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The Meaning of Instagram use for Rheumatoid Arthritis Information

Deborah Lewis
Walden University

Walden University

College of Health Sciences

This is to certify that the doctoral dissertation by

Deborah Lewis

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
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Review Committee
Dr. Eileen Fowles, Committee Chairperson, Nursing Faculty
Dr. Janice Long, Committee Member, Nursing Faculty
Dr. Nancy Moss, University Reviewer, Nursing Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

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Abstract

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Deborah Lewis

MPH, University of Pittsburgh, 1999

EdD, West Virginia University, 1994

MSN, West Virginia University, 1985

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Social media use related to chronic disease has become pervasive, yet few researchers have examined the influence of social media on health care message dissemination and health care outcomes. In this study, the use of Instagram, an image-rich social media platform, for sharing health information was examined. Nurses, as key providers of patient information, need to understand the relative effectiveness of different types of social media for health information, how social media is currently used by health care consumers, and how to best use various social media platforms to improve patient outcomes. The purpose of this study was to gain an understanding of the meaning of Instagram use for visual image sharing related to #rheumatoidarthritis. Guided by Rogers's diffusion of innovation theory, a visual ethnography approach using content analysis was completed. Images for analysis (n = 106) were randomly selected, using the Instagram public search feature, during 7 distinct periods. Content analysis, conducted by 2 coders, was used to identify categories and provide a sentiment analysis of the images. Approximately 75% of the images were determined to be positive by both coders. Social interaction and self-expression were the most frequently identified categories, suggesting that individuals use Instagram primarily for sharing awareness, sharing encouragement, and self-expression regarding rheumatoid arthritis (RA). This finding is consistent with use of Instagram for social networking and self-promotion. The potential for positive social change may ultimately be the ability for Instagram to serve as a social, personal, and health-related information sharing platform for diverse audiences, particularly those who may be socially isolated due to RA.

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While I'm proud that I have achieved this Ph.D., it was a pathway to provide me with a new understanding to do the job that I love to do. If the objective of education is learning, then I have learned more about the role of doctoral students and identified a new research interest that I can pursue. Hopefully, the former will make me a better teacher and the latter will support my love of scholarly inquiry.

No accomplishment is ever achieved in isolation. My gratitude is extended to my committee chair, Dr. Eileen Fowles, committee member Dr. Janice Long and URR, Dr. Nancy Moss. Your insights and feedback made this a better study, and your support made this process enjoyable.

Thank you to my friend and colleague Patti who kept me grounded with our lunch meetings and who served as my second coder. You are a wonderful colleague and friend.

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I am proud of this degree, but my greatest accomplishment will always be my family. Thank you to Emme for always being there for me, to MeiMei for sharing your joy, and to Albert who took care of everything, so I could accomplish this goal. Even Eva who had to wait for play time. I love you all.

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Chapter 1: Introduction to the Study

Smith and Anderson (2018) found that most Americans (73%) are using social media and that they are using various sites including Twitter, Facebook, YouTube, Snapchat, and Instagram. Worldwide Facebook has a reported 2.3 billion active monthly users, whereas 1 billion are active Instagram users and 67 million actively use Twitter (Facebook, 2018; Fox, 2014; Instagram Business, 2019; Maged, Kamel, Dean, & Steve, 2016; Ventola, 2014).

Social media use related to chronic diseases, such as cancer, arthritis, and cardiovascular disease, has become pervasive; however, few studies exist that describe the best approaches for using social media platforms to support optimal health information sharing for health care consumers (Brosseau et al., 2014; Holmes, Bishop, & Calman, 2017; Mamun, Ibrahim, & Turin, 2015). Existing social media studies on rheumatoid arthritis (RA) health care consumers have been limited to web-based gaming, online searching, e-mail, and web-based communication technologies (Allam, Kostova, Nakamoto, & Schulz, 2015; Mathijssen, Vriezekolk, Eijsbouts, van den Hoogen, & van den Bemt, 2018).

Nurses, and other key providers of health information, need to understand the effectiveness of different social media for health information, how social media is currently being used by health care consumers, and how to best use it to positively influence patient outcomes (Agency for Healthcare Research and Quality [AHRQ], 2012; Ashton & Oermann, 2014; MacDowall & Souza, 2018; Menefee, Thompson, Guterbock, Williams, & Valdez, 2016; Mo, 2013; Pellegrini et al., 2012; Schuff, 2017). An improved

understanding of the ways in which social media has influenced available health information, in part, begins with an understanding of the meaning of messages shared by individuals. The way that health care consumers use social media has the potential to promote social change by creating new ways to access health information, and, ultimately improving health outcomes.

This study addressed the meanings of information shared on Instagram, a graphic-rich social media platform, related to the #rheumatoidarthritis. It is important to understand RA use among Instagram users and, to do that, researchers must capture how Instagram users experience the disease and the meaning of the images posted. Recommendations from this study should support new knowledge related to how health care practitioners share information with patients with RA and their families.

In this first chapter, I will review the purpose of this study, the conceptual framework, and the nature of the study. I will define key terms to increase understanding of concepts related to social media and health information. I will then describe the scope and significance of an increased understanding of the meaning of Instagram messages and the possible future influence.

Background

Social media use is part of everyday life for most Americans (Maged et al., 2016; Smith & Anderson, 2018; Ventola, 2014). Use of social media for health information has been shown to help health care consumers with chronic disease through the creation of awareness, provision of education, improvement of self-management, provision of online support, provision of services and improved communications with health care providers

(Brosseau et al., 2014; Hajli, 2015; Holmes et al., 2017; Mamun et al., 2015; Mathijssen, et al., 2018). Social media is also used by health care organizations to share public health messages (Kuo, Shabestari, & Courtney, 2013; Maged et al., 2016).

Social media refers to online communication platforms that allow the sharing of content by users. Each platform has a unique approach to content-sharing and ways of collaboration. Facebook is a social networking site where users post photos and text that often represent life stories with groups of friends. Twitter is used to share information and is text based. Instagram is image-based and seen as the visual media platform that represents each individual in their own way (Boczkowski, Matassi, & Mitchelstein, 2018). The differences offered by each platform provide unique research opportunities. Unlike other platforms Instagram requires an image or short video per post making it the most visual social media platform and creating a research environment that conveys meaning through images with minimal text and hashtags used for context (Laestadius, 2017).

Arthritis is one chronic condition where only a few studies exist to describe the use and meaning of content posted to social media. Arthritis is an important focus for this study because it is a principal cause of disability in the United States (Hunter et al., 2017). The most common form of arthritis, RA, affects more than 1.28 million adults (Hunter et al., 2017) with annual disease-related costs reaching $304 billion (Centers for Disease Control [CDC], 2018). Disabling fatigue resulting from RA can lead to social isolation for many with the disease (Katz, 2017). Social media is one way that patients

and caregivers can seek and share health information while also participating in social groups (Fox, 2014).

RA is represented by several unique hashtags (#) on Instagram; however, no published studies are available to explain how Instagram is being used for information sharing regarding RA or the meaning of the messages shared. A quick search of Instagram posts on December 31, 2018, indicated 237,464 individual posts related to the #rheumatoidarthritis (Instagram, 2018a). The unique graphic-rich aspects of Instagram make it worthy of study to understand how this media platform could best be used to share socially meaningful RA-related content (Leonard, 2018; Pajaczkowska, 2016).

A gap in knowledge exists as health care consumers are using Instagram to share information even though the nature and meaning of the information shared is not apparent. Although authors note the importance of understanding consumer preferences and use of different types of social media, there is no current literature to help professionals and patient advocates understand the best ways to represent the meaning of RA to influence patient care and outcomes (AHRQ, 2012; Ashton & Oermann, 2014; MacDowall & Souza, 2018; Menefee et al., 2016; Mo, 2013; Pellegrini et al., 2012; Schuff, 2017).

This study could be relevant to those who use Instagram to seek information, and for those who develop content for outreach regarding RA. It is important for nurses and others who develop patient information to recognize the meaning and context of Instagram as a venue for providing health information and how to adapt the content posted to Instagram to improve health outcomes for persons with RA (AHRQ, 2012;

Ashton & Oermann, 2014; MacDowall & Souza, 2018; Menefee et al., 2016; Mo, 2013; Pellegrini et al.,2012; Schuff, 2017).

Problem Statement

The use of social media and web-based health resources provides access to information and community for many who were previously isolated with limited access to resources and support from others who are dealing with similar health care issues (Fox, 2014). Various social media platforms can be particularly important when the disease of interest is a rare or debilitating disease. RA can be socially isolating due to the many disabling sequalae of the disease (Katz, 2017). Little research exists that investigates how health care consumers are using social media to share and gather information on RA. Health care consumers are using Instagram to share information about RA but the nature and meaning of the information shared is not apparent. Whereas Allam and colleagues (2015) noted that web-based gaming can improve patient outcomes for health care consumers with RA, other authors noted that the literature regarding the use of social media related to RA and other health conditions is limited. These authors have identified the need for additional studies to best understand the effects of social media as a source of consumer health information and for the best methodologies for scholarly inquiry of this unique source for data (Donelle & Booth, 2012; Mamun et al., 2015; Surani et al., 2017; Zhang, Albrecht, & Scott, 2018).

This research will fill a gap in scholarship related to the context of Instagram use for sharing health information and the meaning those images hold. This information may help nurses, other health care professionals, and patient advocates understand the best

ways to effectively represent the meaning of RA, using the Instagram format, to improve care to patients with RA. Considering how the images posted on Instagram represent the users and what these images might mean will inform social media developers and those who provide patient information. These end-users and developers need to understand the relative effectiveness of Instagram as a venue for providing health information and how to adapt the content posted to Instagram to improve health outcomes for persons with RA (AHRQ, 2012; Ashton & Oermann, 2014; MacDowall & Souza, 2018; Menefee et al., 2016; Mo, 2013; Pellegrini et al., 2012; Schuff, 2017).

Purpose of the Study

My purpose in this research was to gain an understanding of the use of Instagram for information sharing regarding RA, and the meaning that information sharing has for the health care consumers who use Instagram. The unique image-based characteristics of Instagram make it worthy of study as a novel way to share information (Leonard, 2018; Pajaczkowska, 2016). Selected Instagram images were analyzed using visual ethnographic/content analysis techniques to determine the meaning portrayed by each image (MacDowall & Souza, 2018; Seltzer, Horst-Martz, Lu, & Merchant, 2017).

The phenomenon of interest was health care consumers use of social media, particularly Instagram, as an information resource. The phenomenon includes concepts such as consumer health information, health care consumers, and social media. The limited number of studies in this area support the need to gain further understanding of the meanings inherent in the phenomenon; therefore, this research will contribute to knowledge regarding how Instagram is being used by health care consumers for health

information and evaluation of the meaning that Instagram images portray. The decision regarding a qualitative approach stems from the desire to understand the meaning of the images represented by the Instagram posts. A better understanding of the meanings associated with the images shared will in turn provide insights to health care providers into how Instagram is used to share images related to #rheumatoidarthritis.

Research Question

This research resulted in a comprehensive statement about the meaning of Instagram images posted regarding RA. The research question was:

> What are the meanings expressed through images shared on Instagram associated with #rheumatoidarthritis?

Theoretical Framework

E. M. Rogers's (1962) diffusion of innovation theory can help to explain the adoption and use of innovation and can contribute to our understanding of how health care consumers use Instagram for health information. Rogers (1995) conceptualized diffusion as a dynamic process in which innovations are communicated over time among the members of a social system. Rogers (2003) further posited that innovation can change the way information is communicated. The adoption of innovation often proceeds in stages that include awareness, persuasion, decision, implementation, and continuation. These stages do not necessarily occur in sequence. The first stage of awareness includes awareness of new knowledge (Rogers, 2003). This stage of the diffusion innovation process was my focus in the current study.

Each type of social media has distinctive characteristics that may favor different levels of adoption. The advantages of each social media type may also influence the rate of adoption (Archibald & Clark, 2014). As an adopter, the individual's level of innovativeness supports their choice to engage in the innovation, in this case Instagram. Diffusion can be represented in this theory by those who use the innovation, Instagram, to reach individual health care consumers. For this project, individual use and the meaning attached to the use of images shared on Instagram for #rheumatoidarthritis may shed light on the rate of adoption within the framework of innovation adoption.

Nature of the Study

The nature of this study was qualitative and consisted of a visual ethnography approach using content analysis to analyze the selected Instagram images. Images provide a visual representation of the culture of the individual or group who posts them. Visual ethnography was the best method for review of the properties and meaning represented by the selected Instagram posts (Mead, 1975; Pauwels, 2010). The images and related hashtags and the number of likes for each post were captured through an Instagram search over seven selected time periods. Because there were a large number of images, a simple random sample of the identified images was reviewed. There are data to support the approach of selecting different periods and using a simple random sample of the identified images (Highfield & Leaver, 2014; Kim, Jang, Kim, & Wan, 2018; Salzmann-Erikson & Eriksson, 2018). Initially the Instagram posts were reviewed, and duplicates and advertising posts were removed. This strategy was consistent with methods described by Seltzer et al. (2017). I conducted the initial review with an

individual who has knowledge of RA. The final codebook contained images only. A minimum of two different persons who have knowledge of RA and social media coded the images to add trustworthiness to the results. A third coder was available to settle any disputes but was not used. The study aligned with Rogers's (2003) diffusion of innovation as it adds clarity to the adoption of Instagram through an appraisal of the current use and the meaning derived from the use of Instagram.

Definitions

Consumer health information: Information focused on how patients, as consumers, access and use information to make decisions about their health (Flaherty, Hoffman-Goetz, & Arocha, 2015).

Health care consumers: Patients, families, and caregivers interested in health care issues regardless if they are currently receiving health care (Eysenbach, 2000; Hung et al., 2013; Lewis, Eysenbach, Kukafka, & Jimison, 2005).

Instagram: A free photo and video sharing app. Anyone 13 years and older can create an account and share photos and video with followers and friends. Each Instagram post includes a photo or short video and may include a caption (short text). Other Instagram users can like and comment on the public posts. The individual user chooses their own user name and decides the level of privacy associated with their account. Private account posts with hashtags were not identified by using the Instagram search engine. Only approved followers can see those posts (Instagram, 2018b).

Instagram image: Photo that is uploaded from a cell phone to the Instagram social media platform. You cannot upload photos from a desktop or laptop computer to Instagram (Instagram, 2018d).

Instagram likes: When images are liked on Instagram the number of followers who like the image are noted by a number next to the ♥ icon. If the account is private likes on the image won't appear in the ♥ activity (Instagram, 2018c).

Social media: "Web-based services that allow individuals, communities, and organizations to collaborate, connect, interact, and build community by enabling them to create, co-create, modifies, share, and engage with user-generated content that is easily accessible" (Sloan & Quan-Haase, 2017, p. 17).

Assumptions

Grove, Burns, and Gray (2013) identified assumptions as statements considered true even though they may not have been empirically tested. I made the following three assumptions regarding this study:

- Health care consumers use social media to seek and share health information, and the meaning of health information found on social media can influence the user.
- Individuals with RA may not be ready to review or receive the information shared on Instagram or may perceive that it is personally not useful and will not use it (Donohew, Lorch, & Palmgreen, 1998).
- Images shared on Instagram using #rheumatoidarthritis are representative of RA.

Scope and Delimitations

The scope and complexity of the analysis was developed from the literature and current studies of social media uses in health care (Byrne, 2018; Hu, Manikonda & Kambhampati, 2014; Lee et al., 2017; Neuendorf, 2017; Pink, 2012; Seltzer et al., 2017; Tiggemann & Zaccardo, 2016). The importance of gaining additional knowledge regarding the meaning of Instagram images related to RA informed the design. The scope of the study was intentionally broad to provide a starting point for additional future studies. The science in this area is new and understanding the meaning of these Instagram images could aid in gaining a clearer understanding for how Instagram may be used to inform the development of consumer health information.

Delimitations provide the boundaries for the study and for what was included or not included (O'Leary, 2018). This study was delimited to Instagram images for 7 specific days of the year. The days include the first day of each season and 4 days of special recognition for RA. It was necessary to limit the timeframe to provide a realistic number of images for coding, the first day of each season was selected as there is some seasonal variance in the symptomatology of RA that might affect the type of images shared on Instagram (Watad et al., 2017). The sample size yielded 1,733 images (Instagram, 2018a). A simple random sample of 10% of the images were identified (Highfield & Leaver, 2014; Kim et al., 2018; Salzmann-Erikson & Eriksson, 2018). Two coders with knowledge of RA and social media provide coding of the image categories (Neuendorf, 2017).

I considered a quantitative study but did not choose this methodology because I lack the personal expertise to code the needed software for image analysis and I do not have access to programming support for this type of data collection and analysis. In addition, any quantitative study that would examine the relationship or comparison between social media platforms would require recruitment of health care consumers and addition of a text-based social media like Facebook for comparison, this would be beyond the scope of the current study but could be considered as a future study. I also considered a meta-analysis but quickly learned that there was not enough current literature to support a meaningful meta-analysis.

Donohew, Lorch, and Palmgreen's (1998) activation model of innovation exposure of interest was initially considered for my scholarly work. This model provides an understanding for how the novelty of the innovation influences how individuals receive and perceive information and how they choose to use it. In other words, the Donohew et al. (1998) activation model is based on the action of the innovation and the individual response. Instagram as a social media platform does not create action; rather, it is used by individuals who choose to use it to share images. Rogers's (2003) diffusion of innovation model is better suited to this study as it more related to how the user chooses to communicate meaning and share information through images.

For a qualitative study to be amenable to scientific research, it should be a scholarly approach to describing life experience in a social-cultural context. It was important that appropriate data collection procedures were used to gain an understanding of the meaning of the images. Although data collection and analysis procedures are

determined at the onset of the study, there can be some flexibility to adapt procedures to changes in the emerging findings. It is essential that the researchers are comfortable with qualitative methodologies to be able to adapt to any changes in the study environment and maintain the validity of the data and subsequent findings (Burns, Grove, & Gray, 2012).

Trustworthiness is a term used to indicate accurate and valid results in qualitative research (Creswell, 2014). Lincoln and Gruba (1985) and Merriam (1995) further noted that it is important that the findings reflect the data collected and also that they reflect the perspectives of the data within the context of the environment (or reality). Transferability is one criterion for trustworthiness that seeks to establish if the findings can be applied to a population (Shenton, 2004). The population of individuals with RA were not linked to the images selected for coding; therefore, it may be difficult to generalize to a particular geographic population. However, the finding should provide information related to the meaning of images related to #rheumatoidarthritis and to those with RA who choose to share images on Instagram. Dependability is a second criterion for trustworthiness that seeks to establish if the findings are consistent or reliable if repeated (Shenton, 2004). The dependability of the results should be supported by the image acquisition methodology and simple random sampling strategy. There could be some variation based on the use of a random sample.

Limitations

There are four key limitations for this study. One limitation was related to sample selection. Instagram posts were captured for 1 day of each week of each annual climate

season (i.e., winter, spring, summer and fall) in an effort to capture the documented seasonal variance of RA (National Geographic Society, 2012; Watad et al., 2017). Because Instagram posts may originate from different climates and even different weather zones it may not adequately represent seasonal variations. To help with this issue posts were also captured for one day for each of 4 days or weeks of recognition of RA.

The second limitation was that Instagram users can choose to make their accounts private, so all posts related to RA may not be publicly available (Instagram, 2018a). Third, it was not possible to validate the interpretation of meaning with the persons who posted the images. Instagram is public, and the data related to the authorship of each captured image are not realistically available. The inability to validate the actual origin of the images make it unrealistic to member-check the coders interpretation with those who posted the images resulting in an issue of credibility (Shenton, 2004). Last, Instagram image searches are tailored to the individual who searches and could be influenced by that individuals' followers and posts liked on Instagram (Instagram, 2018d)

Significance

Social media and particularly the use of Instagram for health care information sharing is growing, yet there are limited studies available to understand the meaning and use of the information shared. Research related to Instagram use is challenging due to the large numbers of posts generated and the existing strategies available to collect and analyze the data. Research related to Instagram and other social media can provide a perspective on how individuals represent their health and health management practices (Smith & Milnes, 2016). Marketing research describes the importance of understanding

consumer behavior in the context of the Instagram platform to inform professional communicators as they design social media marketing campaigns (Alhabash & Ma, 2017; Casaló, Flavián, & Ibáñez, 2016). Similar studies are needed to understand the intention of health care consumers as they share health information on Instagram.

This research may support a comprehensive statement about the influence of Instagram on chronic-disease information sharing. An improved understanding for how health care consumers, with chronic-disease, share, seek, and use information on social media will help providers and developers of health-related information be better prepared to support disease-specific knowledge and ultimately improved health care decision-making and health care outcomes. Improved health outcomes in chronic disease supports patients, families, and organizations by improving quality of life and reducing costs of care.

Social change is the opportunity to reach out to those in need (Harper & Leicht, 2018). The concepts of interest for my doctoral work are well related to social change and social impact. The visual nature of Instagram allows for unique properties among the social media platforms. Image-based messages are a powerful way to communicate. Marketing firms have helped to make Instagram the fastest growing social media platform because of the unique appeal of visual messages in marketing. Images are quicker to view and process than text-based messages, making images more engaging and more capable of producing emotional responses than text (Mauch, 2018). The findings from this study will support social change by providing new insights into the

ways that Instagram is being used to meet the information sharing needs of a diverse consumer health care population.

Summary

Social media is being used by health care consumers, but the meaning and context of that use is not clearly understood. It is important for nurses and other who provide health-related education and support to better understand the potential for social media as a way to deliver health information and support. My purpose in this study was to gain a better understanding of the meaning of Instagram use for visual images related to #rheumatoidarthritis. Rogers's diffusion of innovation guided the development of this research. Visual ethnography as a content analysis of the identified images will inform an improved understanding of the meaning of posted images, the context of those images and the themes being shared related to the #rheumatoidarthritis. The findings should promote social change by providing new information to contribute to the growing body of evidence supporting the development of Instagram health condition-specific consumer information.

In Chapter 2, I will describe the current state of the literature on the use of web-based and social media in health care and particularly in RA. I will further discuss the theoretical framework, Rogers's diffusion of innovation. I will then describe the importance of the study as it relates to the body of knowledge regarding social media and consumer health information.

Chapter 2: Literature Review

Introduction

Current research provides few insights into the meaning of Instagram images related to chronic disease. The use of Instagram related to the #rheumatoidarthritis is considerable, yet the literature on the topic of RA and social media is limited. Understanding the meaning portrayed by these images provides additional knowledge to inform developers of consumer health materials related to RA. In this chapter, I describe the literature search strategy and theoretical foundation for the study. In the literature review, I focus on the current-evidence related to Internet-health information, use of social media, RA, and social media and RA, and I conclude with current research related to the use of Instagram in health care.

Literature Search Strategy

To reach content saturation, I initiated a systematic approach to the review of literature and article selection (Moher, Liberati,Tetzlaff, & Altman, 2009). The initial search included the terms *Instagram* and *rheumatoid arthritis* utilizing the databases CINAHL, PubMed, and Thoreau, a multidatabase search tool. The search was limited to articles published between 2012 and 2018 that were written in English and peer reviewed. That search yielded no results. I then broadened the search to include the terms *social media* and *rheumatoid arthritis,* using the same databases. After review of the identified articles and elimination of duplicates, there were a total of three peer-reviewed research articles. From a review of the three articles the search was expanded to include the terms *chronic disease and social media, theory and social media, content analysis and social*

media, *social media and research methodology*, *Instagram and research methodology*, *Instagram and chronic disease*, and *Instagram and rheumatoid arthritis*. I identified 352 articles. After elimination of duplicates and duplicate content, there were a total of 63 articles that were relevant to the study background, problem statemen, and research question. I used citation chaining, which yielded 11 additional articles that were published before 2012 and included seminal works in the field.

Theoretical Foundation

The process of identifying frameworks that lead to the successful adoption and use of consumer health information was challenging; there is limited theoretical development related to consumer's use of health information. One theory was identified that was related and supports the development of this research. E. M. Rogers's diffusion of innovation (1962, 1995, 2003) helps to explain the adoption and use of innovation and can contribute to our understanding of how consumers use digital health information.

Origination of the Theory

Rogers's diffusion of innovation is based on Rogers's (1962) work and subsequent works (1995, 2001, 2003). The adoption of an innovation, such as the use of Internet-based information and digital social media, occurs as a process whereby the innovation is communicated to members of a social system over time. Rogers (1995) conceptualized innovation adoption as a dynamic process occurring in response to changes in experience with the innovation. Innovations represent new ideas that relate to a gap in a participant's current practice and lead toward goal development. Diffusion is the process by which the innovations are communicated and adopted. The adoption of an

innovation often proceeds in stages: knowledge, persuasion, decision, implementation, and confirmation of the commitment to adopt the innovation (see Figure 1; Rogers, 2003).

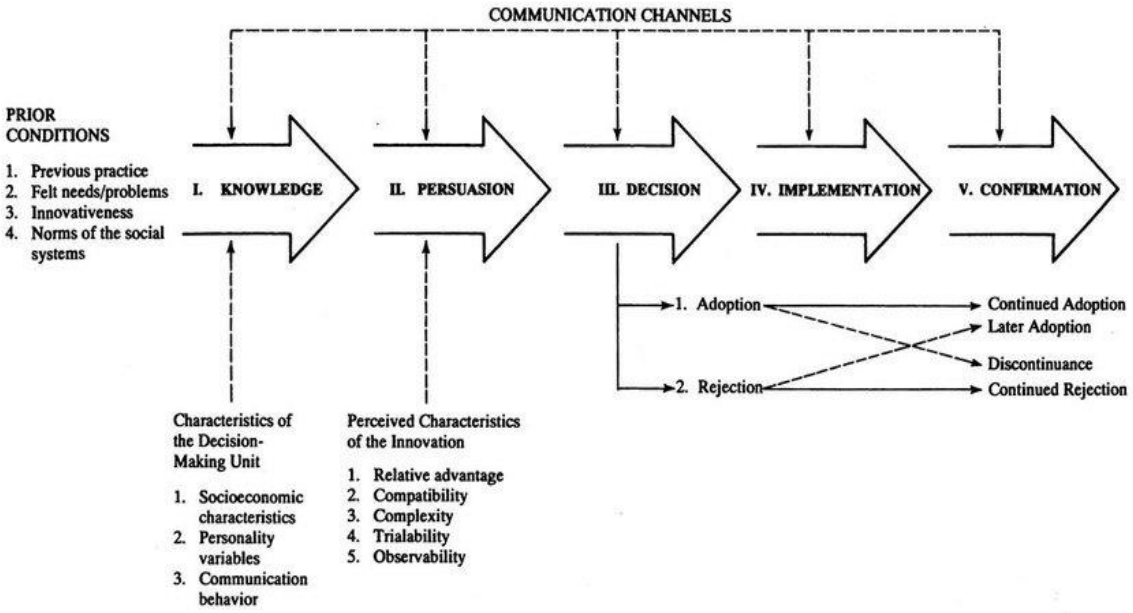

Figure 1. A model of five stages in the innovation-decision process. From DIFFUSION OF INNOVATIONS, 5E by Everett M. Rogers. Copyright © 1995, 2003 by Everett M. Rogers. Copyright © 1962, 1971, 1983 by The Free Press. Reprinted with the permission of The Free Press, a Division of Simon & Schuster, Inc. All rights reserved.

Health care consumers progress through these stages at different rates depending on their access to the innovation and the roles that opinion leaders have in influencing their behavior. Individual characteristics that affect adoption of innovation are part of a larger framework of health care consumer concerns and expectations. For health care consumers, these factors may include (a) personal life circumstances, (b) relationships, (c) relationship with health care professionals, (d) view of the health care system, and (e) view of cost/health benefit offered by the innovation (Rogers, 2003).

Applicability for use in Research

Rogers (2003) examined the individual as part of the process and provides a model for a broad research study that seeks to understand where consumers are in their use of social media and how they are using social media to portray the meaning of their personal health. There was no need to modify, or change, the theory to fit the proposed research. An assumption was made that the process of knowledge, persuasion and decision is iterative and not always linear. The graphic model provided below (Figure 2) illustrates how the concepts of consumer health information fit within the Rogers's (2003) model.

Graphic Model

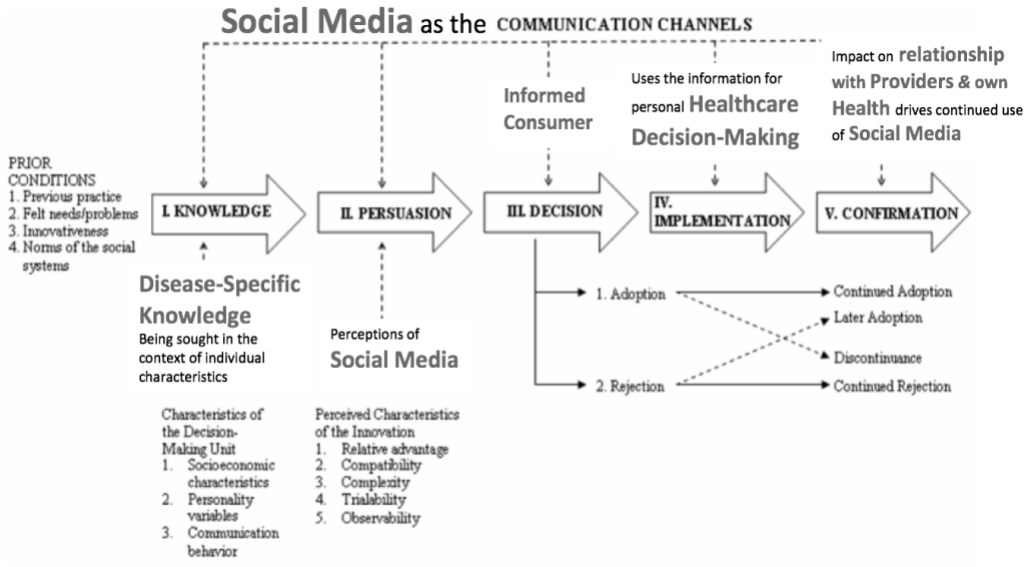

Figure 2. Consumer Health Information (CHI) conceptual relationships in the context of the Five Stages of the Innovation-Decision Process. A graphic depicting how health care consumers may use the related CHI concepts to transform health care information into decisions that impact their health care outcomes and provider relationships, presented as an overlay to demonstrate the relationship with Rogers' (2003) Five Stages of the

Innovation-Decision Process. The concepts of consumer health information are identified in the graphic model.

Figure 2 depicts the conceptual relationships as a continuum of consumer health information in the context of the five stages of the innovation-decision process (Rogers, 2003). The concepts of consumer health information are social media, disease-specific knowledge, health care decision-making, patient-provider relationships, and improved health outcomes. In the model, health care consumers use social media as a communication channel to seek and find disease-specific information (Knowledge Stage) to support the process of health care decision-making. The Persuasion Stage, in the process, is likely impacted by the individual's perception of the accuracy, validity, and safety of the information found using social media. Once a decision has been made, by the consumer, to use the information (Decision Stage) will result in the health care consumer making a health care decision (Implementation Stage) that will impact their health outcomes and potentially their relationships with providers. While improved health outcomes would be the goal, all decisions may not result in improved outcomes. Those results may impact the health care consumers continued use of social media or their discontinuance (Confirmation Stage; Rogers, 2003). For this study, the focus was on the first stage, Knowledge.

As new ideas are introduced, like Instagram, the initial rate of adoption is slow but as individuals become familiar adoption accelerates and then either stabilizes or slows based on its perceived value by the users (Bandura, 2002). Archibald and Clark (2014) described the use of Twitter by nurses and noted the value of support information access and research dissemination using this social media platform. They shared that Rogers'

diffusion of innovation can help us understand how innovation adoption occurs and how academics can use this theory to support adoption of innovation. They noted the benefits of Twitter in tailoring information to an individual's preferences. Tailoring and the concept of compatibility are aspects of innovation that meets the needs of those who seek to adopt new technologies. This concept is consistent with Rogers' theory. Each type of social media has distinctive characteristics that may favor different levels of adoption. The advantages of each media type may also influence the rate of adoption (Archibald & Clark, 2014).

Sundstrom (2016) described the relationship between qualitative research related to the use of social media and Rogers' diffusion of innovation theory. Sundstrom noted that introducing new ideas, in new ways online can help to reach underserved populations and result in outcomes that lead to social change. Sundstrom further stated that mass media may be an effective way to reach a large audience. Sundstrom interviewed 44 mothers of newborns regarding their personal meaning of their health. The participants noted using, texting, e-mail, and Google. Sundstrom called for further studies to understand the diffusion process of new media.

The use and meaning of Instagram for RA has not been studied in the context of Rogers' adoption of innovation theory. My proposed research parallels these authors' papers as I seek to understand how users have adopted Instagram and the meaning of the images currently being shared on Instagram for information regarding RA (Archibald & Clark, 2014; Sundstrom, 2016).

Internet-Based Health Information

The Pew Research center has studied the use of social media since the year 2012 (Smith & Anderson, 2018). While Facebook remains the most widely used platform, used by 68% of American Adults, Instagram has had the fastest growing rate of adoption (Smith & Anderson, 2018). Fox (2014) looked at health related use specifically, they found that nearly two-thirds of Americans search online for health information, most often about disease-specific treatments. Twenty-six percent of adult Internet users have viewed information about another person's health experience and more than 15% have sought social support online (Fox, 2014). Fox (2014) further noted that when users seek social support, they often report sharing their own health information as a way perhaps to seek comfort from a community of others who understand the issues faced by living with a disease.

The notion of health care consumers using computer-based information for health care decision-making was first described in the literature by Slack (1972, 1997). More recently, the authors noted below have studied the use of the Internet and mobile health information and its impact on patient outcomes, and while it was not the focus of this research, it was important to review these studies to understand the scope of use that has evolved.

Health care consumers use of the Internet is complex and likely related to the health care consumers own experience of self-management (Holmes et al., 2017). Valdez, Holden, Novak, and Veinot (2015) described the information seeking efforts of the individual patient and family as "patient work" (p.22). This term is intended to support

the design of consumer health information applications that consider the activities and perspectives of the individual. This patient work or Internet health information seeking has been found to improve the relationship patients have with their health care providers by improving the patient's willingness to discuss identified information with their providers. As a result, if access to reliable Internet information is available, patients feels more engaged in decision-making related to their health care (Tan & Goonawardene, 2017).

Informed health care consumers may make better decisions that lead to improved health outcomes, but how the information is presented may impact the outcome. The goal of the study by Holmes et al. (2017) was to better understand the relationship between breast cancer survivors' and their use of the Internet as a self-management tool when deciding whether to utilize complementary and alternative medicine (CAM). The study revealed that the decision-making process is complex, indicating how searching for information on CAM was not always a deliberate choice. Rather, while searching for general self-management resources and information, CAM information was identified. (Holmes et al., 2017). Hajizadeh et al. (2017) evaluated the usability of a web-based patient decision aid called, Informed Together. The aid was designed to assist patients, caregivers, and clinicians when making shared decisions during a severe COPD (chronic obstructive pulmonary disease) event. The investigators found that despite the researcher's best efforts, several of the participants were unable to transfer the results of their responses into an informed decision. They concluded that it would be beneficial for

clinicians to aggregate patient/surrogate's basic knowledge of their condition and lived experiences before the implementation of the aid (Hajizadeh et al., 2017).

Two studies illustrate the potential for Internet-based health information on health outcomes. LeRouge, Dickhut, Lisetti, Sangameswaran, and Malasanos (2016) found that the use of avatars (personal digital icon) and virtual agents (a digital character that acts a teacher or coach or friend) to deliver interventions for chronic weight management helped to increase the probability of engagement and retention in a weight management programs for adolescents. McInnes et al. (2017) found that the use of electronic prescription refills did contribute to improved human immunodeficiency virus (HIV) patient outcomes.

Mobile health is evolving as a way for health care consumers to find information and, in some cases, control their health. Mobile apps can help to empower users to actively participate in their self-care and shared health care decision-making with their providers (Faiola & Holden, 2017; Perret, Bonevski, McDonald, & Abramson, 2016). There are more than 165,000 health-related applications (apps) available for use with mobile devices. Similar to online information and education, most of the apps are related to wellness management, symptom management, personal diagnosis and medication reminders (Kao & Liebovitz, 2017).

The nature of how consumers access information will continue to evolve. These studies provide insight into the Internet and mobile apps as accessible and readily available health information and support resource for health care consumers that may impact their understanding regarding diagnosis or health management (Holmes et al.,

2017). Several authors cautioned that there are barriers to the use of online and mobile health information including security, privacy concerns, and cost (Hajizadeh et al., 2017; Laxman, Banu Krishnan, & Dhillon, 2015). These barriers must be considered in any future development and planning for Internet and mobile app-based health resources.

Use of Social Media

Social media refers to websites and applications providing access to information sharing and social networking. Sites including Twitter, Facebook, and Instagram have had some limited research into their use in health care information sharing and support. Understanding how consumer use information resources is important for developers of consumer health information. There is a need for consumer health information that fits the choices and information needs for focused groups of health care consumers. Review of health-related social media sites helps to identify consumers preferences for user interface design and the types of health issues that are addressed. Focused review of disease specific sites can support developers in better understanding how health consumers choose to use different social media platforms including their preferences and the key issues that are being shared and discussed. Providing social media-based health information that is tailored to the individual may lead to improved health outcomes (AHRQ, 2012; Menefee et al., 2016).

The use of social media may be particularly well-suited to meet the needs of some with chronic and rare diseases as it provides a broad and quickly adaptable platform for sharing (Fox, 2014). Younger adults tend to use social media more often, but adults 65 and older also report high-levels of use (Smith & Anderson, 2018). Health-related social

media groups are used by health care organizations, professionals, advocacy groups, and patient support groups primarily for information sharing, marketing, fund-raising, access to consumer health resources, support, and education (Ventola, 2014). The number of studies was limited, and not all are clearly related making synthesis difficult. Current studies are described in this chapter related to the use of social media and the use of social media in health care.

In a qualitative study, Powell, Gray, and Reese (2013) sought to understand the participant's heavy use of online social networking sites and the impact that use may have. The goal was to determine the significance of the participant's experiences and a description of their online and offline social relationships. Powell and colleagues (2013) identified five themes including, connections, emotions, continual use, preferred online to offline relationships, and ease of use compared to offline interaction. The study also touched on the possibility that overuse of social networking sights might represent online addiction. The authors stated that determining the gain or harm from excessive use of online social networking sites is difficult. Several variables can contribute to an individual's perspective of whether their actions related to social networking are having a positive or negative effect on their lifestyle and social status (Powell et al., 2013).

In a study of social media use related to health care workers (physicians and nurses), Surani et al. (2017) were interested in which social media was used most, the amount of time spent per day using social media, the health care workers awareness of organization policies regarding social media use and if the health care workers encouraged health care consumers to use social media. Three hundred and sixty-six

health care workers participated. Most used social media (89.7%) reportedly spending at least 1 hour per day. Most social media users were under age 40, and there was no difference in the use of social media between doctors and nurses. Both groups encouraged patients to use social media. Surprisingly 40% were unaware of the online health care policies in their organization. It was clear from their study that providers and consumers were using social media for health information, but it is not clear what the benefits or impacts on health care quality and outcomes might be. The issue of privacy and security was also a consideration due to the lack of awareness of organizational policies (Surani et al., 2017).

The two studies described above identified potential positives and barriers to the use of social media. Both studies described the use of social media as potentially contributing to social networking (Powell et al., 2013; Surani et al., 2017). Surani et al. (2017) further described the potential for use to support health care communication. The overuse of social media and awareness of privacy issues are noted as areas of concern that need further investigation.

Other authors have examined the use of social media to support health care information sharing, education, support, and health care outcomes. Mamun and colleagues (2015) explored the use of Facebook for information and support related to hypertension and noted that of the 187 Facebook groups identified, most were focused on the creation of awareness or provision of products and services. Additionally, they found that the size of most Facebook groups was small and that they were not very active but

that they did help provide comfort for health care consumers by connecting them with others and by helping to raise awareness.

Patients with Lupus, in one rheumatology practice, reported primarily using Facebook; however, blogs, YouTube, and Instagram were also noted in the order of frequency of use. Patients in this study were using these media tools to seek information on their disease, especially new treatments; new ways to self-manage; and support. The primary type of information sought was regarding skin and joint complaints and family planning. In this study the participants were primarily female (64%) and were between the ages of 26 and 45 years. Most (66%) of patients stated that the rheumatology team should communicate with them through social media (Wheeler et al., 2018).

Donelle and Booth (2012) collected a 24-hour cross-section of tweets (N = 2400) containing the word health, the word health as part of a word (health care), or as a URL or hashtag (#health) for analysis. They conducted a content analysis and found that the predominant themes identified were personal health practices, health services, and health education. They also noted that many of the tweets reflected current political and social issues and how they could be influenced by news media and advertising.

Merolli, Gray, and Martin-Sanchez (2013) reviewed the literature regarding the use of social media and its impact on patient outcomes; they found that few studies have investigated the impact of social media on chronic-disease. But the few studies they identified produced positive results, supporting the potential of social media as an influential health information resource. They further reported that little research exists to understand how health-related discussions are conceptualized and carried out among

social media users and if that information impacts health outcomes. Another literature review conducted in 2018 by Zang, Albrecht, and Scott provides an overview of the use of Twitter's for data collection and the potential of Twitter for research purposes focusing on patient and family–oriented health. They noted that Twitter, as one of the most popular social media platforms, has been used both to search and mine research data and has the potential to be a prime source of research to connect people with shared health-related interests and questions. This research serves as a particularly useful support for qualitative health researchers and provides researchers with access to insights into the current literature in the field (Zhang et al., 2018).

The findings regarding the use of social media are useful and support an understanding of the impact social media has for health care consumers who are part of a common group of individuals with the same disease. The research is limited, and a consistent theme was the need for additional studies, not only to better understand how social media can impact consumer health but also into the best practices for conducting research using social media.

Rheumatoid Arthritis

Arthritis is a leading cause of disability in the United States. Twenty-two percent of US adults have been told that they some form of arthritis. Arthritis limits the activities of over 23 million adults. Adults with arthritis are 2.5 times more likely to have a fall injury than adults without arthritis. The estimated cost of arthritis in 2013 was $304 billion dollars (CDC, 2018). Of the most common types of arthritis, RA affects an estimated 1.28-1.36 million adults in the US (Hunter et al., 2017).

There is a need for health care consumers with RA to have access to support and education. Focus groups were conducted with 28 RA health care consumers regarding their perceived support needs related to medication use. The researchers identified three related themes, informational support, emotional support and practical support. Informational support included information seeking related to facts, advice and suggestions, as well as feedback from health care providers. Emotional support included the patient-provider relationship and effective communication. Practical support included access to medical aids and pharmacy services. The need for high-quality, accurate information was the need most frequently identified by these patients. The participants did describe use of eHealth technologies to meet these support needs and they were seen as a compliment to health care providers (Mathijssen et al., 2018).

Social Media and Rheumatoid Arthritis

A few studies were found that related to social media use and RA. Curtis et al. (2017) reviewed 785,656 arthritis-related posts on Facebook and found that most posts were from health care consumers under 40 years of age and that medication safety was a key concern. Brosseau et al. (2014) studied ninety-nine health care consumers with osteoarthritis and RA who participated in a Facebook group web page that provided video clips regarding management interventions including aquatic therapy, aquatic jogging, and yoga. The participants completed questionnaires regarding prior knowledge, use of the self-management strategies, self-efficacy and confidence in managing their condition. After 3 months, knowledge acquisitions scores improved as well as intent to complete self-management. The Facebook initiative supported the participants self-

management and provided awareness of community resources to support their arthritis care.

Allam and colleagues (2015) found that when health care consumers with RA were provided with web-based social support and gaming they had improved levels of physical activity and empowerment. The authors further noted that the advice received from other participants improved the participants coping skills and self-care management. Through the use of the social support and gaming the participants were able to identify personally appropriate exercises. The personal support and advice found through the media also improved the participants adherence with exercise and a reduction in health care utilization (Allam et al., 2015).

Green and colleagues (2018) noted that online health communities can help health care consumers with RA reframe their health care experiences and support improved coping strategies. The proportion of health care consumers using social media to identify information and support for their health provides further encouragement for the use of social media by health care consumers with chronic disease and lends further support to the significance for my research.

Instagram

Even less research exists that compares Instagram to Facebook and other social media platforms. Instagram is graphically rich when compared to other forms of social media making it a unique way of sharing socially meaningful content. Instagram as a photo sharing site uses smartphones and computers to encourage mobile learning. Instagram is primarily used for education, information, motivation, and support (Leonard,

2018; Pajaczkowska, 2016). The use of graphically rich messages provides a unique opportunity for sharing. Using visuals to communicate messages has always been a central aspect of the communication. Visuals are known to be a very powerful way to communicate information (Foster, 2016; Leonard, 2018; Mead, 1975; Pajaczkowska, 2016). The use of image-rich digital media, like Instagram, provides a way to share information with images as the primary mode of communication. Colors and backgrounds add to the meaning conveyed. Fonts and text as captions also add to the meaning of the image. Appropriate use of images can create an effective message even in the absence of words (Leonard, 2018; Pajaczkowska, 2016). Foster (2016) added that Instagram images, hashtags and emojis allow us to assemble the context of the images presented. Foster further noted that Instagram images, emojis, and hashtags can provide objective data related to accepted meanings.

Instagram is used by the World Health Organization (WHO) and the CDC to share visually rich public health messages (Maged et al., 2016). When young people were surveyed regarding their use of social media for health information, they reported increased use of video for information (Fergie, Hilton, & Hunt, 2016). It is important to consider how the images posted on Instagram represent the users and what they might mean for those who develop social media content (MacDowall & Souza, 2018). Most studies that do exist related to Instagram use in health care specifically address research methodologies related to use of Instagram data (Highfield & Leaver, 2014; Kim et al., 2018; Lee et al., 2017; Pila, Mond, Griffiths, Mitchison, & Murray, 2017; Salzmann-Erikson & Eriksson, 2018).

Visual communication provides enhanced engagement with the content presented (Brubaker & Wilson, 2018). Images are an effective way to communicate complex ideas making images a useful way to communicate messages. Health care consumers retain as much as 30% of the information from a visual message, where the written message is retained at a 10% level (Avery & Park, 2018; Bowden, Sheehan, & Foureur, 2016). Images are also known to have subtle powers of persuasion and are one reason they are often used in advertising (Alexander et al., 2017). Images also help to understand the construct of the meaning in the message communicated (Tyner, 2000). The more a media is able to meet an individual's needs the more likely the individual is to use that media. Information is a key motivator for individuals to use media (Tsai & Men, 2018). Results related to the meaning of Instagram information will inform the literature related to compatibility of Instagram as a platform to share information as images (Archibald & Clark, 2014; Sundstrom, 2016).

In a study by Pittman and Reich (2016), health care consumer's use of Instagram caused increased happiness and improved satisfaction with life when compared with health care consumers who use text-based media alone. In the only other study found related to Instagram use in health information Seltzer and colleagues (2017) conducted a retrospective review of Instagram posts regarding Zika Virus. They found that of 500 images tagged, 58% contained images related to Zika. Codes included health, public interest, and transmission. Most images were targeted to women (95%). A sentiment analysis expressed fear in 51% of the posts. The authors noted that awareness of public sentiment on a topic could identify areas of increased focus for public health

education. The authors determined that Instagram can be used to understand public sentiment about a topic and to support public health message programming (Seltzer et al., 2017).

Summary

Health care consumers are using social media to access health information, and the nature of how they are using that information is evolving. The concepts of interest for this study, consumer health information and social media, are illustrated in the context of Rogers' (2003) diffusion of innovation theory in the first or Knowledge phase.

The nature of how consumers access information and social support is changing. The studies reviewed provide insights into our current understanding of the use of web-based and social media information and support platforms. Health care consumers report high-levels of social media use making this an important area for scholarly inquiry (Smith & Anderson, 2018). RA affects an estimated more than 1.28 million adults in the US. RA can be isolating due to the wide-range of disabilities creating the need for credible information and social support that is easily accessible (Hunter et al., 2017). Currently only three studies exist that describe the impact of social media on this challenging disease (Allam et al., 2015; Brosseau et al., 2014; Curtis et al., 2017). The health care consumers in the identified studies were using social media for information and support related to their RA. Instagram is graphically rich when compared to other forms of social media making it a unique way of sharing socially meaningful content, however there in only one study that has been conducted to understand how Instagram is used by health care consumers. No studies exist that examine the use of Instagram by

persons with RA. Images are retained longer than text-based messages making them a novel way to share information (Avery & Park, 2018; Bowden et al., 2016). The context of the messages can be influenced by the source and by current political and social factors including advertising and popular press (Donelle & Booth, 2012) The more a media is able to meet an individual's needs the more likely the individual is to use that media. Information is a key motivator for individual to use media (Tsai & Men, 2018). This is directly related to the first phase of Rogers' (2003) diffusion of innovation. In the only study conducted related to health care use of Instagram the authors found that increasing the understanding of public sentiment on a topic could identify areas of increased focus for public health education (Seltzer et al., 2017). Review of Instagram images related to #rheumatoidarthritis should provide insights in the meaning and in turn into the sentiment expressed and the context of the images.

The identified research question sought to understand the meaning of #rheumatoidarthritis posts on Instagram. My proposed dissertation should add new information to the growing body of work regarding diffusion of innovation and social media by seeking to understand the meaning of the Instagram images posted related to #rheumatoidarthritis. Chapter 3 was a discussion the research methodology, plan for data analysis and any issues related to ethical considerations and trustworthiness for the identified data.

Chapter 3: Research Method

Introduction

My purpose in this study was to gain an understanding of the meaning of Instagram use for visual images related to #rheumatoidarthritis. This inquiry was accomplished by examination of the meanings expressed through images shared on Instagram associated with #rheumatoidarthritis. In this chapter the research question and rationale for using the qualitative research tradition are discussed. The role of the researcher, process for selection of images, methodology, instrumentation and plan for data analysis are described. The chapter concludes with a discussion of related issues of trustworthiness and ethical protections.

Research Design and Rationale

This research supports a comprehensive statement about the meaning of Instagram images posted regarding RA. The research question was:

> What are the meanings expressed through images shared on Instagram associated with #rheumatoidarthritis?

My phenomenon of interest was health care consumers use of social media, particularly Instagram, as an information sharing resource. Visual ethnography was chosen to support an understanding of the meaning of the images represented by the Instagram posts. A better understanding of the meanings associated with the Instagram images shared will in turn provide insights into how Instagram is used to share images related to #rheumatoidarthritis. Instagram as a social media platform is well suited to small data approaches that rely on visual ethnography and qualitative content analysis.

Analysis of small samples of Instagram data can provide valuable insights into specific phenomena related to small subpopulations of Instagram uses, such as those associated with a single hashtag. These focused data sets allow the researcher to examine, in depth, the context and ways people use the media to interact and express themselves related to a specialized topic (Laestadius, 2017).

Role of the Researcher

My role as researcher was to obtain IRB approval and then to assemble the images associated with #rheumatoidarthritis from a public search of Instagram. I retrospectively selected Instagram images, related to the #rheumatoidarthritis, from the first day of each season, spring, summer, fall, and winter, and for the days of special recognition for RA for the year 2018. I developed a codebook with a volunteer coder, who has knowledge of RA and social media, for their review and input. Myself and the second coder first independently coded the data and then met to discuss the finding in an effort to reach consensus. We analyzed the results including a statistical analysis of intercoder reliability. A third coder was available to participate to address issues of interrater reliability but was not needed.

Methodology

Sampling Selection Logic

Most studies that do exist related to Instagram use in health care specifically addressed research methodologies related to use of Instagram data. Because there are no limitations to the amount and focus of data that can be produced in a given period, there is a need to understand the best methods for data sampling. Kim and colleagues (2018)

examined probability sampling strategies versus constructed week sampling for social media content, particularly Twitter. The authors tested the efficacy of simple random sampling and several different sample sizes with data obtained from Twitter. They found that simple random sampling provided an adequate, representative sample of Twitter data. In another study, Donelle and Booth (2012) collected data for four continuous 24-hour periods. The authors randomly chose the days as a convenience sample. The initial review yielded 36,042 tweets. The sample was further limited to tweets occurring during the first hour of one 24-hour period; and a day at the end of the selected week. The final sample size was 2,400. The only study that reviewed Instagram health-related yielded only 500 images, in their search, and all were used in the analysis (Seltzer et al., 2017). There are additional data from the literature to support the approach of selecting time periods and using a simple random sample of the identified images (Highfield & Leaver, 2014; Salzmann-Erikson & Eriksson, 2018).

A review of Instagram posts related to #rheumatoidarthritis found that on September 5, 2018, there were 211,000 posted images and on December 2, 2018, there were 231,555 posted images (Instagram, 2018a). This indicated a possible 5,000 images posted per month related to the #rheumatoidarthritis. Because large numbers of posts were found on the last day of December 2018 (N = 237,464 images), a simple random sample of 10% of the identified posts were reviewed (Instagram, 2018a).

Instrumentation

The instrumentation of visual ethnography is images. Mead (1975) described images as the "instruments that would do for anthropology what instrumentation has done

for other sciences – refine and expand the areas of accurate observation" (p. 10). Images illuminate our knowledge and provide a gateway to the culture of the image creator and the audience (Mead, 1975; Pauwels, 2010). The properties of the image, the relationship between the visual form and function, and applied collective uses of the visual representations are all central to understanding the meanings represented (Mead, 1975). Image retrieval can be labor-intensive and there are no best practice tools easily available for searching social media. Instagram allows searching for public image hashtag posts but does not allow focused searching for date ranges. More specialized searches must be completed through websites which charge for searches that can be specialized to limit findings to date/s and may provide a sentiment analysis and other demographic data (Pauwels, 2010). In the case of image content analysis the coders themselves become part of the instrumentation. It may be important that the coders have some level of expertise of the content being reviewed to be able to contextualize the images through their knowledge of the content/data and from their own experience (Pauwels, 2010). The codebook also served as an instrument for this study. The completed process for developing the codebook is further described in Chapter 4.

Procedures for Data Collection

This study was a retrospective review of publicly posted images about RA on Instagram. The images and related hashtags and likes were identified and collected, as screen captures, using Instagram's publicly available search engine using the hashtag #rheumatoidarthritis. The timeframe was specified to limit the search results. The images covered seven days, the first day of the week of each season (winter, spring, summer, and

fall) and a day of the week of special recognition related to RA (Rheumatoid Arthritis Day, Juvenile Arthritis Week, Rheumatoid Arthritis Week, and World Arthritis Day) during the year 2018. Seasons are periods of the year noted by specialized climate conditions (National Geographic Society, 2012). There are data to support a seasonal variation in exacerbation of RA and other autoimmune diseases (Watad et al., 2017). The days of special recognition for Arthritis were added to provide variance across the days of the week. There were 7 total days of the week included Tuesday, Wednesday, Thursday, Friday (3) and Saturday. Seven instead of 8 days are identified because the first day of Summer 2018 also falls on Juvenile Arthritis Week 2018.

The search was completed by entering the #rheumatoidarthritis into the Instagram search box. Private posts were not included in the search. All posts for the identified seven days were collected, by me, as screen captures and stored in seven separate files identified by the date represented by the Instagram posts. The posts were listed in chronological order for each day beginning with the first post of the day. The total number of posts for each of the 7 days were noted (see Figure 3).

Data Collection and Analysis

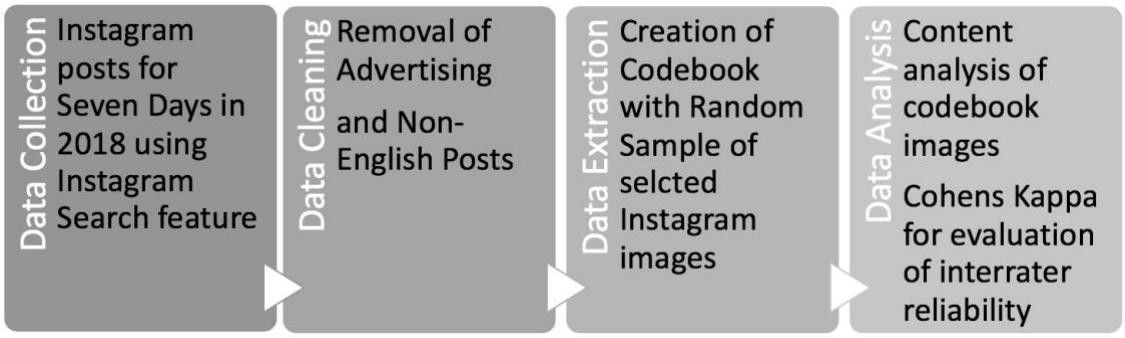

Figure 3. Summarizes the data collection and analysis process. I completed the data collection and cleaning with a second coder who is a health care professional familiar with RA and social media. We also created the codebook and coded the final images. A third coder with knowledge of RA was available to settle disputes but was not needed.

Initially the identified Instagram posts were reviewed, and the data cleaned. I conducted this step, with my second coder, by removing non-English language and advertising posts. Advertising posts were posts that include services or goods offered for sale. The total number of advertising (*n* =284 images) and non-English language posts are noted (*n* =72 images). This strategy was consistent with methods described by Seltzer et al. (2017). It was more straightforward to identify advertising posts and non-English language posts to accomplish data cleansing with the full post including image, hashtag, likes and post origin. Full agreement was achieved by the two coders.

Advertising posts and non-English language posts were removed and a simple random sample of 10% were taken for each of the seven dates. Random.org, an online true random number generator was used to generate a string of random numbers equivalent to 10% for each of the seven sets of Instagram posts (Haahr, 2018). A sample codebook was created from 10% of the selected images to support development of a coding scheme. The coding scheme was developed by me and the second coder, using inductive and deductive processes (Elo, et al., 2014; Miles, Huberman, & Saldaña, 2020). The remaining images were compiled into a final codebook for review. The final codebook contained the Instagram images (*n* =106 images), date the image represents, and a space for recording of image type, subject (human or non-human), codes and notes.

Both coders reviewed the images individually and then met to discuss discrepancies. The final codes were compiled using Microsoft Excel (see Figure 3).

Data Analysis Plan

Content analysis of the selected Instagram images was conducted. While it was not feasible to validate findings with the image source, content analysis is considered acceptable for facilitating reasonable inference of image characteristics and qualitatively establishing patterns to interpret underlying meaning and the situations in which they become meaningful (Byrne, 2018; Neuendorf, 2017; Pink, 2012; Seltzer et al., 2017; Tiggemann & Zaccardo, 2016). A minimum of two coders with knowledge of RA (a health care professional and myself) and social media reviewed the images to add trustworthiness to the results. A third reviewer who also has knowledge of RA was available to review, however no discrepancies arose that required review by the third coder.

Seltzer et al. (2017) provided a coding approach that guides the methodology for iterative coding of Instagram images that was useful for my own research. After training, a codebook was created for use during the coding process (Byrne, 2018; Neuendorf, 2017; Seltzer et al., 2017; Tiggemann & Zaccardo, 2016). Inductive and deductive development was used to create the codebook (Elo, et al., 2014; Miles et al., 2020). Initially the coders, reviewed a 10% sample of the images selected. Words or phrases were recorded that were attributed to each image. The coded words were grouped into categories and reviewed by the two coders, any disagreements were negotiated with the coder group. A third coder was available to settle any disputes but was not used as

consensus was reached. Once the categories were finalized, they were developed into a final codebook. Sentiment was one of the categories, the codes positive, negative, and neutral are typically used to describe the continuum of sentiment expressed through images (Lipschultz, 2018; Seltzer et al., 2017). The finalized codebook was used to code the selected sample images (Lee et al., 2017; Neuendorf, 2017) (see Figure 3).

Use of a second coder who also had knowledge related to RA and social media, and analysis of intercoder reliability was important to ensure that the coders can use the coding scheme with similar results. Cohen's *kappa* scores and percent agreement were used to calculate inter-rater agreement between the two coders. Cohen's *kappa* is the agreement reliability coefficient used to account for occurrence of similar observations/results by chance. A Cohen's kappa of .60 - .80 indicates moderate agreement, with preference to .80, any score below.60 indicates disagreement between the coders (Lund Research, 2018; McHugh, 2012; Neuendorf, 2017) (see Figure 3).

Issues of Trustworthiness

Qualitative reliability is supported when the study procedures are consistent (Creswell, 2014). Several authors noted strategies used to improve the accuracy and trustworthiness of qualitative research studies. Creswell (2014), Lincoln and Gruba (1985), Merriam (1995), Ravitch and Carl (2016), and Stewart and Hitchcock (2016) all note the following strategies to enhance accuracy and trustworthiness; having more than one researcher analyzing data or having peers or colleagues review the data for agreement on the findings, member checking or having the members review the findings for accuracy, using different sources of information or triangulation, spending additional

time in the field with the data collection process to more fully understand the phenomenon of interest, having a personal awareness of the researchers own bias and making every effort to maintain an impartial perspective.

Shenton (2004) described four criteria for trustworthiness in qualitative research, credibility, transferability, dependability and confirmability. Credibility refers to the findings that are realistic to the participants and seeks to ensure that they accurately reflect the dialogue. Credibility is similar to internal validity (Shenton, 2004). Lincoln and Gruba (1985) noted that member checking supports credibility in qualitative research. In the case of this study, member checking is not feasible because the individuals posting images cannot be identified through the Instagram public search feature.

Transferability refers to the ability to apply the findings to a population, that is, are the findings generalizable (Shenton, 2004). The process and procedures employed in this study are described in sufficient detail to allow for replication by a second investigator. However, the timing of access and the uniqueness of the media and search strategies might make transferability difficult (Shenton, 2004). The reality that the data for this study was limited to one hashtag (#rheumatoidarthritis) and that the Instagram search algorithm is tailored to the specific user will also make it difficult to generalize beyond that group of Instagram users (Instagram, 2018e; Laestadius, 2017).

Dependability helps to ensure that the findings are consistent in the natural environment, that they are reliable (Shenton, 2004). Dependability would include the codebook of captured Instagram posts.

Confirmability refers to the investigator's objectivity. Confirmability was addressed by having multiple coders review the images to reach consensus and to identify categories. It may not be possible for the coder to review the images without imposing their own views of the meaning portrayed, this cannot be prevented, however much will still be gained by the analysis (Mead, 1975). As a result, it was important to ensure that the results arise from the data and solely not from the investigators perspective (Shenton, 2004; Stewart & Hitchcock, 2016). Additionally, Pauwell (2010) notes that the research could benefit from coders who have some level of knowledge of the content, this knowledge provides experience to support interpretation of the context of the images. To support confirmability two coders with knowledge related to RA and social media participated in coding/data interpretation. This approach can help to reduce threats to qualitative reliability (Shenton, 2004).

Ethical Procedures

Protections to ensure ethical adherence included receiving approval from the Walden University IRB prior to progressing to data collection (approval number 01-28-19-0756185). A consultation with the Walden IRB about the ethics of capturing social media images or posts using a social media site search tool for this research was done. I was advised that as long as I was only searching public databases and not accessing any private users' information, and as long as no user can be identified, then I should be able to collect social media data via the social media site search tool. There may be a possibility that someone has chosen to post their own personal user information and that might be collected via a public search. According to Moreno, Goniu, Moreno, and

Diekema (2013) human subjects, by federal regulations, are individuals that data are collected from either individually or through identifiable private information data sources. Because Instagram information, as proposed in this study, is public and the collection of the information does not require any communication with the individual who posted it then this project does not involve human subjects. This concurs with the recommendations provided from the Walden IRB. Data will be kept on a secure hard drive and deleted after 5 years.

Summary

The data collection strategy was a retrospective review of images posted on Instagram for #rheumatoidarthritis. The selected methodology, content analysis, utilized two coders to categorize and code the meaning represented by the selected images. The coders also reviewed the images to suggest the sentiment shared through the image. Cohen's *kappa* scores and percent agreement were used to calculate inter-rater agreement between the coders. Because of the limited sample, one hashtag, and the search algorithm used by Instagram, generalizability or transferability of results is limited (Instagram, 2018e). The use of two coders with some experience with RA and social media helps to ensure confirmability. Walden IRB approval was obtained before initiating this research project. The next chapter will describe the data analysis and research findings.

Chapter 4: Results

Introduction

My purpose in this study was to gain an understanding of the meaning of Instagram use for visual images related to #rheumatoidarthritis. The research question examined the meanings expressed through images shared on Instagram associated with #rheumatoidarthritis. This chapter begins with a discussion of the research setting. Data collection, analysis, and the evidence of trustworthiness are described. The chapter concludes with a discussion of the results and a summary.

Setting

The study was completed through a public search of the Instagram database for 7 specific days in the year 2018. The 7 days were the first days of the week of each season (winter, spring, summer, and fall) and a day of the week of special recognition related to RA (Rheumatoid Arthritis Day, Juvenile Arthritis Week, Rheumatoid Arthritis Week, and World Arthritis Day). Collecting social media data using a public search tool provided by the platform should not have resulted in access to any information marked as private by the individual who posted. There is the possibility that someone has chosen to post their own personal user information and that would have been collected as part of the public search. There were no changes in the search process that were detailed earlier in Chapter 3.

Demographics

Demographics for the images collected were not reviewed for this study. However, image types were reviewed. The final sample contained 106 images related to

#rheumatoidarthritis. Fifteen images were selfies (14.2%). Fifty-seven of the images were nonhuman (53.8%) and 49 images were of humans (46.2%).

Data Collection

All the Instagram posts, with the #rheumatoidarthritis for the year 2018 were downloaded and searched to find each of the 7 specific 24-hour periods. The images were organized by date, so it was simple to scroll through the dataset to find the images for the seven specific days. All images for each of the 7 days were collected by screen-capture and stored in password protected, labeled folders organized by day.

The total number of Instagram images for the #rheumatoidarthritis for the year 2018 was 237,464 images (Instagram, 2018a). The total number retrieved for the 7-day sample was 1,733 images. There was no change or variation in the data collection process from the plan presented in Chapter 3. No untoward circumstances were encountered during data collection.

Training the Data Coders

Coder training is generally recommended to reduce error that might be introduced from inconsistency between the coders (Bruley, 2014; Miles et al., 2020; Yuan, You, & Luo, 2015). The iterative nature of development of the codebook and the coding scheme required several sessions that included discussion of process and covered many of the elements typically discussed in coder training. Also, both coders viewed a presentation on sentiment analysis of images and discussed an article that presented examples of sentiment coding of the images (Bruley, 2014; Yuan et al., 2015).

Codebook Development

Once the identified Instagram images were retrieved. All non-English language and advertising posts were removed. The total number of advertising (*n* =284 images) and non-English language posts (*n* =72 images) were noted. This strategy was consistent with methods described by Seltzer et al. (2017). It was more straightforward to identify advertising posts and non-English language posts to accomplish data cleansing with the full post including image, hashtag, likes and post origin. The second coder participated in this process, and full agreement was achieved.

Once the advertising posts and non-English language posts were removed, there were 1,176 images. Random.org, an online true random number generator, was used to generate a string of random numbers equivalent to 10% for each of the seven sets of Instagram posts (Haahr, 2018; Seltzer et al., 2017). Each image represented by the identified random number was selected for inclusion in the sample (*n* = 118 images). A sample codebook was developed by taking a 10% sample of the 118 images (*n* =12). Inductive coding was the first step in creating the sample codebook coding scheme (list of codes) (Elo et al., 2014). Both coders worked together to develop the sample coding scheme and reach consensus. Deductive coding as described by Miles et al. (2020) was used to add additional codes to the sample coding scheme through a review of the current literature of studies describing their methodology for reviewing Instagram images (Byrne, 2018; Hu et al., 2014; Lee et al., 2017; Neuendorf, 2017; Pink, 2012; Seltzer et al., 2017; Tiggemann, & Zaccardo, 2016). Hu and colleagues (2014) described the unique challenges of coding images because of the detail and features that are richer than text

data. After repeated discussions, between the coders, consensus was reached, and unique codes were identified for each image in the sample codebook.

The final codebook contained the remaining 106 Instagram images. The codebook also included columns to record the date the image represented, the image type, subject (human or nonhuman), sentiment (positive, negative or neutral) the codes and notes. In addition to the final codebook, the sample codebook and coding scheme (list of codes) were available to provide guidance to the coders during coding. See Figure 4 for a flowchart of the sampling process.

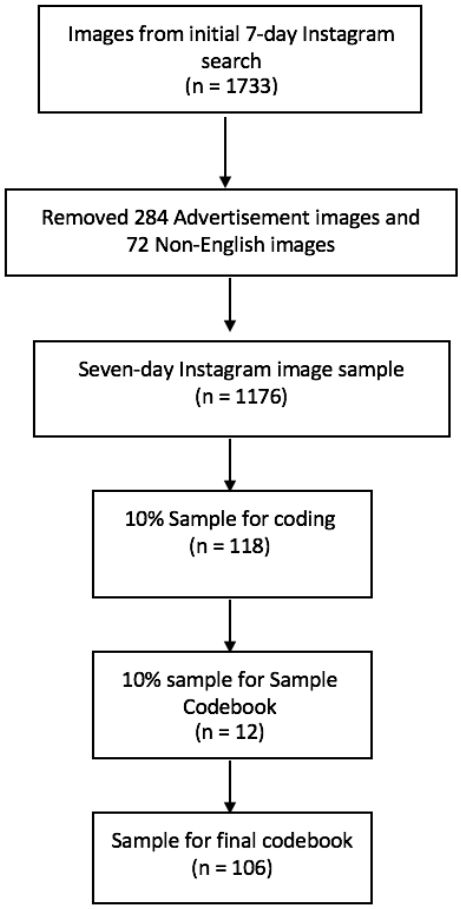

Figure 4. Flowchart of the sampling process. This flowchart illustrates the sampling methods for this study.

Coder Characteristics

Both coders were registered nurse practitioners, each with twenty plus years of experience in the care of chronic disease patients. Neither coder had worked in a setting that focused primarily on patients with rheumatological disorders. One coder is also a rheumatology patient while the other is not. Both coders have experience and are comfortable using social media platforms including Instagram.

Final Coding

All images were coded, there was no missing data. Using the final codebook and coding scheme, the coders independently coded the images (n =106). The coders then met to discuss any discrepancies in an effort to reach consensus. The final codes were compiled using Microsoft Excel.

Data Analysis

Coding Process

The two coders independently examined the images contained in the final codebook and recorded image type, subject type, the image codes and also their perception of the sentiment as positive, negative or neutral. the goal of coding was to identify the meaning the image represented to the coder. As discussed by Hu and colleagues (2014) we were not attempting to infer the motivation of the individual who posted the image. Once the coders had completed coding each image independently, we met to compare our image coding and sentiment coding results. We discussed any discrepancies and reached consensus on a number of images where we had coded

differently. We had a second meeting to review the codes again and to further discuss any discrepancies. We noted our rationale for any discrepancies and recorded the codes. While it was noted that we had a third coder available to support reaching consensus on the codes we did not use that individual. We believed that our coding differences were reflective of our own experiences with the disease and therefore were an interesting and unexpected finding.

Next, we reviewed each code and discussed possible categories. We met twice to discuss the categorization and were able to reach consensus on categorization for the codes. As described by Lee and colleagues (2017) the systematic process of iterative review to develop categories supports reaching consensus and reduces redundancy.

Intercoder Reliability

The coders agreed on coding for 96 images out of the total 106 images. The percent agreement was 90.57% indicating a high level of agreement on image coding. Cohen's k was run to determine if there was agreement between the two coders on whether the 106 images represented positive, negative, or neutral sentiment. There was a moderate level of agreement between the two coders, $k = .649$. The agreement was significant $p < .005$, 95% CI = 0.487 to 0.811. There was full consensus on the categories and placement of the codes into the categories.

Evidence of Trustworthiness

Credibility

Credibility refers to whether the findings are representative of the research participants and if they accurately characterize the participants meaning (Lincoln &

Gruba, 1985; Shenton, 2004). This study did not include member checking to verify the individuals intended meaning of the posted Instagram image. It was not feasible to conduct member checking; this is consistent with other cited studies that informed the methodology for this study (Hu et al., 2014; Lee et al., 2017; Neuendorf, 2017; Pink, 2012; Seltzer et al., 2017; Tiggemann & Zaccardo, 2016). The resulting codes were based on the coder's perceptions of the meaning of the images. Future studies might include member checking to understand the meaning from the perspective of the individual who posted the image to Instagram.

Transferability

The study methodology, data sampling and analysis procedures used for this study are described in sufficient detail to allow for replication (Elo et al., 2014). Representativeness of the data was by addressed by following Instagram image study methodologies described in recent literature (Hu et al., 2014; Lee et al., 2017; Neuendorf, 2017; Pink, 2012; Seltzer et al., 2017; Tiggemann & Zaccardo, 2016). The reality that the data for this study was limited to one hashtag (#rheumatoidarthritis) and that the Instagram search algorithm is tailored to the specific user makes it difficult to generalize beyond this one group of Instagram images (Instagram, 2018e; Laestadius, 2017).

Dependability

Dependability helps to ensure that the findings are consistent and reliable (Shenton, 2004). The systematic development of the codebook and the inductive and deductive development should have improved reliability by following a systematic process that was supported by the literature (Elo et al., 2014; Miles et al., 2020).

Confirmability

Confirmability refers to the investigator's objectivity. Confirmability was addressed by having a coder training session and having the coders first code independently then meet to discuss the findings in an effort to reach consensus. The coders did have a high degree of percent agreement (90.57%) regarding the codes. Full consensus was reached regarding the categories and assignment of codes to categories. Indicating that the categories likely represented the coded data.

Mead (1975) notes that although the coders may impose their own perspective on the images coded, much can still be gained from the analysis. Pauwell, (2010) also notes that visual image coding may benefit from the coders having some prior knowledge of the content. The coders were both health care professionals who also have experience with RA and social media platforms. Interestingly one has a rheumatology diagnosis, and one does not. The discrepancies in sentiment coding seem to be related to this difference and is a finding of this study. While there was moderate agreement between the two coders ($k = .649$), the coder with experience as a rheumatology patient labeled some images as positive while the coder without experience as a patient saw the same images as negative. The positive perspective was that important information was being shared to improve understanding about the disease, while the negative perspective was that the image highlighted the disease in a negative way. Figure 4 illustrates this difference.

Figure 5. Positive and negative codes. Provides representative images when there were discrepancies in sentiment coding. One coder perceived the sentiment of these images to be positive, and the other coder perceived them to be negative. One coder believed that this information made the disease sound worse, the other coder felt that the images would encourage awareness and understanding among those who do not have the disease.

Results

This chapter represents the final codes and categories developed to address the research question: What are the meanings expressed through images shared on Instagram associated with #rheumatoidarthritis? Sentiment analysis and image type are also described. Data are presented to support each finding.

Codes and **Categories**

The majority of images posted were representative of the category Social Interaction. Each category and the related percentage are shown in Figure 5. The codes represented in each category are further described.

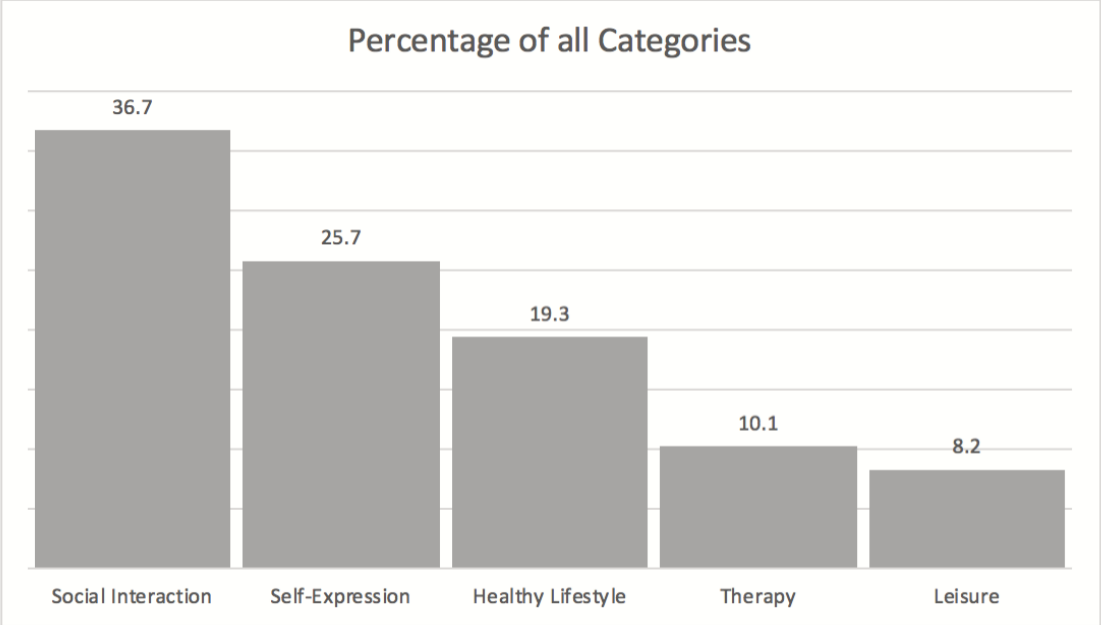

Figure 6. Summarizes the percentage of each data category related to the total for all categories. The majority of images were coded and categorized as representing Social Interaction (36.4%), followed by Self-Expression (26.4%), Healthy Lifestyle (19.1%), Therapy (10%) and Leisure (8.1%). These percentages are based on 109 codes and not 106 codes representing the 106 images. The additional three codes are a result of coder discrepancy.

Categories

Social Interaction. This category (n = 40) included seven image codes: awareness (30%), encouragement (25%), information sharing (20%), support seeking (10%), community support (8%), support sharing (5%), and information seeking (3%). The frequencies for these codes are represented in Figure 7.

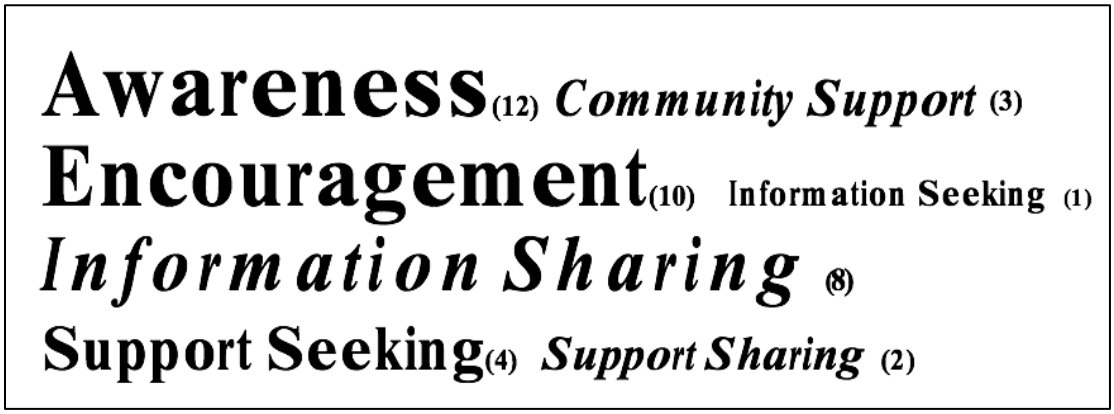

Figure 7. Social interaction codes. This figure represents the frequency of codes for the category social interaction as a word cloud with the frequency of each code noted beside the code.

Self-Expression. This category (*n* = 28) included eleven codes that were further sub-categorized as Positive or Negative. Positive Self-Expression codes included strength (14%), happy (14%), humor (14%), calm (7%), fun (7%), hopeful (4%), and optimistic (4%). Negative Self-Expression codes were frustrated (11%), tired, (7%), unhappy (4%), pain (4%), sad (4%), angry (4%), and apathy(4%). The frequencies for these codes are represented in Figure 8.

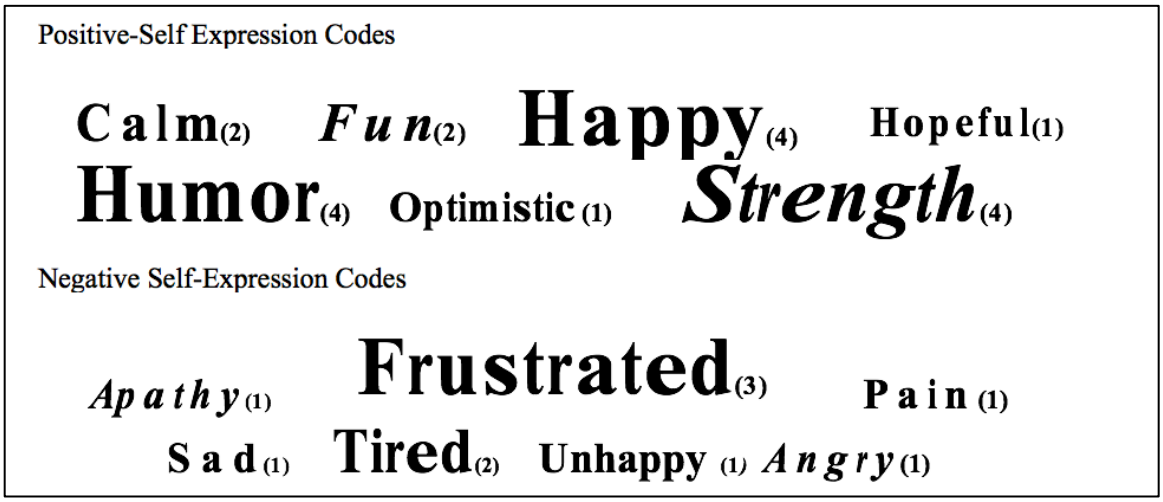

Figure 8. Self-Expression Codes. This figure represents the frequency of codes for the category Self-Expression as a word cloud with the frequency of each code noted beside the code. Codes that are Positive and Negative are grouped.

Healthy Lifestyle. This category (*n* = 21) included four codes: exercise (43%), healthy food (38%), weight loss (10%), and healthy drink (10%). This data is represented in Figure 9.

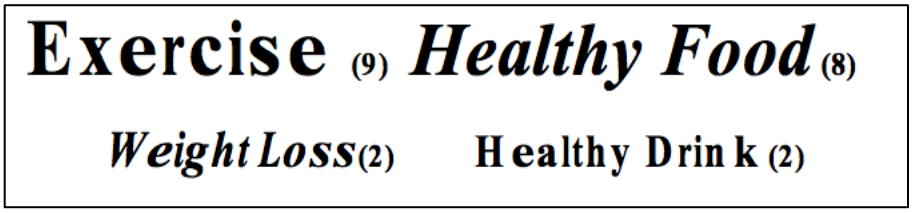

Figure 9. Healthy Lifestyle Codes. This figure represents the frequency of codes for the category Healthy Lifestyle as a word cloud with the frequency of each code noted beside the code.

Therapy. This category (*n* =11) included three codes: treatment (45%), devices (36%), and therapy animals (18%). This data is represented in Figure 10.

Figure 10. Therapy Codes. This figure represents the frequency of codes for the category Therapy as a word cloud with the frequency of each code noted beside the code.

Leisure. The final category (*n* = 9) had five codes including travel (33%), fashion (22%), family (11%), pets (11%), and holidays (11%). This data is represented in Figure 11.

Figure 11. Leisure Codes. This figure represents the frequency of codes for the category Leisure as a word cloud with the frequency of each code noted beside the code.

Images representative of all categories and codes are presented in Figure 12.

Figure 12. Representative Images. Provides representative images for each category. Images where humans were distinguishable were not included.

The images selected generally represented each category. It was decided not to include any distinguishable human images to provide privacy. Although all ethical

guidelines were followed in the development of this study, and each image was available via a public search. I wanted to protect the privacy of the images representing human figures. Prosser (2013) describes the principal of ethical reflexivity as the degree of honesty and truth in dealing with others. Visual research adds an element of ethical discord, and while I adhered to all ethical standards, I am still not comfortable sharing human images. I believe that there will be debate on this topic as research moves forward related to social media and privacy.

Sentiment

Image sentiment was coded independently as positive, neutral, or negative. The majority of the images (*n* = 75) were determined to have a positive sentiment by both coders (70%). Twelve images were considered to have a negative sentiment by both coders (24%), and 5 (6%) percent were determined to be neutral by both coders. The discrepant cases were primarily related to the negative sentiment codes. Coder 1 identified 12 negative sentiments while coder 2 identified 25 negative image sentiments.

Table 1

Coder Image Sentiment

Count

		Coder 2			
		Positive	Negative	Neutral	Total
Coder 1	Positive	75	13	1	89
	Negative	0	12	0	12
	Neutral	0	0	5	5
Total		75	25	6	106

Cohen's k demonstrated a moderate level agreement between the two coders, k = .649. The agreement was significant p < .005, 95% CI = 0.487 to 0.811.

Image Type

The majority of the images were photos (*n* = 68) that finding is consistent with the image-rich digital nature of this social media platform (Leonard, 2018; Pajaczkowska, 2016). Twenty-two images were text with graphics (4 of those were information sharing). Three images were cartoons. Thirteen images were posters supporting one of the days of special recognition (Rheumatoid Arthritis Day (*n* = 9) and World Arthritis Day (*n* = 4). Four posters were also information sharing. The information shared on all images where information seemed to be the primary reason for the image (*n* = 8) appeared to have accurate information. Figure 7 represents the different image types.

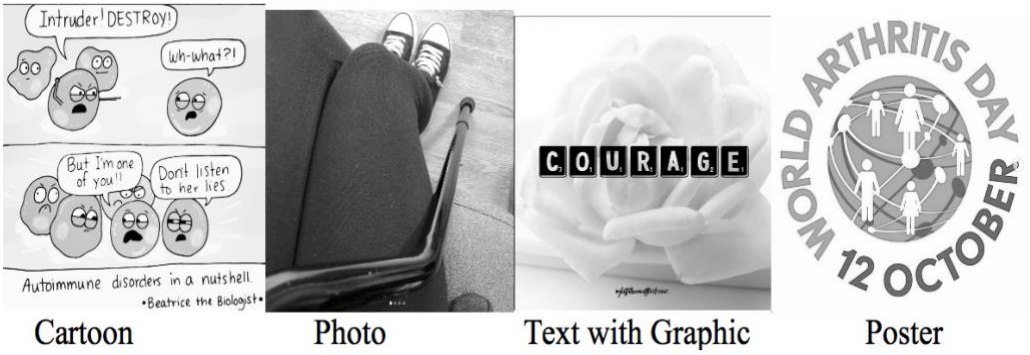

Figure 13. Representative Image Types. Provides representative examples of the different image types. Images where humans were distinguishable were not included.

Summary

In summary, Instagram is used by individuals primarily to share images that relate to social information and self-expression. The two coders were able to reach a moderate and significant level of agreement on the meaning of the identified images. The nature of the discrepancies seemed to be related to the coder's experiences with the disease. Full

consensus was reached regarding the categories and assignment of codes to categories. Indicating that the categories likely represented the coded data.

The current literature guided the design of the study methodology, the methodology was suitable and provided insights to answer the research question. The final chapter will provide an interpretation of the findings, study limitations, implications, and recommendations for future studies.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

My purpose in this qualitative study was to describe the meaning of Instagram posts related to #rheumatoidarthritis. Images, related to the hashtag, were collected for 7 days during 2018. Coder training was completed, a codebook was developed, and the images were analyzed by two coders using inductive and deductive analysis (Elo et al., 2014; Miles et al., 2020). The images identified the meaning of the Instagram images as primarily related to social interaction and self-expression which is consistent with the literature regarding the purpose of using the Instagram social media platform (Avery & Park, 2018; Bowden et al., 2016; Leonard, 2018; Pajaczkowska, 2016; Tsai & Men, 2018). This research may inform future research as well as those who wish to share health information with individuals using social media, particularly Instagram.

Interpretation of the Findings

Findings in the Context of Current Literature

This study had four key findings. First, the majority of the posts were categorized as representative of the meaning of social interaction and self-expression. These findings

suggest that individuals use Instagram primarily for sharing awareness, sharing encouragement and self-expression regarding RA. This finding is consistent with the use of Instagram for social networking and self-promotion noted in the literature (Hu et al., 2014).

Second, both coders found most images represented positive sentiment. Boczkowski et al., (2018) and deVries, Möller, Wieringa, Eigenraam, and Hamelink, (2017) shared similar findings that on Instagram individuals tend to present positive perspectives.

Third, only four images shared information, information sharing was not the primary focus but, when information was shared, it was accurate. This is consistent with findings by Seltzer and colleagues (2017).

Fourth, the majority of images were posted by individuals and not organizations or groups. Tiggemann and Zaccardo (2016) pointed out that Instagram and other social media posts are posted most often by individuals and not by commercial interests. That was the case with the images in this dataset. There were only four organizations that included a link to their website on the images posted.

Although not a key finding, there are large numbers of images shared on Instagram related to the #rheumatoidarthritis (N = 237,464 in 2018), and there is no research currently published to understand what it might mean for sharing health messages and support for individuals living with RA.

Findings in the Context of Rogers's Theory

Each type of social media has distinctive characteristics that may influence the rate of innovation adoption (Archibald & Clark, 2014). Motivation to use the media comes from an individual's perception of their need. Information needs to support the interest of individuals to use social media platforms like Instagram (Tsai & Men, 2018). Interest and use of innovations as a source of information and support are directly related to Rogers's (2003) diffusion of innovation first phase of communication, knowledge.

The findings from this study indicate that self-expression was the primary meaning for the images posted, that finding is well-related to Rogers's (2003) model, which incorporates personal characteristics, personality variables, and communication interests in knowledge communication. Tailoring as described by Archibald and Clark (2014) is also reflected in the findings related to self-expression, individual preferences related to tailoring and the concept of compatibility are aspects of innovation that meet the needs of those who seek to adopt new technologies.

Further, the introduction of new ideas in novel ways, such as Instagram, can provide a communication platform for individuals who may be limited by health or social circumstances from interacting with others in a face-to-face environment (Sundstrom, 2016). These new avenues for social support and information sharing could potentially improve relationships with health care providers and improve health care decision making (Seltzer et al., 2017). Although these may be future goals, they are consistent with the use of social media to develop communication and support knowledge sharing in the context of Rogers's model (2003).

Limitations of the Study

The sample consisted of 106 images from 7 particular days of the year. It was a 10% random sample which was supported by other social media studies but seems small in the context of 237,464 total Instagram image posts for the #rheumatoidarthritis for the year 2018. There could also be a sampling bias related to the days selected. Next, we only reviewed images for the final codebook; it may have provided additional insights to support coding if we had used the entire post including the associated text, comments, and likes (Perloff, 2014).

Without member checking there is no way to verify the intended meaning of the image posted by the individual. The study methodology did not provide a way to validate a person's experience with the disease RA. Demographics including age and gender, are not available on Instagram. Also, private posts were not included and could have had different characteristics.

We used visual coding which includes the factor of human interpretation. We tried to control for human interpretation variation by independently coding first and then having discussions in an effort to compromise on any discrepancies. The methodology of coding allowed for human variation and identified an interesting finding that the lived experience of having a rheumatological disease impacted how one coder saw meaning in the images. This personal perspective can be seen as a limitation, but it is also consistent with Rogers's model (2003) and the description of visual ethnography and the value of prior knowledge to interpretation described by Mead (1975) and Pauwell (2010).

Recommendations

Interpreting the findings of this study provides the groundwork for future studies and raises additional questions. Future research should focus on how use Instagram and other social media platforms can be used to engage individuals and maximize effective health message dispersion (Seltzer et al., 2017). Online communities help to improve health outcomes through information and support sharing, this study demonstrated that Instagram has a large number of individuals sharing images related to the #rheumatoidarthritis. Examining the motivation of individuals to post on Instagram and also the accessibility of Instagram to the audience of individuals with RA is needed. In addition, examining the topic RA across different social media platforms could provide information regarding how the message sentiment and content may change with different social media platform features.

Understanding how social media platforms meet an individual's needs can help developers identify key characteristics of the platform that should be included as design elements to support that individuals ongoing use of the social media platform. Future studies should address the individual characteristics (gender and age) of users across different social media platform and the unique characteristics of different social media platforms that meet the needs of a diverse social media audience. In addition, the complete post including likes and additional hashtags should be included to support understanding of the image.

To address these recommendations, the next steps would be to interview Instagram users to collect demographic information to and ask the following questions;

How do you use Instagram? Why do you use Instagram? Do you have concerns about overuse and privacy? Which social media platforms do you use, and do you post different types of things on different types of social media? Do you use social media to address information needs, facts, advice, social support or practical information? When you take a picture to post on Instagram, do you consider the setting or background of the images? Do you edit images before you post them on Instagram? How is Instagram different from other types of social media? Do you believe the health information that you see on Instagram?

Images contain complex ideas, studies note that people retain 30% of what they see and 10% of what they read (Avery & Park, 2018; Bowden, Sheehan, & Foureur, 2016). Colors, background and other image features also drive how individuals perceive the message from an image (Leonard, 2018; Pajaczkowska, 2016). In addition, the number of 'likes' an image receives reflects the level of engagement with the image by other Instagram users (Seltzer et al., 2017). Future studies should measure the image types by the number of likes received, and the colors and backgrounds used, to have a better understanding for how to best design health messages for health care providers who create and disseminate health information using Instagram.

Further, in a study by Pittman and Reich (2016), health care consumer's use of Instagram caused increased happiness and improved satisfaction with life when compared with health care consumers who use text-based media alone. If Instagram truly supports a positive image, then how will negative images impact the user? Boczkowski et al., (2018) and deVries et al., (2017) noted that Instagram might cause depression if the viewers feel

that their situation is not as positive as the other images posted. They suggest that more studies are needed to determine how Instagram impacts users (deVries et al., 2017). Future studies need to better understand the social and emotional impact of Instagram and other social media platforms on the user's emotions and their health.

Finally, social media provides a unique window into individuals lives. Current ethical frameworks that consider public social media messages as public data for research may change over time as more research examine how people express meaning related to their own health.

Implications

Positive Social Change

Instagram is the fastest growing social media application (Smith, & Anderson, 2018). As such, it offers a novel way to share health information with potentially disparate groups of individuals. RA is a pervasive disease with economic and social impacts that often leave the individual with some form of disability (CDC, 2018). Individuals impacted by RA describe the need for high-quality, accurate information and they report using eHealth technologies to help meet these needs (Mathijssen et al., 2018).

Instagram decreases social isolation and improves life satisfaction (Pittman & Reich, 2016; Casaló et al., 2016). Images are a powerful way to share messages and images are the primary messaging feature of Instagram (Avery & Park, 2018; Bowden et al., 2016). Further, Instagram can be used to understand public sentiment about a topic and to support public health message programming (Seltzer et al., 2017).

This study identified that individuals use Instagram to post images with the #rheumatoidarthritis and that their primary use of Instagram is for social interaction and self-expression. What we do not know is who these individuals are and why they choose to use Instagram in this way. Also, do individual with RA use Instagram with other social media platforms or is Instagram their primary social media platform? There is a clear need for more studies regarding how people use Instagram for health messages and how to best share information regarding RA on Instagram.

The implications for social change come from the information this study provides to those who are sharing health information on Instagram and how the unique visual nature of Instagram may be used to reach out to those in need. The uniqueness of Instagram as a visual media likely provides a powerful way to communicate health messages. If health messages are focused to meet the needs of individuals with RA, then the impact of this disease in terms of the individual should improve and support positive social change.

Methodological Recommendations

Current studies related to Instagram use in health care address research methodologies related to use of Instagram data. (Highfield & Leaver, 2014; Kim et al., 2018; Lee et al., 2017; Pila et al., 2017; Salzmann-Erikson & Eriksson, 2018). The methodology used for this study was modeled after the literature and provided an appropriate approach to address the stated research question. I believe using a second coder supported the quality of the findings and that it was important for the coders to have some knowledge both of RA and social media.

The use of images is a powerful visual tool. Facial expressions help to establish the sentiment the image portrays (Yuan et al., 2015). Sharing those images, including the facial expression as part of the results of a study may strengthen the conclusion. The decision was made not to share distinguishable human images, however, if the reader only sees blurred or blocked images, or no images at all, how can they fully understand the findings of a study? Future research needs to examine the best approaches for sharing visual data that results from social media healthcare research.

The challenge for future studies is also to collect the meanings intended by those who posted them. Tiggemann and Zaccardo (2016) point out that content analysis of Instagram images cannot predict the effect of the image on those viewing them. Further, deVries and colleagues (2017) note that it is important to gain an improved understanding of the impact of Instagram messages on viewers. While the current methodology addressed the current research question, future studies will likely include interview or surveys with users to further expand the understanding of the meaning these messages have for the user.

Conclusion

The literature on the topic of RA and social media is limited although the use of Instagram related to this hashtag is considerable. The findings of this study raise new questions but do provide insights into meanings of images shared by users on Instagram regarding the #rheumatoidarthritis. The findings indicate that individuals use Instagram for the purpose it was intended, to share images related to social interaction and self-expression. The findings support the possibility of Instagram as a health communication

tool. Images are better able than text to produce an emotional response to a message providing new ways to meet the needs of diverse audiences. The preponderance of images posted included content in five categories (social interaction, self-expression, healthy lifestyle, therapy, and leisure) related to awareness, encouragement, and self-expression providing evidence for the potential of Instagram as a way to share support interventions and educational messaging. This study reveals new insights about how individuals create, and share information related to #rheumatoidarthritis on Instagram. This study also raises new questions regarding how Instagram and other social media platforms might best be used by those isolated by the impact of disabilities and fatigue.

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