Network

Variables	N	%	M	SD
Age			58.23	16.15
Gender				
Male	23	23.2		
Female	76	76.8		
Race				
White	85	85.9		
Black or African American	6	6.1		
American Indian or Native American	1	1.0		
Asian	3	3.0		
Biracial or Multiracial	4	4.0		
Self-Efficacy Score			6.3	2.11
Self-Regulation Score			109.6	20.9
Knowledge of Chronic Disease Score			16.9	4.0
Autoimmune Thyroid Disease				
Yes	99	100		
No	0	0.0		
Percent of the Network that is Female	197	61.8		
Health Network Size			3.2	1.19
Percent of Egocentric Network with AITD	46	12.0		

Note. M=mean; SD=standard deviation

Multi-level Models

In multi-level regression analyses, I examined four Level-1 dependent variables for alter egos: these models predict general social support (Model 1), informational support (Model 2), tangible support (Model 3), and emotional support (Model 4). All models have random intercepts and are presented in Table 4.3. Model 1 shows that alter egos' frequency of communication with the ego predicts the general support an ego receives ($\beta=0.010$, $p<0.01$), and as self-efficacy for managing chronic disease increased, the ego received more general support ($\beta=0.098$, $p<0.01$). Model 1 also shows that egos whose networks have a higher percent of alters with AITD receive more general support ($\beta=0.065$, $p<0.035$). Model 2 shows the alter egos' frequency of communication with the ego ($\beta=0.010$, $p<0.01$) is positively related to the emotional support an ego receives. As self-efficacy for managing chronic disease increased, the ego received more emotional support ($\beta=0.103$, $p<0.01$). Model 2 also shows that egos whose networks have a higher percent of alters with AITD received more emotional support ($\beta=0.080$, $p<0.05$). Model 3 suggests that an ego who is unmarried receives more tangible support than an ego who is married ($B=1.091$, $p<.1$), and an ego's spouse is tangibly more supportive than family ($\beta=1.579$, $p<0.1$). Model 3 suggests that the alter's frequency of communication with the ego ($\beta=0.010$, $p<0.01$) predicts greater tangible support. An alter in person communication is positively related to tangible support an ego receives. Lastly, model 3 suggests that those with fewer connections within the networks receive less tangible support than those with denser networks. Model 4 shows the alter egos' frequency of communication with the ego ($\beta=0.010$, $p<0.01$) is positively related to the emotional support an ego receives. As self-efficacy for managing chronic disease increased, the ego received more emotional support ($\beta=0.103$, $p<0.01$). Model 4 also shows that egos whose networks have a higher percent of alters with AITD received more emotional support ($\beta=0.080$, $p<0.05$).

Table 4.3

Random Intercept Multi-level Models Predicting General, Emotional, Tangible, and Informational Support an Ego Receives from their Alter Egos

Predictors	Model 1 General Social Support		Model 2 Emotional Social Support		Model 3 Tangible Social Support		Model 4 Informational Social Support	
	B	S.E.	B	S.E.	B	S.E.	B	S.E.
Gender (Female)	0.026	0.189	-0.026	0.189	0.052	0.251	-0.026	0.189
Age	-0.004	0.005	-0.002	0.005	-0.011	0.007	-0.002	0.005
Relationship (ref= Unmarried)	0.104	0.484	-0.169	0.533	1.091*	0.661	-0.169	0.661
Race (White)	0.258	0.211	0.270	0.208	0.145	0.278	0.270	0.208
Ego SE	0.098***	0.037	0.103***	0.037	0.074	0.049	0.103***	0.037
Ego CKD	0.411	0.549	0.469	0.541	0.309	0.723	0.469	0.541
Ego SRQ	0.003	0.005	0.005	0.005	-0.001	0.007	0.003	0.005
Alter Gender (ref= Male)	0.113	0.092	0.095	0.101	0.100	0.126	0.095	0.101
Alter: Relationship (ref= other)	0.101	0.396	-0.131	0.434	0.605	1.503	-0.131	0.434
Friend	0.277	0.495	0.104	0.545	0.836	0.676	0.104	0.545
Spouse	0.465	0.503	0.158	0.552	1.579**	0.686	0.158	0.552
Mentor	-0.093	0.561	-0.008	0.618	0.194	0.767	-0.008	0.618
HC Provider	-0.400	0.497	-0.292	0.546	-0.481	0.679	-0.292	0.546
Alter: Frequency of Communication	0.010***	0.002	0.010***	0.002	0.010***	0.002	0.010***	0.002
Alter: In Person Communication	-0.002	0.112	-0.172	0.121	0.420***	0.152	-0.172	0.121
Alter: AITD Status	0.070	0.067	0.047	0.073	0.086	0.091	0.070	0.067
Network Measures								
Percent with AITD	0.065*	0.035	0.080*	0.035	0.048	0.046	0.080*	0.035
Network Percent (Female)	0.028	0.033	0.032	0.032	-0.006	0.043	0.032	0.032

Percent (Kin)	0.013	0.029	-0.018	0.029	-0.009	0.038	0.019	0.029
Density	-0.907	0.575	-0.757	0.570	-1.567**	0.759	-0.757	0.570
Degree	0.017	0.090	0.032	0.089	-0.012	0.118	0.032	0.089

Note. *p<0.1; **p<0.05; ***p<0.01; Random intercept is on ego; CKD= knowledge of chronic disease score; SE=self-efficacy of chronic disease management; SRQ= self-regulation score.

Discussion

The purpose of this study was to examine relationships in an AITD patient's networks that provide them with social support. The results show that the ego's self-efficacy, ego's relationship status, ego's spouse, alter's frequency of communication and in-person communication, percent of alters with AITD, and network density were especially explanatory of an ego connecting with an alter ego who provides social support. Overall, egos with a higher frequency of communication with their alter egos generally get more general, emotional, tangible, and informational support. There are differences in factors associated with informational, tangible, and emotional support within AITD patients' networks, with tangible support having the most differences.

Communication and AITD Status

Researchers have shown that the frequency and mode of communication, such as in person, can significantly improve self-management strategies like medication adherence in the chronic disease population (Thakkar et al., 2016; Wohn et al., 2015). Our findings demonstrate that the frequency of communication is positively related to social support in all four models (general, informational, tangible, and emotional). One probable explanation is that frequency of communication could lead to better perceived social support from each of the four categories (Wohn et al., 2015). Additionally, communication duration and frequency have been linked to closeness in previous research (Wohn et al., 2015). As a result, if an ego is currently pursuing a new or existing treatment plan for a chronic condition, they may rely heavily on frequency of communication to help them stick to their therapy.

Homogeneity (i.e., the tendency for someone to connect with others similar to them on a given characteristic; (Perry et al., 2018) may be related to an AITD patient connecting with someone who provides more social support. In this study, a patient with AITD who had a higher percent of alters with AITD was more likely to receive more emotional and informational social support. Whether by choice or by chance, patients with AITD are more likely to have people in their personal network who also have AITD. This is comparable to a health-related study that supports the idea of homophily by demonstrating the benefits of patients learning about chronic illness management via group support networks (Huh & Ackerman, 2012). One explanation might be that they can get support from others who have had similar experiences in a community to discuss their unique approaches to managing their chronic illness.

Social Support and Relationships

Social support has been found to be an important aspect in enhancing self-efficacy, with studies showing that a person's self-efficacy is positively related to the amount of social support they receive (Wang, Qu, & Xu, 2015). High self-efficacy has been associated with a strong sense of support (Karademas, 2006) and improved self-management behaviors (Farrell, Wicks, & Martin, 2004). This aligns with the results in this study in which self-efficacy for managing chronic disease increased as the ego received more emotional and informational support. As a result, emotional and informational social support may improve self-efficacy, improve chronic disease self-management, and contribute to better health outcomes for people with AITD.

Studies have demonstrated that communication and support within social networks can alter health behaviors (Felsher et al., 2021; Hendriks et al., 2014), and social support is vital for health, particularly among chronically ill people (Heaney & Israel, 2008; Sustersic et al., 2018). As a result, social support might be considered a significant component in maintaining healthier habits in chronic illness treatment. Overall, egos with a higher frequency of communication with their alter egos generally get more emotional, tangible, and informational support. I anticipate that the ego has felt generally supported by their alter egos across all areas of social support based on the recent literature that demonstrates a favorable relationship between the frequency of communication and positive social support (Petrovčič et al., 2015). In this study, frequent communication may be favorably related to social support because it allows chronic disease patients to expand their communication domain.

The most significant differences in the characteristics related to providing support were seen in tangible support (Model 3). The term "tangible support" refers to physical, financial, or material assistance (e.g., labor, goods; (Mao et al., 2021). Egos were more likely to receive tangible support if they were married rather than unmarried and from their spouse rather than their family. This is consistent with the research, which suggests that spouses play an essential role in patients adapting and coping with chronic disease (Revenson, 1994) and typically take on additional financial duties as caretakers (Faronbi et al., 2019) because an ill patient may be unable to work. Last, density was statistically significant and inversely related to tangible support. This suggests that when nominated alters did not have a link with one other, egos received less tangible social support. This might be due to the patient's extended experience with AITD, which may result in various social circles and weaken social ties amongst alters. In conclusion, differences in factors associated with the provision of tangible, emotional, and informational support across AITD patients' networks were observed in this study.

Social Network Analysis as an Intervention

In recent years, SNA has been used in various health-related investigations. According to the findings of this research, there are factors linked with social support and differences and factors related to support provisioning inside an AITD network. As a result, it seems appropriate to emphasize the significance of adopting SNA as an intervention. Social Support can include health and social requirements in the setting of a chronic disease population (Fernandez-Pena et al., 2022), and SNA is a useful intervention for identifying particular areas such as the structure and composition of a social network. This study's findings emphasize the importance of community support at the individual level. At the organizational level, physicians can utilize SNA as an intervention to evaluate interpersonal interactions that may alter an AITD patient's social relationships. The network analysis' findings may also be used to concentrate on its efficacy as an intervention for assessing attempts to generate community support through cooperation at both the individual and organizational levels. Therefore, future research should look at using SNA as an intervention to provide more knowledge from a relational viewpoint at the individual and organizational levels.

Limitations

Even though this research adds to the body of knowledge on chronic disease literature, it is not without limitations. The most notable limitations are that this study was cross-sectional with a predominantly white patient population using a convenience sample. Second, this egocentric network was based only on an ego's perspective (i.e., I have no means of knowing whether or not alter egos have been medically diagnosed with AITD); nonetheless, researchers have demonstrated that an ego's perspective influences their actions more than reality (Lally et al., 2011; Pelletier et al., 2014). Overall, this study lays the framework for future research into how the properties at several levels (e.g., ego, alter ego, and network) of an egocentric network are connected to an AITD patient interacting with someone who can provide more social support.

Implications for Future Research and Practice

Using a full network approach, a longitudinal design, and incorporating the network of physicians and how they relay information can assist researchers in better understanding the factors that lead to an AITD patient engaging with someone who can provide more social support. Future research might look at a closed network of AITD patients in a support program with physicians and healthcare professionals to see how knowledge and treatment of AITD spread over time. In terms of future practice, encouraging healthy, supportive connections among a patient group may encourage healthier behavior. Health management of chronic illness might be held in focus group sessions to teach patients how to manage their chronic condition and get social support from friends and family. Finally, considering the importance of support in this community, physicians and psychologists should research interpersonal interactions that may impact an AITD patient's social connection, as our study demonstrates.

Conclusion

This study aimed to examine relationships present within AITD patients' networks that provide them with social support and identify differences in the factors associated with providing tangible, emotional, and informational support. The results show that the ego's self-efficacy, ego's relationship status, ego's spouse, alter's frequency of communication and in-person communication, percent of alters with AITD, and network density were especially explanatory of an ego connecting with an alter ego who provides social support. Overall, egos with a higher frequency of communication with their alter egos generally get more general, emotional, tangible, and informational support. There are differences in factors associated with informational, tangible, and emotional support within AITD patients' networks, with tangible support having the most differences. These findings highlight the importance of social support within a social network and show that there are significant factors related to an AITD patient connecting with someone who provides more social support.

CHAPTER V

CONCLUSION

Findings and Results

This dissertation aimed to explore individual and interpersonal factors associated with self-efficacy about managing chronic disease among an AITD patient population in the United States. To achieve this purpose, three independent articles were written: (1) a systematic review of the current state of the literature regarding the impact of the training of medical health professionals on the early detection and screening of AITD in the United States. This article also has a phase 2 review that explores the social support from a social network perspective on chronic disease (Chapter II), (2) integrate the SCT theoretical framework into the application of egocentric network analysis to determine individual- and network-level factors related to the knowledge and management skills of AITD patients (Chapter III); and (3) integrate the SCT theoretical framework into the application of an egocentric network analysis to examine and understand the relationships within the social networks of patients that provide the social support that is important for acquiring knowledge and managing the disease (Chapter IV).

Summary

In conclusion, the systematic literature reviews in Chapter 2 discovered that medical health professional training can help with early diagnosis and screening of AITD by increasing provider knowledge and skills. Furthermore, regardless of the kind of AITD, perceived adequacy of social support was consistently connected to a better prognosis of the condition. In Chapter 3, I observed that a patient's self-efficacy improved based on race/ethnicity and higher self-regulation scores; however, it reduced if the patient was linked to another person with AITD. I also found that egocentric network variables explained 13.8% of the variance in self-efficacy of chronic disease management above individual-level factors in this sample. Furthermore, in Chapter 4, the ego’s self-efficacy, ego’s relationship status, ego’s spouse, alter’s frequency of communication and in-person communication, percent of alters with AITD, and network density, were especially explanatory of an ego connecting with an alter ego who provides social support. Overall, egos with a higher frequency of communication with their alter egos generally get more general, emotional, tangible, and informational support. Lastly, there are differences in factors associated with informational, tangible, and emotional support within AITD patients’ networks, with tangible support having the most differences.

Chapter Findings and Results

Chapter II: A Systematic Literature Review

Part I of the systematic review examined what (if any) effective training for medical health professionals was dedicated to early detection and screening of AITD existed in the literature. The study examined the relevant literature that provided interventions for educating health professionals on early detection and diagnosis of AITD. The manner in which this education was provided was essential to ensuring that health professionals have the knowledge and tools needed for an accurate diagnosis. The first major finding was that the most commonly used support tools were evidence-based and lecture learning sessions (Dunnington et al., 1987; Houck et al., 2002; Allen et al., 1998; Haymart et al., 2010) followed by medical simulation (n=1; Leviter et al., 2020).

The systematic review's second key conclusion indicated the beneficial outcome of the training was the teaching skills needed to manage patients with thyroid diseases. One study reported that evidence-based support tools positively improved medical students' educational experience with evidence-based medicine (Leung et al., 2003). Lecture-based learning was still effective among medical professionals and, in some cases, preferred (Zinski et al., 2017). Medical simulation was the intervention strategy in which learners reported they were effectively taught the skills necessary for patient care (Leviter et al., 2020). Overall, although the literature was limited, this study showed that the training of medical health professionals can facilitate early detection and screening of AITD through increased knowledge and skills of these professionals.

Part II of the systematic review expanded on Part I by examining the effects of social support on the AITD population and the variances and similarities in how social support affects people. This part led to a summary of the literature on social support and AITD, particularly from a patient's point of view. Part II examined the support provided through social connections for AITD patients in the peer-reviewed literature. Approximately 70% of studies that looked at the effect of social support on the course of AITD focused on thyroid cancer (10 out of 14). Two of the articles focused on Graves Disease (n=2), one article focused on thyroid disease (n=1), and the last article focused on hyperthyroidism (n=1). The first major finding showed the perceived adequacy of social support. Positive social support was consistently linked to better outcomes in thyroid cancer patients, and perceived social support had a positive effect on more objective health metrics measurements among patients with Graves Disease (Chen et al., 2012). Regardless of the numerous types of AITD diseases, there was strong evidence that social support improves subjective health markers, such as quality of life, mental health, and cure rates (Chen et al., 2012, Huang et al., 2004). Therefore, the perceived adequacy of social support was consistently linked to a better prognosis of the illness, regardless of the type of AITD.

The second major finding reflected social support and disease progression. In terms of its effect on AITD progression, I concluded that social support accounted for a wide range of outcomes. The subjective emotions of social support were more relevant than social support measures. Social support was found to be measured by objective measurements of the amount of emotional, psychosocial, and informational support. Graves Disease was discovered to be the only general influence on disease progression (Chen et al., 2012; Yoshiuchi et al., 1998). However, in thyroid cancer, subclinical hypothyroid, and thyroid disorder, unmet emotional and informational support were characteristics connected with the prognosis of the disease (Hyun et al., 2016; Henry et al., 2018). Consequently, Graves Disease had the sole overall influence on disease progress that could be partly related to the disease being curable following ATD treatment, which leads to improved adherence and self-management (Chen et al., 2012; Yoshiuchi et al., 1998).

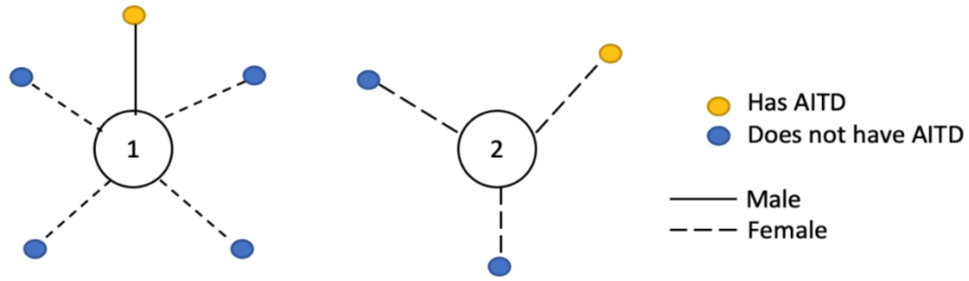
Overall, I discovered that the most relevant element was perceived social support. Functional measures of the amount of support and a better course in the AITD disease were linked to improved mental health and a better patient prognosis. The subjective emotions of social support were more relevant than social support measures. Lastly, the perceived adequacy of social support was consistently linked to a better prognosis of the illness, regardless of the type of AITD.

Chapter III: Egocentric Network Analysis Utilizing Ordinary Least Square Regression

The purpose of Chapter III was to identify 1) what individual-level factors were related to a patient’s self-efficacy about the management of AITD; 2) whether egocentric network variables explain the additional variance in self-efficacy about the management of AITD among a patient population beyond individual-level factors. The dependent variable—self-efficacy—was captured using the Self-Efficacy for Managing Chronic Disease 6-Item Scale (SES6G) (Obeid et al., 2013). The individual-level variables in the statistical model were gender, age, race, relationship status, Chronic Disease Knowledge Questionnaire (CDK; Frantz, 2008), and the Self-Regulation Questionnaire (SSRQ; Neal & Carey, 2005). I generated egocentric network variables and ran an ordinary least square regression analysis to see how much unique variance the egocentric network variables provided to each overall model, in addition to individual-level factors. See Figure 5.1 below.

Figure 5.1

Example of Two Egocentric Networks



Note. That this figure depicts two egos, one (1) related to five alters and the other (2) to three alters, each indicating a feature such as AITD diagnosis (color) and gender (line).

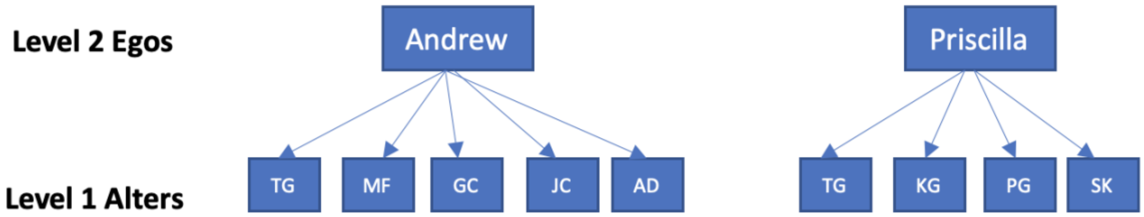
The first block contained only demographic variables (gender, age, race and ethnicity, relationship status), the second added health-related variables (knowledge of chronic disease score and self-regulation score), and the third added network variables (network compositional variables, homophily variables, heterogeneity variables, and structural holes). The results showed that age, race, and self-regulation were related to an ego's self-efficacy about the management of AITD. After controlling for individual-level variables, I found that egocentric network variables, like network composition such as density (interconnectedness) and network degree (number of alters nominated), explained an additional 13.8% of the variance in a patient's self-efficacy about the management of AITD.

Chapter IV: Egocentric Network Analysis Utilizing Multi-level Modeling

The purpose of this study was to provide information on the individual-, dyadic-, and network-level factors that were related to patients connecting with people who provide emotional, tangible, and informational support, thereby supporting the notion that social support is essential for health, particularly among people suffering from chronic diseases. Four multi-level models were computed to assess the likelihood an ego connects with an alter ego who provides social support. The first model predicted the general social support (computed as a social support sum score) that an ego receives from their alter egos, and the following three models assessed the three distinct types of social support (tangible, emotional, and informational). Level 1 consisted of alter ego variables: relationship, gender, race, communication frequency, type of communication, and AITD status; Level 2 consisted of ego- and network-level characteristics (whether an ego had AITD, ego's management self-efficacy scores, network composition based on AITD diagnosis).

Figure 5.2

Hierarchical Data Structure for Egocentric Network Analysis



Note. This figure shows the two-levels of variables. Specifically, the initials (e.g., TG, MF, GC, JC) are Level 1 alters nested in Level 2 egos Andrew and Priscilla.

Model 1 (general social support) showed that alter egos' frequency of communication with the ego predicts the general support an ego receives. As self-efficacy for managing chronic disease increased, the ego received more general support. Model 1 also showed that egos whose networks have a higher percent of alters with AITD receive more general support. Model 2 (emotional support) showed that the alter egos' frequency of communication with the ego is positively related to the emotional support an ego receives. As self-efficacy for managing chronic disease increased, the ego received more emotional support. Model 2 also showed that egos whose networks have a higher percent of alters with AITD received more emotional support. Model 3 (tangible support) suggested that an unmarried ego receives more tangible support than a married ego and an ego's spouse is tangibly more supportive than family. Model 3 suggested that the alter' frequency of communication with the ego predicts greater tangible support, and an alter in person communication was positively related to tangible support an ego receives. Lastly, model 3 suggested that those with fewer connections within the networks receive less tangible support than those with denser networks. Model 4 showed the alter egos' frequency of communication with the ego is positively related to the emotional support an ego receives. As self-efficacy for managing chronic disease increased, the ego received more emotional support. Model 4 also showed that egos whose networks have a higher percent of alters with AITD received more emotional support.

Implications for Future Research and Practice

This dissertation's findings contribute to the existing body of knowledge on chronic disease and have substantial implications for future public health research. The overall purpose of this dissertation was to learn more about how a patient with AITD is supported by their social network and look into individual and interpersonal factors that affect the knowledge and management skills of AITD patients. AITD affects an estimated 20 million Americans, with more than 12% of the US population developing some form of a thyroid condition in their lifetime (American Thyroid Association, 2020). Therefore, it is important to examine how researchers can connect with AITD patients more effectively to investigate and add findings to a collective body of science on this topic. Furthermore, as our literature study disclosed (Chapter II), perceived social support was the most critical component. The reported adequacy of social support was consistently connected to a better prognosis of the illness independent of the kind of AITD. This dissertation underlines the importance of understanding the factors that lead to the engagements of AITD patients and promotes the use of social network analysis in chronic disease research.

Chapter III presented findings indicating that age, race, and self-regulation were related to the ego's self-efficacy for AITD management and that density and network degree predicted self-efficacy for AITD management, providing a rationale for future research using the SNA to further investigate how social networks affect AITD patients' knowledge and management skills. Furthermore, I was able to quantify the benefits of patients connecting with persons who provide emotional, tangible, and informational support in Chapter IV by combining an egocentric network technique with a multi-level modeling statistical design. The egocentric network analysis may be used with larger samples of chronic disease patients to better understand how social support from different relationships influences AITD. Additionally, using a full network approach, a longitudinal design, and incorporating the network of physicians and how they relay information can assist researchers in better understanding the factors that lead to an AITD patient engaging with someone who can provide more social support. Future research might look at a closed network of AITD patients in a support program with physicians and healthcare professionals to see how the knowledge and treatment of AITD spread over time among a popular member of the group (i.e., a medical healthcare professional).

There are a few implications for future health education and practice and implications for future research. To the best of our knowledge, our systematic literature review (Chapter II) was the first to specifically examine the effect of social support on AITD. This study was conducted to bring more attention to the topic and to demonstrate the need for further research in this area. Combined with the knowledge gaps that surround education and training protocols and knowledge dissemination between providers, health professionals must be equipped with practical medical training supported during graduate education and beyond. Increased efforts to incorporate new training for medical providers are needed to evaluate the efficacy of different training modalities used to increase the early detection of AITD.

Intervention points were presented in Chapters III and IV for future health practitioners to consider. In Chapter III, network density and degree were found to be significant predictors of AITD that indicates health professionals and practitioners should be aware of the chronic disease management dissemination methods and models to increase self-efficacy. Additionally, self-regulation is predictive of important outcomes in disease management; therefore, educating patients about self-management of chronic disease strategies could help reinforce positive changes in health behavior. Chapter IV examined relationships within AITD patient networks that provide them with social support and found that egos with a higher frequency of communication with their alter egos generally got more emotional, tangible, and informational support. This result highlights the need for social support in a patient population. As a result, given the significance of community support, physicians and health professionals should investigate interpersonal interactions that may affect an AITD patient's social connection.

In summary, this dissertation, as an integrated body of work, provided a rationale for investigating patients with AITD social networks; identified individual and interpersonal factors that are related to a patient’s self-efficacy about the management of AITD; identified the underlying factors that are related to an AITD patient connecting with someone who provides more social support; and provided specific areas for future research and health education regarding AITD research.

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APPENDIX A

LITERATURE REVIEW SEARCH TERMS AND ALGORITHMS BY DATABASE

Medline Ovid 9/2/2020
99 retrieved

1. exp Thyroiditis, Autoimmune/
2. exp Graves Disease/
3. (autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis).ti,ab.
4. or/1-3
5. exp Physicians/
6. exp Nurses/
7. (physician* or doctor* or nurse*).ti,ab.
8. or/5-7
9. exp Students, Nursing/
10. exp Students, Medical/
11. ((medical or nursing) adj1 student*).ti,ab.
12. or/9-11
13. exp Education/
14. ((continuing or professional) adj1 education).ti,ab.
15. curricul*.ti,ab.
16. or/13-15
17. 4 and (8 or 12) and 16
18. exp Thyroid Diseases/
19. (thyroid adj1 disease*).ti,ab.
20. or/18-19
21. (4or 20) and (8 or 12) and 16

CINAHL 11/3/2020
106 Results

S21 S20 AND (S8 OR S12) AND S16
S20 (S18 OR S19)
S19 TI (thyroid n1 disease*) OR AB (thyroid n1 disease*)
S18 (MH "Thyroid Diseases+")
S17 S4 AND (S8 OR S12) AND S16
S16 S13 OR S14 OR S15

S15 TI curricul* OR AB curricul*
S14 TI ((continuing or professional) n1 education)) OR AB ((continuing or professional) n1 education))
S13 (MH "Education+")
S12 S9 OR S10 OR S11
S11 TI (((medical or nursing) n1 student*)) OR AB (((medical or nursing) n1 student*))
S10 (MH "Students, Medical")
S9 (MH "Students, Nursing+")
S8 (S5 OR S6 OR S7)
S7 TI ((physician* or doctor* or nurse*)
) OR AB ((physician* or doctor* or nurse*))
S6 (MH "Nurses+")
S5 (MH "Physicians+")
S4 (S1 OR S2 OR S3)
S3 TI ((autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis)) OR AB ((autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis))
S2 (MH "Graves' Disease+")
S1 (MH "Thyroiditis, Autoimmune")

Embase 11/4/2020
982 results

1 exp autoimmune thyroiditis/
2 exp Graves disease/
3 (autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis).ti. or (autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis).ab.
4 1 or 2 or 3
5 exp physician/
6 exp nurse/
7 (physician* or doctor* or nurse*).ti. or (physician* or doctor* or nurse*).ab.
8 5 or 6 or 7
9 exp nursing student/
10 exp medical student/
11 ((medical or nursing) adj1 student*).ti. or ((medical or nursing) adj1 student*).ab.

12 9 or 10 or 11
13 exp education/
14 ((continuing or professional) adj1 education).ti. or ((continuing or professional) adj1 education).ab.
15 curricul*.ti. or curricul*.ab.
16 13 or 14 or 15
17 4 and (8 or 12) and 16
18 exp thyroid disease/
19 (thyroid adj1 disease*).ti. or (thyroid adj1 disease*).ab.
20 18 or 19
21 20 and (8 or 12) and 16

APPENDIX B

LITERATURE REVIEW SEARCH TERMS AND ALGORITHMS BY DATABASE

Medline (OVID)
8/25/2021
# of results: 41
# of duplicates:

1 exp Thyroiditis, Autoimmune/

2 exp Graves Disease/

3 exp Thyroid Diseases/

4 exp Hashimoto Disease/

5 exp Hyperthyroidism/

6 (autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis or hyperthyroidism or (thyroid adj2 disorder) or (thyroid adj2 disease*)).ti,ab,kw.

7 1 or 2 or 3 or 4 or 5 or 6

8 exp Social Support/

9 (((social or emotional or tangible or instrumental or informational or belonging) adj1 support*) or social assist*).ti,ab,kw.

10 8 or 9

11 7 and 10

Embase (OVID)
8/25/2021
# of results: 220

# of duplicates: 0

1 exp Thyroiditis, Autoimmune/

2 exp Graves Disease/

3 exp Thyroid Diseases/

4 exp Hashimoto Disease/

5 exp Hyperthyroidism/

6 (autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis or hyperthyroidism or (thyroid adj2 disorder) or (thyroid adj2 disease*)).ti,ab,kw.

7 1 or 2 or 3 or 4 or 5 or 6

8 exp Social Support/

9 (((social or emotional or tangible or instrumental or informational or belonging) adj1 support*) or social assist*).ti,ab,kw.

10 8 or 9

11 7 and 10

CINAHLComplete (EBSCO)
8/25/2021
# of results: 61
# of duplicates:

S1 (MH "Thyroiditis, Autoimmune")

S2 (MH "Graves' Disease+")

S3 (MH "Thyroid Diseases+")

S4 (MH "Hyperthyroidism+")

S5 TI (autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis or hyperthyroidism or (thyroid N2 disorder) or (thyroid Nj2 disease*)) OR AB (autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis or hyperthyroidism or (thyroid N2 disorder) or (thyroid Nj2 disease*))

S6 S1 OR S2 OR S3 OR S4 OR S5

S7 (MH "Support, Psychosocial+")

S8 TX (((social or emotional or tangible or instrumental or informational or belonging) N1 support*) or social assist*) OR TI (((social or emotional or tangible or instrumental or informational or belonging) N1 support*) or social assist*) OR AB (((social or emotional or tangible or instrumental or informational or belonging) N1 support*) or social assist*)

S9 S7 OR S8

S10 S6 AND S9

APA PsycInfo (EBSCO)
8/25/2021
# of results: 9
# of duplicates:

S1 DE "Thyroid Disorders" OR DE "Goiters" OR DE "Hyperthyroidism" OR DE "Hypothyroidism" OR DE "Thyrotoxicosis"

S2 TI (autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis or hyperthyroidism or (thyroid N2 disorder) or (thyroid Nj2 disease*)) OR AB (autoimmune thyroid disease* or AITD or Graves disease or Hashimoto disease or autoimmune thyroiditis or hyperthyroidism or (thyroid N2 disorder) or (thyroid Nj2 disease*))
Expanders - Apply equivalent subjects

S3 S1 OR S2

S4 ((DE "Social Support") OR (DE "Emotional Support")) OR (DE "Social Support")

S5 TX (((social or emotional or tangible or instrumental or informational or belonging) N1 support*) or social assist*) OR TI (((social or emotional or tangible or instrumental or informational or belonging) N1 support*) or social assist*) OR AB (((social or emotional or tangible or instrumental or informational or belonging) N1 support*) or social assist*)
Expanders - Apply equivalent subjects

S6 S4 OR S5

S7 S3 AND S6

APPENDIX C

Review Matrix of Information Extracted from Studies Examining the Effect of Training Medical Health Professionals on Early Screening and Selection for AITD.

Title	Citation	Health Care Setting	Modality	Intervention Strategy	Type of Practitioner	Interdisciplinary Training	Key Findings
Evaluating evidence against diagnostic hypothesis in clinical decision-making by students, residents, and physicians	Allen, V. G., Arocha, J. F., & Patel, V. L. (1998). Evaluating evidence against diagnostic hypotheses in clinical decision-making by students, residents, and physicians. International journal of medical informatics,	Clinic (Boston, MA)	Evidence-based support tools	Provide evidence-based support tools based on the clinician's level of expertise and background knowledge to make appropriate decisions.	Physician	Yes, it could be adapted for NPs and PAs who also have the authority to make a diagnosis.	"Specifically, we show that: (1) the ability to index and use adequate evidence by physicians, residents, and students is a function of the early generation of accurate hypotheses and (2) that the strategies for resolving inconsistent evidence differed as a function of medical expertise".

	51(2-3), 91-105.						
A comparison of the teaching effectiveness of the didactic lecture and the problem-oriented small group session: A prospective study	Dunnington, G., Witzke, D., Rubeck, R., Beck, A., Mohr, J., & Putnam, C. (1987). A comparison of the teaching effectiveness of the didactic lecture and the problem-oriented small group session: a prospective study. Surgery, 102(2), 291-296.	University (Tucson, AZ)	Didactic Lecture (DL) and Problem-Oriented Small Group Sessions (POSGS)	Dissemination of information through lecture or small group sessions	Physician	No, third-year medical students only	"Students in POSGS offers significant advantages over the DL in teaching surgery to third-year medical students."

Thyroid Hormone Replacement in Women of Reproductive Age: Is Surgeon Knowledge Related to Operative Volume?	Haymart, M. R., Cayo, M. A., & Chen, H. (2010). Thyroid hormone replacement in women of reproductive age: is surgeon knowledge related to operative volume?Thyroid, 20(6), 627-631.	Conference (Madison, WI)	Toolkit (Guidelines on the Management of Thyroid Dysfunction during Pregnancy and Postpartum)	Guidelines on Management of Thyroid dysfunction	Physician	Could be disseminated to other disciplines like pharmacists or nurses (maybe even health educators) and other types of physicians like OB/GYN or primary care doctors.	"Surgeons who read the Endocrine Society's 'Guidelines on the Management of Thyroid Dysfunction during Pregnancy and Postpartum' were significantly more likely to inform patients of the need for higher LT4doses with pregnancy. Thyroid surgery volume was associated with guideline awareness.
Learning the Thyroid Examination—A Multimodality Intervention for	Houck, W. A., Soares-Welch, C. V., Montori, V. M., & Li, J. T. (2002). Learning the thyroid examination-a	University (Rochester, MN)	The intervention group received a 60-minute educational session during which an endocrinologist described anatomical	60-minute Training Session	First-year Residents	N/A	"A 1-hour multimodality learning session furthered the ability of first-year internal medicine residents to detect thyroid abnormalities".

Internal Medicine Residents	multimodality intervention for internal medicine residents. Teaching and learning in medicine, 14(1), 24-26.		landmarks, thyroid abnormalities, and examination techniques using a slide show, computerized animation, videotape, and live demonstration on a volunteer with goiter. Residents examined a normal and a goitrous thyroid under the observation of a preceptor and received an evidence-based handout on the thyroid examination.				

Thyrotoxicosis in a Postpartum Adolescent: A Simulation Case for Emergency Medicine Providers	Leviter, J. I., Sojar, S., Ayala, N. K., & Wing, R. (2020). Thyrotoxicosis in a Postpartum Adolescent: A Simulation Case for Emergency Medicine Providers. MedEdPORTAL, 16, 10967.	Hospital	Medical Simulation Center	This simulation activity was implemented during scheduled EM didactics. There were 10-12 learners in each group. Four participants from the learner group actively participated in the simulation case at a time, while the remainder of the participants observed the	Physician	Prerequisite knowledge included identifying and managing abnormal vital signs, abnormal physical exam findings, respiratory distress, altered mental status, and comprehension/interpretation of laboratory results and imaging.	“Learners felt that this case was effective in teaching the skills necessary for caring for postpartum patients with respiratory distress and altered mental status.”

				simulation in the room.			

APPENDIX C

Review Matrix of Information Extracted from Studies Examining Social Support and AITD.

Author Information/Year	Citation	Specific AITD Disorder	Perceived Adequacy of Social Support	Type of Social Support	Subject experience of social support	Key Findings
Banach et al., 2013	Banach, R., Bartès, B., Farnell, K., Rimmele, H., Shey, J., Singer, S., ... & Luster, M. (2013). Results of the Thyroid Cancer Alliance International Patient/Survivor Survey: psychosocial/informational support needs, treatment side effects, and international differences in	Thyroid Cancer	The vast majority of respondents reported that they were not offered assistance from a psychologist/counselor, nurse, or other support professionals, referral to a patient organization, or clear written information about their disease/treatm	Other: Psychosocial/Informational	First, thyroid cancer patients/survivors appear to have important unmet informational and psychological/ emotional support needs. In total, lack of information about the disease/treatment or lack of psychological/ emotional support were cited directly	Moreover, the most frequently cited difficulties, “receiving a cancer diagnosis” and “uncertainty/ anxiety about the future,” together accounting for 46.2% of responses, may be attributable at least partly to a

	care. Hormones, 12(3), 428-438.		ent at diagnosis. Likely due to the limited availability of support, 85.4% of respondents sought information/support outside their clinic, from the internet (88.2% of those seeking outside resources), thyroid organization pamphlets (42.1%), patient groups (30.6%), books		by 15.5% of respondents as the hardest aspect of their thyroid cancer experience.	dearth of information/ support. In some settings, budgetary and logistical constraints may limit routine patient access to support professionals.

			(30.3%), family physicians (28%), other thyroid cancer patients/survivors (27.5%), or friends/family (26.5%).			
Brierley et al., 2016	Bender, J. L., Wiljer, D., Sawka, A. M., Tsang, R., Alkazaz, N., & Brierley, J. D. (2016). Thyroid cancer survivors' perceptions of survivorship care follow-up options: a cross-sectional, mixed-methods survey. Supportive Care	Thyroid Cancer	Respondents agreeable to PCP follow-up had a trusting relationship with their PCP and access to a TC specialist. In-person follow-up was preferred because it was considered more personal, reassuring,	Informational	The absence of these cues that convey important personal and emotional information can affect impression formation.	Ultimately, the extent to which TC survivors are satisfied with their follow-up care depends on their level of trust and confidence in their health professional.

	in Cancer, 24(5), 2007-2015.		and accurate. Lack of verbal cues is a well-recognized limitation of computer-mediated communication, which can lead to misinterpretations.			In this study, patients' preferences for in-person specialist follow-up stemmed from existing trust in their specialist and distrust in their PCP for cancer follow-up, in part influenced by negative primary care experiences.
Chen et al., 2012	Chen, D. Y., Schneider, P. F., Zhang, X. S., He, Z. M., Jing, J., & Chen, T. H.	Graves Disease	Coping strategies and social support networks might modify	Other: psychological	More positive coping styles and increased social support might enhance	Patients with GD should use positive coping strategies

	(2012). Mental Health Status and Factors that Influence the Course of Graves' Disease and Antithyroid Treatments. Experimental and clinical endocrinology & diabetes, 120(09), 524-528.		the effect of life events.		the cure rate of antithyroid treatments.	and receive psychological support to avoid compromising their work-related performance and endangering his or her social status. Social support improves patient prognosis that might otherwise show delayed attenuation.
Henry et al., 2018	Henry, M., Ehrler, A., Rosberger, Z.,	Thyroid Cancer	Patients reported similar	Emotional	Other patients simply refused to talk about	This study emphasizes how the

	Tamilia, M., Hier, M. P., Chang, Y. X., ... & Mlynarek, A. M. (2018, September). Feelings of Disenfranchisement and Support Needs Among Patients With Thyroid Cancer. In Oncology nursing forum (Vol. 45, No. 5).		concerns in relationships with their peers. For example, they felt that their peers occasionally minimized patients' concerns but at other times exaggerated the dangers.		their cancer, feeling that they could not rely on anyone for support, were ashamed, feared being a burden, or wanted to be stoic. The diagnosis was still always in the back of their minds; they struggled in silence as they repeated their mantra that everything was going to be OK. They wanted to believe this.	needs of individuals with thyroid cancer have been overlooked because of a good medical prognosis. Findings from this study highlight the need for healthcare providers to more specifically address the psychosocial complexities and the healthcare system challenges

						of this group of patients. In addition to treating the disease, systematic access to a nurse championing an inter-professional team offers comprehensive support at a time of potential crisis.
Hyun et al., 2016	Hyun, Y. G., Alhashemi, A., Fazelzad, R., Goldberg, A. S., Goldstein, D. P., & Sawka, A. M. (2016). A systematic review of unmet	Thyroid Cancer	This systematic review found that unmet information needs in thyroid cancer survivors were highly variable	Informational	This review also suggests that thyroid cancer survivors perceived that they were offered relatively little	Patient support groups such as Thyroid Cancer Canada (67), ThyCa (68), the butterfly Thyroid

	information and psychosocial support needs of adults diagnosed with thyroid cancer. Thyroid, 26(9), 1239-1250.		relating to the disease, diagnostic tests (including imaging studies), treatments, and coordination of medical care.		psychosocial support for concerns such as management psychological/ emotional issues, fear of recurrence, fear of side effects, financial matters/employment, and impact on the family.	Cancer Trust (69), and the Light of LifeFoundation (70) also provide some information online as well as access to patient support. There are also numerous other patient support groups providing very helpful information and psychosocial support resources in

						various formats and languages throughout the world. Yet, despite the important work of such established organizations, this review suggests that some patients may not be receiving information about these resources or that additional resources may need to be

						developed. It is also important to acknowledge that information and support needs may vary among individual patients, which may explain some of the variability of outcomes observed in this review.
Misra et al., 2013	Misra, S., Meiyappan, S., Heus, L., Freeman, J., Rotstein, L., Brierley, J. D., ... & Sawka, A. M. (2013). Patients'	Thyroid Cancer	The psychosocial support received from personal relations (such as spouses, family, co-	Other: Psychosocial Support	The primary sources of medical information and advice used by patients throughout the	The psychological response to the diagnosis of locally recurrent thyroid

	experiences following local-regional recurrence of thyroid cancer: A qualitative study. Journal of Surgical Oncology, 108(1), 47-51.		workers, or friends) or from formal support organizations was variable. Listening, empathy, and encouragement from relations were generally considered helpful by patients. The opportunity to obtain peer advice and support from individuals who had survived thyroid cancer recurrence was generally highly valued.		experience of diagnosis and treatment of disease recurrence were thyroid cancer specialist physicians and surgeons. Confidence in the thyroid cancer care team was exemplified by statements such as, “My attitude was that the doctor knows what they are doing, they know what’s wrong, so now they can go ahead and fix it” or,	cancer typically includes emotions such as shock, fear, sadness, anger, and frustration. For some patients, this experience may be emotionally devastating. Medical information and psychosocial support needs are heightened at the time of diagnosis and treatment of

					“I trust their judgment.”	disease recurrence. Although recovery from the physical and emotional trauma of treatment of thyroid cancer recurrence is usually positive, some patients may experience unmet information needs and lingering worry related to future recurrence.

Pitt et al., 2019	Pitt, S. C., Wendt, E., Saucke, M. C., Voils, C. I., Orne, J., Macdonald, C. L., ... & Sippel, R. S. (2019). A qualitative analysis of the preoperative needs of patients with papillary thyroid cancer. Journal of Surgical Research, 244, 324-331.	Thyroid Cancer	This study demonstrates that patients with thyroid cancer have a clear need for a strong patient-surgeon relationship, characterized by informational and emotional support and respect for the individual. When these needs were met, patients experienced a deep-seated sense of reassurance, whereas unmet needs	Other: Informational/Emotional	We show that when patients' information needs are satisfied, they feel reassured and confident. Patients also prefer the surgeon to be the primary source of information and want ample time to ask questions. Emotional support is the other key area that we identified as critical for patients with thyroid cancer in the	Our results and others suggest that clinicians can learn behaviors that improve this emotional support, such as eliciting and validating patients' emotions, offering encouragement, avoiding interruptions, and allowing time for patients to discuss expectations and voice

			increased worry and anxiety.		preoperative period.	concerns. These actions improve emotional support and are critical to building trust within the patient-surgeon relationship. Our data suggest this emotional support should also be individualized, and for those patients with thyroid cancer, the “good cancer”

						terminology should be avoided.
Roberts, Lepore, & Urken, 2008	Roberts, K. J., Lepore, S. J., & Urken, M. L. (2008). Quality of life after thyroid cancer: an assessment of patient needs and preferences for information and support. Journal of Cancer Education, 23(3), 186-191.	Thyroid Cancer	On average, patients were largely satisfied with the information that they received. In particular, patients felt that they had received adequate information about survival rates and the reasons for various tests, medications, isolation procedures, and preparing for medical	Informational	There were many areas in which patients rated the received support as inadequate, including support with getting access to nontraditional treatments, understanding why they got cancer, dealing with their families' reaction to their cancer, and dealing with fears of recurrence.	Participants also reported receiving inadequate support in dealing with emotional issues and inadequate guidance from medical professionals and hospital staff on where to find supportive care services. Many clinicians may not

			procedures, including surgery. However, there were some unmet information needs. Patients reported that they did not receive adequate guidance from medical professionals and hospital staff on where to get emotional support.		Thus, there were many unmet needs related to managing emotions, particularly as they relate to diagnosis and possible recurrence.	inquire about emotional support needs, generally deferring to their patients in initiating discussion of psychosocial issues.
Schultz, 2002	Schultz, P. N. (2002). Using internet discussion forums to	Thyroid Cancer	The author's experience with the e-mail group has revealed that	Other: emotional and informational	Local support groups may meet patients' emotional needs but may	Group members know the author's credentials

	address the needs of patients with medullary thyroid carcinoma. Clinical Journal of Oncology Nursing, 6(4).		patients want as much information as they can get to help direct their own care. This comment indicated that patients are in need of more than factual information. The author has chosen not to become involved in addressing emotional support in this group except when furnishing information.		not meet patients' informational needs, as support groups often are organized by facilitators not familiar with this unusual cancer and its treatment.	and name; no participant ever disputed this information. Sometimes patients apparently misunderstand information that has been provided to them, and occasionally, medical misinformation is given. In these instances, the author posts a response that usually begins with,

						"In my experience. . ." and may suggest that individuals ask their physicians about the issue. Because so much variation exists in the treatment of MTC.
Huang et al., 2004	Huang, S. M., Lee, C. H., Chien, L. Y., Liu, H. E., & Tai, C. J. (2004). Postoperative quality of life among patients with thyroid cancer. Journal of Advanced	Thyroid Cancer	On the four dimensions of social support, informational support was the only subscale on which perceived support from healthcare	Other: All Four	We found that social support from families and friends explained about one-third of the variance in quality of life among patients with thyroid cancer.	Social support from families and friends had positive effects on quality of life. Nurses could improve the quality of

	Nursing, 47(5), 492-499.		providers was higher than that from families and friends. Despite this, only social support from families and friends retained its significance in predicting quality of life in the regression model.			life among patients with thyroid cancer by strengthening their social support and educating them in the self-management of uncomfortable symptoms.
Shiue, 2015	Shiue, I. (2015). Urinary parabens and polyaromatic hydrocarbons independent of health conditions are associated with adult	Other: Thyroid Disorder	People with diabetes, asthma, arthritis, stroke, thyroid disorder, chronic bronchitis, sleep	Emotional	N/A	People with diabetes, asthma, arthritis, stroke, thyroid disorder, chronic bronchitis,

	emotional support needs: USA NHANES, 2005–2008. Environmental Science and Pollution Research, 22(17), 12951-12959.		complaint, sleep disorder, or trouble seeing need more emotional support.			sleep complaint, sleep disorder, or trouble seeing need more emotional support.
Wiener et al., 2009	Wiener, C. H., Cassisi, J. E., Paulson, D., Husson, O., & Gupta, R. A. (2019). Information support, illness perceptions, and distress in survivors of differentiated thyroid cancer. Journal of Health Psychology,	Thyroid Cancer	The direct relationship between information support and distress was not significant. Collectively these results suggest that the effect of information on distress is dependent on affecting illness	Informational	Patient perceptions regarding the emotional impact of illness, consequences of illness, symptom experience, and concern regarding illness may be particularly important to target, given	Model results disclosed that greater information support was associated with better illness perceptions and better illness perceptions associated with less distress.

	24(9), 1201-1209.		perceptions. These results also suggest that interventions targeting illness perceptions are needed to affect distress in survivors of DTC and that information provision is one avenue through which patient illness perceptions may be influenced.		that these illness perception domains (“emotional response,” “consequences,” “identity,” and “concern”) demonstrated the strongest relationships with distress.	Information support and distress were indirectly related via illness perceptions. The results highlight the importance of addressing illness perceptions in this population and suggest that informational interventions may help serve this function.

Yoshiuchi et al., 1998	Yoshiuchi, K., Kumano, H., Nomura, S., Yoshimura, H., Ito, K., Kanaji, Y., ... & Suematsu, H. (1998). Psychosocial factors influencing the short-term outcome of antithyroid drug therapy in Graves' disease. Psychosomatic Medicine, 60(5), 592-596	Graves Disease	N/A	Other: All Social Support	N/A	In conclusion, our findings suggest that daily hassles may play a role in the course of Graves disease in women with antithyroid drug therapy. Therefore, psychological intervention may affect the course of Graves disease in women with antithyroid drug therapy.

Zdanowska et al., 2010	Zdanowska, J., Stangierski, A., Sowinski, J., Danuta Glowacka, M., Warmuz-Stangierska, I., Czarnywojtek, A., ... & Stangierski, R. (2010). Subclinical hyperthyroid patients' knowledge about radioiodine therapy—The key role of medical information. Neuroendocrinology Letters, 31(6), 775.	Hyperthyroidism/Hypothyroidism	N/A	Emotional	The results of present investigations indicated that patients' requests for information were concerned with emotional support, explanation, reassurance, and investigation and treatment, which suggested a lack of appropriate messages and deficiency of emotional support.	Our finding of a strong association between patients' report of received information and their emotional conditions related to thyroid disease (Stangierski et al. 2009; Warmuz-Stangierska et al. 2002) may have important implications for the effectiveness of therapy.

APPENDIX D

FULL SURVEY USED IN THIS INVESTIGATION

Note: This instrument will be distributed online using Qualtrics. This is the formatting for the paper version. The instrument has been copied and pasted to this document. The actual survey is larger in font and does not split questions in half at page breaks.

Opening statements: Thank you for taking the time to take this survey. My name is Taylor Graves-Boswell, and I am a doctoral candidate at Texas A&M University. I am surveying patients to better understand their knowledge of chronic disease and how it effects self-management, who they may intend to talk to about Autoimmune Thyroid Disease (AITD) (including hypothyroidism or hyperthyroidism, Graves Disease, Hashimoto Disease, Autoimmune Thyroiditis), and the context in which these conversations may occur. In this survey, you are the expert --I want to learn more about your thoughts, feelings, and experiences about sharing information concerning AITD. I will be asking for some information about people you know, such as who they are to you. You can choose to give me their first name, initials, or make up a name for them if you prefer. The survey will take about 20 minutes. You are under no obligation to complete this survey.

Part I: Background Information. In this section, please answer each question about yourself. Your information will be kept strictly anonymous.

1. How old are you? Answer in years. ___________
2. What is your gender?
    a. Man
    b. Woman
    c. Other, please specify______________________
    d. I would prefer not to answer
3. How would you describe your race? Select all that apply.
    a. American Indian or Alaska Native
    b. Asian
    c. Black or African American
    d. Hispanic or Latino or Spanish
    e. Native Hawaiian or Pacific Islander
    f. White or Caucasian
    g. Other race, please specify _____________________
    h. I would prefer not to answer.
4. Which of the following best describes your current relationship status?

   a. Not dating
   b. Dating several people
   c. Dating one person exclusively
   d. Engaged
   e. Married
   f. Married but separated
   g. Divorced

Part II. Knowledge of Chronic Disease: Please try to answer the questions by selecting your answer to the statements below. Response options for all items below are: Yes, No, and I don't know.

1. Is hypertension another name for high blood pressure?
   a. Yes
   b. No
   c. I don't know
2. Is the following blood pressure considered to be high 130/80?
   a. Yes
   b. No
   c. I don't know
3. Can hypertension be treated with medication, and can weight loss decrease blood pressure?
   a. Yes
   b. No
   c. I don't know
4. Can lifestyle changes such as stopping smoking and weight loss decrease blood pressure?
   a. Yes
   b. No
   c. I don't know
5. Is kidney damage a sign of high blood pressure?
   a. Yes
   b. No
   c. I don't know
6. Is diabetes commonly known as "sugar" sickness?
   a. Yes
   b. No
   c. I don't know
7. Are the following normal blood glucose levels 3.8-7.7?

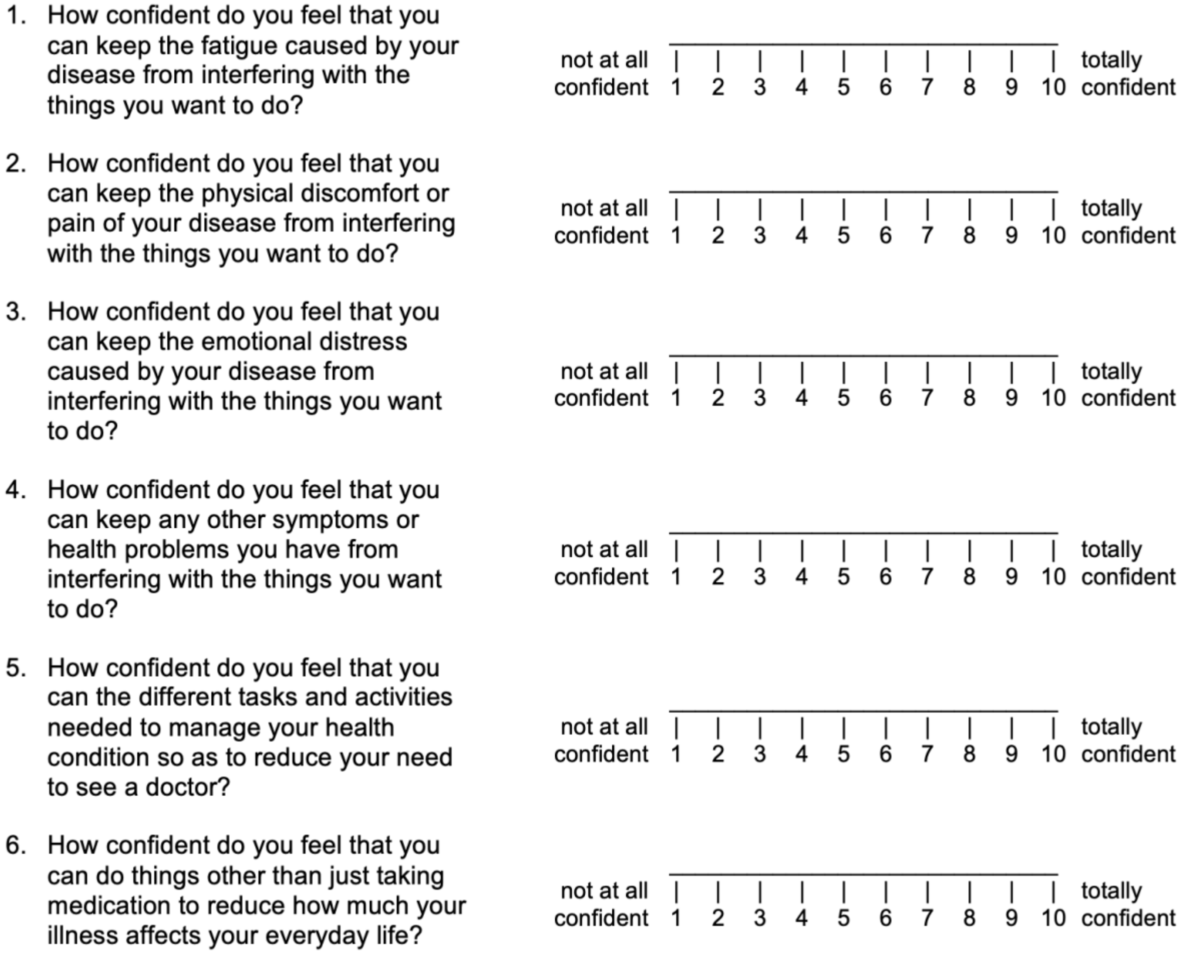
    a. Yes
    b. No
    c. I don’t know
8. Does eating too much sugar and other sweet foods cause diabetes?
    a. Yes
    b. No
    c. I don’t know
9. Can diabetes be cured?
    a. Yes
    b. No
    c. I don’t know
10. Are shaking and sweating signs of high sugar levels?
    a. Yes
    b. No
    c. I don’t know
11. Do the kidneys produce insulin?
    a. Yes
    b. No
    c. I don’t know
12. Is the usual cause of diabetes the lack of effective insulin in the body?
    a. Yes
    b. No
    c. I don’t know
13. Does diabetes cause poor circulation?
    a. Yes
    b. No
    c. I don’t know
14. Is medication more important than diet and exercise in controlling diabetes, namely Type 1 and Type 2?
    a. Yes
    b. No
    c. I don’t know
15. Are there 2 types of diabetes, namely Type 1 and Type 2?
    a. Yes
    b. No
    c. I don’t know
16. Can diabetes damage my kidneys?
    a. Yes

    b. No
    c. I don’t know
17. Is the most common type of stroke when the blood supply to the brain is blocked?
    a. Yes
    b. No
    c. I don’t know
18. Is another name for a stroke cerebrovascular accident?
    a. Yes
    b. No
    c. I don’t know
19. Are the signs of a stroke blurred vision, paralysis on one side of the body, and severe headache?
    a. Yes
    b. No
    c. I don’t know
20. Are you are at risk of getting a stroke if you are obese?
    a. Yes
    b. No
    c. I don’t know
21. Is the most commonly known risk factor for stroke high blood pressure?
    a. Yes
    b. No
    c. I don’t know
22. If you drink alcohol, you are less likely to get a stroke?
    a. Yes
    b. No
    c. I don’t know
23. To reduce the risk of stroke, do you need to eat well and exercise regularly?
    a. Yes
    b. No
    c. I don’t know
24. Could right arm paralysis be a physical disability of stroke?
    a. Yes
    b. No
    c. I don’t know
25. If you stop smoking, can you decrease the risk of having a stroke?
    a. Yes

    b. No
    c. I don’t know

26. Are diabetes and stroke closely linked?
    a. Yes
    b. No
    c. I don’t know

Self-Efficacy about Management of Chronic Disease: We would like to know how confident you are in doing certain activities. For each of the following six questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.



1. How confident do you feel that you can keep the fatigue caused by your disease from interfering with the things you want to do?

   not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

2. How confident do you feel that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?

   not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

3. How confident do you feel that you can keep the emotional distress caused by your disease from interfering with the things you want to do?

   not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

4. How confident do you feel that you can keep any other symptoms or health problems you have from interfering with the things you want to do?

   not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

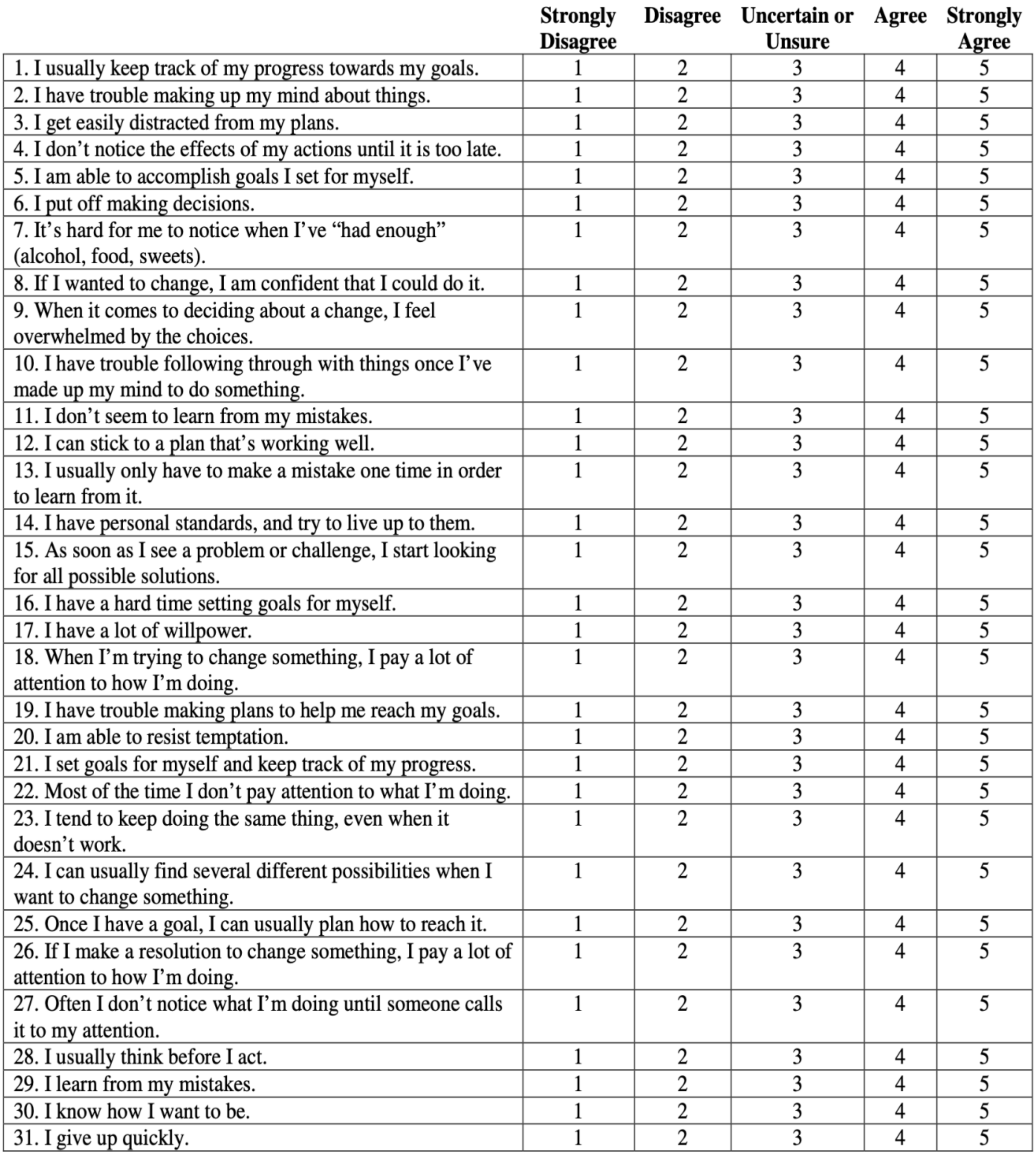
5. How confident do you feel that you can the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

   not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

6. How confident do you feel that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

   not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally confident

Short Form Self-Regulation Questionnaire (SSRQ): Please answer the following questions by selecting the response that best describes how you are. Remember, there are no right or wrong answers.



	Strongly Disagree	Disagree	Uncertain or Unsure	Agree	Strongly Agree
1. I usually keep track of my progress towards my goals.	1	2	3	4	5
2. I have trouble making up my mind about things.	1	2	3	4	5
3. I get easily distracted from my plans.	1	2	3	4	5
4. I don't notice the effects of my actions until it is too late.	1	2	3	4	5
5. I am able to accomplish goals I set for myself.	1	2	3	4	5
6. I put off making decisions.	1	2	3	4	5
7. It's hard for me to notice when I've "had enough" (alcohol, food, sweets).	1	2	3	4	5
8. If I wanted to change, I am confident that I could do it.	1	2	3	4	5
9. When it comes to deciding about a change, I feel overwhelmed by the choices.	1	2	3	4	5
10. I have trouble following through with things once I've made up my mind to do something.	1	2	3	4	5
11. I don't seem to learn from my mistakes.	1	2	3	4	5
12. I can stick to a plan that's working well.	1	2	3	4	5
13. I usually only have to make a mistake one time in order to learn from it.	1	2	3	4	5
14. I have personal standards, and try to live up to them.	1	2	3	4	5
15. As soon as I see a problem or challenge, I start looking for all possible solutions.	1	2	3	4	5
16. I have a hard time setting goals for myself.	1	2	3	4	5
17. I have a lot of willpower.	1	2	3	4	5
18. When I'm trying to change something, I pay a lot of attention to how I'm doing.	1	2	3	4	5
19. I have trouble making plans to help me reach my goals.	1	2	3	4	5
20. I am able to resist temptation.	1	2	3	4	5
21. I set goals for myself and keep track of my progress.	1	2	3	4	5
22. Most of the time I don't pay attention to what I'm doing.	1	2	3	4	5
23. I tend to keep doing the same thing, even when it doesn't work.	1	2	3	4	5
24. I can usually find several different possibilities when I want to change something.	1	2	3	4	5
25. Once I have a goal, I can usually plan how to reach it.	1	2	3	4	5
26. If I make a resolution to change something, I pay a lot of attention to how I'm doing.	1	2	3	4	5
27. Often I don't notice what I'm doing until someone calls it to my attention.	1	2	3	4	5
28. I usually think before I act.	1	2	3	4	5
29. I learn from my mistakes.	1	2	3	4	5
30. I know how I want to be.	1	2	3	4	5
31. I give up quickly.	1	2	3	4	5

Part III. Egocentric Data. In this section, we want you to think through the various social relationships in your life. In the table provided, list the initials of up to **five people** you discuss important health matters with. This can be anyone – relatives, friends, other patients, etc. Put the initials of up to five persons in the top row of the table provided below. Then, answer the following questions for each person you identified.

Please provide the initials of up to five people you discuss important health matters with.					
Initials	**Person 1 ______**	**Person 2 ______**	**Person 3 ______**	**Person 4 ______**	**Person 5 ______**
What is your relationship with this person? Select all that apply	-Parent -Daughter/Son -Sibling -Extended Family Member (e.g., grandparent, aunt, uncle, cousin) -Friend -Significant Other -Mentor/Supervisor -Other ____	-Parent -Daughter/Son -Sibling -Extended Family Member (e.g., grandparent, aunt, uncle, cousin) -Friend -Significant Other -Mentor/Supervisor -Other___	-Parent -Daughter/Son -Sibling -Extended Family Member (e.g., grandparent, aunt, uncle, cousin) -Friend -Significant Other -Mentor/Supervisor Other____	-Parent -Daughter/Son -Sibling -Extended Family Member (e.g., grandparent, aunt, uncle, cousin) -Friend -Significant Other -Mentor/Supervisor Other___	-Parent -Daughter/Son -Sibling -Extended Family Member (e.g., grandparent, aunt, uncle, cousin) -Friend -Significant Other -Mentor/Supervisor Other___
Is this person male or female?	-Male -Female -Other	-Male -Female -Other	- Male -Female -Other	Male -Female -Other	Male -Female -Other
What is that person's race? Select all that apply.	- American Indian or Alaska Native -Asian -Black or African American	- American Indian or Alaska Native -Asian -Black or African American	- American Indian or Alaska Native -Asian -Black or African American	- American Indian or Alaska Native -Asian -Black or African American	- American Indian or Alaska Native -Asian -Black or African American

	-Hispanic or Latino or Spanish -Native Hawaiian or Pacific Islander -White or Caucasian, -Other race, please specify ____ -I would prefer not to answer	-Hispanic or Latino or Spanish -Native Hawaiian or Pacific Islander -White or Caucasian, -Other race, please specify____ - I would prefer not to answer	-Hispanic or Latino or Spanish -Native Hawaiian or Pacific Islander -White or Caucasian, -Other race, please specify___ - I would prefer not to answer	-Hispanic or Latino or Spanish -Native Hawaiian or Pacific Islander -White or Caucasian, -Other race, please specify____ - I would prefer not to answer	-Hispanic or Latino or Spanish -Native Hawaiian or Pacific Islander -White or Caucasian, -Other race, please specify____ - I would prefer not to answer
How frequently do you communicate (in person, via phone, online) with ____? Select one.	-Daily -Weekly -Monthly -A couple times per year -less than once/year -never	-Daily -Weekly -Monthly -A couple times per year -less than once/year -never	-Daily -Weekly -Monthly -A couple times per year -less than once/year -never	-Daily -Weekly -Monthly -A couple times per year -less than once/year -never	-Daily -Weekly -Monthly -A couple times per year -less than once/year -never
What is the most common form of communication with _____? Select one.	-in-person -text message -phone call -social media	-in-person -text message -phone call -social media	-in-person -text message -phone call -social media	-in-person -text message -phone call -social media	-in-person -text message -phone call -social media
Does ___ have AITD?	-Yes -No -Unknown	-Yes -No -Unknown	-Yes -No -Unknown	-Yes -No -Unknown	-Yes -No -Unknown

Is ___ someone you can count on to listen to when you need to talk?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time
Is ___ someone to give you advice about a crisis?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time
Does ____ give you information to help you understand a situation?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time
Is ____ someone you can confide in or talk to	- None of the time - A little of the time	- None of the time - A little of the time	- None of the time - A little of the time	- None of the time - A little of the time	- None of the time - A little of the time

about yourself or your problems?	-Some of the time - Most of the time -All of the time	-Some of the time - Most of the time -All of the time	-Some of the time - Most of the time -All of the time	-Some of the time - Most of the time -All of the time	-Some of the time - Most of the time -All of the time
Is ___ someone whose advice you really want?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time
Is ____ someone who you share your most private worries and fears with?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time
Is _____ someone you turn to for suggestions about how to deal with a personal problem?	- None of the time - A little of the time -Some of the time - Most of the time	- None of the time - A little of the time -Some of the time - Most of the time	- None of the time - A little of the time -Some of the time - Most of the time	- None of the time - A little of the time -Some of the time - Most of the time	- None of the time - A little of the time -Some of the time - Most of the time

	-All of the time	-All of the time	-All of the time	-All of the time	-All of the time
Is ___ someone who understands your problems?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time
Is ___ someone who will take you to the doctor if you needed it?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time
Is ___ someone to prepare your meals if you were unable to do it yourself?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time
Is___ someone	- None of the time	- None of the time	- None of the time	- None of the time	- None of the time

who would help with daily chores if you were sick?	- A little of the time -Some of the time - Most of the time -All of the time	- A little of the time -Some of the time - Most of the time -All of the time	- A little of the time -Some of the time - Most of the time -All of the time	- A little of the time -Some of the time - Most of the time -All of the time	- A little of the time -Some of the time - Most of the time -All of the time
Is ___ someone to do things with to help you get your mind off things?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time
Is ___ someone to help you if you were confined to bed?	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time	- None of the time - A little of the time -Some of the time - Most of the time -All of the time

Now, indicate whether the people you nominated know one another by completing the table below. You will put an X in the shared cell between two people that know each other. For instance, if person 1 and person 3 know each other, insert an X in their shared cells (person 1 row, person 3 column: person 3 row, person 1 row).

	Person 1	Person 2	Person 3	Person 4	Person 5

Person 1					
Person 2					
Person 3					
Person 4					
Person 5					

You have completed the survey. Thank you for your participation!