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# Coping and Support Strategies Portrayed in Rheumatoid Arthritis Illness Blogs

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Abstract

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Dissertation Submitted in Partial Fulfillment

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# Abstract

The symptoms of rheumatoid arthritis (RA), such as pain, fatigue, stiffness, and inflammation, limit individuals' abilities to care for themselves, participate in social events, and complete tasks associated with gender norms. RA is a chronic and debilitating disease that people struggle to cope with physically, mentally, emotionally, socially, and financially, but many have not established effective coping and support strategies. The purpose of this hermeneutic phenomenological qualitative study guided by a combination of Orem's theory of self-care and Watson's theory of the human caring was to explore the coping mechanisms and support strategies of women and men with RA as identified from public illness blogs. Public blogs written in English from 15 women with RA and 6 men with RA were analyzed. Direct quotes from the blogs were not published to protect the identity of the bloggers. The findings of the study from men and women indicated that individuals coped with their RA by learning to conserve their energy, retiring, adopting less physically demanding hobbies, learning more about the disease and treatment options, and participating in patient advocacy. Themes from women with RA were divided into pain management, energy conservation, fertility and motherhood, and sources of support. Findings from men with RA revealed themes of self-management, physical health, RA symptoms and other diseases, emotional struggles, and masculinity. Future studies of bloggers' experience could help to improve understanding of how people live with RA and affect positive social change by improving healthcare through better response to the needs of individuals with RA.

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# Dedication

I dedicate this work to individuals with rheumatoid arthritis, to those who are in the process of determining their diagnosis, to those who have been diagnosed, and to those who are in remission. Knowing how to cope with the disease, family, and work is the key to surviving rheumatoid arthritis. I hope this work aids in supporting individuals with rheumatoid arthritis and the care they receive.

I dedicate this work to my family. To my mother, I thank you for your words of encouragement, for your support, and for the yummy food you cook. To my children, I thank you for your understanding, support, and encouragement throughout my educational journey.

# Acknowledgements

I thank my dissertation committee for giving me the opportunity to conduct this study and working with me through every step of the way to take this topic from premise to a completed 3-manuscript dissertation. I thank each member of my dissertation committee for their reviews, edits, progress tracking, and every approval along the way.

I thank my family for their support and encouragement as I completed my education.

## Table of Contents

# List of Tables

## List of Figures

## Part 1: Overview

### Introduction

Rheumatoid arthritis (RA) is a debilitating and complex autoimmune disorder that causes the immune system to take aggressive action against body cells by destroying the cells instead of protecting them (Poh et al, 2015). The attack on the cells leads to inflammation, pain, stiffness, and swelling in the joints and major organs of the body. Individuals with RA also experience morning stiffness and weakness that can last from a few hours to all day (Orbai, 2014). As a complex disorder, the cause of RA is linked to different genes and environmental influence (Mitchell, 2012). About 1% of the world's population has RA and 1.3 million Americans live with the disease (Simmons, 2013; Vandever, 2017).

Due to the fluctuating effect of inflammation, pain, and swelling, RA reduces the quality of life by impacting individuals' physical, mental, emotional, social, and financial health (Poh et al., 2015). RA can limit individuals' ability to care for themselves, complete chores, and participate in social events (Malm et al., 2017). Currently, RA does not have a cure, but current treatments involving expensive medication and physical therapy along with lifestyle changes may help to slow the progression of the disease (Poh et al, 2017). However, more than half of the individuals with RA who do not receive adequate treatment are unable to work a decade after disease onset (Vandever, 2017).

Moreover, individuals with RA experience stressors from the symptoms of the disease and disease outlook. These stressors along with additional external stressors from work, family, and financial issues can affect an individual psychologically (Cal de Sa, Glustak, & Santiago, 2015). Pain and psychosocial factors have a multifaceted relationship, where psychosocial factors can affect an individual's view of pain, and pain affects an individual's psychosocial well-being through physical limitations and limiting the ability to interact with others (Backman, 2006). Therefore, individuals struggling with RA do not only need treatments that address the pain, swelling, and inflammation, but may also require treatments that address the psychological aspects of their disease. The use of effective coping mechanisms and support strategies will allow individuals to effectively deal with the mental and physical aspect of the disease. One strategy is to attend a support group. Support groups can help individuals with RA by providing them with more education about the disease and how to manage it, allowing them to connect with others, and improving the emotional impact with their disease (Batterman et al. 2014). However, men and younger adults are less likely to actively participate or attend support groups (Flurey et al., 2016; Keim-Malpass & Steeves, 2015). Additional research is necessary to identify effective options for coping mechanisms and support strategies for both men and women with RA (Flurey et al., 2016; Poh et al., 2015).

Most prior studies on coping and support strategies for individuals with RA focused on women and used data sources of interviews, focus groups, and surveys (Coty & Wishnia, 2012; Flurey et al., 2016; Poh et al., 2015). However, many men and women are blogging about their experience with RA along with their coping and support strategies in their personal illness blogs. The personal illness blogs of individuals with RA not only serve as coping strategies for the bloggers, but also provide a wealth of data on the coping and support strategies that empowers other individuals with RA. The illness blog setting allows men and women to express themselves in a different manner than a support group, focus group, or interview setting (Keim-Malpass & Steeves, 2012). In surveys and interviews, participants are asked to reflect on specific aspects of their life based on the intentions of the study. However, an illness blogger will write about the issues related to their disease that are most pressing to them at the time they are ready to share it rather than struggling to recall a past event similar to what an interviewer is asking. When recalling events that may have occurred years ago, participants may have forgotten or have to reconstruct their memory (Prescott, Gray, Smith, McDonagh, 2015). A user maintaining a blog can record an event that occurs closer to the occurrence of the event, which will reduce issues with memory impairment and memory reconstruction (Prescott et al., 2015). Rather than providing data for only a brief interview, a blog contains multiple entries that have accumulated over time. Additionally, blogs cater to those who may not want to participate verbally in focus groups or interviews. (Keim-Malpass & Steeves, 2015). Unlike a survey, the individuals are not limited to one of five to seven options on a Likert scale, but can provide long detailed responses full of rich, thick description, and a variety of emotions. Therefore, I explored the coping mechanisms and support strategies of individuals with RA as identified from public illness blogs and explored the gender differences in effective coping strategies.

With this study, I impact positive social change by identifying effective coping and support strategies for men and women with RA and increasing the awareness of RA and individuals’ experiences with the disease. Health providers and health resources can suggest to individuals with RA multiple ways patients can cope with their disease.

Individuals who learn to cope better with their psychosocial factors may have an increase in their overall well-being because psychosocial factors and pain have a multidimensional relationship (Backman, 2006). Moreover, increasing awareness could encourage people who are experiencing symptoms of RA to seek treatment and receive the diagnosis before severe deformation of the joints occurs.

## Background Synthesis of Existing Literature

### Experience of Individuals with Rheumatoid Arthritis

Individuals with RA have varying levels of pain, stiffness, swelling, and fatigue from one day to the next because of the unpredictable nature of the disease (Orbai et al, 2014 ten Klosster et al., 2014; White, Donvan, & Campbell, 2014). RA is a systemic disease, meaning that the disease affects the whole body. The systemic symptoms of RA include muscle pain, fluctuations in weight, and malaise (McCarron, 2015). In addition to the physical manifestations, there are also consequences of RA on the social body that include the limitations in participation at work or social events, difficulties in completing activities of daily living, and meeting gender, culture, family roles, and identities (White et al., 2014). The loss of identity and loss of independence is caused by the dependence on others to complete daily tasks, which may lead to feelings of guilt and shame (White et al., 2014). Researchers in the Netherlands compared RA patients to those without RA to determine if the limited participation and dependence on others led to feelings of guilt and shame (ten Klosster et al. 2014). Ten Klosster et al. (2014) did not find that RA patients experienced more guilt and shame than their peers without RA but noted that the findings may be culture specific as a similar study in Egypt did find a correlation between RA, guilt, and shame.

Many psychosocial factors are involved with RA because the disease is chronic and progressive. Current treatments may slow the progression of the disease, but no cure exists for RA (McCarron, 2015; Poh et al., 2017). Many RA patients are stressed from their decreased mobility, increased disability, and reduced independence. Symptoms of depression, job loss, economic struggles, social and relationship issues, and changes in relationship status are high among individuals with RA (McCarron, 2015). The effect of RA on the physical, mental, emotional, and social health can lead to reduced quality of life (McCarron, 2015; Poh et al., 2017).

## Coping and Support Strategies

Self-management of a chronic disease such as RA involves following the instructions of the physician and making the necessary lifestyle changes to adapt physically and psychosocially to the disease (Zuidema, Repping-Wuts, Evers, Van Gaal, & Van Achterber, 2015). An example of physically coping with the disease is how some patients used physical activities to cope with the physical pain and fatigue caused by RA (Loeppenthin et al., 2014). Loeppenthin et al. (2014) explained that patients preferred the natural fatigue caused by exercise to the unexplainable fatigue caused by RA. Moreover, individuals managing their RA use a combination of personal resources along with help and emotional support from others, including family, friends, and providers (Bergsten, Bergman, Fridlund, & Arvidsson, 2011). Personal resources for self-management refer to an individual’s perception of the disease and their perception of their ability to handle the disease, which is self-efficacy (Bergsten et al., 2011).

Bandura (1977) described self-efficacy as an individual’s perception of their ability to succeed in adopting a change as the determining factor for whether a coping behavior will be started and maintained despite obstacles faced. Individuals with RA may not feel capable of managing the disease or capable of following the suggested lifestyle changes. Bode et al. (2008) studied the effect of a self-management training program on the self-efficacy of the RA patients who attended. Individuals with RA require self-efficacy to accept the disease, improve their self-esteem, and make lifestyle changes such as reducing hours worked a week, resting more during the day, and exercising. Individuals struggling to accept the disease may not want to make vigorous lifestyle changes such as working less and taking an afternoon nap. For example, some individuals may not feel financially capable to reduce work hours. Bode et al. (2008) found that some participants with decreased self-efficacy after the training program were looking for peer support and long-lasting contacts that they could continue to have intellectual conversations with after the program.

Individuals with the same disease can support one another by sharing their own experience and providing psychosocial support by empowering each other and providing empathy, sympathy, and other emotional support (Dwarswaard, Bakker, Staa, & Beije, 2015). However, individuals respond to self-management support from others differently. Some individuals are willing to accept support from family and friends while others do not trust the support from others and desire greater independence (Bergsten et al., 2011).

Support from family, friends, and providers can also help to improve an individual's disease perception and self-efficacy (Bergsten et al., 2011). The support could be in the form of social, emotional, or informational support. Some individuals with RA struggle to identify support, so there is a need for nursing interventions to support self-management needs based on the perspective of RA patients (Zuidema et al., 2015).

Batterman et al. (2014) conducted a survey of individuals with RA who attended an educational support group program. The program involved a regular support group that met after attending a lecture on RA provided by nursing professionals. After attending the program, the attendants described feeling more confident in the management their RA and found their disease less of a disruption in their life because they learned to deal with the stress of the disease better. Participants of the survey also described feeling more knowledgeable to discuss their treatment with their physician. Over 150 people participated in the study conducted by Batterman et al. (2014), but 93% of the participants were women, and the average age of a participant was 49. Men tend to attend and participate less in support groups than women (Flurey et al., 2016). Flurey et al., (2016) studied the coping styles of men with RA and found that men would not want to participate in a support group because they would not know what to say.

## Coping Strategies Differ for Men and Women

Support groups encourage interactions and peer support among individuals with similar diagnoses; however, individuals experience living with RA and coping strategies differently (Flurey et al., 2016). For example, men and younger adult women are often unable to fully participate in support groups because they find it difficult to relate and express themselves with the actively participating older women (Flurey et al., 2016; Keim-Malpass & Steeves, 2015).

Flurey et al. (2016) and Flurey, White et al (2017) conducted focus groups of men with RA in the United Kingdom and found that RA reduced their strength, physical ability, and ability to work. The men perceived a loss of power and control from the limits that RA placed on their physical ability. The men noted that receiving help from their wife, other family members, and friends was a challenge to their masculinity, so they paid people to help with tasks around the house instead of having a friend or family member do it for free as a way of regaining their sense of masculinity and control.

In another study, Flurey, Hewlett et al. (2017) surveyed 620 men and women with RA about coping and support strategies. The researchers found that maintaining a sense of masculinity was important to men, and factors related to masculinity included being strong and silent, macho, and independent (Flurey et al., 2016; Flurey, Hewlett et al., 2017). Moreover, attending support groups and actively participating does not align with the silent aspect of masculinity (Flurey, White et al., 2017). The silent aspect of masculinity refers to men being stoic and not complaining about their condition (Flurey et al., 2016, Flurey, Hewlett et al., 2017). From the survey, Flurey, Hewlett et al. (2017) found that women indicated that all support strategies listed would be beneficial, but the men indicated that the support options providing information, such as websites or classes would be beneficial rather than discussing their experiences.

## Illness Blogs as a Data Source

Blogs allow individuals to express themselves, publish their experiences in chronological order, connect with others, make new relationships, and share and gain ideas and information (Jones & Alony, 2008). The ability to connect with others is an important factor of coping and support (Ressler, Bradshaw, Gualtieri, & Chui, 2012). Many bloggers offer rich, thick descriptions of their experiences that can provide sufficient data for qualitative research without introducing some of the bias that can occur during interviews or surveys, where participants are responding to specific questions raised by the researchers (Jones & Alony, 2008). With illness blogs, individuals focus on their experience and struggles with the patterns of their disease, treatment, and coping strategies (Keim-Malpass & Steeves, 2015).

Few studies have focused on illness blogs, and fewer studies have focused on illness blogs for RA (Keim-Malpass & Steeves, 2015; Prescott et al., 2015; Ressler et al., 2012). Keim-Malpass and Steeves (2015) studied the illness blog texts of young women with breast cancer and identified themes of the bloggers' experiences and emotions as the women transitioned through different stages of the disease and as the cancer treatment became routine for the bloggers. Keim-Malpass and Steeves (2015) concluded that illness blogs allow bloggers to exchange information, gain social support online, and express their emotions. The researchers noted that the results of their study on cancer illness blogs will help nurses understand the experiences of patients outside of the clinical setting to improve nursing-based interventions (Keim-Malpass & Steeves, 2015).

Prescott et al. (2015) found that blogs were a feasible method to study the experience of individuals with rheumatoid arthritis. Prescott et al. (2015) developed a blog for children with RA seeking treatment at a specific hospital but did not allow the children to communicate with one another through the blog system. Therefore, the blog that Prescott et al. (2015) used in their study lacked the support and connections that exist in online blogs available to the public. Ressler et al. (2012) studied illness bloggers with chronic illnesses and chronic pain but surveyed the participants on their blogging experience rather than focusing on the blog’s context. Ressler et al. (2012) noted that the survey responses indicated that blogging requires a time commitment but can help decrease the isolation and increase understanding of the disease or improve their perspective on the disease pattern.

## Theoretical Framework

The theoretical framework for this study combined the concept of normalcy described through Orem’s (1985) theory of self-care with the holistic nature of Watson’s (2002, 2015) theory of human caring. Important variables in this study on the self-management of RA are coping and support strategies, independence versus dependence, seeking information, emotional support, and impact of gender and roles. The goal of coping and support is to become accustomed to a new normal. For an individual with RA to cope and maintain themselves after diagnosis or to cope with a crisis, individuals need to practice self-management and seek information and emotional support to return to a new normal where they find a comfortable balance among independence, dependence, and meeting their cultural gender roles. Figure 1 depicts how the theories and the variables of my study relate.

Watson's (2002, 2015) theory emphasizes the benefits of support strategies and emotional support from health providers and others, and Orem's (1985) theory emphasizes the individual's role in self-care to shape and accept a new normal. Individuals need help and support from other sources to maximize their self-care potential.

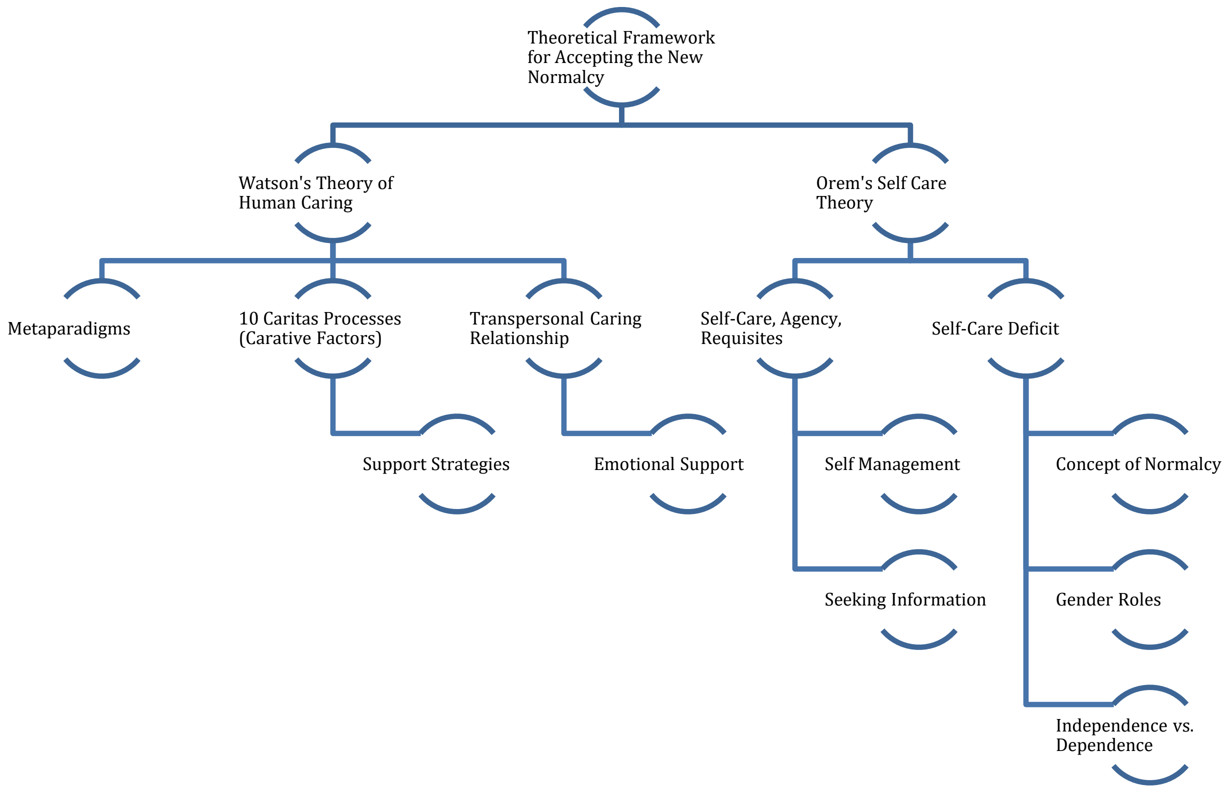

*Figure 1.* Theoretical framework for accepting the new normalcy.

Normalcy within Orem's (1985) theory refers to individuals developing and functioning within their social groups despite their limitations out of a desire to meet certain expectations that they define as their personal normal state (Hartweg & Pickens, 2016). Individuals with RA may have a different sense of normalcy regarding pain than individuals without RA, but individuals with RA want to enjoy the activities of daily living. Under Orem's theory, accepting a new normal involves a person regulating their self-concept, partaking in interpersonal relationships, having the necessities, and executing activities of daily living that align with their interest and values (Hartweg & Pickens, 2016). According to Watson's (2002, 2015) theory, interpersonal relationships help shape self-concept. Watson's theory incorporates self-concept and interpersonal relationships through transpersonal caring relationships (Clark, 2016). Transpersonal caring relationships are interconnected relationships in which people share their lived experiences with each other to connect on a personal and spiritual level (Clark, 2016).

The theory of human caring by Watson is a valuable philosophy that nurses can adopt to provide holistic care to patients while upholding the practices and regulations of nursing (DiNapoli, Nelson, Turkel, & Watson, 2010). RA patients aim to achieve survival and remission with limited disability. For individuals living with RA, the RA pain and fatigue can be very debilitating (Ressler et al., 2012). The condition can make individuals feel isolated and alone (Ressler et al., 2012). By reading the experiences of others in RA blogs, individuals with RA can be reminded that they are not alone in the battle and can learn the coping methods that have worked for others (Ressler et al., 2012). Human beings have the power to communicate and interact with each other and their environment by any means available to them, such as talking, messaging, blogging, taking photos, journaling, and sharing information. In RA blogs, individuals express their daily activities, share how they manage pain, provide education, and inspire others (Ressler et al., 2012). Blogs allow individuals to connect with others and share experiences through a form of digital transpersonal caring relationship.

Watson's (2002, 2015) theory of human caring applies the concept of holistic health, which is caring for the spirit, mind, and body (DiNapoli et al., 2010). Watson defines each of the four metaparadigms, which are person, environment, health, and nursing (DiNapoli et al., 2010). The metaparadigms can be related to illness blogging. Person is the recipient of care and includes individual characteristics of a person, such as personal values, spirituality, and demographics. The environment includes the internal and external factors related to a patient and includes the interactions between the bloggers and the blog visitors. Health includes access to care and the quality and wellness of the individual (Watson, 2002). With blogging access, support is increased as an unlimited number of people online can view and interact with the feelings and experiences shared. Nurses can apply information learned from the blog to patient care and encourage other patients to read blogs for support (Keim-Malpass & Steeves, 2015).

One of Watson's (2002) core concepts is to create a caring environment and caring moment that allows individuals to harness their own spiritual energy to bring their spirit, mind, and body into unity (DiNapoli et al., 2010). The caring occasion, also referred to as the caring moment, which occurs when the bloggers intentionally share their own genuine lived experience online with others (Watson, 2002). The readers honor and partake in the meaningful human transaction by expanding on their view of RA and enter into a new discovery of self and coping strategies. Watson's theory also includes a reflective meditative approach through increasing consciousness. Blogging allows individuals to understand self through self-reflective meditation by journaling their day-to-day experiences with their disease (Ressler et al., 2012). Blogging allows individuals to express themselves, describe their experiences and coping strategies while reflecting on the experience and noting their intuition and personal, cultural, and spiritual values (Ressler et al., 2012).

Watson (2002) described curative and carative factors. The individual with RA using medication prescribed to relieve the pain and slow the progression of the disease is the curative factor. When relief is not achieved, individuals with RA seek other methods to relieve their anxiety and stress of the disease, which are the carative factors. The caring occasion, caring moment, and reflective meditation are part of Watson's 10 carative factors, which can be related directly to illness blogging. The remaining carative factors relate to nursing care (Watson, 2002). The 10 carative factors are the acts of care and compassion that help individuals maintain their health. In 2008, Watson redefined the 10 carative factors as the caritas processes, which include teaching and learning, instilling faith and hope, miracles, spiritual beliefs and practices, holistic care, healing environment, practicing loving kindness, helping and trusting relationship, promoting expression of feelings, and making decisions (DiNapoli et al., 2010; Watson, 2015).

The disability of RA can cause reduced self-esteem, fatigue, depression, and other limitations due to pain (Poh et al., 2017). According to Orem's self-care model, providing self-care is effectively regulating illness symptoms (Denyes, Orem, & Bekel, 2001). For example, individuals with RA can assess their pain level, seek information on therapeutic measures, and apply the coping strategies to reduce pain (Denyes et al., 2001). Orem's model posits that maintenance of self-care behaviors will promote health and wellness (Denyes et al., 2001). The key concepts of Orem's theory include self-care requisites, self-care agency, and self-care deficit (Denyes et al., 2001). Self-care requisites are needs that must be completed or acquired such as basic necessities, interactions with others, and the activity of daily living (Ali, 2018). Human agency is the ability to make a decision regarding the next action or how to handle a situation. In terms of self-care, agency refers to making the decisions related to health. Self-care deficit is when the self-care requisites are not met and nursing care is required (Ali, 2018). For the management of a chronic disease such as RA, self-care is an essential part of the treatment plan so that individuals can maintain their health. When providers interact with patients, the intention of the providers is to form a health partnership with the patient to motivate, teach, and nurture self-care that can be incorporated into the lifestyle of the patient (Denyes et al., 2001).

Orem's theory of self-care is based on the assumptions that individuals can care for themselves (Wagnild, Rodrigues, & Pritchett, 1987). Individuals are free to take actions to manage their care (Wagnild et al, 1987). Orem's theory also has a list of self-care requisites and deficits, which includes the basics, such as air, food, rest, and social interaction (Sürücü & Kizilci, 2012). Some individuals with RA face limited social interaction, which is a social problem (Flurey, Hewlett et al., 2017). In contrast, the theory of human caring encourages a holistic approach to care and defines health to include mental, physical, and social health (Watson, 2015). Individuals with RA are not only affected physically by the disease but also mentally and socially. Therefore, Watson’s theory reflects the holistic nature of health and RA. Additionally, Watson’s theory encourages nurses to develop a transpersonal caring relationship with patients (Lukose, 2011). Nurses can learn from the information gained in the blogs to understand the disease, improve relationships with their RA patients, and find a new platform to encourage patients to follow different coping and support strategies. I used these theories together as the framework of this study to analyze the results and provide recommendations for nursing care.

### Research Gap

A review of the literature revealed gaps in identifying coping and support strategies for individuals with RA. Few studies on coping strategies for RA have focused on men (Flurey et al., 2016). Flurey et al. (2016) called for additional research to identify self-management support strategies that are most beneficial to men with RA. The findings of Flurey et al. (2016) and Flurey, White et al. (2017) have shown that support groups and discussions with the rheumatologists and friends are not attractive support strategies to men. Therefore, a research gap exists in identifying effective support strategies for individuals with RA, especially support strategies that allow men to maintain their sense of masculinity. I addressed the gaps in the literature by providing insight into the blogs of individuals with RA, identifying strategies for coping and support, and exploring the blogs of women and men diagnosed with RA.

## Overview of the Manuscripts

Three research questions are necessary to address the coping and support strategies of RA as described in public illness blogs and to identify which strategies are more beneficial to women and men. Past studies have either been general or focused on only women. Few studies focused on the coping and support strategy of men, and no studies have identified specific coping strategies for men with RA. Therefore, it is important to divide such a broad concept into three separate manuscripts. The first manuscript focuses on coping mechanisms and support strategies of individuals with RA. The second manuscript focuses on women with RA, their experiences and coping mechanisms portrayed in the blogs. Finally, the last manuscript focuses on men with RA, their experiences and coping mechanisms portrayed in the blogs.

## Manuscript 1

**Specific problem.** Chronic disease self-management requires personal and external support for a person to adjust physically and psychosocially to the disease (Zuidema et al., 2015). Many individuals with RA struggle to understand and cope with the disease, which can affect their perception of the disease and their physical, emotional, and social health outcomes (Bergsten et al., 2011; Zuidema et al., 2015). In this study, I addressed the problem of support and coping strategies by identifying effective strategies for individuals with RA.

> **RQ:** What coping mechanisms and support strategies do adults with rheumatoid arthritis portray in public illness blogs to deal with the effect that RA has on their lives?

**Nature of study and design.** The first manuscript serves as an introduction to the illness blogs. Past studies have not examined RA illness blogs, so I investigated the stories and messages of the bloggers. Additionally, I noted the age group and gender of the bloggers to provide an idea of the demographics of the bloggers. The nature of the study was a textual analysis of existing RA public illness blogs with a focus on the coping and support strategies. A textual analysis aligns with the hermeneutic phenomenological approach, which involves the rigorous reading, reflexive writing, and interpretation of text. (Kafle, 2011; Mills, Durepos, & Wiebe, 2010).

**Sources of data.** The study involved a textual analysis of existing public illness blogs; therefore, individual blogs by RA patients were the data source. Many arthritis blogs can be readily found online through internet searchers. Some websites have lists of arthritis illness blogs. The blogs selected for review were public, did not require a login to read the posts, were written in English, and only had one user making the main posts. RA illness blogs included in the study had at least 5 posts from any date range to be considered for inclusion. I identified at least 30 blogs to provide sufficient data for the three studies. For this study, I analyzed 10 blogs from adult men and women and reached saturation (Walden IRB approval no. 06-26-19-0709945).

## Manuscript 2

**Specific problem.** Individuals who were active before they were diagnosed with RA are no longer as active. Their social life, activities of daily living, and work hours may have become limited. According to Sanderson, Calnan and Kumar (2015), women with RA are sometimes concerned with being able to fulfill the gender roles and responsibilities of a mother and wife. Additionally, women with RA are concerned with whether their friends and family (immediate and extended) will be understanding of their adjusted activity level (Sanderson et al, 2015). These concerns will affect individuals emotionally and create stress, which could further increase the physical symptoms of pain, inflammation, and fatigue. To effectively handle such stressors that are specifically related to women, effective coping and support strategies must be identified.

> **RQ:** How do women with rheumatoid arthritis who participate in illness blogs portray coping mechanisms and support strategies to deal with the effect that RA has on their lives?

**Nature of study and design.** I followed the hermeneutic phenomenological approach, which involved textual analysis with a focus on the RA illness blogs written by adult women. With the hermeneutic phenomenology approach, I analyzed, questioned, and interpreted the blog text. I also maintained a reflexive journal to address the biases and assumptions that arise in the subjective nature of the methodology (Laverty, 2003). The gender, age, and other demographic data of the bloggers were determined from the demographic information that the blogger explicitly stated in the text.

**Sources of data.** For this study, I analyzed 15 RA illness blogs written by adult women with a focus on posts related to coping mechanisms and support strategies. I then coded the selected posts and analyzed the frequency of the terms. Blogs included in the study were accessible to the public without requiring a login, the main posts in the blog were written in English by one person, and the blog had at least 5 posts.

## Manuscript 3

**Specific problem.** Fewer studies on individuals with RA have focused on only men (Flurey et al., 2016). Men struggle with the negative aspects and negative thoughts of the disease more than women (Flurey et al., 2016). Therefore, it is important to analyze the illness blogs of men separately and identify male-specific coping and support strategies.

> **RQ:** How do men with rheumatoid arthritis illness blogs portray coping mechanisms and support strategies to cope with the effect that RA has on their lives?

**Nature of study and design.** For this study, I also followed the hermeneutical phenomenological approach and used textual analysis to interpret the text (Laverty, 2003; Kafle, 2011). This study differs from the previous two in that I only focused on the blog posts from men on their coping and support strategies. I included RA illness blogs where the bloggers explicitly identified themselves as men. I analyzed the arthritis illness blogs written by men, coded the blog content into themes, and identified a list of different coping mechanisms and support strategies discussed.

**Sources of data.** For this study, I analyzed 6 RA public illness blogs written in English by adult men. Each blog must have had at least 5 posts from any date range and the blog posts must have been written by only one user. I coded the text of the selected blog posts line by line and analyzed the frequency of the terms.

## Significance

Both external stressors and stressor from the symptoms of RA and disease outlook can affect a patient psychologically (Cal et al., 2015). How individuals cope with the psychological factors affects how they perceive the pain, inflammation, fatigue, and level of disability (Newman, 1993; Zuidema et al., 2015). Review of literature revealed that men and women with RA have different needs and preferences for coping and support strategies and that effective coping and support strategies have not been identified (Flurey, Hewlett et al., 2017). Therefore, more research is needed that focuses on coping mechanisms and support strategies for individuals with RA to identify what strategies may be best for different types of patients (Loeppenthin et al., 2014; Newman, 1993; Orbai et al., 2014; Poh et al., 2017; Prescott et al., 2015). Moreover, men and women cope with RA differently and react to support techniques differently. This research addresses a gap in understanding by focusing on the coping and support strategies of adults with RA in public illness blogs and analyzing coping and support strategies for men and women separately.

Literature on the experiences of RA patients has been gathered from interviews and focus groups (Loeppenthin, et al., 2014; Orbai et al., 2014; Poh et al., 2017; Prescott et al., 2015). However, illness blogs have a wealth of data on individuals' experiences and reflections of their disease that have not been analyzed (Keim-Malpass & Steeves, 2015). This project is unique because it explored the under researched data source of individual bloggers' expressive writing of their symptoms, treatments, emotions, and coping mechanisms for their RA that they produced over time to share with the public and connect with others (Keim-Malpass & Steeves, 2015; Ressler et al., 2012). Because of the broader demographic and geographic range of illness blogs written in English, I provided additional insights into RA that will increase awareness and provide knowledge of how both men and women experience and relate to disease outside of the clinical setting. Learning more about how individuals with RA discuss and perceive the disease and its treatments outside the clinical setting may also help clinicians understand the multiple perspectives patients have and how to relate to their different views (Simons et al., 2017). With this study, I impact social change by increasing the awareness of the lived experience of RA, improving treatment, and strengthening relationship among clinicians, patients, and their families (Poh et al., 2015).

## Summary

The need exists to examine the coping and support strategies of adults with RA to help individuals adjust to the disease and improve health outcomes (Loeppenthin et al., 2014; Orbai et al., 2014; Poh et al., 2017; Prescott et al., 2015; Newman, 1993; Zuidema et al., 2015). Men and women cope and respond to support strategies differently (Flurey et al., 2016; Keim-Malpass & Steeves). Therefore, it is important to analyze the coping strategies of men and women with RA separately. RA public illness blogs have a wealth of data that has not been analyzed, so the potential exists to gain deeper insight into the perceptions and experiences of adults with RA and to identify many coping strategies along with their effectiveness for men and women. I analyzed the blogs using the hermeneutic phenomenology methodology to conduct a textual analysis of the blog texts. Then, I related the findings to nursing care using Watson’s (2002, 2015) theory of human caring and Orem’s (1985) theory of self-care.

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Part 2: Manuscripts

# Manuscript 1: Analysis of Coping and Support Strategies Portrayed in Rheumatoid Arthritis Illness Blogs

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## Outlet for Manuscript

The article will be submitted to the *Journal of Medical Internet Research* (JMIR). JMIR Publications publishes many peer-reviewed journals on health science and technology and provides an open access preprint journal (JMIR, 2019). The preprint service and the *JMIR Nursing* does not have a fee for publication. *JMIR Nursing* is the target journal for this study because I linked the coping and support strategies that emerge in the rheumatoid arthritis (RA) illness blogs to the nursing theories of Watson and Orem. The aim for this first manuscript was to submit it to the JMIR preprint service and the *JMIR Nursing*. The open access preprint journal aligns with my positive social change goal of increasing awareness of RA. Once the article has been accepted into the *JMIR Nursing*, the publishers will link the preprint version of the article to the final version.

JMIR does not have a word limit, but most articles are between 3,000 and 6,000 words. The paper and references must follow the American Medical Association formatting (JMIR Publication, 2019). JMIR provided guidelines and a reference for addressing the ethics of informed consent and opting out for studies analyzing online postings (JMIR Publication, 2019). These helpful resources indicate that JMIR is inclined to accepting research articles using the analysis of online postings methodology. The author guidelines provided a sample layout and headings for the manuscript, and I will follow those headings when I submit for publication.

# Abstract

Individuals with rheumatoid arthritis (RA) struggle to cope physically and emotionally with the symptoms of the disease. A review of the literature revealed a gap in the coping and support strategies of individuals with RA. Past literature has focused on support groups and self-management training for support and noted their limitations. However, many individuals with RA share their experiences and coping methods for the disease online in their personal illness blogs. The purpose of this hermeneutic phenomenological study guided by Watson's theory of the human caring science and Orem's theory of self-care was to explore the mechanisms and support strategies adults with RA portrayed in public illness blogs to cope with the effect that RA has on their lives. The recent posts of public blogs from 7 women and 3 men with RA were analyzed through line-by-line coding with a qualitative data analyzer. The bloggers shared various coping strategies and described the level of support they received from family, friends, providers, the RA community, and other communities. Themes of transpersonal caring relationships with providers, self-care agency and requisites, support and resources, disease progress and normalcy, perception of others: stares and judgement, person, and medical costs and finances emerged from the analysis. Future studies on individuals with RA could further analyze how individuals cope with RA and explore patient interactions with healthcare providers.

## Introduction

Rheumatoid Arthritis (RA) is a chronic debilitating autoimmune disease that is characterized by stiffness, pain, redness, inflammation, and swelling of the joints (Nigrovic & Lee, 2005; Poh et al., 2017). Over a million people suffer from the disease in the United States, and about 2% of the world's population suffer from the disease (Lumley et al., 2015). However, measurement of the prevalence of the disease does not capture the number of undiagnosed individuals living with the disease or the severity of the disease impact on an individual's life. RA does not only affect the joints but can also affect the organs, including lungs, heart, teeth, skin, nerves, muscles, and blood vessels (Kobak & Bes, 2018; Souza, Bansal, Galloway, 2016). Additionally, kidney disease has a high prevalence among individuals with RA (Mori, Yoshitama, Hirakata, & Ueki, 2017). RA can affect people of any gender, socioeconomic status, age group, and ethnic background. The disease can have various clinical presentations and can be difficult to diagnosis at times (Kobak & Bes, 2018). The cause of RA is unknown, but there are some predisposing factors, such as genetics, environment, hormones, and lifestyle (Karlson & Deane, 2012).

RA can lead to severe and chronic stress due to its unpredictable and progressive nature and the sudden onset of severe pain that can occur at any time. The joint damage of RA is progressive and can lead to disability and joint deformity, which results in a loss or reduction in work, activities of daily living, and social activities. The reduction in activity level and fulfilling familial, marital, and social roles can result in psychiatric disorders involving depression and anxiety (Lumley et al., 2015; Poh et al., 2017).

Coping strategies and support mechanisms play an important role in the psychological aspect of the disease and adapting to necessary life-style changes (Lumley et al., 2015). Coping is cognitive and behavioral actions that individuals use to manage the demands that go beyond their personal resources (Lazarus & Folkman, 2004). Beneficial social support consists of the interpersonal relationships that people use to promote their well-being and protect themselves from stressful situations and declines (Umberson, Crosnoe, & Reczek, 2010). Effective coping and support can improve mental health and reduce the depression and stress related to the disease. Individuals suffering with RA can improve their coping skills and find support to reduce the pain associated with the disease and increase their activity level (Lumley et al., 2015). A review of the literature on patient's experiences with rheumatoid arthritis revealed a gap in effective coping and support strategies.

## Significance/Importance

The significance of this study is that it could impact positive social change through analysis of how individuals with RA describe their perceptions of different coping and support mechanisms, by increasing awareness of RA, and by empowering individuals with RA. Understanding the experiences and emotions of individuals with RA will assist providers in caring for patients with RA. Improvements in health care have led to a population of people living longer, which requires chronic disease management for diseases such as RA for an extended period of time. When dealing with RA for a long time, patients play a key role in managing their care in the patient-provider relationship. The physician must not only educate but also identify and address problems affecting the patient’s illness so that the patient can effectively self-care (Grady & Gough, 2014). When managing RA, individuals must become accustomed to complex medication schedules, monitor their physical health with multiple doctor visits, maintain a healthy diet, exercise despite pain and stiffness, and adjust their lifestyle and social life. To adapt, the individual with RA must be ready to psychologically adjust to these changes (Grady & Gough, 2014).

To further contribute to nursing knowledge, the key variables of the study and the results were linked to Orem’s (1985) theory of self-care and Watson’s (2002, 2015) theory of human caring. As the theoretical framework for this study, these theories addressed the concepts of helping individuals with chronic disease self-management and interacting with others to find a healing space for mind, body, and spirit (Denyes, Orem, & Bekel, 2001; Watson, 2002). Orem’s theory of self-care supports patient self-management for improved health outcomes (Denyes et al, 2001). Ensuring available and appropriate peer support and incorporating educational information about the disease help individuals with RA improve their emotional, coping, and support strategies (Grady & Gough, 2014). The role of the provider is to provide education, encouragement, guidance, and problem solving as patients learn to self-manage and adapt to the RA symptoms of pain, fatigue, and stiffness through varying activity levels. RA affects an individual’s physical, emotional, and social well-being (Poh et al., 2017). Watson’s (2002) theory of human caring links the emotional support from providers and spiritual connections as a source of hope and support for patients. Implementing Watson’s (2002) theory along with its concept of holistic care provides support that meets the psychosocial needs of individuals with RA.

Individuals with RA require support to cope because RA is an ongoing condition that systemically affects the body (Grady & Gough, 2014). Individuals with RA must find an empathetic confidant with whom they are comfortable to discuss their disease and related concerns (Flurey et al., 2017). For some people, support groups are helpful, but there are many individuals who do not feel comfortable attending or participating in support groups (Flurey et al., 2017; Keim-Malpass & Steeves, 2012). In this digital age, many patients have gone online to describe their disease journey, their emotions, and what has worked and not worked for them (Keim-Malpass & Steeves, 2012; Prescott, Gray, Smith, McDonagh, 2015). Individual illness blogs have provided longitudinal, detailed, and rich descriptions of the disease process, coping mechanisms, and support strategies from which readers can gain or through which readers can offer emotional support (Prescott et al., 2015).

These blogs serve as a wealth of data to analyze and to gain the perspective of individuals with RA (Prescott et al., 2015). Illness blogs are often overlooked as a data source, and past studies on RA have not analyzed existing RA illness blogs (Keim-Malpass & Steeves, 2012; Prescott et al., 2015). Therefore, the purpose of this research was to conduct a hermeneutic phenomenological qualitative study to explore the literature gap of coping mechanisms and support strategies of women and men with RA as identified in public illness blogs. Analyzing the public illness blogs of individuals with RA was a three-part process that started with an analysis of the topics discussed in the illness blogs. The second article focused on effective coping mechanisms and support strategies for women, and the third article was on coping and support strategies for men.

## Relevant Scholarship

### Physical Effects of Rheumatoid Arthritis

For individuals with RA, the body's immune system is overactive and attacks healthy cells and tissues of the body. RA is a systemic disease that involves the presence of increased mast cells (which indicates infection) and causes interactions between the macrophages T and B lymphocytes of the immune system that leads to inflammation of the synovial tissues and progressive destruction of the synovial joints (Fox, Gizinkski, Morgan, & Lundy, 2011; Nigrovic & Lee, 2005). Synovial joints (also known as diarthrosis joints) are the most flexible type of joints that provide mobility to the body (Fox et al., 2011). Each bone in a synovial joint has a layer of cartilage on the articulating surface. Between the layers of cartilage, is a joint cavity filled with synovial fluid (Rice University, n.d.). Ligaments provide support by connecting the bones to resist some of the excessive or abnormal motions of the joints (Rice University, n.d.). Synovial joints include the pivot joint in the neck at C1 and C2, the ball and socket joints of the shoulders and hips, the hinge joints of the elbows and knees, the saddle joint and condyloid joint in the wrists, and the plane joint in the ankle (Rice University, n.d.). RA causes the deformities in the joints of the fingers, hands, wrists, feet, ankles, knees, shoulders, and elbows. The inflammation and damage that RA causes to the synovial joints leads to pain and reduced mobility which can affect both sides of the body at the same time (Fox et al., 2011). The symptoms of RA differ from other types of arthritis, and the pain of RA can be more severe.

## Coping with Rheumatoid Arthritis

Those who suffer from RA partner with their health care team to combine medication with disease education, physical therapy, lifestyle changes, and support to improve their quality of life (Grady & Gough, 2014). Past studies on the experiences and coping strategies for RA have called for more patient education and research on effective coping and support strategies (Poh et al., 2017). Poh et al. (2017) conducted semi-structured interviews on individuals with RA in Singapore and identified themes such as changes in physical ability and social, emotional and financial support needs. Flurey et al. (2017) surveyed men and women with RA for their psychological impact and source of support preferences and identified that only 22% of 283 participants were accepting and adapting to disease. Therefore, many patients with RA are struggling to self-manage and adapt to the disease as it progresses.

Emotional writing intervention is a coping strategy where individuals write their emotions regarding their disease (Lumley et al., 2014). Lumley et al. (2014) conducted a randomized clinical trial to compare the effectiveness of coping-skills training and emotional writing as psychological interventions for individuals with RA. Lumley et al. (2014) found that coping-skill training was an effective psychological intervention, whereas the benefits of the writing intervention only lasted a short period and was not appropriate for all patients. Illness blogs are different from emotional writing described in the study of Lumley et al. (2014). Individual illness bloggers write to share their thoughts and experiences with others online. Lumley et al. (2014) compared the training of coping skills to the emotional writing which participants wrote specifically for the research study. Therefore, additional research is necessary to examine the effectiveness of blog writing as a coping strategy.

## Research Questions and Design

Individuals with RA suffer from severe chronic pain and fatigue along with multiple comorbidities. Many men and women with RA also struggle to cope (Flurey et al., Souza et al., 2016). To investigate the literature gap of effective coping and support strategies for individuals with RA, the following research question was posed:

> RQ: What coping mechanisms and support strategies do adults with rheumatoid arthritis portray in public illness blogs to deal with the effect that RA has on their lives?

To address this research question, I conducted a textual analysis of existing public illness blogs written in English by adult men and women with RA. With this study design, I uncovered a wealth of data on the experiences of individuals living with RA. The blogs provided more detailed information than a survey or questionnaire. The blog posts were written much closer to the time the event occurred, so the blog data is less subject to memory loss or reconstruction than data from interviews or focus groups (Prescott et al., 2015).

## Methods

I used hermeneutic phenomenology to analyze the blog text. Phenomenology, which was developed mainly by Edmund Husserl, is the study of lived experiences, whereas hermeneutic phenomenology, which was developed by Martin Heidegger, focuses more on understanding and interpreting the meaning of human experiences (Laverty, 2003). Hermeneutic phenomenology has been associated with interpreting meaning in religious texts, but human cultural activity lies in written communication, verbal discussion, artistic images, and music (Laverty, 2003). Hans-Georg Gadamer expands on hermeneutic phenomenology by noting the importance of questioning in the interpretative process and the subjective nature of interpretation (Laverty, 2003). Questioning and interpreting text aligns with conducting a textual analysis of the RA illness blogs. Additionally, I wrote a reflexive journal to address the bias and assumptions in the subjective nature of the methodology (Laverty, 2003).

## Participants and Context

I analyzed the existing illness blogs of adults with RA, who have made their content public by not requiring a login. For each blog, only one blogger can make the main posts. I identified thirty blogs through online searches for RA illness blogs in case other blogs identified did not meet the inclusion criteria. In a study of medical student bloggers, which followed a similar methodology of line by line coding, the researchers identified 75 blogs, but only 32 blogs met the inclusion criteria (Pinilla et al., 2013). By identifying 30 blogs, I had a large pool of blogs to work with. Additionally, I wanted a third of the blogs analyzed to be men RA illness blogs, to reflect that 30% of population of individual’s with RA are men (Flurey et al., 2015). The blogs I analyzed were written in English and indicated that the blogger was at least 20 years old at the time the blog was started. I used a purposeful sampling technique for the analysis. After analyzing 7 RA illness blogs written by women and 3 blogs written by men, I determined the data was saturated because no new codes or themes emerge (Mason, 2010). The bloggers were not considered as participants of this study as I only analyzed their public text. Additionally, direct quotes from the blog were not published to protect the identity of the bloggers (Eysenbach, 2001).

## Data Collection and Data Analysis

I analyzed the blog texts similar to the method of document analysis by selecting relevant posts and coding them line by line. I used the qualitative data analysis software, CATMA 5.0, to annotate the documents and to analyze the frequency of words and their context. The central research question is to identify effective coping and support strategies for individuals with RA in illness blogs; therefore, blog posts which focus on coping and support strategies were the focus. My role was that of a researcher and a nurse. I conducted the study, data collection, data analysis, and formed conclusions. To minimize bias, I maintained a reflection journal during the data collection and analysis stage of this study (Sanjari et al., 2014). As a nurse, my conclusions of the study led to recommendations for nursing practice. To further prevent bias, experienced nursing researchers in qualitative research and chronic disease, were debriefed on the study design, data collection, and analysis on a regular basis and their suggestions are incorporated.

# Trustworthiness/Validity

## Ethical Issues

Considering ethical issues is imperative when researching online public information such as blogs and forums because consent is often not required and the owners of the posts may be difficult to contact (Eysenbach, 2001). Esysenbach (2001) advised researchers of internet communities to discuss the level of intrusiveness, perceived privacy, vulnerability, potential harm, informed consent, confidentially, and intellectual property rights of the bloggers. Researchers actively making posts in the online communities is intrusive and will affect the future posts and responses in the thread. To address the concern of intrusiveness, I read and analyzed the existing blog text and only accessed public blogs that did not require logins to protect the privacy of the members. The target population for this study are adult men and women with RA, who are at least 20 years old; therefore, the target population is not a vulnerable population. The anonymity of the participants was protected by not using any names, residential cities and states, URLs, or direct quotes of the bloggers, so that the bloggers cannot easily be identified through search engines. I did not use direct quotes of the bloggers in the report, so the intellectual properties of the bloggers were not violated. There was no potential harm associated with this study. A potential outcome is that awareness will increase for RA and illness blogs.

According to Shenton (2004), the trustworthiness for qualitative research lies in the credibility, dependability, transferability, and confirmability of the study design and implementation. For the credibility of this study, I used established qualitative methods for analyzing text and interview transcripts. To analyze the data, I first summarized the data for context. Then, I coded the blog texts line by line to eliminate bias that may be generated from only summarizing the text. Lastly, I submitted the excerpts to a qualitative data analyzer to gain a different perspective of the texts. Both blogs of men and women were included in this study to increase the transferability of the findings. The study design was dependable and transferable as sufficient information was provided for the replication and comparison of the study. To further relate to the context and meaning of the findings, I used in vivo coding to name codes appearing in more than two blogs. In qualitative research, in vivo coding is naming codes with words used by the participants (Manning, 2017). For confirmability, I maintained a reflection journal from the time I began identifying blogs and throughout the data analysis process to increase transparency by tracking why certain codes were included or changed.

# Findings

## Execution

The data collection began with a search for RA illness blogs that met the inclusion criteria of the study. Two blogs were excluded because they were started by a minor. The bloggers had to self-identify as having RA or the blog was excluded. For example, a blog of a rheumatologist was excluded. Blogs that had multiple users making the main posts or blogs composed of links to stories not written by a single user were also excluded. Only six RA illness blogs written by men that met the inclusion criteria were found. Other male RA illness blogs required login information to access. Most of the female blogs found did not require a login except for one female blogger that only allowed frequent readers to access selected password protected posts. Because that blog required a password to view some posts, the blog was excluded from the study. I found many female RA illness blogs, so I excluded female blogs without new posts in the last 12 months. After reducing the list, only 20 female blogs were eligible for the study. Of the 26 blogs found, I analyzed 3 male RA blogs and 7 female RA blogs. Men and women from around the world with ages ranging from late 20s to over 70 years wrote the blogs I analyzed.

After identifying the blogs, I read through the posts and selected the most recent 5 or 6 posts that provided a range of topics discussed by the blogger. I excluded sponsored posts and product reviews. If multiple consecutive posts discussed the same topic, I continued to read through the blog to gather a wider range of topics. Each excerpt of 5 to 6 posts, usually resulted in a document of 11 or more pages of text. I coded each document line by line with CATMA 5.0 (a qualitative data analyzer software). Additionally, I wrote short summaries for each excerpt as part of the process of interpreting the text. The codes were open, which means that I identified the codes as they emerged in the text, as opposed to closed coding, where the codes are defined before the coding of the documents begins. After coding the excerpts of the 10 blogs, the codes were sorted into themes.

## Results

The codes that emerged in the text were arranged into themes and subthemes based on the theoretical frameworks of Watson’s theory of the human caring science and Orem’s theory of self care. I identified themes of transpersonal caring relationships with providers, self-care agency and requisites, support/resources, disease progress and normalcy, perception of others, person, and medical costs and finances. Table 1 shows the themes and subthemes identified.

Table 1

*Themes and Subthemes in Rheumatoid Arthritis Illness Blogs of Men and Women*

| Themes | Subthemes |
|---|---|
| Transpersonal caring relationships with providers | Positive experiences with providers |
| | Negative experiences with providers |
| Self-care agency and requisites | Adaptations for RA |
| | Self-experimentation |
| | Managing medications & side effects |
| Support/resources | Family & friends |
| | Advocacy groups |
| | Community |
| | Websites |
| Disease progression & normalcy | Symptoms & flares |
| | Related comorbidities |
| | Good times & remission |
| Perception of others: stares & Judgement | Lack of understanding |
| | Emotional support |
| Person | Personal identity & self-esteem |
| | Other diseases |
| Medical costs and finances | Income sources |
| | Personal finances & medical care costs |
| | Costs in the health care industry |

**Transpersonal caring relationships with providers.** This theme was inspired by the transpersonal caring relationship between a nurse and a patient that Watson (2002) described in the theory of human caring science. The bloggers described both positive and negative in-person and over-the-phone interactions with their providers, including primary care physicians, rheumatologists, surgeons, pharmacists, and medical office staff. Positive experiences involved receiving practical advice on coping with their symptoms, friendly and caring interactions, and effective visits where each of their concerns were addressed. One blogger shared a pleasant encounter at the hospital where the staff ensured that the blogger was comfortable. The physician showed an understanding of the blogger's concerns and paid close attention to the blogger. Other features that the bloggers described in a positive experience were believing the patient and taking their concerns seriously. When bloggers felt the physician had not believed or understood them, the bloggers were upset and described the visit as a negative experience. Another blogger described multiple incidents where doctors did not believe the severity of pain felt until the doctors physically examined the patient and saw evidence that the blogger must have been in great pain.

Bloggers provided tips for navigating doctors and appointments, such as the best time for an appointment, getting callback from physicians, and connecting the various specialists together. Most bloggers discussed having multiple physicians for each related comorbidity. Bloggers described the stress of doctors providing conflicting orders, and a blogger suggested connecting physicians by sending them a group email. The bloggers described the role of doctors as providing treatments such as prescriptions, injections, and monitoring their labs to ensure they are properly responding to treatment. When bloggers wanted to try something new such as changing diet or using cannabidiol (CBD) oil extracted from hemp plants, they consulted their physicians first and moved forward with their approval. The bloggers reminded readers that if they did not receive the best treatments available, they should change the doctor.

Bloggers also discussed the technological advancements in health care. Telemedicine was viewed as a fast and easy way to get care on the go. One blogger noted that physician offices were becoming full of technological devices which makes access to health care difficult for the elderly population who need the most care. The blogger noted that most treatment trials exclude the elderly, despite their interest.

While discussing their relationship with their providers, two bloggers discussed the violation of informed consent. A blogger described finding out about a new diagnosis in online visit notes, but the physician did not mention the new diagnosis in the last visit. The blogger felt the physician should have discussed the diagnosis at the visit, so that the blogger could work with the physician to decide if further examination and treatment were necessary. Another blogger felt informed consent was violated when a provider had carried out a procedure that terrified the blogger because of a past bad experience. The blogger was not sure if the provider planned to conduct the procedure from the beginning or if an emergency had caused for the treatment to escalate.

The opioid crisis also fell under this theme. Many bloggers wrote posts about the crisis, but one blogger described how the physician made the blogger feel like an addict while educating the blogger on prescription drugs. The blogger wrote about how the opioid crisis was impeding treatment and felt doctors were judging patients without examination. Once the doctors examined the blogger, the physicians realized the severity of the blogger's conditions and developed better treatment plans. The bloggers also discussed conflicts with physicians when patients did not follow treatment plans.

**Self-care agency and requisites.** This theme was based on Orem's theory of self-care with subthemes of adaptations that bloggers made for their RA, self-experimentation, and managing medications and their side effects. Many of the bloggers described physically adapting to RA by giving up their job or hobbies they loved to do. Bloggers discussed the importance of exercise and movement, such as walking, cycling, and swimming, as activities that were good for them. Many of the bloggers mentioned physical therapy as part of their treatment. One blogger goes to physical therapy regularly and has increased visits in the winter as a proactive effort to combat the pain and stiffness that increases in the colder months. To deal with the fatigue of RA, the bloggers described sleeping in and taking naps during the day. A component of managing their strength for the bloggers was to know when to rest and when they felt strong enough to do something they loved, such as cooking, or run more errands than normal.

The bloggers described their various surgeries. Some of the surgeries were to alleviate pain related to RA, and other surgeries were related to other diseases. The bloggers explained that recovering from surgery takes longer for individuals with RA because the weak muscles and joints have to compensate for the part of the body that is immobilized and healing after surgery. One blogger explained that RA is an auto-immune disease, so it makes recovering from surgery harder and described increased levels of pain as some RA medications had to be stopped in advance of the surgery. Most bloggers described pain and deformity in the hand, knee, feet, and spine, and some bloggers had surgeries in the hands and feet.

About half of the bloggers discussed using food to manage or cure their RA. The bloggers noted that the food they consumed had the ability to increase their pain. Some bloggers described experimenting with food to identify which foods led to a flare up so they could avoid those foods. A few bloggers followed diets they found online that involved no dairy, no sugar, and no meat. One blogger was not ready to give up sugar, so the blogger opted out of using diet to manage RA. However, that blogger identified that an over-the-counter medication led to increased flare-ups which stopped after discontinuing the drug.

Two of the bloggers felt these dietary changes had cured their RA, because they no longer felt the pain and fatigue, and they had energy to do things again. As a nurse and researcher, it is important to note that there is no cure for RA. The bloggers who described finding a cure still experience flare-ups and try to identify which food caused the flare up and readjust their diet. Other bloggers also shared their experimentation with different medical treatment plans, over the counter medications, and CBD oil. The medical treatments described included methotrexate, biologics, anti-inflammatories, steroids (prednisone), and injections.

The results of the self-experimentation and the medical treatments can be reviewed through blood work. Bloggers described that if their c-reactive protein levels are reducing, then the rheumatologist can reduce the weekly dose of methotrexate as they are responding well to treatment. The bloggers gave methotrexate mixed reviews. Some bloggers disliked taking the drug and was trying to get to zero tablets of methotrexate a week, whereas other bloggers said the medication helped manage their pain and felt better the day after taking it. Rheumatologists also check other lab levels to ensure that a drug that works for the patient's RA is not adversely affecting other organs. One blogger described struggles with a treatment regime that worked for the RA but adversely affected other organs. The rheumatologist had the blogger stop most RA medications until the blogger is stable enough to try a new medication. Many of the bloggers also described the painstaking process of finding a treatment plan that works, then the medications stop working after two to three years, and they must start trying different medications again until their levels are back under control.

**Support/resources.** The bloggers described various avenues for their support and resources, which I divided into subthemes of family and friends, advocacy groups, community, and websites. A few bloggers discussed their family members and their activities. However, most bloggers only discussed family and friends in relationship to how they support them. Bloggers described their friends taking them to appointments, spouses picking up prescriptions, parents helping to watch their children, and friends helping them test CBD oil brands. Bloggers described not being able to spend much time with friends because of fatigue, but they enjoyed the time they spent with friends.

The bloggers acknowledged that through their blogs they have become advocates for individuals with RA. The blogs create awareness for national and international advocacy groups and events, and sometimes the bloggers attend or speak at the events.

The bloggers have developed an online community of bloggers with RA that have online blogging events. Some bloggers refer to other bloggers and link to their blogs. The community extends past the individual blog sites and extends to social media such as Twitter and Facebook. The bloggers have a community for their own sites, hold their own events, and sell fan gear. Many of the bloggers are content writers and write posts for larger blogs for RA and other chronic illnesses. The bloggers refer to many online resources, such as journal articles, the Center for Disease Control, and press releases, for getting information on their condition, treatment options, and health care issues. Bloggers also discussed their participation in non-RA communities.

**Disease progression and normalcy.** Bloggers discussed how they constantly readjust to a new normal as the disease progresses and their bodies and treatments change. Many bloggers described having comorbidities that affected their musculoskeletal structure, their mental health, and increased their pain. These comorbidities required the blogger to visit physician offices several times a month. The main symptoms discussed were pain and fatigue. The chronic pain affected their ability to sit, stand, or walk for prolong periods. Bloggers described a loss of concentration and a weakened immune system. Many bloggers described needing to rest after performing activities of daily living such as bathing or cooking. During a flare, the bloggers described not wanting to go anywhere and trying to rest but unable to rest well because of the pain. A blogger described the pain of RA as being hit forcibly repetitively, and further explained how medication could reduce the pain, but the damage caused by the hitting would still be occurring.

The bloggers also discussed the days they felt less pain and fatigue or times they felt they were in remission. Remission of RA is a time of no pain and fatigue but can last for any amount of time. Bloggers often write posts to apologize for writing less often and explained that they felt their disease was under control as they experienced less pain and fatigue. Some bloggers described less pain after a surgery or procedure such as an injection or nerve block. However, one blogger explained how surgery is not always a viable option as RA could continue to affect the replaced joint as soon as it healed. One blogger advocated for early diagnosis. Early diagnosis of RA could lead to a better response to treatment.

**Perception of others: Stares and judgement.** How the blogger perceived the reaction of their family, friends, physicians, and strangers was a significant theme. Subthemes of a lack of understanding and emotional support emerged for this theme. The bloggers explained that many people did not understand what RA is and did not grasp the severity of the disease. The abbreviation RA/RD often appeared in the blog text, and one blogger explained that RD stood for rheumatoid disease as a movement away from RA which is perceived as just another type of arthritis. Bloggers described that they felt that some of their physicians, family, members, and friends did not take them seriously. Bloggers described instances where other people, including physicians, did not believe them or made them feel like the pain was in their heads. One blogger shared that other individuals with RA claim to have worse RA and more pain than the blogger, but another blogger described never experiencing such judgment from other individuals with RA. The bloggers experienced judgment and feel embarrassed when people stare at them using assistive devices or when they explain their health issues and how it prevents them from completing activities with their family and friends. Bloggers described close family members, such as their children, and true friends as people who will listen and try to understand. However, there are days when they still have to explain to their children or friends why they cannot do certain activities or have to cancel a prearranged outing.

Bloggers also described experiencing judgement when discussing their health and treatment. A blogger discussed an instance when a physician was not “on board” with using diet as a treatment because the physician did not think diet affected the disease. Another blogger addressed online critics regarding adjusting food intake for RA. The blogger explained that the food changes were more than a diet and provided more suggestions to help others incorporate the new eating habit into their lives and help those who did not benefit from the food changes previously.

Bloggers discussed the myths about RA that some of their providers believed. The myths included that RA only affects old people, RA only affects the hands, and RA cannot affect organs or other bones such as the spine. The bloggers also discussed that lab work is not the best determinant of RA or the activity of the disease. Bloggers described that it is possible to have a negative RA factor and still have RA, and encouraged physicians to use other tests and physical examinations to diagnose for RA.

**Person.** The theme of person has subthemes of personal identity and self-esteem, other disease, and vacation and leisure. The bloggers described how their diagnosis and the adaptions they made forces them to redefine themselves. Bloggers described how the pain and disability took away their sense of self and made them feel like strangers to themselves and like ghosts among others. Bloggers described feeling invisible, scared, and alone as others did not understand their illness. The bloggers had posts where they poured out their emotions, fears, and frustrations as if they were working through their emotions in the post. A blogger described how the pain lead to problems with anxiety and depression. Another blogger described reaching a point of having no self-esteem. Eventually, the blogger was able to rebuild self-esteem and not be ashamed of the physical changes taking over the body. Bloggers described activities, such as listening to music, to calm their emotions. Some bloggers judged themselves for not being able to be more active. Other bloggers judged themselves for being overweight.

The bloggers also shared more about themselves by discussing their other health issues and treatments, their relationships with their significant others, their vacations, and their leisure activities. The bloggers shared their reading lists, their hobbies, and their wish lists. Bloggers discussed the good and bad aspects of their relationships and their divorces. The bloggers described how lovely their vacations were despite their symptoms and even shared some photos.

**Medical costs and finances.** The theme of medical costs and finances covers the income sources of the bloggers, their personal finances, costs of care, and costs in the health care industry. Some bloggers described not being able to work because of the disability caused by RA. Others continued working and some did not work prior to their diagnosis. Some bloggers discussed the work of their spouse. Some bloggers explained their personal and financial issues that caused them not to post for a while. Bloggers discussed their care costs and co-pays for visits, procedures, and medications. Because the bloggers are based around the world, they have different health care coverage. One blogger lamented about the numerous co-pays that the chronically ill must pay for every visit. If the bills are not paid, then the bill goes to a collection agency and eventually becomes an adverse note on a blogger's credit report. Whereas another blogger discussed the benefits of universal health care coverage but realized individuals would have to spend money out of pocket to find a new primary care specialist or treatments that are not covered.

Additionally, bloggers discussed the costs of care in the health industry. One blogger analyzed that four RA biologics are among the top 10 drug sales by costs. One blogger described that a biologic cost over $10,000 per shot. However, none of the RA drugs are among the top 15 most filled prescriptions. A blogger discussed an increase of transparency for drug companies but concluded that the development of the transparency document costs money and will not help to reduce drug costs. Another blogger concluded that regulating symptoms through diet is free and takes the power away from the drug companies. Bloggers also discussed the graduated system of third-party payers requiring physicians to prescribe cheaper medications and treatment until providing patients with preferred treatment or approving surgery. One of the worst aspects of this process is that when individuals change insurance companies, the process of testing cheaper treatments that are less effective may have to restart. Bloggers discussed legislation for eradicating this graduated system and make medications affordable.

**Word frequency and mapping.** Figure 2 below is a word chart depicting the frequency of the most common words among the blog excerpts. The most frequent words are in the middle with very large font, the less frequently used terms are in smaller font at outside of the circle. The most frequently used words were *arthritis*, *pain*, *can*, and *RA*.

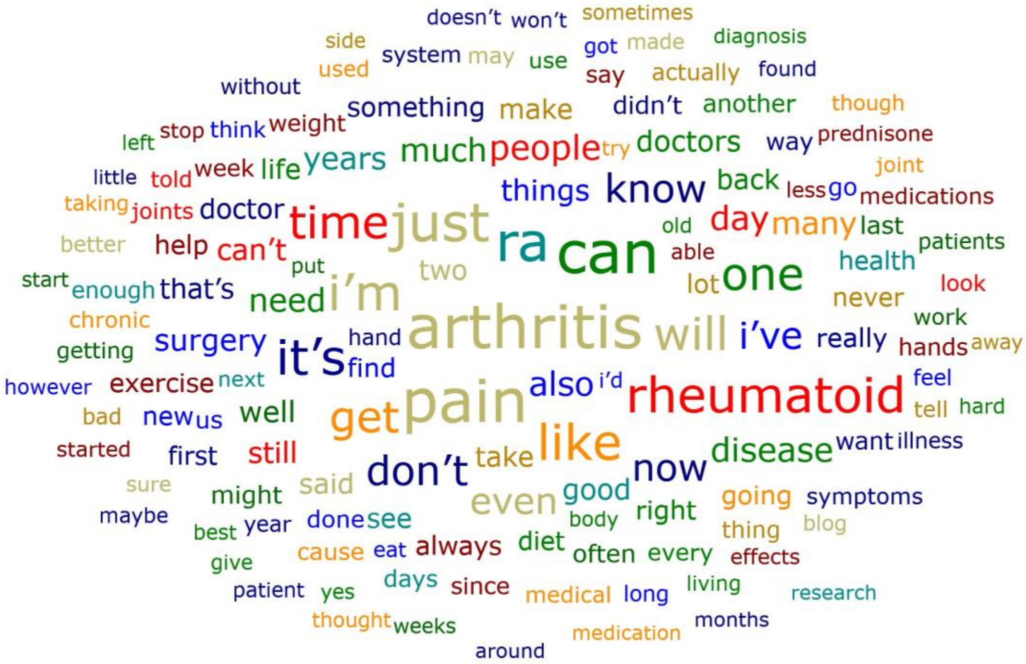

*Figure 2.* Word frequency map of rheumatoid arthritis bloggers.

## Discussion

### Interpretation

Individuals with RA struggle to physically and emotionally cope with the symptoms of the disease and comorbidities that affect their musculoskeletal system. While adapting to their new diagnosis, bloggers described feeling alone and invisible until they came to terms with the diagnosis and the physical changes in their lives. Bloggers described still struggling emotionally about the effects of the disease and shared ways they handle those thoughts to accept their new normal. The findings for this study validated the theoretical framework for accepting the new normalcy that I created from combining Watson's and Orem's nursing theories. Watson's theory focuses on the role of the provider in developing a relationship that fosters care with patients. The metaparadigms for Watson's theory are person, environment, and health (Watson, 2002). Orem's theory focused on the patients' roles of caring for themselves with the help of providers to fill their self-care deficits (Denyes et al., 2001).

In the model for the theoretical framework for accepting the new normalcy, the concept of normalcy was placed under self-care deficit. Normalcy takes time for a person to reach. Emotionally, the bloggers described having to accept the new identity of having RA, being in chronic pain, and the progressive deformity and disability that will occur to their body. Throughout the posts, bloggers described how they learned to react to different types of pain or symptoms they experienced. When the bloggers were not sure how to handle their symptoms or required prescribed treatments, they visited their physicians, shared their pain with their readers, and welcomed their comments and suggestions.

Watson's theory of human caring emphasized the importance for caring for a person holistically by caring for the mind, body, and spirit. Watson's theory also noted the importance of a healing environment and a transpersonal relationship between patient and providers. These concepts were reflected in the findings of this study. The bloggers explained how interactions with providers and staff members of a facility affected their health care experience. Although there were a few good examples of positive and productive visits to physicians and hospitals, bloggers provided many examples of negative experiences. Dwarswaard, Bakker, van Staa, and Boeijie (2015) conducted a qualitative review on self -management support and found that individuals with chronic illness valued the expertise of their providers but needed their providers to do more, such as sympathetic listening, and maintaining a more collaborative partnership with the patient.

My findings expand the findings of Dwarswaared et al. (2015) by also highlighting the importance of receiving the best treatment in an efficient manner. The bloggers described a positive experience with a provider if their concerns were addressed at the appointment. The bloggers provided tips for ensuring their needs are met through physical appointments or receiving call-backs from the physician's office. Although the relationship aspect largely affected the bloggers' perceptions of their visit, bloggers described changing physicians because they were not addressing a health problem or receiving effective treatment. For example, one blogger described changing to the top providers in the area to address chronic pain and swelling in the lower extremities. Physicians not taking patients seriously was a reoccurring topic in the blogs, so it is important for providers to educate the patient while positively supporting them.

The process of managing a chronic disease involves more than receiving a treatment plan from the physician. The bloggers described their self-care through a trial and error process of finding what methods helped them manage their disease. The self-experimentation with their treatment aligns with the concept of self-care in Orem's theory. The bloggers discussed topical analgesic, ice, heat, prescriptions, over-the-counter medications, food adjustments, exercise, physical therapy, and surgeries that helped. Additionally, they discussed the side effects of ineffective measures. This study focused on recent blog posts, so the bloggers discussed contemporary issues such as the opioid crisis and the legalization of marijuana and how these issues affected treatment and coping strategies.

Food changes involved individuals following a diet free of meat, dairy, sugar, and alcohol. Dietary changes are not part of a rheumatologist's medical treatment plan. However, some bloggers mentioned the importance of diet, and a couple of bloggers that adopted the diet changes went into remission. The literature supports the effects of diet on RA. Basu, Schell, and Scofield (2018) found that certain berries and pomegranates had the ability to reduce pain and inflammation but called for rigorous scientific study to support such claims. Similarly, Tedeschi and Costenbader (2016) wrote an article on complementary and alternative medicine that reviews evidence relating RA disease activity to dietary supplements, such as vitamin D and omega-3, alcohol, and the Mediterranean diet, but also concluded that further study was required before making diet recommendations to RA patients. Tedeschi and Costenbader (2016) mentioned that there were fewer studies on food and its effect on RA and described food as an older treatment option. With many of the bloggers suggesting a link between food and RA disease activity, more rigorous studies on diet and RA are necessary to develop proper clinical recommendations.

Bloggers described receiving assistance, support, and resources that included emotional support and support with understanding their illness. Bloggers shared health information they acquired from health care organizations such as the CDC, journal articles, press releases, and other bloggers. Independence and dependence are concepts from the theoretical framework for developing the new normalcy. The bloggers explained their dependence on family and friends and celebrated their independence when they were strong enough to run errands. Bloggers unable to work from their disability also expressed their financial dependence on government assistance. Most bloggers discussed their struggles with the costs of care and medications and asked for legislative changes to reduce costs and gain access to additional coverage.

Bloggers described their level of social support and strain in their posts. Bloggers expected support from providers, family, and friends, but realized that people were not always understanding. Bloggers described finding people who understood them through the RA community or other communities that reflected their interests. Posts about attending an advocacy event or spending time with friends and family have more empowered and positive tones, compared to posts where a blogger describes feeling misunderstood, lost, and alone. However, the bloggers also discussed how the unpredictable round of fatigue or flare up could “mess up” their plans to spend time with family and friends. The bloggers described scheduling naps during the day and informing family and friends in advance that the illness may not allow them to keep plans. Bloggers described feeling guilty for not being able to keep plans or not being present with their families, so it is important for family and friends to show support by showing they understand and accept.

My findings support those of Walen and Lachman (2000) who studied social support and strain, and their effect on physical health and psychological well-being. Walen and Lachman (2000) found strain from the spouse was predictive of health problems, and that social exchanges can affect psychological well-being. Furthermore, family and friend support can affect well-being and assist in buffering the effects of strained interactions. (Walen & Lachman, 2000). My analysis of the blogs revealed that spending time with family and friends and receiving their words of support not only helped bloggers feel better about a strained interaction with others, but also helped bloggers cope with pain physically and emotionally. In most blog posts about family vacations or evenings with friends, the bloggers did not discuss their pain and symptoms. When a blogger did mention feeling ill during a vacation, the blogger focused on enjoyable aspects of the trip and reinforced that most of the trip was pleasant. Moreover, bloggers shared how friends, family, and blog readers helped alleviate symptoms by providing suggestions to soothe their pain.

## Limitations

The limitation of the study is that the words of the blogger must be accepted as fact. There is no way to verify the age, gender, location, or diagnoses of the blogger. However, the demographic data were not a significant aspect of the findings. This study analyzed the bloggers' texts for the perception of their experience with the disease. Moreover, the literature supports many of the findings of my study, which increases the trustworthiness of the study. The bloggers were from countries around the world, yet they had similar issues. Therefore, the findings are transferable. For example, bloggers living in countries with free universal health care still worried about out-of-pocket health care costs. The methods and execution of the study were described well enough for the study to be repeated. To protect the identities of the bloggers, direct quotations could not be used to describe the themes. So, as a researcher and writer, I had to convey the main points of the bloggers.

## Implications

The bloggers described their individual efforts to cope with their conditions and issues they dealt with as others did not understand their disease and were not sympathetic. The findings of this study expressed a need for people, including providers, to listen and be more understanding. The bloggers described RA as an invisible disease, where an individual appears healthy while the disease is destroying their joints and causing extreme pain and fatigue. The findings of my study show that there is a need for positive social change in the way people understand RA. The bloggers have described how RA affects more than their hands and should not be confused with osteoarthritis. The bloggers have called for people to be more supportive and called for their providers to develop better relationships with them.

With this study, I introduced RA illness blogs as a viable data source. This study is the first of three studies on the RA illness blogs which investigates the topics discussed as well as the coping and support strategies. This study has revealed how illness blogs have a wealth of data on a variety of concepts.

## Recommendations

I analyzed the content of RA illness blogs of both men and women and noted their coping and support strategies. However, men and women respond to treatment and cope differently (Flurey et al., 2017; Poh et al., 2017). In the next part of the study on the coping and support strategies of individuals with RA, I studied the coping and support strategies for women and men separately.

This study also revealed that bloggers found that their food intake affected their disease activities. Although the bloggers described similar food changes, the diet changes may affect people on an individual basis. More rigorous studies would be required for clinical suggestions on controlling RA symptoms through diet.

## Conclusion

Providers must be aware that RA can affect the whole body and many individuals with RA have multiple comorbidities. Providers should focus on developing positive transpersonal caring relationships with their patients and try to coordinate care with the other providers of their patients. Individuals with RA looking for additional support should go online and try to connect with the RA community or find another community that aligns with their interest and values. When it comes to coping strategies for pain and fatigue, many options exist but individuals must find what works best for them through trial and error.

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# Manuscript 2: Analysis of Coping and Support Strategies of Women Portrayed in Rheumatoid Arthritis Illness Blogs

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## Outlet

The target journal for this article is the *British Journal of Health Psychology*. The journal requires the American Psychological Association (APA) formatting style and an article length of less than 8000 words. The journal promised fast publication and no author charges (British Journal of Psychology, 2019). The journal accepts articles from around the world and invites interdisciplinary work. The topic of this article is effective coping and support strategies for women with rheumatoid arthritis (RA) to promote emotional, social, and physical health. Without coping mechanisms and support, individuals with RA may present with symptoms of depression and anxiety; therefore, the article topic relates to health psychology.

# Abstract

Women make up two thirds of the individuals with RA, which is a systemic chronic disease that affects an individual physically, emotionally, socially, and financially. A review of the literature revealed a gap in effective coping and support strategies for women with RA. To address the gap, this hermeneutic phenomenological study used a combination of Watson’s and Orem’s nursing theories to analyze 15 illness blogs from women with RA to identify how RA affects their lives, their coping strategies, and their sources of support. The bloggers described ways they managed their pain, conserved their energy, and emotionally coped with their RA symptoms. Writing the blog allowed the women to work through their symptoms and emotions. The bloggers described listening to music to uplift their mood when their symptoms had them feeling down. Sources of support included friends who understood them, help from family members, provider support, and financial support to cover their treatments. The bloggers discussed the role of the online RA community and described advocacy events and opportunities that promote awareness of the disease and improve treatments. The implications for practice are that providers should assess how patients are coping with their RA and suggest that individuals connect with other individuals with RA online for additional social support. Future studies on individuals with RA could focus on how providers incorporate coping and support strategies into the care plan.

## Introduction

Rheumatoid Arthritis (RA) is a chronic disease where the body's immune system strikes healthy body cells instead of protecting them (Irwing, Davis, Zautra, 2008; Nigrovic & Lee, 2005; Poh et al., 2017). The overactive immune system leads to pain, inflammation, stiffness, and fatigue. The disease can progress to severe joint damage and deformity (Nigrovic & Lee, 2005; Poh et al., 2017). RA can strike any organ. Medical treatments exist to slow the progression of the disease and prevent joint deformity; however, the symptoms of the disease leave individuals with RA struggling to cope with their symptoms and their ability to work and complete the activities of daily living (Aletaha & Smolen, 2018; Hwang, Kim, & Jun, 2004; Poh et al., 2017). Over 60% of individuals with RA experience psychiatric disorders and about 20% have major depression (Irwing et al., 2008). According to Souza, Bansal, and Galloway (2016), the effective self-management of RA should include nonpharmacological treatments such as psychological support and patient education to help individuals cope and adapt to lifestyle changes with the disease. Few researchers have conducted studies that analyzed the effectiveness of different coping strategies through the experiences of individuals with RA (Flurey et al., 2017; Poh et al., 2017).

## Significance/Importance

Between 0.5% to 2% of the world's population has rheumatoid arthritis (Aletaha & Smolen, 2018; Hwang et al., 2004; Carmona et al., 2002). Although anyone can develop RA, the prevalence of RA in women is twice the prevalence of RA in men. The higher prevalence of RA in women has been linked to reproduction, hormonal factors, physiologic characteristics, and chromosome complements. The onset of RA in women begins earlier than in men. Women often are diagnosed between the ages of 30 and 60 years, which overlap with the childbearing years (Gupta, 2013). Women with RA psychologically struggle with self-esteem, social roles, body image, sexuality, anxiety, and depression (Irwing et al., 2008; Ryan, 2014). Furthermore, Flurey et al. (2017) and Poh et al. (2017) identified that women and men respond differently to coping mechanisms and sources of support; therefore, analyzing the effective RA coping strategies for women separately from the strategies for men is necessary.

## Relevant Scholarship

### Experiences of Women with Rheumatoid Arthritis

Past studies on women with RA focused on the lived experiences of women. Haggstrom and Nilsson (2009) conducted a single case study on the diary of a 60-year-old woman who had RA for 8 years using a phenomenological hermeneutical approach. The researchers analyzed the text of diary entries dated from 1998 to 2006 and found that after years of living with RA, the informant described a lack of confidence, loss of identity, and self-image. For individuals with RA, a support system is necessary to cope with the effect of RA on their lives (Hwang, Kim, & Jun, 2004). However, the limitation in physical activity from the disease can lead to reduced social interactions, which results in a deteriorating social network of families and friends (Hwang et al., 2004). Haggstrom and Nilsson (2009) concluded that individuals with RA require continuous support and suggested that providers incorporate individuals and their families into their care to build a more positive image of the disease.

Hwang et al. (2004) interviewed women with RA in Korea to explore what changes RA had made in their lives and identified the themes of pain, decreased activity, self-recovery, reflection of life before RA, new life, family support, negative feelings, and self-esteem. The women described missing their healthy life and feeling anxious, annoyed, shameful, regretful, and guilty for the effect of the disease on their family. The researchers noted that support was necessary to help the women cope with the physical and psychological effects of the disease (Hwang et al. 2004).

Iaquinta and Larrabee (2004) conducted 1- to 2-hour interviews with 6 women with RA in West Virginia to gather insights on the lived experience of RA. The researchers identified themes of adapting to the disease by changing habits and lifestyle, proving to themselves and others that RA is real, coping with the negative feelings, and handling the healthcare system (Iaquinta & Larrabee, 2004). The researchers recommended that nursing and medical teams should help individuals with RA cope with the struggles of the disease to reduce the negative effects (Iaquinta & Larrabee, 2004).

## Support and Coping with Rheumatoid Arthritis

Limited research has been conducted on coping and support strategies for women with RA (Poh et al, 2017). Brandstetter et al. (2017) conducted a cross-sectional study to quantitatively analyze the relationship between pain, symptoms of depression, and support in adults with RA using the stress-buffering model as the theoretical framework. The stress-buffering model posits that social support improves health outcomes by reducing the effects of stressors, such as pain and psychological issues such as depression. Through questionnaire responses and health records, Brandsetter et al. (2017)

found that social support may not have any effect on physical pain, but increased pain and low social support was linked to more symptoms of depression (Brandsetter et al, 2017). Similarly, Liu, Xu, and Wang (2017) analyzed the effect of self-efficacy on social support and symptoms of depression and anxiety. Self-efficacy is how much individuals believe in themselves to complete a task or goal. Liu et al. (2017) found that among the study participants with RA, symptoms of depression and anxiety were prevalent for about 58% and 48% respectively. Liu et al. (2017) concluded that as the level of self-efficacy and social support increased, the symptoms of anxiety and depression reduced.

Liu et al. (2017) defined social support as support from family, significant others, friends, and colleagues. Social support can be provided as instrumental, emotional, and informational (Liu et al., 2017). Flurey et al. (2017) surveyed men and women with RA on their support preferences. More than half of the women who participated indicated they would be interested in every option provided. The top support strategies selected by the female participants were as follows:

- discussion groups with other individuals with RA,
- one-on-one consultation and question and answer sessions with a nurse or consultant,
- talks or lectures from lifestyle experts and research experts,
- education sessions for managing symptoms,
- physical activity skills improvement sessions,
- attending events to raise awareness of RA, and

- reading information and the stories of other patients online (Flurey et al., 2017).

Ostlund, Bjork, Thyberg, Valtersson, and Sverker (2018) conducted semi structured interviews to identify how Swedish women with RA coped with specific situations. Ostlund et al. (2018) divided coping styles into four groups, which were acceptance of the disease, avoidance of certain tasks, such as carrying heavy objects, interacting with others through communication or asking for help, and adjusting their behavior. Accepting the disease and adjusting to everyday tasks is essential for coping (Ostland et al., 2018). According to Ostland et al. (2018) studying the coping strategies of women separately from men is necessary because women become disabled faster than men. Ostlund et al. (2018) noted that women interacted with others more frequently and described adjusting their behavior for a wider variety of tasks than men. The women included adjusting how they woke up because of their morning stiffness, how they completed tasks at work, and how they completed tasks around the home such as cleaning. The researchers attributed the wider variety of tasks described by the women than men to the difference in gender roles (Ostland et al., 2018).

Kwissa-Gajewska, Olesinska, and Tomkiewicz (2014) studied optimism, coping strategies for pain, and pain levels for 1 week in 54 women with RA in Poland. The researchers found that hoping and praying was the most common strategy to cope with pain among the women (Kwissa-Gajewska et al., 2014). Furthermore, Kwissa-Gajewska et al. (2014) noted that those working indicated more pain than the women not working. Women who were optimistic had less pain and increased activity, whereas the women who were pessimistic had higher levels of pain (Kwissa-Gajewska et al., 2014). Health care professionals should evaluate the level of the patient’s optimism and provide information and treatment details in a positive way to increase the optimism of the patient and promote positive results (Kwissa-Gajewska et al., 2014).

### Literature Gap

Past studies covered the experiences, coping, and psychological symptoms of individuals with RA, but very limited research exists on the coping and support strategies for women with RA (Flurey et al., 2017; Haggstrom and Nilsson, 2009; Hwang et al., 2004; Iaquinta & Larrabee, 2004; Ostand et al., 2018). RA affects women physically and emotionally (Flurey et al., 2017; Ostland et al., 2018). Haggstrom and Nilsson (2009), Hwang et al. (2004), and Iaquinta and Larrabee (2004) found that women with RA have negative feelings, such as annoyance, guilt, regret, shame, and issues with self and body image. Men and women cope, adapt, and experience the disease differently so it is important to study effective coping and support for men and women separately (Flurey et al., 2017; Ostland et al., 2018). Flurey et al. (2017) looked at the coping and support preferences of women, and Ostland et al., (2018) categorized coping responses, but none of the existing literature focused on identifying effective coping strategies of women with RA.

## Research Question and Design

The purpose of my study was to identify how women with RA portrayed coping and support sources in online illness blogs. The research question for my study was:

RQ: How do women with rheumatoid arthritis who participate in illness blogs portray coping mechanisms and support strategies to deal with the effect that RA has on their lives?

To address the research question, I conducted a textual analysis of existing public illness blogs written in English by women with RA. The internet is a source of health-information support, and social media can provide information and social support for individuals with a chronic disease (Ressler, Bradshaw, Gualtieri, & Chui, 2012). Illness blogs are digital diaries written by individuals sharing their experiences with their illness for online readers. Illness bloggers write about how they were diagnosed, their symptoms, their treatment and responses, coping strategies, and their perceptions of family, friends, and providers (Keim-Malpass & Steeves, 2012). Bloggers find the writing process therapeutic, helpful to others who might be suffering the same thing, and a source of social support from their followers and commenters (Prescott, Gray, Smith, & McDonagh, 2015). Health researchers must study the information online, especially in social media to gain more insight of the patient perspective and prevent the spread of misinformation. For these reasons, I analyzed illness blogs to study the literature gap of coping and support strategies of women with RA.

## Theoretical Framework

Orem’s theory and Watsons theory served as the theoretical framework for my study. Research on the lived experiences and coping strategies of RA adds to the body of nursing knowledge to help nurses understand the perspective of patients to better help them. According to Ryan (2014), nurses have a role in creating a time and space for individual patients to discuss their thoughts and feelings of their RA. The nurse must be ready to provide emotional support and empower the patient with information and education about the disease process, the treatment plan, and effective coping strategies (Ryan, 2014). The time and space that Ryan (2014) referred to echoes the caring moment of Watson's theory of the human caring science. Watson's theory encourages a balance in caring, teaching, and connecting with the patient to address the needs of the patient (Watson, 2002). Additionally, the management of RA requires self-care to control pain, reduce anxiety, prevent depression, promote wellbeing, and maintain a healthy balance on body image, sexuality, social role, and self-esteem (Iaquinta & Larrabee, 2004; Ostland et al., 2018). Orem (1985) defined self-care as an important learned behavior to regulates oneself. In the management of RA, self-care is an important tool in controlling pain and promoting psychological wellbeing. According to Orem's theory when self-care is unable to meet the needs of an individual, additional systems are required to maintain health (Orem, 1985). Applying Orem's theory of self-care and Watson theory of human caring to nursing care will help reduce pain, promote relief, and encourage self-care behaviors in individuals with RA.

## Methods

For my study, I aimed to investigate the lived experiences of women with RA through their blogs with a hermeneutic phenomenological design (Laverty, 2003). Hermeneutic phenomenology developed by Martin Heidegger differs from phenomenology developed by Edmund Husserl (Laverty, 2003). Phenomenology is the study of the lived experiences of a phenomenon and is studied through interviews and observation. Heidegger emphasized that interpretation, based on background and personal experiences, is essential to how people understand the world (Laverty, 2003). Hermeneutic phenomenology is usually associated with the analysis and interpretation of text, which can be written text, visual, arts, or music (Laverty, 2003).

## Participants and Context

For my study, I conducted a textual analysis of the recent posts of at least 10 public illness blogs of women who are over 20 years and living with RA. Haggstrom and Nilsson (2009) conducted a textual analysis of the eight year diary of one woman with RA and gained significant insight into her experiences. Therefore, I gained insight into a variety of coping strategies from the 15 blogs that I analyzed. The blogs were written in English, and the main posts of the blog were posted by the same blogger. The gender, age, and other demographic information of the bloggers were determined from the bloggers’ self-identification in the text.

## Data Collection and Analysis

The purpose of my study was to analyze the coping and support strategies for women with RA. Therefore, I reviewed each blog and identified posts related to coping and support strategies. The text of posts related to coping and support strategies were coded line by line and separated into the themes. Additionally, I generated a list of the coping and support strategies mentioned in the blog posts, along with the perspective of the bloggers response to the strategies. I used CATMA 5.0, a qualitative analysis software, to analyze the frequency and context of words in the blogs posts.

I had the roles of the researcher and the nurse. As a researcher, I designed the study, collected and analyzed the data, and drew conclusions. As a nurse, I applied nursing theories and provided recommendations for practice based on my findings. To prevent bias in this study, I maintained a reflection journal throughout the data collection and analysis process and debriefed every aspect of the study design with nursing researchers experienced in chronic disease and qualitative research.

## Ethical Issues

Blog posts fall under the realm of public information. Eysenbach (2001) described the ethical issues that must be addressed in studies of online communities, and I followed the guidelines listed in that article. Consent for studies on blogs and online communities is often not required. Furthermore, locating the contact information of the owners of the posts for consent may be difficult (Eysenbach, 2001). To protect the privacy and intellectual property of the bloggers, I only included blogs that did not require a login to read posts in the study, and I did not include any names, cities, direct quotes, or URLs in the report (Eysenbach, 2001). The target population for the study were women with RA over age 20. This study was not intrusive as I did not post or directly interact with the online community.

## Trustworthiness and Validity

For qualitative research, the trustworthiness and validity of the study refer to the dependability, transferability, confirmability, and credibility of the study design and execution (Shenton, 2004). For the dependability and transferability of the study, I provided detailed information on the study design, data collection, and analysis process for others to replicate or to compare my study. I made my study process transparent by maintaining a reflection journal from the start of my study during blog selection process and throughout the process of coding, data analysis, drawing conclusions, and making recommendations. The credibility of my study lies in the use of established qualitative method for the textual analysis.

## Findings

### Execution

I identified 23 individual RA illness blogs written by women. The bloggers indicated living in different countries, but the bloggers included in the study wrote posts in English. Three blogs were excluded because the last post was from over a year ago. Saturation was reached after analyzing 15 blogs as no new themes emerged. The blogs were numbered in the order that I analyzed them. I used a deductive coding process to analyze the most recent posts of each blog that were relevant to my study. I selected posts where the women described their coping mechanisms or sources of support for the effects of RA on their lives. I selected at least 5 posts from each blog but included as many as 10 posts for bloggers who wrote short posts or bloggers who shared a different coping or support strategy than previously described. I defined codes that focused on coping and support strategies, and other emerging topics, such as advocacy. I coded the selected blog posts line by line using the annotation functions of CATMA 5.0. I used CATMA 5.0 because it is a free qualitative data analyzer, and its annotation feature highlights each code a different color for easy reference.

## Results

The themes and subthemes that I focused on were the coping and support strategies for the symptoms of women with RA. The bloggers detailed their symptoms and comorbidities, and the coping and support strategies that they applied. The coping and support strategies provided were based on the women's symptoms. To understand how the coping and support strategies helped the women, I developed a theme of the symptoms and comorbidities described. The themes related to the coping and support strategies were divided into pain management, energy conservation, coping mechanisms, fertility and motherhood, and sources of support. Subthemes were also identified for sources of support. Additionally, advocacy emerged as a theme. Table 2 shows the themes and subthemes identified.

Table 2

*Themes and Subthemes in Rheumatoid Arthritis Illness Blogs of Women*

| Themes | Subthemes |
|---|---|
| Symptoms & comorbidities | |
| Pain management | |
| Energy conservation | |
| Coping mechanisms | |
| Fertility & motherhood | |
| Sources of support | Family support |
| | Friend support |
| | Provider support |
| | Financial support |
| | Community support |
| Advocacy | |

**Symptoms and comorbidities.** Bloggers described their daily symptoms and flare ups. Daily symptoms included pain, swelling, redness, numbness, migraines, difficulty walking, muscle weakness, muscular pain and spasms, fatigue, and brain fog. The bloggers attributed their brain fog to the reason they were forgetful and double-booking appointments. RA pain was described as symmetrical, but not synchronized meaning that pain may be worse on one side or start on the other side later. In addition, to the pain and fatigue experienced by individuals with RA, the bloggers listed other autoimmune diseases, such as lupus and fibromyalgia, and other musculoskeletal disease, such as osteoarthritis and disk issues, which increased their joint and back pain. Bloggers had significant joint damage that required surgery in the shoulder, hand, knee, and feet. Time before and after surgery are periods of extreme pain. Before a surgery, individuals with RA must stop most of their medication for a few days and after surgery the person remains in pain because of the soreness from surgery. Furthermore, the bloggers described taking a long time to heal which is common in autoimmune diseases.

The women described allergies and sensitivities to food and gastrointestinal issues that required them to see gastroenterologists. The food sensitivities caused bloggers to adopt special diets, which made dining out difficult. Dry eyes and dry mouth, known as Sjogren’s syndrome, was a common symptom described in the women’s blog. Two of the women described extremely dry and bleeding hands and feet. The female bloggers also listed history of fluid retention and tachycardia. Tachycardia is increased pulse rates. The women related other symptoms, such as skin cancer and liver problems, as side effects to their medications. Bloggers acknowledged that an upset stomach was a side effect of anti-inflammatories.

RA flares are sudden onset of intense pain, swelling, fatigue, and may be accompanied with a fever. During flare ups, bloggers describe feeling weak and lying down in pain. Bloggers described flare ups as pain that starts in one joint, but eventually affects multiple parts of the body. The pain can make it difficult to fall asleep. The bloggers described feeling emotionally low during times of flare ups. Bloggers described feeling anxious wondering when their current treatment plan will stop working. Bloggers described past treatment plans that only worked for 2 to 3 years before flare ups became more frequent. Bloggers also shared experiences of treatment plans with harsh side effects that affected other organs. The bloggers described stability as reaching a point with less frequent flares on a treatment plan that they have been on for a few years.

**Pain management.** The theme pain management described the efforts to alleviate physical symptoms, such as pain and inflammation. RA medication such as methotrexate, biologics, and biosimilars prevent joint damage and reduce disease activity to provide some pain relief (Torpy, Perezza, & Golub, 2011). The bloggers described biologics as a more aggressive treatment for severe RA that led to significantly improved symptoms. The injectable biologics require patients to self-inject on a regular basis. To alleviate the extreme pain of RA, the bloggers use pain killers and anti-inflammatories, such as prednisone, ibuprofen, Advil, and diclofenac gel, and other rubbing gels. Narcotic pain killers, such as opioids, are used during flares-ups and as needed. The bloggers noted that pain killers take time to work, but only last a scheduled number of hours, and have side effects. Some of the bloggers found CBD oil and medical marijuana helpful. Bloggers described that prednisone tablets and steroid cream alleviated symptoms of dry, cracking, and bleeding skin on the soles of their hands and feet. Bloggers also take vitamins and supplements to improve bone and joint health. Two women described drinking tea for pain. For one woman, the tea was soothing, and the other woman drank herbal teas to help with symptoms. Other pain relief options included icepacks, heating pads, essential oils, teas, orthotics, shoe inserts, and biofeedback. Surgery was a last resort option for pain caused by correctable mechanical issues.

Exercise was an important part of maintaining stability with RA. Bloggers acknowledge that exercise can be painful, but an effective medication treatment plan can help them handle the pain of exercise. The bloggers noted that despite the pain of exercise, skipping an exercise session would result in more pain and stiffness later. Forms of exercise included stretching, yoga, going to the gym, walking, and attending physical therapy. In additional to physical therapy, bloggers attended message sessions, chiropractor, reiki, and traditional Chinese medicine therapies, such as acupuncture.

**Energy conservation.** The theme of energy conservation relates to bloggers describing how they coped with fatigue and avoided exacerbating their symptoms by managing their energy and adapting tasks. Medication side effects can cause drowsiness, so bloggers described taking medications according to their own sleep and rest schedule. Bloggers considered how active and productive they want to be versus the amount of pain they were in to decide whether to endure the pain or take their pain medication. Women with RA work and complete other activities, such as gardening, repairing their home, and caring for their children, while struggling with their pain. Bloggers described reaching a point of stability that is still susceptible to unpredictable flares. Bloggers try to prevent the flares by trying not to overdo activities, scheduling extra rest time between activities, limiting their stress, and putting their health first.

The bloggers explained that they know they should not overdo activities, but sometimes they push themselves to get things done. The aftermath may be severe pain, sickness, and swelling for a few days. Individuals with RA learn to conserve themselves by identifying their limits and strictly following their limits to gain the benefits. However, the unpredictable nature of flares require individuals with RA to reschedule appointments and planned events with family and friends on short notice. Bloggers complained about the responsibility necessary in following such strict rules and missing out on outings. After a flare has started, bloggers described isolating themselves and resting because they were too weak and in too much pain to participate in activity. The bloggers also scheduled rest time for their surgeries and stressed the importance of alerting family, friends, and their job of the length of recovery time.

The pain and fatigue experienced with RA significantly affected the lives of individuals with RA, so the bloggers shared how they made an effort to complete activities while handling their symptoms. As their RA progressed, the bloggers described how their activity participation decreased and how they adapted. Bloggers described their adaptations to use technological devices, cook, and care for their children. Bloggers explained how they paced themselves by taking a few days to write each blog post. Bloggers encouraged the use of machines in the kitchen for kneading, mixing, and cutting food, and the use of pre-cut and pre-prepped foods to reduce the stress on their hands. A blogger described cooking meals that store well in bulk, so that she had something to eat on the days she did not have the energy to cook. Bloggers also discussed having easy to prepare meals available or ordering takeout on the days they do not have the strength to cook. Small adaptations can help women who have children at home such as selecting children's clothes with zippers, because zippers are less painful to use than buttons. Bloggers described finding someone to drive them to long distance appointments because driving far causes back pain and pain in other joints. Bloggers asked others to help them move heavy objects. Additionally, Bloggers considered their needs when they are shopping for new items or purchasing a home. For example, bloggers described shopping for lightweight dishes that will not hurt their hands and living in ranch style homes that do not have stairs. Bloggers shared how they stretched out large activities such as moving over the period of a few weeks instead of a few days to save energy and to reduce the toll of activity on their bodies.

Some of the bloggers do not work, but those that do work choose to work from home or limit their work schedule to the basic work week without overtime. Bloggers described being too tired from work to do anything after work, and their off days become their scheduled recovery time until they return to work. The bloggers described understanding their body, their physical limits, and the consequences for exceeding the limits. Periods of rest include lying down, resting their legs, or conducting a low energy activity, such as coloring, reading, writing, or quilting, to take their mind off the pain. These low energy activities serve as coping strategies.

**Coping mechanisms.** This theme represents the emotional struggles and coping mechanisms of the female bloggers with RA. These women described that the pain and fatigue they experience is often invisible to others. People that see them active on their good days may not believe that they have days of extreme pain and weakness or that they follow strict medication regimes that may include injectables. The bloggers explained that people insinuating that they do not look sick is hurtful, because that statement delegitimizes the diagnosis that for many individuals with RA was long and difficult process to obtain. The bloggers described the stress when dealing with providers who may not believe they have RA and try to change their diagnosis. Bloggers described that before receiving the diagnosis of RA, they felt like their pain and symptoms were in their heads. However, when the symptoms, such as walking with a limp or having red and swollen hands, become visible to others, the bloggers described the stress in explaining their condition to multiple people unfamiliar with RA. Bloggers also shared how they are embarrassed when other see them struggle with daily activities such as walking or sitting.

Bloggers described their fear and anxiety about the uncertainty of their disease. For example, bloggers where anxious about when they would experience another flare or when their medication treatment plan would fail or cause adverse reactions and must be changed to a new medication that might not work as well. Bloggers reported being afraid of surgery, because of the complications that could occur during or after surgery. Over time though, their RA symptoms become normal to the bloggers and any new diagnosis that arose became the scary and troublesome disease.

Coping mechanisms that bloggers reported using to handle their emotions included socializing, participating in creative activities, listening to music, putting forth confidence, staying positive and realistic, not allowing the RA to hold them back, and instantly adapting to the flow of the changes of their bodies. Bloggers shared songs that they felt represented their struggles with their disease and shared playlists of songs that fit different moods. The way the bloggers described how music can be soothing, meditative, and relaxing for them showed that listening to music was among their coping strategies. Talking with others about their disease and emotions or writing out their feelings in the blog for others to read and comment helped the bloggers cope with their disease. The bloggers noted how some of their blog posts were about them working through their emotions and going through the grieving process to mourn their past life without RA. For those who had to give up their active careers and interests, they went through an emotional process of accepting that their old life is gone and embraced their new limitations.

**Fertility and motherhood.** Many of the women did not receive their RA diagnosis until years after having children. The women who struggled with RA symptoms immediately after giving birth described developing post-partum depression because of their pain symptoms and not being able to care for the child the way they had imagined. The women described struggling to lift their child at times and struggling with fatigue. After the stressful experience with their first child, these women decided not to have another child. Those who were married had a spouse who helped the women care for their child, but women with and without spouses decided not to have another child because of their RA struggles with their first child. Women with RA who wanted to get pregnant, struggled with their providers to find a medication treatment plan that was safe for the fetus and effective for the mother. Two of the female bloggers described getting a hysterectomy but did not explain why. For the young female bloggers with RA under forty and within the childbearing ages, the idea of a hysterectomy or choosing not to have another child made them sad. The bloggers who had children, remembered their stress with their first child before accepting that they had made the right decision.

**Sources of support.** The sources of support were divided into family, friends, providers, financial support, and the community which supported the social roles of wife, mother, daughter, friend, and patient. The family of the bloggers included their parents, spouse or partner, siblings, children, and pets. Many of the bloggers discussed their pets in their blogs, so I considered pets as part of the family. Pets offered the blogger companionship. Bloggers described the level of understanding and support their families offered. Parents took bloggers to specialists and did not give up until a diagnosis was made. Bloggers described feeling dependent towards their parents because their parents provided them with help during their recovery from surgery and helped with childcare. The bloggers needed the support of their family during physically and emotionally hard times. The bloggers shared the examples and metaphors that they provided to their families to explain how the disease affects them. Additionally, bloggers needed the support of the family when they cannot make events. The women often shared examples of caring moments when their husband helped them. However, some bloggers often had their friends take them to appointments instead of their husbands. The bloggers emphasized that spouses and friends who appreciated them for their uniqueness helped them process their emotions rather than add to their emotional distress.

***Friend support.*** Bloggers described that chronic illness affects their friendships. Bloggers explained that they had difficulty being a good friend because they could not always keep plans and commit to events because of the unpredictable nature of RA. When they go out with friends, the blogger's friends must make accommodations for physical activities such as reducing walking distances and incorporating the blogger's diet restrictions. Friendships are lost if a friend does not want to be part of the blogger's support system. Bloggers stated that their true friends listened to them for hours if necessary, were supportive, and were not judgmental. Many of the bloggers find true friends, who understand them and provide emotional support, within the online RA blogging community.

***Provider support.*** The bloggers thanked their providers for their care. The bloggers portrayed a positive perspective of their providers when the treatments and suggestions of the providers improved their condition. I noticed the condition of the disease related to the relationship with providers. For example, bloggers who indicated that their treatment plan was working and had reduced disease activity had a more positive perspective of their providers, than the bloggers whose providers had not found a working treatment plan or questioned their diagnosis of RA. Rheumatologists are only seen a few times a year, so changing a treatment plan takes time. An individual with RA could be suffering with an ineffective treatment plan for almost a year or longer.

Each blogger had a bad provider experience and reminded readers to switch providers if they were not receiving adequate treatment. Discussion of providers in the blogs do not only include rheumatologists, but also primary care physicians, pain specialists, and surgeons. A post on a provider interaction included how the receptionists, assistants, and doctors contributed to the blogger's experience. The bloggers encouraged providers to share the emerging diagnoses they find, so that the patient and the provider can decide on the treatment together. The bloggers reported receiving conflicting treatment plans from the many specialists they see. Bloggers described instances of a doctor ordering for a medication to be discontinued, while another doctor will threaten to stop seeing the individual for not adhering to the treatment plan.

The bloggers brought up issues with providers and opioids. Bloggers shared experiences with RA regarding opioids and explained that individuals with RA struggle with extreme pain and are not opioid seekers. Bloggers described having a high level of pain tolerance and saved their strong pain medications for the days when they had unbearable pain. The bloggers wanted others to understand that they were not taking opioids because they were addicted or that it will help with mental or emotional stress. Many bloggers described not wanting to take medication that will keep them in bed all day and prevent them from working or participating in other activities.

***Community support.*** The bloggers are part of different types of communities that can support them. One community is the community in which they live and consists of their friends, family neighbors, and supporting organizations in their communities. The bloggers encouraged readers to find support within their community and create awareness about RA. The bloggers described how an advocacy group provided an activity to start a discussion with others about RA by exchanging questions and answers. There is the community of RA illness bloggers, and there is a larger RA community of individuals with RA on social media and in-person groups of providers, researchers, and their stakeholder organizations, such as advocacy groups. Researchers can use the large RA community to find participants or provide insight on research committees.

Each blogger also has their own community of readers for their individual illness blogs. The bloggers personal community may also follow them on social media, read the bloggers posts on major health care forums, and purchase their fan gear and books. The bloggers often provide links in their blogs to the post they wrote for other websites. Some bloggers met close friends through the online blogging community. The bloggers also have online blogging events where they blog with a common prompt for a week. The bloggers comment on each other’s posts and expand their talks to social media platforms such as Twitter and Facebook. Bloggers write some posts to respond to what they found on social media, online, or the television that is related to RA or health issues.

A common topic related to community discussed in the blogs is the fear of criticism when their RA and personal life are going well. There is fear that people may accuse them of not having RA or say that their RA is not that bad. Bloggers explained that they and their friends have experienced negatives comments that make them feel like leaving the blogging community and that some of their friends have stopped sharing online. The bloggers encouraged members of the community not to compare symptoms and activity levels as people are in different stages of the disease. Bloggers posted that community members should not accuse each other of not having RA or claim to have worse RA. Bloggers explained that they need friends in the community who understand them and are grateful for their readers and support.

The bloggers explained that because they fear criticism, they tend to write more when they feel bad and are actively struggling with their RA. For example, bloggers may make daily posts to update readers about their flare. When their RA and personal life were going well, the bloggers reduced the frequency of posts from daily to only a few posts a year. I also attributed this reduction in posting to the use of blog posts as a coping mechanism. If the bloggers do not have much content to work out emotionally, they would write less. A blogger noted that since she is stable, she did not feel like she had anything to write that was helpful to her readers. However, bloggers recognized the importance of sharing the stability of RA to show how they coped better with the disease over time. Bloggers explained that they did not see such positive posts when they were first diagnosed, and such posts would have given them more hope. Bloggers also described wanting to share more about their lives rather than only focus on the disease. As the extreme symptoms of their disease reduce in frequency, the bloggers can share the positive events occurring in their lives.

***Financial support.*** The bloggers needed financial support either through their own funds or third-party payers to cover the cost of treatment and other personal expenses. Some of the bloggers had stable jobs while others worked as writers or consultants. Some of the women mentioned that they had husbands who worked. Bloggers who are working described their struggles in managing their appointments, their symptoms, and their work schedules. Some bloggers described having a physically demanding career before their RA diagnosis. Bloggers who are no longer able to work due to the nature of the debilitating disease, described receiving disability payments and health coverage through the government. The bloggers who worked desk jobs also struggled with RA. One blogger noted that her RA got worse at a desk job. Women who had stopped working noticed that their flares occurred less often and indicated that work aggravated their RA. For many of the women though, not working means they are living at a limited, fixed income which makes covering their personal expenses difficult.

Many of the pain management options such as massage, chiropractor, acupuncture, supplements, medical marijuana, and CBD oil are not covered by insurance companies, so the bloggers can only use them when they can afford it. A blogger described that health saving plans can be helpful in covering these treatment costs. Another blogger pointed out that amid the opioid crisis, there is a call for nonpharmacological treatment for pain, but insurance companies are more willing to pay for opioids than expensive, ongoing nonpharmacological treatment sessions. The blogger also noted that less addictive drugs are often not covered by insurance. Additionally, bloggers shared experiences of being “stuck” with the rest of the bill, if the insurance company denied coverage for services already received. A blogger, who received a bill because a physician ordered the wrong tests, suggested that insurance companies have patient advocates that fight for patients with complex provider-insurance issues.

Bloggers on limited fixed incomes struggled with the disability process and the treatments and medications that insurance did not cover. Applying for government support or losing the support created stress and anxiety for bloggers. A blogger described the nervousness and anxiety of going through the disability application process. The blogger described how she needed assistance and support to fill the forms because the pain and memory lapses made it difficult to complete the forms. Moreover, the bloggers worried about how laws can change the governments coverage and advocated for more coverage.

**Advocacy.** Advocacy is a significant theme in the blogs. Many of the women described themselves as patient advocates and attended advocacy events. Maintaining the RA illness blogs is one example of advocacy and creating awareness. Some bloggers studied patient advocacy, and others read about health care and medical research. Bloggers teamed up with health organizations and companies, such as drug companies, for advocacy events. Bloggers described participating as experts on health panels.

Bloggers advocated for health care and insurance related legislation. Bloggers also advocated for more individuals with RA to take part in research and clinical trials. A research organization held an essay contest on increasing participation in health research. Both bloggers who indicated they participated in the contest and those who did not participate described their active participation in research. A blogger noted that participating in a clinical trial poses the same risks as trying a new RA treatment plan or getting a vaccination.

In the research setting, bloggers described wanting to be respected, engaged in the process, and have their voices heard. A blogger explained how researchers in a panel indicated a desire for participants from more diverse backgrounds and age groups. The blogger felt that panel members did not value her participation and suggested for researchers to use social media and the online communities to find more diverse patient experts. The blogger did not like the terms “expert” or “professional” patient. The blogger felt that the term “expert” or “professional” patient was dehumanizing and did not capture that she still struggled with negative health care interactions.

## Discussion

### Interpretation

I used the guiding theoretical framework to interpret the results of the study. The theoretical framework for this study is accepting the new normalcy, which incorporates Watson’s theory of human caring and Orem’s self-care theory. The bloggers shared their self-management of medication, diet, and methods of conserving energy. The bloggers detailed the research they conducted about their health concerns and how their findings and experiences affected their health decisions. Self-management and seeking information relate to self-care agency and requisites of Orem’s theory of self care (1985). The 10 caritas processes and transpersonal caring relationship in Watson’s (2002, 2015) theory relate to the support from nurses, but the findings of this study showed the need for support in other providers, such as rheumatologists and the entire care team.

The bloggers described coping with more RA symptoms than pain and fatigue. The bloggers discussed how they struggled to cope with dryness in their eyes, mouth, hands, and feet. The bloggers attributed dry eyes and mouth to Sjogren’s syndrome. The literature supports the systemic symptoms of dry eyes and mouth. According to He et al. (2013) and Yang et al. (2018), Sjogren Syndrome is a progressive autoimmune disease that is often accompanied with severe RA. The extra dryness of the eyes can damage the surface of the eye, and the extra dryness of the mouth can lead to increased tooth decay (Jadhav et al., 2015). Bloggers described coping with the dry mouth and eyes by drinking more fluid and receiving treatment from an ophthalmologist. A blogger described as her ophthalmologist prescribed eye drops and placed plugs in the tear ducts to keep the eyes hydrated.

The two bloggers who described the dry and bleeding hands and feet did not know their diagnosis. Creams provided by their dermatologists offered limited improvement for the dry hands and feet, and one blogger found prednisone tablets significantly improved the state of her hands. The literature linked the irritation of the soles of the hands and feet to RA. In a case study on a woman with RA, Abreu-Velez, Pinto, and Howard (2009) described a woman’s struggle with treating pompholyx or dyshidrotic eczema and examined the immune response of the condition. Abreu-Velez et. al. (2009) used results of a skin-biopsy to determine that the irritation was caused by a type of eczema, rather than psoriasis or fungus. Dyshidrotic eczema is characterized by blistering that may be filled with liquid in its first stage, but it has a second stage of painful, dry, cracked, and bleeding soles that is similar to the symptoms of dry hands and feet that the women described in their blogs. Abreu-Velez et al. (2009) did not note subdermal blisters on the woman they studied and concluded that the skin condition was an immune response that is treated with immune suppressing drugs. However, a variety of conditions could have caused the dry hands and feet described by the bloggers. An autoimmune condition could have caused the dry hands and feet because prednisone, which is often used as immunosuppressant, improved the dry hands and feet symptoms for one of the bloggers.

The bloggers adopted special diets to deal with food sensitivities that increased gastrointestinal issues or worsened RA pain and fatigue. A few female RA bloggers described curing their symptoms through diet. According to Campbell (2014), allergies and autoimmune disease relate because allergies are controlled by the immune system, and autoimmune diseases involve the immune system attacking the body. Vieira, Pagovich, and Kriegel (2014) and Campbell (2014), noted that studies in mice have shown that what people eat affects their gut bacteria, and changes in gut bacteria increase inflammatory autoimmune diseases. Manzel et al. (2014) discussed the effect of the excess portions, fat, and salt of the “western diet” on autoimmune diseases. Manzel et al. (2014) noted that the success of dietary interventions may depend on how well the individual responds to current pharmacological treatments. However, Manzel et al. (2014) acknowledged that individuals with autoimmune diseases, such as RA, attribute special diet and supplements as treatments. Manzel et al. (2014) noted that the diet effects occurred on an individual basis but found that trends about diet and autoimmune disease did not exist in a large population. The bloggers indicated that they experimented to identify irritating foods and beneficial supplements and explained that other people might have different responses.

In addition to diet, some bloggers described managing their symptoms with alternative treatments such as cannabidiol (CBD) oil, marijuana, and Chinese traditional medicine. The literature supports the use of such alternative therapies. Hammell et al.

(2016) studied the use of CBD oil to treat arthritis pain and inflammation in rats. Hammell et al. (2016) explained that THC and CBD are the primary active chemicals in medical marijuana. THC has psychoactive side-effects and can lead to an increase risk of developing psychosis and schizophrenia (Hammell, 2016). CBD has a similar structure to THC but does not have the psychoactive side effects of THC. Hammell et al. (2016) found that transdermal CBD oil gels can provide relief for arthritis pain and inflammation.

Bloggers discussed the use of traditional Chinese medicine and therapies. Traditional Chinese medicine involves the use of Chinese herbs, such as ginger and cat's claw, and alternative therapies (Zhang et al., 2010). Zhang et al. (2010) noted that Chinese herbs can inhibit the development of RA. Additionally, traditional Chinese treatments such as acupuncture and massage can relieve pain and increase the mobility of joints to improve the quality of life for individuals with RA. Yuan et al. (2015) reviewed more types of traditional Chinese therapies including acupuncture, cupping, gua sha, tai chi, qigong, and acupressure. Yuan et al. (2015) found these therapies can be beneficial to neck pain and low back pain but called for additional research to draw significant conclusions.

The bloggers described their ideals of motherhood and a sense of independence that reflected their individual values and discussed how their disease affected their ability to maintain those values. The model I developed for the theoretical framework includes the impact of gender roles under self-care deficit, because gender roles align with the values of an individual, and in turn affects an individual's concept of normal (Hartweg &

Pickens, 2016). The bloggers described reaching a point where their RA has become part of their normal lives. Under the concept of normalcy, the bloggers described as they developed their new sense of normal and accepted their limitations with RA. Bloggers described feeling dependent on others, such as their parents. During surgical recovery, the women described coping by informing their friends and family of their scheduled downtime ahead of time and receiving assistance from their families.

Orem’s theory of self care includes the concept of the self-care deficit which incorporates individuals attempt to care for themselves and their dependence on others (Orem, 1985). Social interaction is also an important need among Orem’s self-care deficits (Ali, 2018). Despite the restrictions RA places on their social life, blogging allowed the women to socialize though their blogs and social media outlets that eventually led to long-lasting friendships offline. The bloggers discussed losing friends, their dependence on others, and expressed a need to grieve for their lives before their RA diagnosis. The emotions that the women described were supported in the literature. Katz & Yelin (1995) studied women with RA and identified that the loss of valued activities leads to the depressive symptoms rather than the functional impairment. Ahlstrom (2007) studied loss in individuals with chronic diseases who were receiving personal assistance. The findings of Ahlstrom (2007) indicated that the individuals with chronic illness experience a cyclical, chronic sorrow because of their losses which includes a loss of imagined life, identity, autonomy, independence, and relationships.

The female RA bloggers expressed how their careers aspirations and dreams of having children have depressed them from time to time. Bloggers described how their RA symptoms led to struggles in caring for their newborn and caused limited activity which saddened them and contributed to post-partum depression and the decision to not have more children. RA bloggers who have not had children yet are aware of the challenge and are working with their rheumatologists and gynecologists to identify an RA treatment plan that works for the mother but will keep the fetus safe. According to Gayed and Gordon (2007) and Littlejohn (2019), individuals with RA often achieve remission during pregnancy, but experience flares postpartum. Littlejohn (2019) suggested that women should consider becoming pregnant during periods of low disease activity and for the mothers to work with their rheumatologists to switch to pregnancy safe RA medications for the entire pregnancy.

My analysis of the female blogs revealed that the women had roles of mother, wife, daughter, sister, and friend, and through some of those roles they find support. However, some friends and family members are not as supportive. Additionally, individuals with RA experience great restriction in socializing (Geusken et al., 2007). Individuals with higher restrictions of social activity, experienced more RA symptoms, struggled with more anxiety and depression, and had less mastery of the disease (Geusken et al., 2007). This pattern was noticed in the analysis of my study as bloggers described more social gathering, and a positive self-esteem when their symptoms were controlled. Women with RA need provider support to include social participation in health goals to decrease the effect of RA on their quality of life (Benka, et al., 2015).

The bloggers participated in patient advocacy through writing informative posts on their blogs and other sites, attending advocacy events in the physical world, and participating in health care research. The bloggers' posts helped them cope with their emotions as they expressed their thoughts and concerns online, and their advocacy work gave bloggers a sense of purpose to create awareness. The community, RA blogosphere, and social media were entwined into the social support, health resources, and advocacy efforts of the bloggers. Through their own experiences, the bloggers have become knowledgeable on the disease and want to share it with others. Tsai et al. (2018) and Ressler et al. (2012) supported the findings of my study by concluding that chronic illness blogging helps to decrease isolation and give bloggers a social purpose of helping others. The bloggers described connecting and receiving support through non-RA social groups. Gasteiger et al. (2018) studied a social media community of quilters and noted that bloggers supported one another related to quilting designs and suggested adaptations to crafting methods to cope with pain. In my findings, the bloggers also connected with health care companies and organizations to educate patients and promote products. Sosnowy (2014) noted that health care companies and health organizations are encouraging bloggers to promote their products, policies, and legislation.

Encouraging others to participate in research was a common topic in the women's blog posts. A blogger explained how she prepared for the research discussions by studying the research language and guidelines guiding research such as informed consent. The blogger noted how researchers struggle to acquire a more diverse group of participants and the need for researchers to engage patients. The literature supports the importance of communication, active participation, and involvement with participants (American Journal of Medical Genetics (AJMG) Sequence, 2014; de Jorge et al., 2015).

The AJMG Sequence (2014) encouraged researchers to engage with the patient advocates and attend their events to expand their potential participant pool.

## Limitations

The validity of research relates to whether the methodology is appropriate to answer the research question (Leung, 2015). For my study, the analysis of the illness blogs was a valid method to explore the coping mechanisms and support of women with RA. A limitation of my study is that the blogs cannot be quoted to protect the identity of the bloggers, so I must capture the essence of the bloggers and relate their ideas.

To enhance validity, my study design involved two theories. Additionally, I established confirmability by maintaining a reflection journal from the process of identifying the blogs, to determining saturation, and throughout the analysis and theme development process. Moreover, the literature strongly supports my findings which increases the reliability of the study. For dependability, I described the process of carrying out the study in detail, so it can be repeated. The findings are transferrable because the bloggers were from different continents of the world but had similar experiences. Additionally, each comment, symptom, and scenario were described by more than one blogger which shows the findings are transferrable to others with RA.

## Implications

This study impacts social change by creating awareness of the struggles of women with RA and the need for support from the family, community, providers, and third-party payers. The findings of my study suggested improvement for providers, researchers, and third-party payers to be more sensitive to individuals with RA and help empower them.

In practice, providers can assess individuals with RA for depression and social involvement. Providers can work with their patients to incorporate an increase in social involvement into the care plan as necessary. For individuals struggling to find support in their physical communities, providers can redirect them to virtual communities. Additionally, this study impacts social change by showing the value of online communities as a reliable source for health care research and health promotion.

## Recommendations

In this study, I analyzed how RA affects women and the coping and support strategies of women with RA. However, the effective coping and support strategies of men with RA is another literature gap (Flurey et al., 2016; Poh et al., 2015). For my next study, I analyzed the illness blogs of men with RA to identify their coping and support strategies. Because my findings from this study identified that some patients who volunteer in research communities had a bad experience, I recommend additional research to study patient volunteers to identify how researchers can improve their engagement and how to improve diversity and inclusion in those studies.

## Conclusions

This study was designed to identify how women portrayed the effect of RA on their lives, their coping strategies, and sources of support in RA illness blogs. The textual analysis of the blog posts of 15 women with RA revealed how the disease affects women physically, socially, emotionally, and financially. The women described symptoms of pain, fatigue, flare-ups, brain fog, food sensitivities, and dryness of the eyes, mouth, hands, and feet. The blog posts revealed how the women managed their symptoms with medication, alternative therapies, and energy conservation. The women coped with their symptoms by focusing on another activity, talking or writing about their disease and emotions, and accepting their limitations. The women portrayed that over time they became more knowledgeable in handling their RA and gained a sense of normalcy. When the women felt that they had reached a point of stability with their RA symptoms, they focused on other aspects of their lives in their blogs such as finding love, purchasing a home, starting a family, planning retirement, and participating in advocacy and awareness events.

The women received social support from family, friends, providers, and their communities, and financial support through work, spouses, health insurance, and the government. The online RA community served as support for the bloggers but can also be a source of criticism. The bloggers speak up for themselves and continue to share the positive aspects of their lives as a source of hope for other individuals with RA. Illness bloggers are not only an informal source of health information, but an outlet to promote health research, and health care organizations that connect with them. With proper planning and networking, health care organizations can use the blogosphere for health promotion. The significance of these findings is the extensive description of how RA affected the bloggers, how they managed their symptoms, coped with their disease, and their sources of support. This study impacts positive social change by increasing awareness of the nature of RA and providing effective coping and support strategies that have helped individuals with RA.

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# Manuscript 3: Analysis of Coping and Support Strategies for Men with Rheumatoid Arthritis

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[Notes]

# Outlet for Manuscript

This article will be submitted to the *Journal of Research in Nursing* from SAGE Publishing. The journal publishes research to inform nurses and other providers on the global health care issues (Journal of Research in Nursing, 2019). The aim of the journal aligns with my aim for this paper, which was to inform providers and create more awareness of the psychological effect of rheumatoid arthritis in the lives of men. There are no fees to submit or publish in this journal. The word limit is 5,000 words for the main article, 200 words for the abstract, and about 100 to 150 for the author biography (Journal of Research in Nursing, 2019). The journal requires use of the SAGE Harvard style guide.

# Abstract

Rheumatoid arthritis (RA) is a systemic chronic disease that is accompanied by multiple comorbidities. Individuals with RA often struggle to cope and find adequate support physically, emotionally, socially, and financially. About one third of individuals with RA are men, but limited research focuses on the effective coping and support strategies of men with RA. The purpose of this hermeneutic phenomenological study guided by a combination Watson’s and Orem’s nursing theories was to explore the coping and support strategies of men with RA through public blogs. Public blogs of 6 men revealed different coping methods and explained that individuals cope with RA differently. The men shared their emotional struggles and how they adapted their work, social life, and hobbies. The themes identified were RA self-management, physical health, RA symptoms and other diseases, emotional struggles, masculinity, community and advocacy, their work, career, and hobbies, family and friends, perception of others, and health care providers. The findings imply that providers should encourage men with RA to identify self-management methods that work best for them and incorporate patient input into the care plan to improve outcomes. The study revealed that men with RA participate in podcasts and videos, so a future study could explore men with RA through online video and audio.

## Introduction

Rheumatoid arthritis (RA) is a chronic disorder defined by pain, inflammation, and stiffness that affects the skeletal system and other organs, including the heart and lungs (de Souza, Bansal, & Galloway, 2017). RA cells attack the body resulting in the thickening of the synovial membrane and the damaging of cartilages, bones, and joints. The etiology of RA is unknown, but factors such as genetics, environmental factors, and stress have been linked to the onset of the disease (de Souza et al, 2017; Hassett & Clauw, 2010). About 1% to 2 % of the world's population have RA, and about one third of the individuals with RA are men. As a systemic chronic disease, RA does not only affect patients' physical health, but also affects the mental, social, and emotional health of the patients as they struggle to cope with the effect that the disease has on their lives, such as their relationships with others and careers. Men have different roles and social expectations than women. Male norms stress values such as courage, inner direction, central forms of aggression, mastery, technological skill, solidarity, toughness, and independence (Donaldson, 1993). The way men cope reflects their values; therefore, men cope differently from women (Flurey et al., 2016b). Coping strategies effective for women such as support groups are often not effective for men who are less likely than woman to participate in one (Flurey et al, 2016b). However, limited literature exists on the coping strategies of men with RA.

### Significance/Importance

Men and women experience RA differently and cope with RA differently. Hegemonic masculinity plays a large role in how men cope with RA, as the social role of men involves them being strong, independent, and less vocal about their struggles. However, RA limits individuals' abilities to move and care for themselves. Sharing the issues of the disease with others can help individuals with RA acquire sufficient support to cope with the physical and emotional symptoms. Nurses have a vital role in chronic disease management in providing supplementary care and instruction to help patients heal, cope, and better manage the disease (Health Quality Ontario, 2013). If nurses are knowledgeable about effective coping and support strategies, they can make suggestions to improve a patient's self-management of RA. Additionally, nurses have a role in developing a caring relationship so that patients can confide in nurses about their struggles and receive treatments or suggestions that can help them (Health Quality Ontario, 2013). Increasing the awareness and understanding of how patients experience and cope with RA will improve the care patients receive.

I combined Orem's (1985) theory of self-care and Watson's (2002, 2015) theory of human caring for the theoretical framework for my study. Orem's theory focuses on the role of nurses to assist patients in returning to a state of normalcy, where patients have adapted to the disease and are capable of providing self-care (Hartweg & Pickens, 2016). Watson's theory incorporates the ideas of caring for the mind, body, and spirit and developing a transpersonal caring relationship (Clark, 2016). This study contributes to the body of literature by identifying the longitudinal effects of RA and effective coping strategies for men. I linked the results of my study to recommendations for nursing practice through Orem's and Watson's theory of self-care. Past studies on men with RA have been through questionnaires, focus groups, and cross-sectional studies. With this study, I provided longitudinal insights into experiences of men with RA by studying the illness blogs of men with RA. The purpose of this study was to explore how men with RA blog about their coping mechanisms and support strategies for how RA effects their lives.

## Relevant Scholarship

**Masculinity and RA.** Research has linked men's reluctance to seek help with their health to their desire to align themselves with the sociocultural ideals of masculine norms and values (Chambers et al., 2016). Male social norms include solidarity, courage, self-reliance, autonomy, strength, toughness, and some forms of aggression (Chambers et al., 2016; Donaldson 1993). The norm that men should be self-reliant, stoic, and have control of their emotions can prevent men from asking for help, seeking treatment, or sharing their emotions concerning their health (Chambers et al., 2016). Men dealing with RA need coping and support strategies to enable them to accept and adapt to their condition.

In the literature on masculinity and chronic disease, the term "hegemonic masculinity" often appears (Gibbs, 2004). Hegemony refers to the dominance or power that a person or group has over others. Some literature related hegemonic masculinity to men's dominance over women and connects that to men's violence towards women (Jewkes et al., 2015). However, hegemonic masculinity can also relate to the literary ideal of strong, heroic men (Donaldson, 1993). Men who wish to align themselves with the ideal of a strong man who provides and protects his family may find it difficult to adapt when diagnosed with RA. The symptoms of RA, such as joint pain, inflammation, stiffness, and fatigue, can make it difficult for people to work 40 hours a week, complete chores around the house, and complete the activities of daily living (Flurey et al., 2016b). The reduction in physical ability will emotionally affect men, especially those who feel they should be able to do more for their family. Living with RA, affects men's sense of masculinity, self-image, and perceived ability to fulfill the social roles with family and friends (Gibbs, 2004). The social image of a man affects how he will express his emotions and attitudes (Gibbs, 2004).

For example, Flurey et al. (2016b) held a focus group of men with RA and found that men would rather pay someone to help them complete a task they cannot complete themselves instead of accepting help from a family or friend for free. Some men described their adaption to the disease as mastering the way they handle the pain rather than adjusting their activity to reduce pain (Flurey et al., 2016a). The men in the focus group also described difficulty discussing how they cope physically or emotionally with their family, friends, health practitioners, and with RA focus groups (Flurey et al., 2016b; Hill, Bird, & Thrope, 2003; Lack, Nodding, & Hewlett, 2011). When caring for men with RA, medical practitioners should be aware that some men struggle with the loss of independence and struggle to express their feelings with others. To master their adaptation to the progress of their RA, men with RA must adjust their masculine identity and ideals of hegemonic masculinity (Gibbs, 2004).

**Experience of men with rheumatoid arthritis.** RA can affect men's physical, emotional, and social health differently from women (Hill et al., 2003; Lack et al., 2011; Sokkla et al., 2009). RA affects men differently physically, because men have larger and stronger musculoskeletal systems than women (Sokkla et al., 2009). RA symptoms may progress further in women, because women have longer life expectancies than men (Sokkla et al., 2009). However, men with RA have a higher risk for isolation than women (Lack et al., 2011). Men with RA often blame themselves for the strain of the disease on the relationship with their partner (Hill, Bird, & Thrope, 2003). Men with RA experience a loss of power and control when they were not able to complete certain tasks and assert power. Men struggling to control their RA may continue with the routine activities of their life such as going to work. Men who have an accepting attitude towards their RA respect the limits of their bodies (Lack et al., 2011). To better understand how RA affects men physically and emotionally on the long-term, Sokka et al. (2009) called for a longitudinal study of men with RA rather than a cross-sectional study.

**Self-management.** The personal perception of individual capacity and social environment affects an individual's self-management of a disease (Gibbs, 2004). Patient sustained self-management involves more than receiving information from providers at the regular appointments. Actively seeking information and support about the disease and applying those suggestions will enhance an individual's ability to self-manage their conditions. Gibbs (2004) interviewed 17 men with RA about their experience and factors that affect their willingness to attend self-management programs. The study revealed that the friendly and inviting slogans offering help to men through the RA self-management program looked like ads for a support group, so the men were discouraged to attend. The ads for the program did not explain that it was an instructional program with lessons on pain management and exercise. The research linked the men's resistance to attending a support group to the men’s ideal of hegemonic masculinity, because publicly sharing emotions did not align with the stoic and silent values of men (Gibbs, 2004).

Flurey et al. (2016a) conducted a mixed-method study where 30 men sorted statements on their experiences of living with RA. The men ranked the need for information on their medication with high importance. The researchers identified that the men divided themselves into two philosophies of coping. One set of the men leaned toward accepting and adapting to their disease by changing the way they did things, whereas another set of the men leaned toward the masculine ideal being macho by pushing themselves despite the pain (Flurey et al. 2016a). The men that were pushing themselves too hard internalized their pain and struggled to cope. Past studies on the experiences of men with RA and their coping strategies, revealed hegemonic masculinity played a role in how men accepted and coped with the disease (Flurey et al., 2016a; Gibbs, 2004).

## Research Questions and Design

A review of the literature revealed a gap in the longitudinal effects of RA and the coping and support strategies for men. To gain more insight into the literature gap, this study investigates the following research question:

> RQ: How do men with rheumatoid arthritis illness blogs portray coping mechanisms and support strategies to deal with the effect that RA has on their lives?

I conducted a qualitative study which involved conducting a textual analysis of illness blogs written by men with RA.

## Methods

To study the experiences and coping strategies of men with RA, I used the text of RA illness blogs. Past studies showed that the men did not feel comfortable openly discussing their disease in a face-to-face support group; however, an illness blog allows participants to share their experiences anonymously (Flurey et al, 2016b, Gibbs, 2004). The illness blogs not only serve as a coping strategy for the individual maintaining the blog but also serve as a knowledge bank and support for others with similar experiences. Blogs are a valuable data source as they provide detailed longitudinal data (Prescott et al., 2015).

### Participants and Context

I identified blogs for the study through Google searches for individual RA illness blogs. The blogs studied were written in English by men over 21 years with RA. I determined the demographic data of the bloggers from the age and sex that bloggers shared in the posts. Additional inclusion criteria included that the main posts were written by a single user and that the blog did not require a login to read. The goal was to identify at least 10 blogs with at least 5 posts that meet the criteria; however, only 6 male RA illness blogs met the inclusion criteria.

### Data Collection and Analysis

The data collection strategy for this study was document analysis. For each blog, I downloaded the texts of the most recent 20 blog posts into a Word file, and I read through the text to remove personal identifiable information such as names and places. Then, I textually analyzed the text following the hermeneutic phenomenology method by Martin

Heidegger. Compared to Edmund Husserl's phenomenology, which focuses on the study of lived experiences through observation and interviews, hermeneutic phenomenology focuses on studying written text or artwork (Laverty, 2003). The process of analyzing the text consisted of line by line coding and running the text through a qualitative data analysis software, CATMA 5.0, to analyze the frequency of words and their context. Posts related to coping and support strategies were flagged for more detailed analysis on how the blogger described the effectiveness of the various strategies described. Using the codes identified and the output of the CATMA 5.0 word frequencies, I was able to identify common themes from the data.

For this study, I served as the roles of the researcher, study designer, data collector, data analyzer, and nurse. I interacted with only the blog text of the bloggers, so the bloggers were not participants of the study. I only studied the anonymous words from their blogs. As a researcher, I had the role to protect the identity of the bloggers by not sharing the names of the blog, names of individuals, direct quotations, and web links. Blogs are online and easily accessible to the public, so consent was not obtained from the bloggers (see Eysenbach, 2001). However, to protect the privacy of the bloggers, any blogs that required a login to view and read posts were excluded from the study.

## Trustworthiness and Validity

The trustworthiness and validity of the study refer to the dependability, transferability, confirmability, and credibility of the study design and execution (Shenton, 2004). With the information provided on the study design, data collection, and analysis, the study can be replicated and compared to similar studies. To eliminate bias, I maintained a reflection journal from the blog selection stage through data analysis process. For the credibility of this study, I used established qualitative methods to analyze the text.

## Findings

### Execution

Six male RA illness blogs that met the inclusion requirements were used for my study. Additional blogs were not available publicly and did not meet the inclusion criteria of my study. To gather sufficient data from the smaller sample size, 15 to 20 of the most recent blog posts were selected in 5 of the blogs. One blog had 6 posts, so each of the 6 posts were analyzed. The blogs excerpts were then assigned numbers 1 through 6 for easy identification. The blog text excerpts were coded line by line with the qualitative data analyzer CATMA 5.0. From the codes and quotations, themes emerged that related to how the men coped with RA and received support. Then, the blog excerpts were sent through word frequency analyzers to develop word maps and word trees.

### Results

Two overarching themes emerged in this study. The first was a theme of health management which encompassed subthemes of self-management, physical health, RA symptoms and other diseases, and health care providers. The second theme was emotional struggles and support which included subthemes of emotional struggles, masculinity, community and advocacy, work, career, and hobbies, family and friends, and perception of others. Table 3 shows the grouping of the themes and subthemes.

Table 3

*Themes and Subthemes in Rheumatoid Arthritis Illness Blogs of Men*

| Themes | Subthemes |
|---|---|
| Health management | RA self-management |
| | Physical health |
| | RA symptoms & other diseases |
| | Health care providers |
| Emotional struggles and support | Emotional struggles |
| | Masculinity |
| | Community and advocacy |
| | Work, career, and hobbies |
| | Family and friends |
| | Perception of others |

## Health Management

The male RA illness bloggers described the systemic nature of RA and how they managed their symptoms of RA and other diseases. While describing how they managed their RA, the bloggers explained how they maintained their physical health and appearance. The bloggers also noted the role of providers in their care by discussing their visits and tips for navigating the health care system.

**RA self-management.** The theme of self-management emerged after reading two different approaches in blog excerpts 1 and 4. Blog excerpt 1 described how RA is curable with diet, and the blogger defined “curing RA” as the RA symptoms entering a period of remission. On the other hand, blog excerpt 4 explained how medication was effective for RA rather than diet, while acknowledging that diet has worked well for others. Of the 6 blogs, 3 bloggers indicated that they follow a diet-based treatment plan, and 3 of the bloggers described using prescription medication. Although they varied on the effectiveness of diet and medication for RA, each of the men said that exercise helped them reduce joint stiffness, inflammation, and fatigue. The bloggers incorporated exercise and stretching into their self-management of RA and reminded readers not to exercise too hard before it starts hurting. Each of the blogs indicated that the man has been diagnosed with RA for over 15 years. Over time the men discovered what strategies worked best for themselves and explained that each person with RA needs to figure out their comfortable self-management and coping strategies.

The bloggers shared what lifestyle changes worked for them and how they changed their perspective so they could find a way to live life despite their symptoms. When they experienced an increase in pain or a flare, the bloggers described analyzing what factors may have caused it. They considered food intake, new medications, actions such as over exercising, and then tried to make a change to improve their pain. They tried remedies such as resting, heating, or cooling the area to reduce the inflammation. The bloggers also described using durable medical equipment such as braces, canes, and crutches. Lastly, bloggers described attempting to mentally block out the pain. One blogger referred to the mental blocking as a mindfulness method to cope with the pain if pain medications were not accessible at a time.

The medication treatment plans involved diseased modifying drugs and anti-inflammatories pills, biologics through injections, or intravenous infusions to stop and reverse the arthritis damage. Some of the bloggers discussed taking steroids such as prednisone and pain medications such as opioids for pain. Bloggers described side effects of some of their medication as causing hair loss, creating brain fog, reducing their immunity, and destroying joints. The bloggers described trying different medications if one method did not work or became ineffective. It can take over a year to determine that a treatment plan is ineffective, because these medications must be taken for a while before they start working. Bloggers who chose diet found the medications ineffective, made them feel worse, or were life threatening. The diet-based treatment plan involved eating fresh foods, seafood, and aiming for a whole plant-based diet. The bloggers stated that a diet treatment plan that eliminates processed foods, dairy, animal products, and artificial sweeteners reduces inflammation. In addition, increasing superpower foods that provide necessary nutrients such as omega fatty acids boost the immune system. Bloggers discussed some vitamin supplements but explained that it was better to acquire nutrients from whole foods. Other aspects of treatment include physical therapy and surgical replacements of major joints**.**

**Physical health.** The bloggers discussed what being healthy means to them regarding their chronic symptoms. The bloggers defined health as feeling well, having less pain and stiffness, and sleeping through the night. The bloggers described being more active when they can and resting on the days that they have more pain, fatigued, and stiffness. Bloggers discussed good days with less pain and bad days with severe pain.

One blogger explained that he stopped categorizing the days as good or bad to focus on appreciating every day.

The bloggers described how symptoms, such as the flu, that seems unrelated to RA can still relate to their RA. Blogger discussed trying to differentiate between being sick from RA symptoms or from normal illness such as the flu, but the bloggers realized it was difficult to separate. Bloggers further explained that a cold or a flu was likely caused by an immune system suppressed from RA medications. Bloggers explained that they were more likely to catch a cold or flu after an RA treatment infusion.

**Rheumatoid arthritis symptoms & other diseases.** The bloggers explained that the systemic nature of RA causes it to affect more than the bones and joint. For example, bloggers explained that RA also attacks the soft connective tissue, which causes joint and muscle pain for individuals with RA. A blogger declared that the chronic pain of RA is the hardest symptom to treat. All bloggers agreed that the pain was isolating and difficult to explain to others in words or with numbers. Bloggers explained that people have different levels of pain tolerance so the meaning of numbers on a pain scale varied from person to person. All stated they had constant pain, but on some days the pain is less and other days the pain is worse. Each blogger described how the pain saps their energy, can make people feel empty, and can easily lead to depression. A good metaphor for pain in the blog texts was the description of pain as a blanket of pain that made it difficult to stand up from bed. The men described having stiffness that could last a few hours on a good day and for most of the day on a bad day. They also described an increase in pain and fatigue in winter and spring. In addition to the pain, stiffness, and fatigue, bloggers also described weakness in their hands causing them to drop items unexpectedly.

A blogger clearly explained the concept of RA and its comorbidities, by explaining how the damage from the symptoms of RA can lead to several comorbidities, and how those comorbidities can have their own secondary comorbidities. Bloggers also noted that RA and side effects of RA medications can affect other organs such as the eyes and lungs. Hair loss was a common medication side effect described in the blogs. Bloggers listed other diagnoses they had and discussed how those diseases related and interacted with their RA or RA medications. For example, a blogger described having anemia, which is a marker for RA. Another blogger described how RA medications made medications for his other auto-immune diseases less effective. That blogger did not feel the medication interactions was a significant problem, because his RA medications were not taken daily, and he had become used to the process. Bloggers also discussed their severe back pain and skeletal problems and how their conditions could easily cause complications during surgery and recovery periods for joint replacement or back surgeries.

**Health care providers.** While discussing their treatments, the bloggers discussed their rheumatologists and other providers. Bloggers explained that they had a different physician for each new diagnosis. Coordinating care among several doctors is difficult. Bloggers described having treatments for other conditions being adversely affected by RA medications and struggled to get their doctors to work together. Bloggers described instances of doctors refusing to continue seeing a patient if the treatment plan was not followed even if another doctor recommended the deviation from the treatment plan. A blogger shared tips to get physicians on the same page by sending group emails, but not all physicians shared their emails with their patients.

Bloggers explained that because they have been handling their symptoms for years, they know more about what works for them than healthcare providers who had treated them for a short time. Both bloggers on diet-based treatment plans and bloggers on medication-based treatment plans described incidents where they did not get along with their providers. Diet modifications for RA work best when working with physicians, but a blogger described how multiple physicians coldly refused to accept his proposition of adding diet into the treatment plan. Another blogger explained how physicians and pharmacists became uneasy about refilling his pain medications after the onset of the opioid crisis. There were examples of good patient provider experiences where the physician agreed to work diet into the treatment plan. There were also examples where bloggers had been seeing the same physician for over a decade and had very good relationships.

Lastly, the bloggers addressed difficulties in receiving a return call from a provider. Bloggers suggested being friendly with office staff, so that they will be more considerate when an individual needs to contact the doctor. The bloggers also informed readers that an on-call doctor may not be familiar with each patient’s medical history and will not have charts in front of them. The last suggestion was that emails and messages through online patient portals may be faster ways to contact the doctor.

**Emotional struggles and support.** The second main theme is emotional struggles and support. The male bloggers explored their emotions of pain, frustrations, happiness, and sadness with coping with their symptoms and maintaining their careers and hobbies in their blogs. They explored their fears, worries, and how others perceive them, and found peace with those thoughts in their posts. In some of those emotional posts, the bloggers explained the desire for individuals recently diagnosed to learn from their experiences. To further help others, bloggers wrote books and posts on health care blogging forums. The bloggers also participated in other forms of health care advocacy. The bloggers recognized that the RA community and blogging community are a source of support and reminded readers that individuals with RA need the help and support of family and friends.

***Emotional struggles.*** The bloggers described fear and anxiety about not knowing what comes next. For example, when the next flare will be, when their RA medications will stop working, whether the next drug will alleviate RA symptoms or cause adverse side effects. They also described anger and frustration when they are not able to do what they want when they want to do it. For example, bloggers described feeling sad and upset to cancel plans at the last minute. Another example is that bloggers described arm pain and weakness that sometimes causes them to drop things or stay away from hobbies such as cooking. Bloggers were sad discussing how they had to give up a hobby or job because of their RA symptoms.

***Masculinity.*** Some ideas aligned with the theme of masculinity within the theme of emotional struggles. A clear example of masculinity is a blogger not wanting to admit his own interest in a feminine music group while discussing how his RA affected him from going to an event. A blogger described occasions when he waited too long to seek medical treatment and his condition became worse. The blogger advised readers to get help when they need it because the longer it takes to seek treatment, the longer it will take to heal. A blogger was sad about giving up a hobby that is popular among men because of increased RA pain. Another blogger had worked for many years and did not want to stop working because of RA symptoms. The blogger eventually realized that he could not perform well as he struggled with RA and that the increased stress of taking on additional obligations would worsen his RA. Not being able to work anymore was an emotional struggle, and the blogger volunteered for a few projects. Bloggers want people to understand the disease and are willing to accept help, but the bloggers do not want people to feel pity for them because they are not pitiful.

***Community and advocacy.*** The bloggers recognized that the online community is a source of support and encouraged connecting bloggers together from around the world by blogging about the same topics at the same time. Because a significant percentage of RA bloggers are women, it is important to connect with the women who comment on their blogs and female illness bloggers. One of the topics the RA community addressed was about members of the RA community being harsh to one another and accusing someone of not having RA. These comments are hurtful, so the bloggers encouraged educating members of the community about how RA affects individuals differently and changing the culture of the community so that such improper and offensive comments are not condoned.

In addition to maintaining a personal illness blog, the male RA illness bloggers engaged in the RA community through research and RA organizations. Bloggers described writing articles for forums and blogs for other chronic illnesses they have. Blog 2 and 6 discussed how they established their own foundations and online support groups to address the needs they saw in the RA community. Through the posts, I discovered that men shared their experience with RA through social media, podcasts, and online videos to reach a greater audience.

The blogs also create a social community where bloggers discussed other topics. The bloggers not only provide updates on their health, but they sometimes share updates on family and other aspects of their lives such as hobbies. They also share stories that they had promised to share in a previous post. Bloggers also shared random stories of their childhood and other parts of their lives that did not necessarily pertain to RA. Readers might follow up with a blogger to see if they are okay if a blogger did not write in a while.

Bloggers discussed the difference between talking to family and friends and talking to others with RA. Bloggers acknowledged that although RA affects each person differently, individuals with RA still share commonalities. Those commonalities make it easier for individuals with RA to understand the symptoms such as pain, stiffness, and fatigue. Bloggers also try to reach out to more people with their blogs. At times they generalize that what they are saying applies to people with chronic diseases, chronic pain, or other types of arthritis. For example, a blogger explained that his diet and exercise suggestions apply to people with chronic disease. Some of the male bloggers studied have other diseases and write posts for forums for those diseases and arthritis forums.

**Work, career, and hobbies.** The men described the effect of RA on their work and hobbies. A blogger identified cooking as a physically demanding hobby that stressed his hands, and other bloggers identified taking photos or looking at photos as a less physically demanding hobby. For example, a blogger described giving up his hobby and selling his materials, while adapting to a new hobby that is less stressful on his body. The blogger still works and describes resting more to have enough strength for work.

Of the 6 bloggers, only one described currently working. However, for illness bloggers, patient advocacy efforts, such as serving on advocacy communities and maintaining the blog is similar to work. The bloggers explained juggling time commitments with those groups and writing on the blog. A blogger described fighting against RA by taking on more tasks at work. Then, the blogger returned to school, trying different public positions. The blogger wanted to work as long as possible; however, the blogger has now embraced his work limitations. The blogger evaluated the volunteer activities he has committed to and limits his patient advocacy roles to just a few outlets to manage his energy.

**Family and friends.** The male bloggers identified themselves as mostly older men, over 50 years, so some of the men had spouses, some were divorced, and some had adult children. The bloggers described that RA disrupts the life of an individual with RA and the lives of the people around them. Each blogger had a passage dedicated to helping family members, caregivers, and friends of individuals with RA, because they realize the disease can be hard on them too. The men explained how they feared scaring their loved ones away and draining their energy and emotions. For example, a blogger was preparing for surgery and realized that he and his spouse would be losing their freedom as he recovered. The blogger reflected on how his spouse stood by him through illness, surgeries, and other issues that arose during the marriage and wondered how much additional stress a person could take. The blogger concluded that he loved his spouse and their everlasting relationship.

Despite not wanting to burden their family and friends, the bloggers realized the need for family, friends, and the community to support individuals with RA in dealing with the physical, mental, emotional, and social effects of RA. The bloggers explained that living with chronic illness and chronic pain is scary and lonely, but the assistance and support from others, helps them realized that they are not alone. The bloggers explained that individuals with RA often operate in survival mode and have the heart to do more than they can handle, so the bloggers urged loved ones to step in and tell individuals with RA if the action they want to take is not good for their disease. The bloggers also reminded family and friends to understand that RA is constantly attacking the body and mind, and that they should not feel that an individual with RA is just talking about pain every day. The bloggers stressed that whenever someone with RA is talking to someone about how they feel physically and emotionally, it is better than them struggling with the depression of their chronic illness and pain alone. Bloggers explained that they understand that it is difficult for friends without RA or chronic illnesses to understand how sick they are. However, they can talk with other friends with RA or chronic pain.

One blogger also explained that female friends with RA or similar conditions are also another source of support.

Missing events with family and friends because of fatigue, pain, or unpredictable flare ups, affects both the individual with RA and their loved ones. One blogger explained how every event missed seemed like his friends had the best time ever no matter how normal the event may have been. The bloggers also asked others to be accepting that the uncertainty of RA may cause them to miss events, even at the last minute. Bloggers described not being to spend time with friends and having difficulties scheduling events or canceling because of pain. A blogger described being happy to meet a new friend that recently moved close by that he could enjoy his hobby with. However, the blogger worried about explaining his illness when it impacts their plans.

**Perceptions of others.** The bloggers reflected on how they think others perceive them and provided responses for those perceptions. A blogger explained that some people tell him that they could not handle living with the disease, but the blogger explained that a person would have to handle it to live. Bloggers felt like some people judge or look down at them and think they are faking their illness or seeking attention, but they want people to understand they have a chronic illness, several comorbidities, and a variety of symptoms. The bloggers explained that they understand that it may be draining for others to hear that they are in pain all the time. The bloggers do not want people to feel pity for them and want people to feel better rather than sad after interacting with them. Bloggers described not wanting to overload people with their conditions or the full extent of their chronic diseases. One blogger explained that he tries to be honest about how he feels but does not want to describe it in a way that emotionally affects another person.

Bloggers discussed the stigma that chronic pain patients feel from the opioid crisis. Bloggers described how the issue affected them and their friends who have prescriptions for opioids. The bloggers said the media makes it seem that opioid addiction causes people to solicit medication from shady doctors, but the media forgets about chronic pain patients who use their medication as prescribed with a reputable doctor. The bloggers described receiving judgement from doctors and pharmacies after the onset of the opioid crisis for the pain medications that they have been taking for a long time. A blogger explained that knowing what he knows now, he would not have taken opioids, but since he has been on them for a long time, he must continue them to manage his pain.

## Word Maps

Below are the word maps and word trees produced in the qualitative data analyzer. The size of the font reflects the frequency of the words. Words used more often in the blog excerpts appear larger than words used less often. Figure 3 below shows the words used over 55 times in blogs.

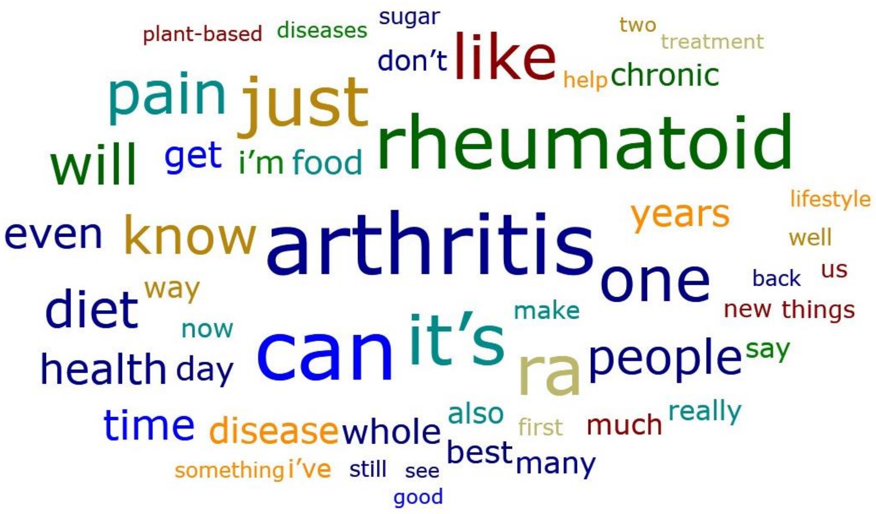

*Figure 3.* Word cloud for men blogs at frequency of 55.

Then, Figure 4 shows the words used at least 100 times in the blog excerpts. *Diet* still appears in the higher word frequency map showing how important diet was to the discussion of the bloggers even though they were split on the effectiveness of diet in their RA treatment plans. The bloggers agreed on the importance of exercise in their treatment plan, but the term *exercise* did not appear at either frequency.

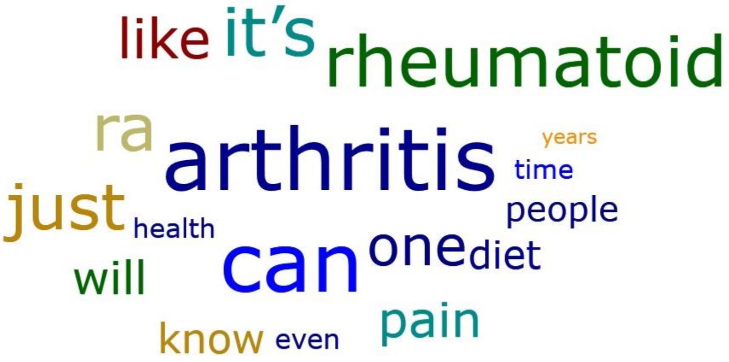

*Figure 4*. Word cloud for men blogs at frequency of 100.

Another type of word frequency image produced from the blog text are word trees that show how words were used with other words. Figure 5 is the word tree for the word *health*. The words used most often before and after the center word are larger. In Figure 5, the terms *health advice, health benefits,* and *health promoting* were most used. The term health was selected for a word tree because bloggers discussed what health meant to them since they have a chronic disease. According to this word tree, the bloggers used *health* in terms of how to be healthy, making good choices, and health research.

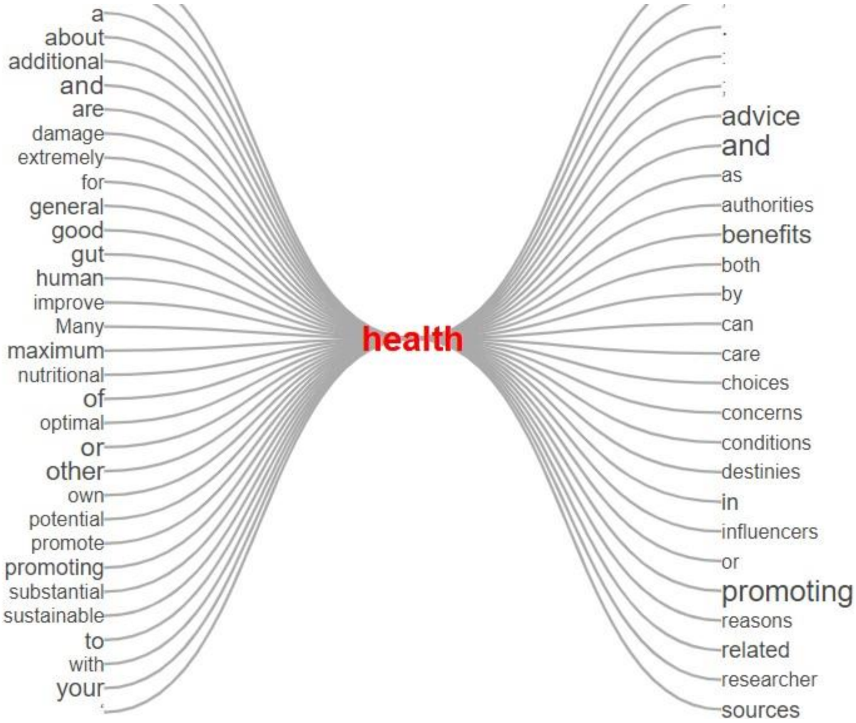

*Figure 5*. Word tree for health.

*Lifestyle* was another key term to develop a word tree for because the bloggers discussed their lifestyle changes. Based on the word tree in Figure 6, the bloggers discussed lifestyle changes, nutritional lifestyle changes, and their improvement.

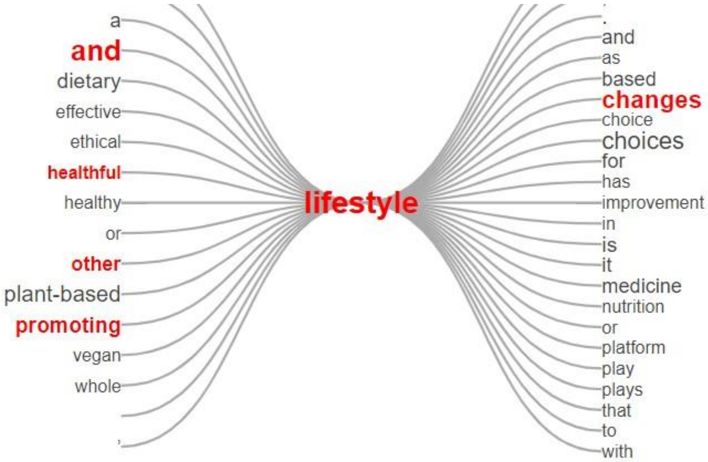

*Figure 6*. Word tree for lifestyle.

The term *rheumatoid* had a few terms following it, and the term *arthritis* had a few terms before it, so I combined their word trees in Figure 7 below for more analysis. Based on the font sizes, *rheumatoid arthritis sufferers* was a term often used. When I selected the Boolean operator "and," I realized that *rheumatoid arthritis and OA* was a common expression used because OA has a larger font size than other words in Figure 7. The term "other" was only a bit smaller than "OA." I realized that although bloggers explained how RA is different from OA and other types of arthritis, they still wanted their blogs and social network to help other pain sufferers. The bloggers also realized that not all their readers had RA. The bloggers often related their generalizable experience and diet suggestions to people with OA and other diseases.

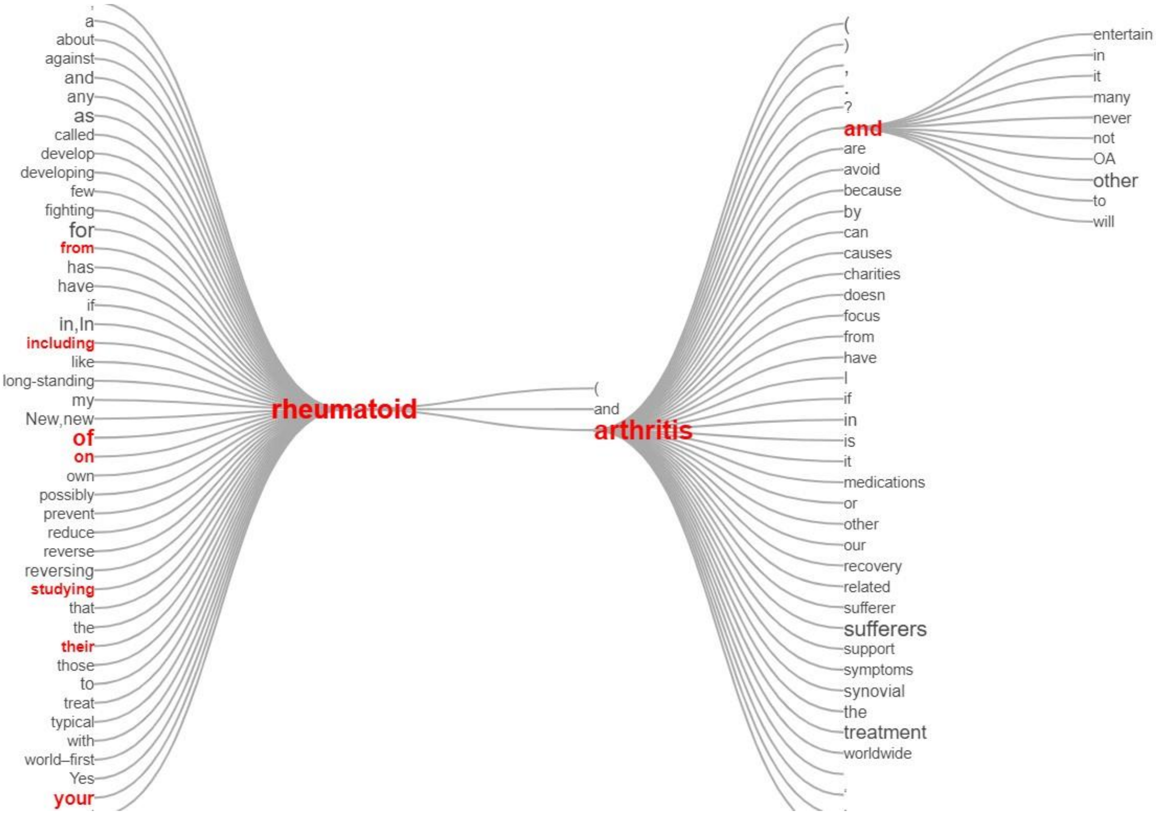

*Figure 7*. Word tree for rheumatoid arthritis.

# Discussion

## Interpretation

I combined concepts from Watson's theory of human caring and Orem's self-care theory to develop the study's theoretical framework for accepting the new normalcy. The findings of this study supported the theoretical framework. The blogs of male RA illness bloggers discussed how the men practiced self-care agency and requisites. Food, activity, rest, social interaction, and promotion of normalcy are part of the universal self-care requisites (Ali, 2018; Orem 1985). Some of the men used the types of food they consumed to reduce their RA symptoms. The men agreed that exercise, reducing their activities, committing to less events, and discussing their worries with others can help them manage their physical, mental, and emotional health.

The RA illness blogs studied described how men who have adapted their daily life and work to meet the physical and emotional strains of RA that they have had for several years. The blogger who is still working also struggled to give up a hobby that RA prevented him from fully enjoying. He has a routine, but he is still adapting. Even bloggers who seem to have fully adapted have newer posts about reducing obligations or physically and emotionally struggling with a new diagnosis or flare. The bloggers described constantly adapting to the unexpected nature of symptoms. Ziarko et al. (2019) also discussed the anxiety and depression among individuals with RA and found that developing mental resilience will help individuals with RA adapt to their changing conditions.

From the blog analyzed, normalcy can be defined as periods without RA flares, remaining stable on a specific RA treatment plan, and becoming accustomed to any new conditions that arise. The bloggers described having RA for at least a decade and remaining stable on their current treatment plan for a few years. New diagnoses unrelated to RA and treatments plans can break up the sense of the normalcy that the men have. Once they treat that new diagnosis and recover the men can return to a state of normalcy, or they can incorporate the new treatments into their care plan and adapt a new sense of normalcy. Changing ineffective RA treatment plans interrupts the sense of normalcy, as it can take months for the new drug to start working, and individuals fear that the new drug may not be effective or have adverse side effects. The sense of normalcy is reached when an individual has become accustomed to the new drug and their continuous symptoms of pain, swelling, stiffness, and fatigue are within a range they can withstand. It is important for other people including providers to remember that individuals with RA are constantly in pain, so adjusting to a tolerable level of pain and reducing activities such as work or hobbies often become part of the new normalcy for an individual with RA. Taking their medications, adjusting their diet, and incorporating exercise are ways the male bloggers described self-managing their health.

Another aspect of Orem’s theory incorporated into the theoretical framework for this study was self-care deficit. Orem’s theory of self-care focuses on individuals caring for themselves to maintain and improve their health; however, an individual with a self-care deficit cannot complete activities of daily living by themselves and may feel frustrated or depressed (Ali, 2018; Orem 1985). In Orem’s theory a nurse must assess individuals self-care deficits and intervene as necessary while incorporating the patient's autonomy because the theory proposes that individuals feeling more independent in their treatment is important for recovery (Orem 1985).

Gender roles, independence and dependence were part of the self-care deficit factors considered in this study. The male bloggers described needing help from their spouse during recovery. There were some anecdotes in the blogs that seemed related to masculinity, such as the men delaying treatment and struggling with the decision to stop working. Flurey et al. (2018) found that men with RA concentrate on their physical health more than their psychological well-being. Flurey et al. (2018) noted that men with RA are less likely to seek medical help, so they may be less likely to participate in research. The illness bloggers did blog about being less likely to seek medical treatment, but bloggers also discussed their participation in research. Illness bloggers are patient advocates, so the bloggers studied were more likely to participate in research than other men with RA.

Watson's theory of human caring includes support strategies as part of the 10 caritas processes (Watson, 2002, 2015). Emotional support was also included as part of the transpersonal caring relationship in Watson's (2002) theory of human caring. Providers have a role in a transpersonal caring relationship to develop a healthy relationship with their patients that supports their goals. For example, incorporating dietary changes into an RA treatment plan is most effective when working with a physician, so providers must be more open to accepting and incorporating their patients' treatment preferences (Koch & Manno, 2015). The bloggers described changing physicians if their physician did not want to incorporate their treatment preferences.

When caring for an individual with RA, it is important to respect the patient’s autonomy and their experience with their illness to develop an individualized care plan.

As for mental and emotional health, the bloggers encouraged their readers to talk to others about how they feel and encouraged readers to listen even if its repetitive. Illness bloggers shared their illness experience online though posts, videos, and podcasts and interacted with other bloggers by responding to their posts. The bloggers suggested that talking to someone helps with the isolation, depression, and anxiety of chronic illness. Flurey et al (2018) and Flurey et al. (2015) and the blog posts analyzed in this study revealed that men did not prefer to speak to their friends about their RA, because friends without RA do not understand the illness or often compared it to osteoarthritis. However, the bloggers suggested connecting with others who have RA including women because more women have RA than men.

Providers should assess the mental and emotional health of individuals with RA and their level of social interaction. These factors can be incorporated into the care plan as necessary. The waiting space in health care facilities could be used to increase communication among men. Talking points could be posted on signs or added to preprogrammed health tips playing on the televisions of the offices. Signs could say, “Did you know that asking someone what they thought about the weather today could brighten their day. Please respect those who prefer to be quiet.” Providers could also encourage individuals with RA to connect with people with RA online by reading their posts.

## Limitations

A limitation of this study was that only 6 blogs were analyzed. However, to make up for the fewer number of public male RA illness blogs found, I analyzed more posts for each blog. The steps of the study are repeatable, and the coping and support mechanisms identified could help other men with RA. However, male RA illness bloggers are publicly expressing their experience with RA, and their willingness to share their physical and emotional struggles may be different from men with RA who do not blog about it.

## Implications

Pain can be isolating and depressing, so men with RA need support from family, friends, the community, and providers. Providers and researchers need to be more sensitive to individuals with RA and help empower them. In practice, providers can assess individuals with RA for depression and social involvement and incorporate an increase in social involvement into the care plan as necessary (Kjeken, Dagfinrud, Mowinckel, Uhlig, Kvien, Finset, 2006; Klak, Raciborski, Samel-Kowalik, 2016). For individuals struggling to find support in their physical communities, providers can redirect them to virtual communities where the men can remain anonymous and read about the experiences of others in a matter that is more similar to researching online than sharing at a support group (Ressler, Bradshaw, Gualtieri, & Chui, 2012; Tsai, Crawford, Strong, 2018). Additionally, providers should be open to incorporating diet into the care plan upon patient request, so that patients wishing to try diet modification as a treatment option can safely do so with physician monitoring. Incorporating the patient into the care plan increases their satisfaction of care and health outcome (Kjeken et al., 2006).

With this study, I affected positive social change by showing the value of online communities as a reliable source for health care research and health promotion. Additionally, I increased the awareness of RA and empowered individuals with RA. The findings can improve the management of RA and improve the relationship among clinicians, patients, and their families.

## Recommendations

Illness blogs are only one outlet for men with RA. While conducting this study, I found that men are also sharing their experience in YouTube videos and podcasts. Future studies could analyze video sharing platforms, podcasts, and other aspects of social media to identify if one public outlet is more common among men with RA.

## Conclusion

The aim of this study was to identify effective coping mechanisms and support strategies of men with RA as identified from public illness blogs. Individuals with RA are continuously adapting as the disease progresses and other illnesses arise. As the mobility and dexterity of their hands reduce in individuals with RA, they struggle to cope. For men who are often the breadwinner in their homes, the emotional struggle of their physical illness may seem overwhelming. RA is less common in men, so they are less likely to have friends who understand their struggles. Additionally, past research identified that men were less likely to participate in a focus group, and more likely to research online (Flurey et al., 2016b; Flurey et al., 2018).

RA illness blogs are online resources that also allow for users to communicate. The findings of this studied revealed that male RA illness bloggers stressed the importance of men with RA finding someone to talk to because of the isolation and depression that can be invoked by chronic pain. Men with RA can communicate with other men and women online with RA or use social media to connect with someone near them. Another finding of this study was that the blogs stressed the importance of regular exercise at home or in physical therapy for handling RA. When it came to treatment plans, some individuals took medication whereas others relied on a more plant-based diet with fish, but without dairy products. To manage RA, individuals must work with their rheumatologists to find the best plan that works for them because not all medications or diets work for everyone. These findings suggest that providers should be more open to incorporating diet and social interaction into the care plan for individuals with RA as necessary.

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# Part 3: Summary

## Integration of the Studies

The broad research purpose for this three-part study was to explore effective coping and support strategies for individuals with RA as portrayed by individuals with RA. Additional goals of the project were to increase awareness of rheumatoid arthritis and to introduce illness blogs as a valuable resource in health care research. The first manuscript explored coping and support strategies of both men and women with RA, the second manuscript focused on women with RA, and the third was on men with RA. Existing literature revealed limited studies on men with RA and few studies on effective coping mechanisms and support strategies for individuals with RA (Flurey et al., 2016; Poh et al., 2017).

Each subsequent study provided additional insight into coping and support strategies of individuals with RA. For example, I identified that some RA illness bloggers referred to diet as a "cure for RA." However, it was in the third study when I gained a greater understanding of incorporating diet into treatment. In the third study, half the blogs described the use of medications, such as disease modifying drugs and analgesics, for treatment, and the other half described changing diet to eliminate foods that aggravated their RA. Bloggers on both sides of the spectrum expressed that people would criticize them for their treatment preferences but explained that each person must find the treatment plan that works for them and that diet should be incorporated with the help of a rheumatologist. Therefore, providers should be more open to incorporate diet changes as necessary.

In addition to medication and diet, bloggers listed many strategies they used to cope with their physical symptoms of pain and fatigue and maintain their emotional well-being. Bloggers suggested exercise, physical therapy, traditional Chinese medicine, and different products including pain rubs and cannabidiol (CBD) oils. However, during flare ups, individuals with RA stated that none of their treatments worked and only resting alone in their bed or on the sofa was effective. To prevent flare ups and cope with fatigue, bloggers encouraged resting and not to “overdo it.” Bloggers encouraged others to schedule rest periods and cancel events when they do not feel up to participating in activities. The bloggers also described participating in low energy level activities such as coloring or looking at photos during times of rest. Bloggers also provided many strategies for making daily activities easier on their hands. They provided tips for cooking, such as using precut vegetables, or dressing their children in zippered outfits rather than buttons.

Both men and women described being hesitant to retire after their RA diagnosis and realized they had to retire because they could not physically continue their jobs or maintain a paying job. For many of the bloggers, patient advocacy became their new profession which allowed them to help themselves by researching the disease and treatment options and discussing their issues and new research findings with others. Advocating for others with RA helped the blogger to empower others by letting them know they are not alone and increasing awareness. Both men and women described struggling with their loss of independence as they needed help from their spouse and parents. Both men and women described struggling to discuss their illness with friends who do not have RA, but the men seemed to describe the loneliness of chronic disease more. Women discussed how they felt odd not being able to eat what their friends did at outings and not being able to walk far on a night out with friends. Women also described how RA affected motherhood and their decision not to have more children. However, the men described feeling isolated and stressed the importance of listening to people with chronic pain so that they are not alone thinking about the pain. The men also suggested connecting with women with RA because they have a better understanding than their friends who do not have RA.

An unexpected finding that this study also revealed was that illness blogs and social media are a good source to connect with perspective research participants. Researchers can reach out to bloggers and the social media page of health care advocates to find participants using the snowball effect. Researchers can find out about advocacy events on social media and attend those events to find participants and partners. The blogs analyzed in this study provided valuable data on the good and bad experiences they had participating in health research. Future studies of bloggers' experiences could help to improve health research and increase participants in health studies.

The study findings aligned with the theoretical framework for this study that merged Watson's (2002, 2015) theory of human caring and Orem's (1985) self-care theory. Watson's theory of human caring emphasized the importance of a transpersonal caring relationship between a provider and a patient (Watson, 2002). Orem's theory emphasized the importance of a patient's independence in self-care and recovery. According to Orem's theory, when an individual is not able to care for themselves, a provider must assess and intervene while respecting an individual's autonomy (Ali, 2018;

Orem 1985). The findings of my three-part study revealed that providers have a vital role in supporting individuals and incorporating their input into the care plan. The male and female RA illness bloggers described looking for providers with whom they could develop a strong relationship and who supported their preferred method of treatment, whether medication based or changing their diet. Additionally, the findings of the study revealed that individuals with RA could struggle with depression and isolation. Following Watson's and Orem's theories, rheumatologists and other providers should analyze individuals with RA holistically by assessing individuals with RA for how well they are coping with the disease, symptoms of depression, and desires for an increased social life. Then, providers must work with an individual to address those issues in the care plan. At times an individual with RA may want to add nonconventional treatment such as diet modifications. The provider should work with the patient to incorporate the modification because the findings of my study revealed that with the support of a physician different treatment plans work for different individuals with RA.

The findings also show the role of third-party payers as patients with RA are often financially stressed by not working or working limited hours because of illness. Therefore, individuals with RA often have health treatments and visits that they cannot afford. However, RA illness blogs described unnecessary and unexplainable charges from providers' mistakes. The bloggers suggested that insurance companies have an advocacy line that would provide information and help on issues such as a dispute on a charge. Otherwise treatments not covered by insurance are reported to the credit bureaus and affect the patient’s credit, which further affects the patient’s financial and emotional health.

## Conclusion

This three-part study can impact social change by increasing awareness of rheumatoid arthritis and the struggles of individuals with the disease. The findings of my study show that individuals with RA need support from family, friends, providers, and third-party payers. Although more women have RA than men, both men and women struggle physically and emotionally with the disease. However, men and women tend to cope with their emotions differently. Social media is a valuable resource for both men and women with RA to connect and explain their thoughts and struggles with others anonymously. The blogs provided many ideas of effective ways to cope physically and emotionally with RA; however, the blogs emphasized the importance of other individuals with RA trying the methods for themselves and figuring out what works for them as an individual.

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