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Case Study of Learning and Instruction for Members of an Online Reflex Sympathetic Dystrophy Support Group

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This is to certify that the doctoral dissertation by

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Abstract

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by

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MA, California State University, Los Angeles, 2010

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Dissertation Submitted in Partial Fulfillment

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Abstract

Research has shown that individual members of traditional support groups gain a sense of identity and community and feelings of respect and support. Online support groups provide individuals avenues to find medical information and thus learn more about a given condition or illness. Little has been studied about the learning and instruction that occurs in online social support groups, especially in groups about chronic pain. The purpose of this qualitative case study was to explore the perceptions and experiences of members who participated in one open social support group. Siemen's constructivism theory served as the basis for comprehending the learning and instruction that took place in this group, and the research questions focused on the support group members' perceptions of this learning and instruction. Data were collected from 10 individuals who participated in a Facebook Reflex Sympathetic Dystrophy support group. Yin's case study framework provided additional support data analysis. Data were collected through individual, semistructured telephone interviews and observations of online discussions. A combination of open and axial coding was used to support content analysis. Themes identified were learning, knowledge, persuasion, and acceptance of underlying negativity. Online social support group participation involved shared experiences that facilitated learning and instruction; these findings could influence the structures of other support groups. Positive social change occurs when individuals are knowledgeable and well educated about social support groups because it is in these groups that trends, issues, and new information are learned. Informal learning occurs with the increased digital skills, especially within a person's virtual support networks.

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Dedication

To my guardian angel, Evelyn Marie Griswald. Also to my parents, my best buddy Ron Gilmore, and my beautiful mom Iris Gilmore, who have eternally provided the bravery, dedication, support, tough-love, guidance, fun, laughter, support, and unconditional love that has allowed me to continue my life's passion that encompasses personal and professional growth and zest for learning and knowledge over the last 4 years

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Chapter 1: Introduction to the Study

In a multifaceted, rapidly changing world where information is readily available to everyone with digital access, social networking permits individuals to share knowledge and interact with dynamic substance. The evolution and attractiveness of online communication has formed an innovative world of collaboration and interaction (Cheung, Chiu, & Lee, 2011) where more than a billion individuals are linked to construct, collaborate, and provide their knowledge and understanding (Hu, Bell, Kravitz, & Orrange, 2012). Korda and Itani (2013) have noted that there has been a rapid and innovative development in participative Internet communications, also known as social media. Many social media platforms permit handlers to participate anonymously. Persons of all demographics are embracing these tools and interactions using their computers or mobile devices. Many online social networks function as learning networks (LNs) that maintain informal learning. In most LNs, learners construct their own knowledge through information sharing with others (Hsiao, Brouns, Kester, & Sloep, 2013).

Facebook is among the most visited social networking sites (SNSs) on the World Wide Web (Web). The integration of social networking in the United States has been a phenomenon for approximately 10 years (*Facebook*, 2013), and Facebook and other social networking sites present diverse opportunities for their users. Despite the increased academic interest in Facebook and other social media (Rambe, 2012), there is limited understanding of virtual support groups and the learning that occurs in them.

Learners are satisfying their own needs by developing and adapting nonformal learning styles. Social media educational settings are better equipped than traditional learning environments to accommodate for personalized learning goals. Nonformal learning can be described as purposeful learning grounded in personal learning goals outside of recognized educational channels (Hsiao, Brouns, Kester, & Sloep, 2013). In online social networks, individuals gain knowledge through collaboration, constructing their own knowledge by interacting with peers (Kester, Van Rosmalen, Sloep, Brouns, Kone, & Koper, 2007). Motivations for joining an online support group vary with the type of group (generic or thematic) in which an individual participates. For instance, if people join a generic group, sharing ideas and being active are far less important, whereas if they belong to a thematic group, they feel less alone and their behavior tends to be proactive. Topics and the type of content shared in the group are distributed equally across these group types. However, the expression of mood and the sharing personal experiences occurs more often in thematic groups (Ranieri, Manca, & Fini, 2012). While research is attempting to understand how people are learning through social networking sites and different uses of technologies (e.g. mobile phones), health education has been widely overlooked (Pimmer, Linxen, & Grohniel, 2012).

The information overload created by social media tools has changed the way learners learn and from whom (Sie et al., 2013). Because of the increasing number of online support groups (OSGs), individuals with both acute and chronic illnesses are using these as motivators for social interaction, venues in which to make one-to-one connections, and sources for information (Chung, 2014).

Every year, more and more individuals diagnosed with disorders and illnesses are searching online for information about their diagnoses (McGuire, Daly, & Smyth, 2010).

Traditional support groups have offered participants support for thematic, generally troublesome (drug and/or alcohol abuse) behaviors or characteristics (Seymour-Smith, 2013). Individuals who are searching for online support groups often have a difficult time because they cannot find the practical knowledge, information sharing, and interpretation of information they are looking for in online support groups (Grohl & Wensing, 2004). Online support groups have not reached their full potential because of several factors including inadequate development, lack of audience involvement, lack of appropriate groups, user-friendliness issues, privacy issues, and group quality (Potts, 2005, & Gendron, Pelco, Pryor, Barsness, & Seward, 2013). Caregivers seeking knowledge and collective help often regard online support services as key tools, but continue to be unsure if online support groups supplement or replace traditional support groups (Lai et al., 2012). The exchange of advice about health is correlated with confidence, knowledge, and admission. Advice exchange happens in virtual groups, but some physicians have questioned the helpfulness of online peer support because the accuracy of knowledge and advice offered on the Web is not regulated and could be inadequate or incorrect (Sillence, 2013). Additionally, the exchange process online has received little critical attention (Kazanjian, Smillie, & Stephen, 2013).

This study explored the learning and instruction that occurs among individuals who participate in a virtual Reflex Sympathetic Dystrophy (RSD) support group using Facebook. I observed the individuals using a Facebook social networking group in which the participants were already active and which they used to educate, learn, network, and collaborate with one another to build a community through their experiences of sharing the same illness. Research on medical education social networking has generally focused on the devices, tools, and technology available for doctors (Jain, 2009). There has been minimal empirical research on web-based, virtual support groups and their contribution to pedagogy. This study of learning and instruction in online social networking support groups fills the gap in research regarding patient education through online support groups, and supplements the relatively little theory-driven empirical research available that addresses this new type of communication and interaction phenomena. Although people are using social media for health-related issues, social media have considerable potential as tools for health promotion and education. These media, like traditional health promotion media, require careful application and may not always achieve their desired outcomes. Understanding online patient support groups has implications for social change because more individuals are looking for information virtually (Barak, Boniel-Nissim, & Suler, 2008). Due to the social change of finding information virtually, potential changes of improved communication, treatment plans, information-sharing, and further understanding between individuals with a chronic illness and their healthcare provider can occur.

In this chapter, I provide a background for the research, the problem statement, and the purpose of the study. I operationalize the learning and instruction of members' views in virtual support groups, present the research questions, and explain how Siemens's (2005) theory of connectivism provided a framework to understand the research. In Chapter 2, I elaborate on this conceptual framework.

Background

Individuals are increasingly using the Web for health information (Fox & Jones, 2009) rather than relying solely on the information given by their health care provider (Elkin, 2010). As a result, individuals are using social networking to share medical knowledge and to provide and receive support (Hawn, 2009). Several disease-specific information groups now exist on Facebook and other online social networking sites such as Instagram and Twitter. Using these tools and websites, participants share knowledge, support, and engagement. Miller (2006) has suggested that more research should be conducted in virtual support groups, especially disease-specific groups. Very little research has focused on virtual support groups, and even less has focused on the instruction and learning that occurs within these groups.

Prior research has illustrated elements that influence learning in Web-based patient support groups. Elkin (2010) examined social networks and found that they hold considerable potential value for health care professionals looking to reach patients and to collaborate with other medical professionals. Fox and Jones (2009) have noted that Americans increasingly pursue their healthcare information through social networking sites. They no longer call a healthcare professional or talk to friends face-to-face, but rather read blogs, update their social networking profiles, and post comments online. Moreover, Greene, Choudhry, Kilabuk, and Shrank (2010) conducted a study about how family and friends who use Facebook to share personal and clinical information regarding patients with diabetes. The authors also examined how patients use Facebook as an educational and social support tool. Their findings suggested that if people with diabetes, family, and friends share personal information, that each person is able to gain substantial disease-specific feedback, and receive emotional support. Hawn (2009) also suggested that primary care practices are using Web-based media, social media, and support groups as tools for doctors and patients to communicate with each other because of their cost effectiveness.

Noting the need for virtual support groups to be integrated with patients' care, researchers have suggested that there is no single approach to education likely to suit all people newly diagnosed with an illness (Greene et al., 2010) and have found that individual orientations and preferences play a large role in education and self-management (Ockleford, Shaw, Willars, & Dixon-Woods, 2008). As far back as 2002, social support was beginning to occur via computer-mediated communication (CMC). This was especially true for big groups where individuals who did not know one another or communicate conventionally used this method to obtain support from others who have common interests (Walther & Boyd, 2002). In their discussions on virtual social support, Scheerhorn, Warisse, and McNeilis (1995) and Harris (1996) both suggested that providing emotional and educational assistance should be specific reasons of offering peer-to-peer support that is medically related. Given that these studies were conducted in the mid-90s, they provide evidence that a study such as mine has been needed for a long time. Taken together, these studies show that interactions, educational material, and social support foster integration of virtual support groups in an individual's method of understanding his or her specific disease. However, more research needs to be conducted to determine if virtual support groups foster the same understanding as that fostered by traditional forms of support.

In their attempts to understand virtual support groups, researchers have found that traditional support groups are adopting new processes of social support originating in virtual communities (Caines, 2010). However, little research exists concerning the learning and education that is occurring in virtual support groups (Ruiz, Qadri, Nader, & Wang, 2010). Thus, my study explored learning and instruction within these groups. Additionally, it is important to understand the perceptions of individuals with the illness, caretakers, and medical professionals who use virtual support groups. The results of this study provided a description of the connectivism occurring in social networking settings. Given the lack of empirical research on learning and instruction in virtual support groups, the results of this study demonstrate more information on the social phenomenon of virtual support groups, indicate potential avenues for social change, and point to the need for further research on learning and instruction in online virtual support group communities.

Problem Statement

When collecting knowledge about health disorders or management, people are increasingly looking to the Web for data (Fox & Jones, 2009). Elkin (2010) suggested that people search the Web more often than they communicate with their physicians about their health care needs. Individuals with an illness also seek to meet and network with others whose experiences parallel their own in order to share clinical information and to provide and receive support (Hawn, 2009). This type of online social support offers people opportunities to benefit from a social network by learning about their illnesses and connecting with others in similar situations. Greene, Choudhry, Lilabuk, and Shrank (2010) indicated that support groups allow individuals to develop a significant awareness about themselves. In simpler terms, patients learn more about themselves and their identity in a virtual support group because they are connecting with others who are similar to them (Chung, 2014).

With over 1.2 billion registered users worldwide, Facebook is one example of a virtual meeting tool for social support groups. According to Greene, Choudhry, Lilabuk, and Shrank (2010) various disease-specific groups have emerged on Facebook, providing information, support, and engagement for patients with chronic diseases. However, little research to date has investigated the knowledge that patients gain or request, information that is provided, or the type of health-oriented virtual communities that gather on Facebook. Social networking on sites such as Facebook is another resource for patients with chronic illnesses because it allows patients to feel comfortable within a safe environment that provides a common understanding of shared experiences (Ockleford, Shaw, Willars, & Dixon, 2008). Chopra (2013) has stated, “Patients with RSD have an especially difficult time learning about their diagnosis” (personal communication, April 11, 2013). According to Rambe, “meaningful engagement” and “different perspectives” (2012, p. 132) are possible factors that contribute to this problem. As social networking is continuing to grow, established social support groups are a critical part of creating virtual social support environments (Rambe, 2012). In this study, I analyzed the involvement of people with RSD who were members in one RSD Facebook support group.

Purpose of the Study

The purpose of this qualitative case study was to explore the perceptions and experiences of members who participate in one open (public) Facebook social support group called RSD/CRPS Fighting Warriors. My study focused on the learning and instruction that occurred in this group. I anticipated that this study would shed light on how best to provide learning and instruction to individuals with RSD and other forms of chronic pain in a social networking support group.

This study filled a gap in current research by exploring support group participants' perceptions of their learning and instruction in virtual support groups. The original findings of this study identified the quality and value of learning and instruction that is happening in Facebook social support groups.

Research Question

The following questions formed the basis of this qualitative inquiry.

1. How does social networking enable learning in an online support group?
2. How does social networking enable instruction in an online support group?
3. What are the perceptions of the RSD participants regarding learning and instruction in online social networking?

Conceptual Framework

I used Siemens' theory of connectivism as the conceptual framework for this study. Siemens' (2004) theory of connectivism builds upon the argument that practical education involves applying the tools and technologies of the digital age in the classroom and in life. Connectivism, Arteaga (2012) notes, “is defined as learning that leads to actionable knowledge that can reside outside of learners within an organization or database” (p. 12). It is learning that connects particular information to the learner’s present needs and state of knowing (Siemens, 2004).

Because of evolving 21st century skills, Siemens (2005) argued that the digital age demands a reorientation of knowledge, knowledge construction, the practice of knowledge, and the type of learning. Siemens (2006) has also emphasized that information is not stagnant and within Internet-enhanced actions, “the ability to work with others opens doors for innovation and rapid development of ideas and concepts” (p. 6). The current digital period allows for innovative learning to emerge. However, Siemens’ (2005) maintains the need to develop learning standards. Connectivist learning is recurring, related, and intensified by a connective individual or digital social networks. Individuals connect knowledge and learning through networks, and use that information for themselves, the organization, and the public to facilitate intellectual expansion. Connectivism was helpful as I interpreted research question results because people with RSD, caregivers, and medical professionals exchange, network, search, imitate, and disclose their learning through discourse and international collaboration. In Chapter 2, I offer a comprehensive exploration of the connectivist conceptual framework.

Nature of the Study

My intention for this research study was to capture members who have RSD, caregivers’, and medical professionals’ perceptions of virtual support group cultures and how they affect their learning satisfaction. I conducted a qualitative study to answer the research questions that pertain to learning and instruction in online support groups. Qualitative research enabled me to interact with the participants in a natural setting, to acquire a steadiness around the human being or setting, and to be deeply associated with real occurrences of the participants (Maxwell, 2013). Merriam (2002) has defined the case study approach as an "intensive description of analysis of a phenomenon or social unit. The case is a bounded, integrated system. By concentrating upon a single phenomenon or entity (case), this approach seeks to describe the phenomenon in-depth" (p. 8). I used the qualitative method for this interpretive study because it was appropriate for comprehending how the participants made sense of their experiences, circumstances, or the atmosphere in which they associate. Furthermore, this method allowed me to serve as a research device, and use an inductive approach to describe my findings.

In this qualitative case study, I was interested in the perceptions of participants who use social networking support groups. More specifically, because patient information sharing is extremely sensitive and private, this study emphasized patient education, patient knowledge, and overall patient learning and instruction. The participants were asked to complete a one-hour interview with questions regarding their perceptions of what they were learning and teaching in the Facebook group. Additionally, I used observation analysis of the Facebook group. I used these methods in attempt to understand the members with RSD, caregivers, and medical staff's perceptions of virtual support groups and their senses of what they are learning and teaching.

Definitions

Support Group: face-to-face groups that provide members with various types of help, usually regarding particular shared characteristics. Members typically have the same issues and they come together for information sharing, which allows for a sense of community and belonging (Franks, Cronan, & Oliver, 2004).

Online or Virtual Support Group: people from all over the world can connect and relate with one another. There are many opportunities for interactions at the sites to which individuals may belong. Virtual support groups are a powerful relational medium that provide access to various kinds of online information and interactive groups (Haberstroh & Moyer, 2011).

Specialized Online Support Groups: some groups are age- and/or gender-specific, or focus on specific needs or characteristics (Juneau & Remolino, 2000).

Social Support: refers to discourse between individuals seeking to gather information to decrease ambiguity in their situations and to develop individual control of one's knowledge. It includes observations of interpersonal acknowledgement, understanding, and request to give and receive help (Finn & Kerman, 2004).

Online Social Networking (OSN): a service that provides a platform to build social networks or social relations among people who share interests, activities, backgrounds, or real-life connections (Raju, Valsaraj, & Noronha, 2014, p. 289).

Reflex Sympathetic Dystrophy (RSD): Reflex Sympathetic Dystrophy Association (RSDSA) defines RSD as a chronic neurological pain disease characterized by severe burning pain, pathological changes in the bone and skin, excessive sweating, edema, extreme sensitivity to touch, and severe chronic pain such as sharp, dull, throbbing, achy, mild, and burning (2014, April 20).

Assumptions

Qualitative inquiry assumes that "reality is socially constructed primarily through an insider's point of view (Glesne & Peshkin, 2007, as cited in Abraham-Shea, p. 16). For this study, I made the following assumptions:

1. Participants shared honest examples/stories, of self-experiences.
2. My views were kept out of the experiences and interpretations.
3. I objectively captured perceptions through research texts, photographs, documents, and observations of the support group.

Scope and Delimitations

There has been a lack of empirical research on the learning and instruction that occurs in virtual support groups. In my study, I explored how people with RSD, caregivers, and medical professionals use social media to understand what they are learning and how instruction is taking place in a social media network support group. The scope was limited to individuals with RSD who are active participants in one Facebook open support group. Their geographical location was not a boundary. To fit the study's criteria, participants were required to be active members of the open Facebook group focused specifically on members with RSD. I chose to undertake this study in order to fill a gap in the research.

The population of interest was delimited to people with RSD, caregivers, and medical professionals. The most salient delimitation was to explore the perceptions of members who are a part of an online RSD support group via Facebook. The theory of connectivism, in that RSD members share information through their networks. The veteran members who have lived with and cared for (not all) of the theories' later understanding more or less by experiences the similar issues, questions, concerns, and problems and then in return being able to instruct newly diagnosed people with RSD, caregivers, and medical professionals. Quantitate and mixed-methods study methods were considered but rejected because they did not allow an in-depth examination of the perceptions of participants. A more detailed discussion of the study's methodology is found in Chapter 3.

The questions for this case study interview were created and structured with a particular group of people in an online support group by exploring their perceptions about learning and instruction. Therefore, the potential for transferability is low. RSD/CRPS Fighting Warriors support group assists people with RSD, caregivers, and medical professionals. This study targeted active members of 3 months or more who were a part of an open Facebook RSD support group. This is critical because members often share very personal information or images. Since this information and pictures are shared in the public forum, there may be seen as distasteful or offensive and reported to Facebook administrators.

Lastly, the advice, information-sharing, upcoming events, and answers to questions in the open RSD support group are mainly given by the experienced veteran person with RSD. Although they might not have medical or mental health qualifications, they share their experiences and advice but strongly recommend that newly diagnosed people with RSD, caregivers, and medical professionals follow up with their medical providers as soon as possible.

Limitations

My study had some limitations because I observed only one open RSD Facebook support group. Thus, my findings are particular to this Facebook group and its active participants. I conducted the study during a 2-week period in 2015. The participants included members with RSD, caregivers, and medical professionals who were active participants in the Facebook support group. Participants may have had a bias based on expectations of what I wanted to hear, and thus may not have honestly shared their honest perceptions of the learning and instruction taking place in the Facebook group. They also brought other biases from other support groups that they were participating in concurrently. In my communication with participants, I worked to keep them focused on this one particular Facebook support group. This study was further limited by the fact that I am a single researcher with RSD and many people with RSD, caregivers, and medical professionals know who I am in the RSD community. Furthermore, I selected this Facebook group because it is open to the public. I chose an open group rather than a closed group that could have taken more time for IRB approval and research logistics

My biases were a small limitation or potential weakness of this qualitative case study. It was likely that personal views, beliefs, and familiarities might sway the interviews and Facebook status updates analysis by means of “the characteristics of the interviewer, the characteristics of the respondent, and the substantive content of the questions” (Briggs & Coleman, 2007, p. 98). In order to stay objective during the data collection process and to help me remain focused and reduce bias, I did not interview any participant I knew personally. I also kept a reflexive journal during the data collection and analysis phase of the study. In the reflexive journal, I recorded my experiences, beliefs, judgments, and feelings (Ortlipp, 2008). After each interview was conducted, I wrote in my reflexive journal because I felt myself during the interviews trying to engage further, but I knew I could not. Therefore, after each interview I made sure to keep notes about how I was feeling about what was shared, and about emotions that happened during the interview. For instance, each participant non-verbally expressed some sort of emotion (anger, sadness, and stress), and to stay focused, non-biased, and professional, I did not communicate personally about their emotions. This was very difficult for me, and marked a limitation to my research practice because I wanted to acknowledge their feelings, but realized that I could not. The reflexive journal not only helped to keep me focused, but also allowed me to reflect on what I learned from each interview.

Additionally, I did have an issue with one of my interview questions. Most of the participants did not fully understand it. All participants attempted to answer it, but they had a difficult time understanding what I had meant. I am not sure if this resulted from the way I was asking the question or if they just truly did not understand what I was asking. Thus, I derived most of the data from this question through the observation analysis.

Moreover, RSD caregivers were reluctant to share personal information about their RSD loved-one because they wanted to make sure that the individual's confidentiality was protected. I reassured the caregivers that anything they shared for the purposes of this study was confidential, and I even re-read the confidentiality section of the IRB application to one caregiver. After this participant received my reassurance, they were willing to share and ended up participating in one of the longer interviews.

Lastly, the study was limited to a single group. Thus, I cannot assume that all RSD Facebook support groups would have the same results as the one I analyzed. It is thus important not to generalize the findings of the case study.

Significance

Some education and medical researchers claim that social support is a traditional face-to-face interaction that occurs in different types of communities (Walther & Boyd, 2002). However, one of the most interesting recent phenomena in social support is computer-mediated communication (CMC) and Web usage that involves the development of virtual support communities in which people network. Individuals who are members of these virtual network share similar interests and exchange social support by sharing various images, videos, and materials that may help another member. Therefore, online support groups provide individuals avenues to find medical information and thus learn more about a given condition or illness (Haberstroh & Moyer, 2012). Furthermore, with the challenges and demands of patient privacy and the control of medical information such as Health Insurance Portability and Accountability Act (HIPAA), patients and medical providers are seeking a variety of new patient support approaches.

This qualitative case study is significant in that it examined the perceptions of members with RSD, caregivers, and medical providers regarding their involvement in an online support group named RSD/CRPS Fighting Warriors Group, and sought to determine whether their involvement in the group helped build information sharing and learning. My findings are indispensable for the members of the RSD/CRPS Fighting Warriors Group, which members typically join because they want to network with others fighting the same disease. The findings may foster networking and contribute to the vitality of the educational environment. Members involved in the RSD group also benefited from this study for the reason virtual support groups “carry on public discussions long enough, with sufficient human feeling, to form webs of personal relationships” (Rheingold, 1993, p. 5). My findings show the volume of educational information exchanged between members of RSD/CRPS Fighting Warriors Group (Walther & Boyd, 2002).

This study carries social change implications because it offers a better understanding of how learning and instruction in online support groups contribute to the wellbeing of group members such as those in the RSD/CRPS Fighting Warriors Group (George, 2011). The study facilitated social change because, I my research process, I facilitated new and different interactions between individuals in the group (Adler, Rosenfeld, & Proctor II, 2013). The findings show that educational materials provided for learning and sharing have the ability to create a supporting culture and learning environment where everyone takes part in the group mission, vision, and goals that lead to improving the group support. As Dr. Richmeier stated, “RSD patients are continuously looking for support, educational material, and networks because often times they feel isolated, alone and abandoned due to this disease not having a cure and [the fact that] there is not a lot of information given to them through medical professionals" (personal communication, June 19, 2014). As a result, members who have RSD, caregivers, and medical professionals struggle to find the support they need; therefore, this case study also could also encourage the development of more RSD/CRPS support groups. There is great potential for the group members' further understanding of RSD, "however new knowledge can be frightening and difficult for some group members" (Broatch, personal communication, February 20, 2014). The findings from this study could be used by all types of online support groups to change the lives of members who do not just suffer from RSD.

Summary

In Chapter 1, I opened with a brief historical account of the traditional support groups and emphasized the need for people with a chronic illness to use online support groups given their lived realities in an increasingly digital world. I operationalized and used the members' concept to guide the limits of the research. I established that demands for social, collaborative, and educational knowledge as practiced in online social networking by members marked a gap in research. I emphasized the need to understand members with RSD, caregivers', and medical professionals' perspectives regarding learning and instruction in a virtual social support.

In this chapter, I also presented the research questions and made an argument about the need for this study. I included an explanation of how the data was collected, analyzed, and thematically organized to construct meaning out of status updates and interviews of members with RSD, caregivers, and medical professionals. I defined

Siemens (2005) theory of connectivism and positioned it as the conceptual framework that guided my research. The section culminated with a discussion of the assumptions, scope, and limitations, and marked the significance of this study for 21st century education. In Chapter 2, I provide a thorough explanation of the current literature and research that addresses online support groups' uses of social media, and in the process, I emphasize the need for research to fill the identified gap in the literature.

Chapter 2: Literature Review

The purpose of this qualitative inquiry was to explore members' perceptions of learning and instruction in an online social networking support group. Extensive research has shown that the use of traditional support groups is a desirable practice that contributes to participants' feelings of respect and support (Booth, 2012). There has been limited empirical research on virtual support groups and their pedagogy. Much of the research on the use of social media focuses on physicians' attempts to integrate technologies in their medical practices (George, 2011). I found a gap in the literature with regard to stories of individuals with illnesses who self-direct and transform traditional support groups using social media. This qualitative inquiry into members learning and instruction in online support groups serves as a direct contribution to the literature on social media and fills the identified gap.

Extensive research has confirmed that face-to-face support groups positively influence teaching and learning (Booth, 2012). The minimal research I found on patients who collaborated through the use of social media has also identified the positive aspects of collaboration, and has noted that social media contributes to students' feelings of connection and to their further understanding of the information presented (Finn & Kerman, 2004). As previously noted, there is minimal empirical research on social networking support groups, especially with regard to the learning and instruction that occurs in these groups. The purpose of this chapter is to present a review of literature that explores experimental inquiries in addition to research studies on social media and online support groups. This section includes discussions of the following: online/virtual support groups, learning and instruction in online support groups, and social media support groups. This section concludes with a review of the methodology that I used in this qualitative case study.

My review of literature for this qualitative research study involved a variety of resources related to *social media, social networking, traditional support groups, online/virtual support groups, collaboration, instruction, learning*, and *information sharing*. I used these keywords to search the following resources: recent dissertations; websites including but not limited to Google Scholar; books from experts in the field of psychology; Facebook postings; lectures and paper presentations from academic conferences; and peer reviewed journals which I accessed using databases including Academic Search Premier, Education Research Complete, Eric, ProQuest Central, and Sage.

Traditional Support Groups

Support groups are commonly face-to-face groups that provide members with various types of help, usually particular to shared characteristics. Members typically have the same issues and they come together for information sharing, which allows for a sense of community and belonging (Franks, Cronan, & Oliver, 2004). Through peer-support programs, the social construction of survivor identity provides members with positive role models, shared lived experiences, and the shaping of identity and personal growth (Morris, Campbell, Dwyer, Dunn, & Chambers, 2011). Additionally, support groups have been shown to generate a sense of community, especially for women (Gill & Shipigelman, 2014).

The support group provides individuals an opportunity to develop positive disability identities, and to gain new information about their disability. Furthermore, support groups cultivate bonds because the groups allow for friendships, and welcome community members from all over, thus creating a platform for a sense of belonging (Gill & Shipigelman, 2014). Schotanus-Dijkstra et al. (2014) argued that traditional support groups allow persons to find identification and share thoughts and occurrences regarding a variety of diseases, disorders, and issues. Feigelman, Jordan, and Gorman (2009) said that contributing information to a group serves as a valuable basis for coping with grief and can even encourage personal growth. Current mental health care professionals stress that verbal communication is more beneficial than nonverbal communication but also note that both talking and writing are beneficial (Pennebaker, Zech, & Rime, 2007).

Many researchers agree that traditional support groups, especially for people with chronic conditions, are effective in helping individuals overcome some social norms and stereotypes (Mejias & Gill, 2014). Badger and Royse (2010) conducted a study with 30 men and women burn victims regarding their perceptions of the value of peer support. The results indicated that the participants had heightened senses of belonging, acceptance, comfort, and trust. Additionally, the same group of individuals said that they felt less alone. Subramaniam, Stewart, and Smith (1999) found similar results in a study focused on people who were members of a chronic pain support group. These results indicated a sense of belonging and the possibility to develop new relationships in traditional support groups. Kriegsman and Celotta (1981) reported that face-to-face groups focused on relationship building and problem solving among group members;

these are therapeutic to individuals in the group. Another study tested the effect of institutional peer support of nursing home residents. The authors concluded that peer support inside an institution is positively correlated to the patients' psychological wellbeing (Yeung, Kwok, & Chung, 2013). Moreover, researcher have found that traditional support groups are essential during the "post-diagnostic, treatment, and post-treatment stages when medical, emotional, informational, and functional needs are most acute" (Ashing-Giwa, Tapp, Rosales, McDowell, Martin, Santifer, & et al, 2012, pp. 589-590). The distinctive assets of grassroots, community-based support groups are to be found in multilayered types of groups. Peer-based groups are culturally consonant and receptive to individual and topic-associated needs and desires (Ashing-Giwa, et al., 2012).

Cline (1999) argued that traditional social support groups benefit individuals that are members of these groups by enhancing quality of life, improved decision-making, and increased survival time. Audet (2014) performed a study about people with diabetes who use either traditional or virtual support groups. The findings suggested that both face-to-face groups and Internet-based groups helped individuals manage their diabetes. Furthermore, the author claimed that this helps promote positive social change through an increase in availability and diversity of social support for diabetes. Setoyama, Yamazaki, and Nakayama (2011) compared traditional support groups to online support groups for individuals with breast cancer. Their study concluded that if patients used both virtual and face-to-face support groups, then they received more social support. If patients were only a part of one and not the other, they did not receive the benefits of belonging to both groups.

For as long as most Americans can remember, U.S. society has been described as individualistic. As young children, Americans are taught to be independent; however, with that families have eroded. Because of this deficit in traditional forms of support, many self-help small groups have gathered to provide emotional support. Wuthnow (1994) mentioned that the support-group movement is revitalizing American society. For example, individuals are redeeming persons from destructive behaviors to turn the attention more toward the needs of others (p. ix).

Addressing the behaviors of individuals with any type of illness is critical. However, it is also important to note the education that is taking place in peer support groups. Jacobs, Ross, Walker, and Stockdale (1983) conducted two controlled studies to determine if psychological and social functioning could be enhanced in patients with Hodgkin's disease by either education or participation in a peer-support therapy group. The researchers evaluated 81 patients using the Cancer Patient Behavior scale prior to and following intervention. The results indicated that following education, patients experienced significant improvement in the frequency of anxiety, treatment problems, depression, and life disruption (p less than or equal to 0.1) compared to a control group. However, after participating in peer support groups, patients showed no improvement in any of the 10 areas of life functioning. Thus, their study found that education represents an effective, efficient, and inexpensive means of improving psychological and social behavior in patients with Hodgkin's disease. However, the authors noted that although their findings were significant, participation in their peer support therapy group did not result in significant behavioral changes.

Anderson (2013) conducted a phenomenological study to compare the social support communication of different types of support groups for women with postpartum depression (PPD). Each participant was asked to attend one of three different types of face-to-face support groups: a postpartum depression support group, a local mothers group, or a working mothers group. Significant results indicated that there were differences in the way social support functions with these groups. However, all participants indicated that attending the support group served as a means of sharing with and obtaining information similar to others. Moreover, these support groups stimulated disclosure and offered interaction with comparable others. Findings also indicated, "despite being beneficial for new mothers, women who suffer from PPD may receive all benefits of social support groups only while attending condition-specific groups" (p. 721).

An interactive peer support group is also an important factor when it comes to support groups. Leaders of each peer support group play an integral role, especially in virtual support groups. An interesting study concluded that, for women who had survived breast cancer and attended peer support group therapy, the therapist's behavior was essential for aligning the interactive support that occurs during group gatherings (Roustan, Rodriguez, & Argilaga, 2013). Additionally, organizers of OSGs or face-to-face support groups have specific strengths and challenges. For instance, Owen, Bantum, and Golant (2009) studied how facilitators' roles in online support groups might differ from face-to-face support groups. Outcomes showed that strengths and weaknesses of online support group leaders could be captured in three categories: group practices, organizational components, and facilitator responsibilities. Overall, facilitators described their online groups as helpful to participants. Additionally, facilitators reported that learning how to facilitate an online group strengthened their skills in facilitating face-to-face groups. However, OSGs had more challenges. For example, they discussed “how online facilitators need to attempt to ‘work around’ shortcomings of the Internet as a medium for delivering psychological services” (pp. 151-152).

Sarsi and Rice (2012) tried to comprehend the involvement of girls with emotional and behavioral disorder in a gender-responsive face-to-face support group. The authors decided to stick to traditional face-to-face support groups for several reasons. First, they observed teenage girls with emotional and behavioral disorders (EBD) and these girls needed to be participating in a support group. The authors concentrated on the girls’ perceptions of companionship, association with others, and capability to form and uphold connections within the group. What they found was that the support group was seen as typical. Second, they found that there was certainly an influence of bad events that permitted the girls’ to feel attached to others in the group. They were thus able to identify with somebody. Additionally, these girls shared that they were not given the chance to have female interactions and heroes. Lastly, the authors maintained that the outcomes of the background of the support group undoubtedly permit for positive impacts in these girls’ lives. Nevertheless, the authors recommended that it would be exciting for future studies to tell if comparable support groups happen virtually, if the environment would have similar outcomes on girls' views.

Interactive support, which assumes the give and take of cognitive and emotional support by a group of members from their different roles in the group, generates a dynamic that is focused on the exploration of information, information sharing, and focused to one particular type of group. A great example of a traditional support group would be Alcoholics Anonymous, also referred to as AA. Alcoholics Anonymous is a fellowship of men and women who share their experiences, strength, and hope with one another. There is only one requirement for being a group member, "a desire to stop drinking" (2014, January 1). Additionally, relatively little research has been studied on peer advice virtually.

In a face-to-face group involving women who have survived breast cancer, participants listen and talk about pain, worries, faiths, and desire to live a typical life again, but through social support groups, the women become more involved because the therapist/mediator nurtures specific topics in the conversation. Furthermore, face-to-face support groups acknowledge members to understand upbeat and undesirable behaviors. In addition, in traditional support groups the mediator can get members to become involved, consequently being subjective by guiding their conduct and actions (Roustan, Rodriguez, & Argilaga, 2013). The "unique strengths of traditional peer-based support groups are that they need to remain culturally cognizant, peer-based, and receptive" (Ashing-Giwa, Tapp, Rosales, McDowell, Martin, Santifer, Clark, et al., 2012, pp. 589-591).

As noted previously, virtual support groups are new phenomena that have risen within the past decade. Online support group users from all over the world can connect and relate with one another.

Online/Virtual Support Groups

With the emergence of the Web, there are additional possibilities for sharing experiences through participating in social networking sites such as Twitter, Facebook, and Instagram. McDaid, Trowman, Golder, Hawton, and Sowden (2008) suggested that little research has been conducted on online peer support groups. For members bereaved by suicide, face-to-face support groups may be challenging because they may not be accessible in their neighborhood and/or the times that they meet (Schotanus-Dijkstra, Havinga, van Ballegooigen, Delfosse, Mokkenstorm, & Boon, 2014, p. 28) are not valuable for them. There are a number of unique communication characteristics specific to online support groups: geographical and text-based communication (Coulson & Greenwood, 2011). These specific features are prone to have an impact on the online support society. For instance, online support groups are constantly available which lets members to access them at their convenience. A further benefit connected with asynchronous interaction is the chance for contacts to occupy time reflecting upon their opinions and attitudes as well as collaboration with other participants (pp. 870-871).

Social networks assist in forming relationships and offer an awareness of belonging throughout social connectedness. The social, emotional, and physical support offered by social networks produce an important task in emerging survivorship inferences. Ashing-Giwa, Tapp, Rosales, McDowell, Martin, Santifer, Clark, et al.,

(2012) established that fighters emphasized that a socially embedded importance was desired for their involvement in an online cancer support group. The members equally learned that the support group offered multilevel functions, including emotional, mutual, religious, understanding, and financial help as well as patient triangulation. Furthermore, the group encouraged individual development, prevention knowledge, and exploration.

Crafton (2010) says that World Wide Web users in the U.S. seeking health information increased from 54 million to 117 million in 2005. Moreover, according to Internet Live Stats (2014), around 40% of the world's population has the Internet. In addition, the first billion of Internet users boosted from one billion in 2005 to three billion by the end of 2014. There are numerous profits of patients enlightening themselves via the Web that involve, but not limited to enhanced health results, improved doctor-patient discourse, and mutual decision-making (Crafton, 2010). Additionally, Crafton (2010) perceived that the combination of Web-based technology and patient health is an emerging experience.

Social networks are a dominant interactive vehicle that offers entry to diverse types of resources of virtual knowledge and collaborating groups (Haberstroh & Moyer, 2011). Specified online support groups should comprise of, but not limited to age-and/or gender-specific or focus on particular desires or features (Juneau & Remolino, 2007). Social support refers to discourse between individuals that gather information to decrease ambiguity in the connection and to develop an awareness of individual control in one's knowledge. It includes observations of interpersonal acknowledgment, understanding, and requests to give and receive help (Finn & Kerman, 2004). In recent studies about online social support groups, a common theme emerged where the construction of interpersonal relationships builds over time through these social support groups (Finn & Kerman, 2004). Interpersonal relationships are concrete, insightful, or close connections amongst two or more people. These relationships are formed through social, cultural, and other influences. The relationship can be based on interpretation, fondness, professional, or social commitments (Adler & Proctor II, 2010). Online social networking (OSN) is a service can shape social networks or social relationships among people who share interests, behaviors, experiences, or real-life associations (Raju, Valsaraj & Noronha, 2014, p. 289).

Social support is a type of communication among persons who try to decrease ambiguity in a relationship or situation. Albrecht and Adelman (1987) say that social support contains views of interpersonal approval, compassion, and need to offer and accept help. Cohen (2004) defined social support as a social network of emotional and substantial resources for an individual's capability to cope. Members of online support groups may provide social support. For example, Coulson (2005) analyzed messages posted to an online support group with individuals of irritable bowel syndrome. "The results discovered both informational and emotional support to be prevalent in this online context" (p. 583). Various studies propose that physical and psychological benefits transpire when someone is obtaining social support (Turnbull, 2010).

Patients' attitudes and beliefs on the benefits of being a part of an online support group have shown to improve coping and self-efficacy for disease self-management (Wald, Dube, & Anthony, 2007). Patients who are involved in web-based health care illustrate a positive health behavior. More specifically, there have been improvements in behavioral, psychological, and biological outcomes (Dahl, Wilson, & Nilsson, 2004). Individuals who suffer from long-term conditions must contend with the potential of a valued identity of sense of self (Sharpe & Alderson, 2013). More specifically, women are more likely than men to seek out medical web-based medical treatment (Fillingim, King, Riberiro-Dasilva, Rahim-William, & Riley, 2009). According to a Pew Foundation report (2013), 84% of those who use the Internet had contacted an online group and half of those said they got to know people they would not have otherwise met. Individuals who are looking for support for issues such as health and medical concerns are being assisted within an immense network of social media discussion groups, listservs, chat rooms, and virtual communities (Boutin-Foster & Charl- son, 2002; Finn & Holden, 2000; Schopler, Abell, & Galinsky, 1998; Maciuszko, 1990; Madera, 2001).

Given the need, it is not unexpected that numerous females try the Internet for support and information. In fact, “distressed cancer patients may be more likely to participate in Internet support groups than traditional, because of their anonymity, which makes it easier to discuss highly personal issues” (Classen, Chivers, Urowitz, Barbera, Wiljer, O’Rinn, & Ferguson, 2011, p. 931). Online support groups are often seen as a safe substitute for receiving encouragement when one is dealing with a delicate problem (Classen et al., 2011).

Keim-Malpass and Steeves (2012) discussed how there is a lack in disease specific support groups. As a result, they said that many young adults are beginning to socially network through blogs and social media. The authors discussed that once young adults connected to virtual support groups such as Twitter and Facebook, they exchanged information, shared their stories, and shared their individual journeys through blogs as a diary in order to express their illnesses. According to Treadgold and Kuperberg (2010), they discovered that online support groups are fostering support opportunities for young adults. They found that 95% of adults age 18 or older have used or want to use Internet sites that offer appropriate cancer education or support. Additionally, Zickhur (2010) mentioned that in today's society, 86-95% of adults go online on a daily basis. Keim-Malpass and Steeves (2012) determined that online communities are a safe place for women to express themselves. Furthermore, the authors discovered that women who connect in an online support community build bonds and relations that they would not have had beforehand. Additionally, the women were able to share stories endorsed by others to appreciate members and feel instant connections: "The readers, whether they know the person or not, quickly become an engaged part of the narrative" (p. 7).

There are various benefits associated to online support groups. White and Dorman (2001) mentioned that some of these benefits include implications for health education. Online support group environments allow for members the opportunity to connect because they are available 24 hours a day, 7 days a week. The members are also able to develop responses, status updates, and messages at their own pace. Furthermore, geographical and transportation barriers are nonexistent. Individuals who have mobility issues, speech and hearing impairments, or caregiving can also partake easily with Internet access. Furthermore, the authors explored and acknowledged that individuals who have a stigma disorders find virtual support a more welcoming environment in order to discuss delicate issues.

In 2010, Owen, Boxley, Goldstein, Lee, Breen, and Rowland wanted to conduct a study about patients who use online support groups (OSGs) with chronic illnesses. They mainly focused on individuals who live in California with chronic conditions. Some chronic conditions included arthritis, diabetes, depression, stroke, and cancer. What they established was that people with chronic illnesses do not essentially use online support groups; but offered that if there were more internet-based-health services, social support groups would increase for those living with chronic conditions.

Online support groups for cancer and cancer patients have been studied extensively but a limited number have focused on gynecologic cancer. More specifically, a pilot test was conducted for gynecologic cancer patients and it assessed women's perceptions of the intervention. The forum provided women with easy access to the support group and privacy in talking about psychosexual worries. What the authors found was that women with gynecologic cancer might profit from joining in online support groups that afford a setting of virtual privacy to converse psychosexual worries. These women shared information such as body image, feelings of sexuality, and security of talking about sexuality online (Wiljer et al., 2011).

Coulson and Knibb (2007) explored the role of online support groups with individuals coping with food allergies. They were very concerned for a few reasons. One of the main reasons that the authors wanted to examine the role of online support groups was that there was a large increase of food allergies in adults and children. Additionally, the authors recognized the growing numbers of individuals accessing the Internet for health-related information, advice, and support. Therefore, the primary purposes of the study were to investigate the participants' perceptions of the advantages and disadvantages of engaging in online support groups specific to food allergies. Group members identified a range of benefits: convenience, social support, assistance, and managing approaches. There was only one weakness recognized which was about the accuracy and certainty in information exchanged in the group newsletter. Overall, virtual group involvement did seem to have positive significance on relationships with healthcare providers with several participants reported greater empowerment through decision-making, although many others found it difficult to discuss their online support experience and information obtained with their healthcare providers.

Since the initiation of the World Wide Web and social media networks, computer-mediated communication has developed, especially within online support groups. However, a study investigated empathy in online support communities for teenagers because they are one of the largest populations to use social media. Outcomes suggested that adolescent individuals exchanged a considerable quantity of empathetic emotional communication when contributing in online support groups. The youth were able to talk on levels that are more private while adults conveyed proper interaction amongst one another. Lastly, teens exhibited a high level of sympathy but lesser level of trepidation rivaled to older folks when articulating empathy online (Siriaraya, Tang, Ang, Pfeil, and Zaphiris, 2011).

Instruction & Learning in Online Support Groups

Self-management is an expression that occurs in online support communities. For instance, Ockleford, Shaw, Willars, and Dixon-Woods (2008) argued that education and self-management occurs when participants attend some form of a group-based education about their illness. In addition, participants who engage in group-based education shared that group education was a part of their care routine, especially when newly diagnosed. The authors discussed that the traditional role of being sick, in which the doctors are the authority and knowledge, now has been replaced with patients being independent and proactive. Self-care actions should be understood in terms of the meanings attached: the context, the norms, and finally, the relationships being built and education being shared and learned through virtual support groups (Ockleford, Shaw, Willars, and Dixon-Woods, 2008, pp. 33-35).

Christie and Bloustein (2010) followed a young woman who underwent a cochlear implant surgery. Rather than sharing her information with her doctors and family members, she decided to share her story online using Facebook and creating a cochlear implant support group as a way to involve and educate others about surgery. The authors followed her journey, and they found that “human beings are evolving into ‘cyborgs’ as a result of new technological applications that offer new understandings, meanings, and what it means to culturally learn about your illness through the use of social networking support groups” (p. 498). It was also recognized that public pedagogy occurs through social media support groups. Not only have they grown and developed, but also individuals feel a sense of identity, learning new information about their disease, and have daily encounters that engage individuals to continue to be a part of a support group (pp. 484-485). Online support groups are "powerful and effective vehicles, especially when, for example, challenging medical discourses of disability, because they have the potential to 'reimagine…disabled bodies' (pp. 492-493).

Coping is often used in traditional and virtual support groups. Gary and Remolino (2000-2007) discussed how coping with loss and grief through online support groups are a growing cyber service (p. 2). Online support groups can be reached through Internet portals or specialized web sites. "The benefits of online support groups allow for intimate, honest discourse and expressions, that allow the grieving person to not feel isolated" (p. 3). "Online support groups reduce the sense of isolation and loneliness" (p. 3). Gary and Remolino established that online support groups offer help by connecting grief-stricken persons who pursue help particularly if support is not obtainable. Conversely, they argue that support groups are not suitable for everybody and must not be considered a cure-all.

Ward (2003) mentioned how technology in support groups has evolved considerably over the past several decades because of the growth of the Internet; individuals have greater access and join support communities. Haberstroh and Moyer (2011) explored an online support group of individuals who self-injure. What they found was that individuals who were a part of the self-injury support group made beneficial relations and learned that patients' occurrences are comparable. One of the leading findings was that some participants conveyed that online support is a supplementary resource for them. Even a few members would rather be involved in the online support group because there is such poor behavior and damaging humiliation from traditional providers and traditional support groups. Additionally, they found that most members of self-injury virtual support groups use it as an information tool to gather information and extra support where it is missing in their lives. Common themes emerged through current literature: empathetic support, interpersonal relationships, and helpful responses (pp. 11-14). This study explored participants' experiences in an online self-injury support group. "When there is a relational context and a strategy to cope with emotions, online group support can offer opportunities for healthy self-expression and connection with others recovering from SI" (p. 15). Furthermore, in online support groups, beneficial qualities of writing associated with understanding and coordinated relationships endorsed SI recovery. Besides, online support group members have expectancies. Frequently, group members trust profoundly on their Internet group and other online resources as they get ready for future medical appointments (Hu, Bell, Kravitz, & Orange, 2012). Additionally, the authors uncovered that members are looking for "four types of different information seeking: reliance on the online support group, use of other online health resources, the use of offline resources, and personal network contacts" (pp. 970-978). Nevertheless, the main outcome of the study was that members relied greatly on online support group members because trust is created inside the group and contribution in decision-making aids while relying on group members. Also, as stated previously, with the increasing access to the World Wide Web, new chances are obtainable to not only patients seeking support, but there are also opportunities for relatives and caretakers.

Families and caregivers also seek information, advice, and support about specific illnesses. One specific study examined families seeking support online for childhood cancer. Ultimately, the authors retrieved over 450 messages from several childhood cancer groups looking for support-intended communication. The results indicated that five types of social support exist: emotional, informational, esteem support, and tangible assistance. The authors suggest that online support groups may offer support to potential family members of children with cancer. Moreover, they suggest that online support groups may be a useful resource for emotional and information support (Coulson & Greenwood, 2012).

Amid the consistent theme that more women seek online social support, there is a difference amongst the genders. As Blank, Schmidt, Vangsness, Monteiro, and Santagata (2010) as well as Seale, Ziebland, and Charteris-Black (2009) agreed that gender difference in the frequency of emotion language used in virtual cancer forums, men were more likely to seek medical information and women more likely to seek social and emotional support. Seymour-Smith (2013) investigated virtual support groups to examine support mechanisms that men do when deciding whether to have testicular implant surgery or not. The findings illustrated that men employ a number of particular strategies in showing support. This includes, but limited to assessments, accountability, humor, alternative information, constructing decision making as a personal choice and not the groups, and emotional talk. Additionally, the author suggested that online support to men with testicular cancer is recommended for their psychological healing journey. In addition to men being members of support groups, there are often times messages that occur within these online forums - for example, suicidal messages. Gilat, Tobin, and Shahar (2011) stated how important messages that are left in support groups are. The analysis suggested that online support groups enable suicidal members to generate an environment that provides emotional support and offer alternatives to suicide.

Medical professionals and medical providers are attempting to engage in online social support groups. One study suggested that with suitable instruction and exercise over time, therapists accustomed with face-to-face support groups to cancer patients enhanced their proficiencies and involvement in leading online social groups for cancer patients (Stephen, Christie, Flood, Golant, Rahn, Rennie, & Turner, 2011). Learning to assist online support groups changed traditions by notably developing the possibility of services they were able to offer their patients and has consequences for increasing access to support aids.

Decision-making is a consistent theme that occurs in most online support groups. What is known about social support is that it plays a major role for decision-making in prostate cancer. However, most information generated is formal and statistical. The study by Huber, Ihrig, Peters, Huber, Kessle, Hadaschik, and Hohenfellner (2011) wanted to add to understanding the content and dynamic of peer-to-peer counseling in an online support group. Most information that was learned from individuals in the group was that members were looking for therapy recommendations, information about treatments, and emotional support. Additionally, the study suggests that the learning in the group occurred from the patients in the group. Patients readily receive information, advice, and emotional support. Additionally, the authors suggest that their scientific evaluation of an online support group is a complementary way of getting to know patient's needs and worries. Lastly, the authors argued that this information was "vital for patient-physician contact because the doctor can benefit from the knowledge the patients are learning from being an active participant in online support groups" (pp. 1571-1574).

Malik and Coulson (2008) focused on computer-mediated infertility support groups. They were curious about the experiences of individuals who have dealt with infertility and the growing number of online support groups now available to those individuals. The results indicated a few learning themes: improved relationships with their partners, reduced sense of isolation, and empowerment. In addition, the authors said that there are a number of advantages but they also found disadvantages of online infertility support groups. These disadvantages were mostly discussing how negativity has an impact on the experiences of infertile individuals. However, the authors suggested that online support groups would only help medical professionals on how to better understand and support psychological needs of patients experiencing infertility (p. 111).

Carroll (2012, January 1) mentioned in her blog about moment of clarity and what patients learn while attending alcoholic anonymous (AA). She mentioned that patients will go through the following learning as being a part of this community: learn acceptance, learn self-approval, learn self-reliance, learn forgiveness, learn to go with your instincts, learning to say no, learn about love, learn that life is a self-fulfilling prophecy, learn that in order to achieve success that you need direction, discipline, and perseverance, learn that you cannot do this alone, learn that it is okay to ask for help, and learn to let go of ones ego. Moreover, an alcoholic anonymous sponsor mentioned that there were specific lessons learned while being a member of AA. They mentioned that following lessons are learned by going through the program: individuals are powerless, a person must be responsible for what they have done and not look at others to blame for their problems, individuals should seek progress and not perfection, there is always room for improvement, and that individuals should also be a service to others. AA strongly believes that the best way to help oneself is to help others. Lastly, addiction is not easy. "An individual must stay motivated, willing, and remember that it is a journey that takes a lot of courage" (Anonymous, personal communication, July 16, 2014).

Weight Watchers is also known as a traditional support group for people who want to lose weight and become healthier. In the traditional setting, an individual will meet with a personal counselor to go over food programs, nutrition, and some counseling from individuals who have gone through the program and succeeded. However, Weight Watchers has realized they can reach more people if they built online support communities. Although there is a cost to be a member, where AA is free to all members, Weight Watcher gives people the opportunity to share their stories, log their weight loss, food, calorie intake, order their food, as well as be a part of a weight watchers support group virtually. This allows individuals the safe environment to have others not judge them, as well as to customize who they want to meet (Weight Watchers, 2014).

Most of the time, it is people living with an illness that create online support groups. In order to manage an online support group (OSG), there are two important stages: initiation and the evolution. The initiation stage consists of what happens prior to the group that goes online. During this stage, webmasters need to make decisions about the content, design, and access. For example, will the group be open or closed? Who will run the group? Will anyone run the group? In the evolution stage, it begins from the moment that the group goes online and it is ongoing. In this stage, the webmasters should make decisions about the management/administrative duties and people in the online group.

While support groups are great, simply building/creating social support groups cannot achieve the achievement of success by inviting similar individuals with characteristics, and expecting everyone will instinctively network in beneficial techniques. This is especially vital for the online communities. An online group can have the precise user interface, instruments, and ethos; but if group participants are not involved, the community will not flourish (Bishop, 2007). Barab, Kling, and Gray (2004) discussed some of the challenges faced by online communities. One of the biggest problems is fostering and sustaining knowledge sharing. Without a continuing interchange of information, online social support communities collapse.

If online support groups can continue to function as an instrument to keep the members in a community unified and connected, trust is erected and interpersonal relationships can develop which can lead to quality knowledge sharing (Hoy & Tschannen-Moran, 1999). As growing trust creates fertile ground for knowledge sharing, increased knowledge sharing mutually deepens trust (Bryk & Schneider, 2002). Following a study on motivation and barriers to contributing in online knowledge-sharing communities, Ardichvili et al. (2003) suggested that researchers essentially should recognize the instrument of trust between group participants in order to grasp how to overcome the impediments to virtual information sharing. Furthermore, results indicated that involvement in a virtual support group discovered that participants who predominantly are the most active versus the quiet members has no significant difference in how they feel about themselves in an online patient support group (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). Additionally, the authors mentioned that individuals who have the same illness create most online support groups. Ultimately, the webmaster (creator of the group) has altruistic and intrinsic motives. Webmasters define success of the group through personal goals they set for the group. For example, they are moderating messages, organization of the group, management and coherent messages that the group wants to portray. "Promoting the group and keeping it lively and functional, management takes a lot of time and ultimately does not help serve the Webmaster as a social support group, therefore many will be a part of different groups, to just be a regular active member" (pp. 33-34). Ultimately, webmasters typically are a part of other groups that they do not have to manage, so they can benefit from support groups.

Aitken (2008) presented findings of the communication purposes in an online support group. She was analyzing parental use of online support group about children with disabilities. Ultimately, the content analysis provided vital educational material for caregivers involved in a support group. The findings suggest that parents use online support groups because they either want to express their stories, seek and give advice, provide information, are looking for or sharing resources, and sharing success stories to encourage hope in the group (pp.8-16). There are also additional benefits for individuals who are involved in online support groups. Preece (1998) concluded that participation in virtual support groups showed that there is an increased perception of emotional support, and reduces depression and stress. Note, that even in 1998, how crucial participation was and should be today in virtual support groups. However, despite the proposed benefits of studies conducted on online support groups, the overall impact had not been studied. Rains and Young (2007) were interested in socio-emotional outcomes, behavior change, or increased social support. Although the study has not been conducted, the authors expect "to demonstrate the effects and relative effectiveness of online support groups" (p. 3).

Lai, Wong, Liu, Lui, Chan, and Yap (2013) conducted a pilot study about outcomes between online and face-to-face support services for caregivers. More particularly, the authors were focused on caregivers and their knowledge about dementia. The most significant finding was that online group participants used the online resources more than the face-to-face participants did because they were more convenient. In addition, online workshops helped enable the caregivers with more knowledge and skills. The knowledge definitely helped caregivers resolve caregiving problems. For example, they learned to control their tempers, stress levels, and ability to calm down. Erickson & Johnson (2011) suggest it could be conceivable for older adult caregivers to identify themselves as more valuable from using the Internet at a tool to help them learn, lead an autonomous life, and remain in contact with family members unaware of decisions that need to be made.

The use of online support groups is emerging; however, there was still a gap in the literature with what is being learned and instructed in these support groups. Although researchers have found common themes that occur as participants become active members in online support groups, but little is still known as to what they are learning or instructing. McTavish, Hawkins, Han, Shaw, Gustafson concluded a pilot study, and Witherly (2006) examined the comparative effectiveness of peer-to-peer or patient-to-expert discourse to improve the learning results of information service use in a collaborative cancer forum. Consistent with the authors' expectations, "the use of discussions amplified the learning effects of using the information services" (p. 1). However, the section that participants could ask an expert service did not increase the learning outcomes as the authors had projected. Moreover, and most importantly, the study proposes that online support groups could complement and encompass the learning and potential information services. The authors also explained further research to optimize "how breast cancer patients use and benefit from access to an online cancer expert" (pp. 17-18) because there is not enough information out there.

Without worrying about health problems, socio-economic, specific illnesses, or caregivers, specific careers have also been under examined. However, a specific study was conducted about social workers and how they cope with the job stress and burnout. The authors developed a specific listserv group to provide members with emotional support and validation of their feelings about work and to provide them with information about job stressor and alternative ways of coping. What the research suggests is that group intervention in online support groups, that online support groups can be "useful and helpful to social workers in coping with psychosocial stressors, but it remains unclear whether it is an effective means helping less technology inclined workers cope with stress caused by office automation or the dominance of the Internet" (Meier, 2002, p. 129).

Social Networking Research

The emergence and adoption of social networking technologies and approaches have been greatly changed by the design; look, influence, and ease-of-use in ways users interact with them (Eysenbach, 2008). The user is engaging technology to construct, collect, and share knowledge, network, and intermingle, binding a combined intellect (Ockleford, Shaw, Willars, & Dixon-Woods, 2008). Ultimately, social networking signifies change from singular expression to an involved philosophy (Bloom, 2010). The term social media will be used to describe how the World Wide Web is the 21st century's central technology for knowledge and learning inside our universal society.

Incorporating social networking and joining social support groups for patients with various illnesses increased the level of collaboration among patients and building a sense of belonging and coping skills moved from being private to comfortable around individuals with their similar characteristics (Coulson, 2007). More knowledge, understanding, compassion, and support occur when Web 2.0 support groups are integrated in a patient's care (Finn & Kerman, 2004). Literature on educative uses of social networking has covered topics such as relationships, discourse, and coping mechanisms (Coulson, 2007). Still, literature has mainly focused on the conditions, user characteristics, and support. The literature did not construct any practical research on the learning and instruction that occurs in online support groups. However, there are many diverse ways to socially network in various forums such as Twitter, Instagram, and Facebook.

Social media technologies help users remain up to date on the rapidly changing "information access, collaboration technology, and convergence, among other factors" (Friedman & Friedman, 2013, p. 1). Up to date entertainment, education, news, and assets through social media allows most to share knowledge (VanDoorn & Eklund, 2013). However, platforms for uses of medical education and support have been neglected (Godbold, 2013). Social media reminds educators of how individuals enter into virtual domains and quickly restructure this setting as part of their daily lives while understanding and sharing their worldview perspectives (Leu & Forzani, 2012). There are many ways this is done: photo, video, music sharing, blogging, and social networking.

A number of indicators suggest that the evidence for using social media for health care is growing; for example, the number of articles indexed in PubMed has nearly doubled each year for the last four years (Grahales III, Sheps, HO, Novak-Lauscher, & Eysenbach, 2014). Patient isolation is common in many chronic pain, cancer, Aids, and other serious illnesses throughout the United States (Sarasohn-Khan, 2008). However, despite these helpful understandings, our combined comprehension of how social media is being used by patients remains fragmented. One possible strategy that influences how patients interact among each other is being a part of social media support groups. Online support groups provide individuals the opportunity to practice collaboration, gain a sense of identity, and not feel isolated (Clifford & Minnes, 2013).

Social Networks that Promote Support Groups

Dewey (1938) argued that the “principle of continuity of experience means that every experience both takes up something from those which have gone before and modifies in some way the quality of those which come after” (p. 35). On Facebook, and especially in support groups, an individual (more particularly a person with RSD) “is able to post pictures, how they feel (status updates), share emoticons expressing how they are feeling nonverbally, share information such as petitions, surveys, medical studies, give and receive comments, build relationships, and be a member of a community similar to themselves (Anonymous, personal communication, July 10, 2014). From the experiences, each member allows individuals to learn from experiences and usually is fruitful because it is quality over quantity (Hawn, 2009). An example of how health care is changing from modern medicine is the “Hello Health”, the Brooklyn, New York primary care practice. Hello Health is a paperless agent that is new, well liked, and a positive interactive tool because it engages Web-based social media. Furthermore, “across the health care industry, from enormous hospital networks to patient support groups, new media tools like social networking websites, blogs, and video chat are reengineering the way doctors and patients interact” (Hawn, 2009, p. 362).

An Internet search with Safari browser conducted in July 2014 using the terms support groups and web 2.0 produced over 50 million responses, patients and social networking over 21 million, Facebook, Twitter, and Instagram and support groups over 425 million entries. Adding education, learning, instruction, patients and web 2.0 reduced the number to 125,000. Research findings confirmed there is less formal research available to chronic pain illnesses like Reflex Sympathetic Dystrophy. Many of the search results were not specific to RSD or chronic pain. Furthermore, there is less evidence for patients, caregivers, and medical professionals who are using the World Wide Web for education and learning that occur in virtual support groups. These explorations afforded sufficient confirmation of the informal preoccupation with social media technologies in education.

This unofficial contribution of material using the Internet remains to mature as the education and business groups advise or exploit on opportunities of a virtual feature that compromises new ways to connect, share, construct, and collaborate. Formal research pursuits in scholarly peer-reviewed databases such as ERIC, Education Research Complete, Communication & Mass Media Complete, MEDLINE, and PsychINFO produced little research on learning and teaching in support groups. Moreover, formal research about who uses social media to connect with participants simultaneously provides their traditional face-to-face support groups and individuals with real life global collaborative teaching and learning experiences. There is a lack of empirical research that has been conducted on the learning and instruction in virtual support groups. Notwithstanding, empirical research on traditional support groups, virtual support group characteristics, and communication between doctors and patients social media use led to an understanding of current research findings and gaps in the research.

In learning and instruction, social media research has focused on students and teachers within the context of using social media tools in their classrooms to build learning communities, collaboration, as well as increase students' 21st century skills

(Lemire & Hotte, 2010). The current literature recognized opportunities in the integration of social media in education. Wireless tools are the latest vehicle of the digital era and essential to be standard and innovative to teaching and learning (Holotescu & Grosseck, 2011). While the educational community understands traditional teaching and learning, it still leaves slight instances to shape competencies in-group analysis, discussion of communal significance, and co-construction of difficult decision-making (Dede, 2009). Dede suggests that in the 21st century teachers must remain proficient conversationalists.

Offering support to individuals with specific needs has been seen repeatedly. However, there is little empirical evidence to show if these individuals who are a part of online support groups learn and or instruct one another. Gilat, Tobin, and Shahar (2011) suggested that the revealing of status updates, responses, with an interpersonal perspective found that if individuals are a part of an online support group, they can shape their environmental and mental health. Furthermore, offering "online support groups enable suicidal individuals to generate an environment that provides emotional support, and offers alternatives to the suicidal view" (p. 195).

Dewey's (1938) advanced education encouraged individual and student-centered learning. More modern theoretical progresses encompass learning opportunities of social media, social media networking, networking, casual learning, and personalized or tailored learning programs where "teachers curate the learning environment" (Arteaga, 2012, p. 89). Dewey (1925) suggested that individuals should set some sort of standard of excellence for others to model their techniques, adopt them, and make adjustments to make them better. Online support groups use global communication because they are using the tools of social media and digital devices confirm research outcomes that propose learner-centered teaching. Members of virtual social media support groups are constructing an innovative pedagogy and revolutionizing the conventional method of education. The use of social media acknowledges the likely progression of Dewey's viewpoint into the digital era.

Siemens and Connectivism

The concept of social media and social networking is supported by Siemen's (2005) theory of connectivism. Connectivism is a learning theory for today's world (Siemens, 2008). Siemens has acknowledged that in a constant rising multifaceted world where information doubles annually, individuals' knowledge expenditures are changed. In particular ages, distinctive tools and advancements form what it means to be knowledgeable. Today's level of literacy in the digital era does not ask if you can read a book, "but what levels of competence with digital literacies – can you navigate a network, can you make sense of different technologies, can you access your network through various devices" (Siemens, personal communication, January 26, 2012, as cited in Arteaga, 2012, p. 89)? Networked learning and open learning are vocabularies frequently discovered in concurrence with connectivism. Connectivism can be used as a model to explain an individual's manner for learning. People with RSD, caregivers, and medical professionals are largely connected learners that flourish in networks and form a universal existence within the practice of social media.

Siemens expressed that networked learning encompasses neural, abstract, and social stages of advancement focused within individuals' capabilities to regulate digital material and form networks for connecting to one another. Today, people are able to construct and reuse evidence through the usage of the World Wide Web electronics such as social media outlets, blogs, wikis, podcasts, and videos have transformed conventional sources and amplified the volume of information exponentially.

In 2004, Siemens listed key components of connectivism:

- Learning and understanding occurs in a variety of beliefs.
- Learning is a practice of involving specific evidence resources.
- Learning could exist in non-human applications.
- Competence to understand further is above anything that is presently identified.
- Supporting and sustaining connections is necessary to assist in common knowledge.
- Capability to grasp networks amongst subjects, philosophies, and views is an essential ability.
- Exchange (correct, current information) is the focus of each connectivist learning activity.
- Decision-making is itself a learning process. Deciding what to acquire and the value of inbound knowledge is understood within the scope of an ever-changing world.
- Although there is a correct response today, it might be incorrect tomorrow suitable to changes in the information environment disturbing the conclusion. (Siemens, n.d.)

Connectivism relies upon accessible learning, collected, self-directed, proper, or unofficial learning performances provided through developing digital technologies. The new opportunities should allow the information itself, because it involves perspective, experience, past, public knowledge, and social resources that can facilitate knowledge to expand related value and relevancy. From a social perspective, connectivism acknowledges, “people have been learning in social, networked ways since recorded history” (Siemens, 2006, para. 3). However, learning today must be seen as social, knowledge distributed across a network, capacity enhanced by enlarging the network, learning/knowledge as multi-faceted and complex incorporating technology. In this sense, learning becomes social and connected with possibilities for problem solving and the creating of artifacts that become identities in themselves, able to meet networkers’ just in time needs locally and globally.

Limited Research of Virtual Support Groups

In addition to emerging themes, a number of gaps and deficiencies were found in this literature review. Very few journal articles were found in the literature review on the use of virtual support groups for learning and instruction. Limited literature was also found on chronic pain patients, who are a big population in their own entity. The roles of participants were barely mentioned in the few journal articles concerning patients using online virtual support groups through social networking sites. Some researchers made several suggestions about various methods that could be used to help communicate and form successful virtual support groups, but little research was found concerning specific methods to improve or understand how patients, caregivers, and medical professionals can all share information and take it into daily life. Little research was also found on how to develop a shared philosophy of partaking and innovation in relation to the integration of virtual support groups for chronic pain individuals who have it, care for it, or manage it.

This study addressed these gaps and deficiencies by exploring and understanding the learning and instruction that occurs in one open Facebook RSD/CRPS online support group. The study described what types of learning and instruction occurs during this process. In addition, members with RSD, caregivers', and medical provider's perceptions about specific learning and instruction were examined and determined. This study contributed to the literature on virtual support groups by providing a detailed description of individuals with RSD, caregiver's, and medical professional's perceptions in the learning and instruction process with particular focus on what is actually occurring in these virtual support groups.

Chapter 3: Research Method

In this study, I addressed the problem of the lack of learning and instruction in online social support groups. The purpose of this qualitative case study was to investigate the perceptions of people who participate in one open (public) Facebook social support group named RSD/CRPS Fighting Warriors. The study included seven in-depth interview questions and a 2-week observation period of the Facebook group. I conducted the interviews and observations congruently. The interview questions investigated the members' perceptions of learning and instruction in the RSD/CRPS Fighting Warriors support group. The study gave me insight into how learning and instruction occurs between chronic pain people with RSD, caregivers, and medical professionals in a social networking environment.

In Chapter 3, I present a discussion of the methodology that I used to answer the research questions. This chapter includes descriptions of my research design approaches, the context of the study, the measures I took for ethical protection of participants, my criteria for selecting participants, my role as researcher, the data collection and recording procedures I used, my data analysis and interpretation, and evidence of the quality of the research study.

Research Design

I used a qualitative case study design in order to provide a deep explanation of the practices of the learning and instruction in a single open Facebook support group page. According to Yin (2014), "A case study is a firsthand inquiry that explores a current phenomenon in depth and within its real-world context. The case study involves various sources of support to help data collection and overall analysis" (pp. 133-142). A Case study's objectivity relies on various sources of evidence. In order to provide an in-depth understanding of the phenomenon of this study, I gathered data from two sources t for triangulation. The two elements of analysis were rooted in this single case. These two units were interviews with members of the support group, and the observation of the Facebook support group for status updates, emoticons, information sharing, and communication between active members.

As Yin (2014) explained, a case study might include additional units of analysis. Case study approaches are used when three conditions are present: (a) the research question posed should be in the form of how or why, (b) the study focuses on a contemporary set of events, over which (c) a researcher has little or no control (Yin, 2014, p. 14). Consequently, the research questions for this study were in the method of how inquiries. Digital data mining is a technique used to find patterning or clustering of similar kind of words. Frequent terms appear in electronic data, and show similarity between stories, news, emails, status updates, and information sharing (Agnihotri, Verma, & Tripathi, 2014). There are three distinctive kinds of data mining: demographic, "behavioral," and psychographic (Sevindik & Demirkeser, 2010). Demographic data are the kinds of data that are hard to modify, such as individual characteristics, age, sex, educational level, marital status, and racial origin. Behavioral data are acquired through measuring a particular process and action. Last, psychographic data is information acquired from views, beliefs, and attitudes. I used data mining to extract data from online documentation in participant status updates, shared photographs, emoticons, article sharing, and other information posted in the Facebook group.

Research Questions

The research questions were based on the theoretical framework presented in Chapter 2. Yin (2014) suggested identifying a research question that informed the reader of the approach or design use in the qualitative study to collect, validate, and analyze data (pp. 190-192).

1. How does the social networking site Facebook enable instruction in online support groups?
2. How does the social networking site Facebook enable learning in online support groups?
3. What are the perceptions of the group participants regarding learning and instruction in online social networking?

Qualitative research has advanced from numerous disciplines, including psychology, anthropology, and sociology (Leedy, 1997). It involves extensive communication with participants, and researchers can be less formal when collecting data. Researchers are focused on detail and use an inductive approach (Miles, Huberman, & Saldana, 2014). Moreover, this type of research is interpretative research where the researcher is seeking to “understand the world from the perspective of those living in it” (Hatch, 2002, p. 7). The method I used for this study was semi-structured and centered on collecting data from the social media site Facebook. The qualitative approach permitted me to assemble of rich data. Qualitative researchers acquire knowledge based on constructivist approaches (Yin, 2014) which use interviews, observations, unobtrusive data, video, journaling, and focus groups (Hatch, 2002). Interpretation comes in numerous methods, such that “the variety of evidence can include relativist orientation allowing for multiple perspective and meanings” (Yin, 2014, p. 220). As qualitative researchers examine their data, they are able to discover repetitions, topics, themes, associations, and make interpretations. Regrettably, qualitative studies frequently contain fewer participants; therefore, generalization to a greater population is limited.

The research design for this study was a qualitative case study based upon the characteristics outlined by Yin (2014). Qualitative researchers attempt to understand the worldviews of people through their real life experiences (Yin, 2014 & Hanna, 2012). Secondly, the researcher is the main tool for data collection and evaluation; that is to say, the researcher can be dynamically involved in the study by generating and sustaining a connection with the participants so that rich and exhaustive data can be acquired through words and images rather than numerical data. Other characteristics associated with qualitative research include normal environments, various sources of data, inductive data analysis, participants’ values, and evolving strategies (Yin, 2014). The researcher must attempt to remain unbiased and objective throughout the data collection phase.

I considered other qualitative methods for this study, including a social media analysis, phenomenology, and ethnography. I rejected a social media analysis because it did not adequately answer the research questions for this particular study. I wanted more information than that which would result from conducting a social media analysis of the interactions amongst members. I wanted to hear directly from the study participants. I also considered phenomenology because it allows for access to an in-depth understanding of the essence of each participant's experiences in the diffusion process. However, phenomenological methodology focuses on extensive interviews and does not require multiple sources of evidence; therefore, a rich description of the learning and instruction in online support groups might not be possible. I also considered ethnographic research because of the descriptive nature of the method; however, the purpose of ethnography is to describe and interpret a social group (Maxwell, 2013). The goal of my study was not to explore a social group during an extended period of time in the field, but rather to identify the learning and instruction occurring in the Facebook setting. Therefore, I rejected ethnography as a possible research design.

The final characteristic that influenced my choice of methodology is the inductive nature of qualitative research. Simply stated, in a case study, data are collected and analyzed to build concepts. Since the phenomena I studied were the learning and instruction occurring in an online social networking support group, the participants' perceptions of those phenomena were the most important data sources.

Setting

Facebook is an online social networking website that was founded in 2004. After registering for Facebook, users can create personal profiles; add other users as their friends; exchange messages similar to email; and post status updates, photographs, videos, and links to other articles or websites. Additionally, users can also create or become members of common-interest groups, support groups, workplace groups, schools groups, and groups based on any other type of characteristic. It is important to note that

Facebook has privacy settings that allow the individual or users to set the parameters. The privacy settings include: (a) “Who can see my stuff,” (b) “Who can contact me,” and (c) “Who can look me up.” This is important to note, because if a user wants to join a Facebook group, they need to know that some are open and some are closed. Closed groups can be defined as those that require permission to add an individual to the group. It is up to the group administrators and member to accept the private groups’ rules. The group administrators attempt to keep interactions within the group positive and supportive. Administrators also follow the group bylaws and remove comments or posts that do not follow the bylaws for that group. According to an anonymous administrator of an RSD closed support group (personal communication, February 18, 2015), “administrators keep things moving smoothly, find support groups for members to attend, being a listening ear, problem solve, and create opportunities for advocacy.” The group determines what and who is to be accepted in it. Some groups want to make sure you are a good fit (share the same illnesses, share similar demographics, and share similar interests). For example, when attempting to join a closed Facebook support group, I had to tell my personal story to see if I was the right match for the group. Often times, the individual will be accepted, asked further questions privately, or asked to share his or her story. It is then that the group administrators will either accept or reject these individuals. The RSD/CRPS Fighting Warriors was an open/public Facebook support group that was the focus of this study. This group is comprised of nearly 150 members. Although members are parts of other groups, open and closed, there are members from all over the globe including Canada, India, and Australia. While this online support group allows members from around the world to join and participate as active members, they must behave according to the bylaws of the group. In addition, the open group status enables anyone to join without restriction, and anyone can add other individuals to the group.

I gathered two sets of data:

1. Open-ended interviews with individual members of the Facebook page.
2. Observation of Facebook page.

Interviews

In order to obtain an in-depth understanding of the participant perceptions of the learning and instruction in their Facebook page, semistructured interviews were conducted. The research questions and sub-questions were the basis for the questions during the interviews with the members who have RSD, caregivers, and medical professionals. The interview questions focused on how and why the participants use social media outlets, such as Facebook to join a support group, and their perceptions of the learning and instruction that occurs in the Facebook group. Each participant signed an Informed Consent Form (see Appendix B). Each interview allotted one hour, which were conducted by telephone.

Once approval was secured from the IRB 8-20-15-0316006, I chose a 2-week period from which to analyze the Facebook page. The interviews were conducted congruently with the data mining of the Facebook page. All interviews were audio-recorded using the digital application, GarageBand, and subsequently transcribed. I transcribed each interview. Each transcribed interview was stored in my password-protected laptop and backed up in a password-protected external hard drive locked in my home safe. The analysis of the data took place in my home office, and the data were kept in my locked personal computer.

Digital Data Mining

Digital data mining was used to extract data from the Facebook page. Digital data mining includes online documentation in participant status updates, shared photographs, emoticons, article sharing, and other information posted. There are three distinctive kinds of data mining: demographic, behavioral, and psychographic (Sevindik & Demirkeser, 2010). Demographic data are usually the kinds of data that are easily obtainable, such as individual characteristics, age, sex, educational level, marital status, and racial origin. Compared to the other data mining types, these are easy to obtain. Behavioral data are acquired through measuring a particular process and action. According to the characteristics of the area observed, data such as dates, types of status updates, feelings, medical processes, and communication between members will tend “to give better results in estimating behavior” (p. 3216). Last, psychographic data is information acquired from views, beliefs, and attitudes. Data mining enabled me to analyze the content posted in the Facebook group. Members’ posts were analyzed to determine what they were sharing and discussing. Information sharing that occurs within the group was interpreted. The behaviors of the group members were determined as a result of the analysis. I compared and contrasted data collected from the participant with the data mining of the Facebook group. Themes and patterns emerged. Data collected from this Facebook support group are discussed in the Data Analysis section.

Ethical Considerations

Researchers should focus their attention of ethical concerns when managing a study. It is critical that the participants be safeguarded from harm, that their information remains confidential, that permission is acquired, and the concern of dishonesty must to be contemplated (Merriam, 2009). Walden University has a well-defined method through the process of the Institutional Review Board (IRB). Associated with these procedures, data collection and analysis occurred once IRB determined that the benefits of the study of the Facebook group and page outweigh the threats to participants. In compliance with IRB protocol, processes, members with RSD, caretakers, and medical professionals, and the RSD/CRPS Fighting Warriors Group were not approached and data was not collected until IRB approval was secured.

Each participant was asked to sign a consent form (see Appendix B) agreeing to participate in the study. Full understanding of the terms and conditions and approval of the study prior to participation was secured. Participants understood that they could opt out of the study at any time without consequences. I was aware that even though social media is typically a public environment, the participants of the study had the right to their privacy. Participants in this study (a) fully understood and consented to being interviewed and their posts analyzed, and (b) understood that the purpose of the research was to identify the learning and instruction occurring in online support groups.

Role of the Researcher

I was interested in online support groups for two distinct reasons. First, I was heavily involved in multiple social media support groups, which includes several social media sites for people with RSD and RSD caregivers. Secondly, I was interested in social media support groups because I wanted to identify how participants in virtual support groups experience learning and instruction.

I am a veteran RSD member and involved in the RSD/CRPS Fighting Warriors Facebook group. Because I have RSD and have been educating in the Facebook group for the past 5 years and the group is the principal site for this research study, this Facebook group posed benefits and biases. I was still involved in the Facebook group, but during the data collection and analysis process, I became private and no longer heavily involved. I considered myself an active member as I have not left the group but I lowered my profile. I no longer responded to status updates, I did not share information, I no longer answered questions asked specifically to me or generally to the group, and I stepped down as one of the administrators of the group. I was not as active in order to ensure that researcher bias was minimized and there were no communications or posts that could be detrimental to or have a persuasive effect.

Ever since my diagnosis of Reflex Sympathetic Dystrophy, I have encouraged friends, family, physicians, other medical professionals, and fellow RSD Warriors the benefits of joining a support group. I understand that I am not a physician or consultant, but having RSD for nearly 20 years, I am considered very educated on the topic. I also acknowledge the provocation for research on the topic of online support groups comes from a life-long learner and a proponent of education as dominant theme in making decisions. This acknowledgement of potential causes of preconceived viewpoints and biases could have lessened the likelihood of this studies discoveries being affected by preconceived philosophies and prejudices.

My role was that of a participant as an observer, meaning that I acted as the data-gathering instrument. In quantitative research, the data are typically collected through surveys, questionnaires, tests, scales, and other measureable tools (Hatch, 2002); whereas in qualitative research, the researcher serves as the data collection instrument (Yin, 2014). The data frequently contained “field notes from participant observation, notes from or transcriptions of interviews with the informants, and unobtrusive data such as artifacts from the research site or records related to the social phenomena under investigation” (Hatch, 2002, p. 7). During the observation analysis of the support group, I took field notes for a specific period.

Researcher biases rarely occurred as I gathered and evaluated the data. The key cause of biases contains features of the evaluator, the features of the participant, and the fundamental content of the inquiries (Yin, 2014). First, there may be a chance that researchers may find what they are looking for through careful notice to features and discerning clarification to data. Second, investigators may choose contributors who imitate established preferences and prejudices. Therefore, to prevent some biases of this qualitative case study, I followed the sampling approach summarized in this study, and I used an assortment of sources and techniques to gather, validate, and explore the data. I mentioned earlier that I kept a reflexive journal during the data collection and analysis phase of the study. This journal allowed me to record my experiences, beliefs, judgments, and feelings during the data collection process.

Concerning this qualitative research study, I conducted and digitally taped all semistructured interviews of the participants: RSD members, caregivers, and medical professionals. In addition, recorded interviews were transcribed, and I coded the data. I took field notes of the Facebook page, as well as investigated and translated all interviews.

Participants

Using a purposive sampling technique, the participants of this study were drawn from the 150 members of the public RSD/CRPS Fighting Warriors Facebook Group. Ten participants were chosen for the interviews: (a) six members with Reflex Sympathetic Dystrophy, (b) two caregivers of Reflex Sympathetic Dystrophy individuals, and (c) two medical providers who treat Reflex Sympathetic Dystrophy. I attempted no communication with the members until the study proposal and the Institutional Review Board (IRB) application were approved. Furthermore, I was not an active participant of the group in order to ensure that researcher bias was minimized and that there were no communications with members or posts on the Facebook site that could have been detrimental to or have a persuasive effect on the study.

The purposive sampling was required to understand the learning and instruction that occurred in online support groups. It has become evident that in time, many members who are a part of the RSD/CRPS Fighting Warriors Group are also members of other online support groups, but that those groups are closed to public access. The purpose of the selection phase was to create a list of 10 active RSD/CRPS Fighting Warriors Facebook Group participants.

A critical analysis was used to rank-order collected names of people with RSD, caregivers, and medical professional candidates in the Facebook group. These criteria required that members have extensive collaboration and information sharing as evidenced by their posts, status updates, uploaded photographs, and educational materials. Members with RSD participants had an established membership in the Facebook page for a minimum of 3 months. Caregiver participants had an established membership of 3 months in the Facebook group, and they must have worked directly with an individual with RSD on a daily basis. Medical personnel participants were members of the Facebook group of at least 1 month. Medical personnel needed at least 1 year of experience having cared and treated individuals with RSD at the time of the study. Participants were agreeable to communicate on the telephone for a one-hour, recorded interview. Once IRB gave approval, the members were contacted to assess the level of interest and commitment to the study.

Participants who met these requirements were sent a private message through Facebook (similar to an email) inviting them to be a part of the study. The participants for this study were secured by inviting members of the RSD/CRPS Fighting Warriors Facebook Group with no previous contact with or participation from other Facebook online support groups after the approval of the Walden Institutional Review Board (IRB). Each private message included the consent-form (see Appendix B) and requested the participants read, electronically sign, and date the form, and return it to me at heather.gilmore-dooley@waldenu.edu. The returned consent to participate followed up with a private message to set up an interview. The private message also requested for a convenient time and date for that participant and me. The interview-schedule private message requested participants ensure the date they selected had a minimum of 1 hour in which they had no outside distractions (except for taking medications, a break, flaring, or caring for a person with RSD) or appointments.

Instrumentation

A case study is both the methodology and the data collection. Data from two sources were collected to answer the research questions. Table 1 shows the data sources for each of the research questions.

Table 1

Research Questions and Data Sources

Research Question	Data Source
RQ 1: How does social networking enable learning in an online support group?	• Open-ended and semistructured interviews with members who have RSD, Caregivers, and Medical professionals who are members of the Facebook page • Data mining of Facebook page/Content Analysis
RQ 2: How does social networking enable instruction in an online support group?	• Open-ended and semistructured interviews with members who have RSD, Caregivers, and Medical professionals who are members of the Facebook page • Data mining of Facebook page/Content Analysis
RQ3: What are the perceptions of the Reflex Sympathetic Dystrophy participants regarding learning and instruction in online social networking?	• Open-ended and semistructured interviews with members who have RSD, Caregivers, and Medical professionals who are members of the Facebook page • Data mining of Facebook page/Content Analysis

Data Sources

Oral questionnaires were developed for this study. The participants were asked to respond to unambiguous statements/questions about their perceptions of learning and instruction in the Facebook support group (see Appendix A). Interviews were a method applied through verbal communication to collect information that could not be observed. Such information contained participants' feelings, interpretations of a certain event, and/or descriptions of past events (Merriam, 2009). The interviews were both structured and semistructured (see Appendix A). Each interview consisted of multiple questions, avoided jargon, and avoided leading questions (Merriam, 2009). The interview was open-ended to offer chances for supplementary questions that allowed for deeper inquiry into certain components of the phenomenon under study. The questions were written this way to reduce researcher prejudice and subjectivity concerning involvements with RSD Facebook support groups. Involvement, performance, and knowledge questions were used to gain evidence from members concerning the learning and instruction that occurs in this online RSD support group. Attitude, emotion, and sensory questions were used to establish individual perceptions of each participant about several characteristics of the phenomenon to conclude the impact this data had on the data set. Throughout the interviews, each participant was asked to conduct a single audio-recorded telephone interview. I transcribed each interview. Steps were taken to prohibit researcher bias, assumptions, and prejudgments.

The second method that was used is a content data analysis. Content analysis is commonly used in qualitative research. Existing purposes of content analysis describe three definite methods: conventional, directed, or summative (Hseieh & Shannon, 2005). Each approach used allows for interpretation of the content of data that follows real-life examples for a case study. The major differences among each are: coding patterns, backgrounds of data, and risks to reliability. This proposed study used a conventional content analysis. More specifically, the coding categories were originated straight from the texts, photos, emoticons, and status updates data from the Facebook support group. During the content analysis, the following was observed: for word-frequency, content categories, and correspondences (Conger, 1996). During the content analysis, an observation sheet was used to keep notes. From the moment that the IRB approved the research study, I began my content analysis for a 2-week observation of the Facebook group. This is important because the content was new and fresh without the potential of allowing any of my personal status updates that could hinder researcher bias as well as hinder the credibility of the study and the data from the group.

Data Analysis and Interpretation

The preliminary phase in qualitative analysis is interpreting the interview records, observational summaries, or documents to acquire provisional concepts about classifications and associations (Maxwell, 2013). The case study interviews integrated social media and connectivism concepts (outlined in Chapter 2) through insightful questions that generated replies of authentic experiences and knowledge suitable for fullness in this study. The first stage of analysis involved categorizing the data by making the interview records and unassuming data which included discovery, filtering, and explaining ideas, topics, and occurrences. During the second phase, I read and listened to all of the data “and keep notes and memos on what you see or hear in your data, and develop tentative ideas about categories and relationships” (Maxwell, 2013, p. 105). I began the coding process by color-coding the interviews. Coding interviews includes labeling patterns, ideas, themes, and events that were readily obtainable to assess all of the data that suggested similar focuses across all the interviews (Rubin & Rubin, 2005). After coding the interviews arrangement of the data was assembled by all of the identical data components into groups and then explored for the topics, patterns, themes, events, or inconsistent cases. In the final stage, I reviewed the discoveries using tables, photographs, and screen shots. Finally, interpretation of the data in the final stage of the data analysis process occurred. In fact, Merriam (2002) noted that there are several ways of reporting the findings, as well as there is no standard format for reporting qualitative research. For instance, a variety of status updates was used to report the findings. I looked to use rich, heavy expressive interviews and observations to understand the outcomes of the research study. The plan was as follows: classify and discuss the research problem, purpose of the study, and the research methodology; explain the case and its situation, present and review any significant matters that related with the instance; and review the investigators understanding of the research study (Yin, 2014).

Issues of Trustworthiness

Maxwell (2013) asserted that validity in a qualitative research study is not the same as validity in a quantitative study. For instance, validity in a quantitative study refers to the results that have no guarantee by following typical, established measures. Rather, it varies on the connection of your inferences to authenticity, and no approaches can entirely guarantee that you have captured this. Validity in a qualitative study refers to whether the study was conducted in a thorough, methodical, and ethical approach, such that the outcomes can be reliable (Merriam, 2002). The following tactics were used to authenticate the research: triangulation by means of telephone audio-recorded semi-structured interviews, focus group, and discreet data.

In exercising a qualitative case study method, it was important that the research discovers, investigates, and establishes truthfulness and reliability in the study. Qualitative research was filled with description and outcomes that does not follow inflexible restrictions (Thomas & Magilvy, 2011). Researchers generally have previous understandings and information being brought into the study, but it was essential for me to put away my personal biases regarding RSD and truly listen to my participants.

According to Thomas and Magilvy (2011), qualitative thoroughness or research validity was established in the researcher because they use themselves as a tool of examination. Consequently, I was capable to focus on participants' perceptions and meanings through their lived experiences. Reflex Sympathetic Dystrophy participants' stories are complex. Due to the members' complex stories, I had to involve tactics to confirm the accounts remained interpreted in a significant and reliable manner. A few strategies were used, such as triangulation (Yin, 2014), not cutting interviews short, and tenacious observation. However, what improved the study's trustworthiness were credibility, transferability, dependability, and conformability. These subjects will be further explained in the following part.

Credibility

I am knowledgeable about Reflex Sympathetic Dystrophy because I have been diagnosed for 12 years and ultimately, have had it for 20 years. I was actively involved in the RSD/CRPS Fighting Warriors Group for 5 years; however, I was not an active member during the time of study. As an active member of the RSD community nationally, I had gained trust and respect from collaborators, fellow RSD warriors, and the association, which makes me capable of carrying out this research study in the RSD/CRPS Fighting Warriors Facebook group. However, it is through interaction in these online social support groups that I have been able to network, observe, talk, and read about others. The themes that were found through digital data mining were double-checked with the interviews. This approach maintained “triangulation of data and is recommended as an activity that increases credibility in qualitative inquiry” (Arteaga, 2012). It is important to note that ethical reflections and confidentiality declarations did not need direct quotes from the Facebook support group.

I kept a reflexive journal during the data collection process. Journaling allowed me to further clarify how I was feeling, what was being said, and it was a way to validate each participant that helped increase credibility. Reflexivity can be communicated in positions of association, evaluation, and different explanations (Tribe, Xiao, & Chambers, 2012). This allowed me to check what I was reflecting on and helped me understand what my participants were sharing, and I was able to peer check.

Transferability

Transferability suggests that the outcomes of qualitative research can be generalized or shifted to new circumstances or situations. From the qualitative standpoint, transferability is mainly the obligation of the researcher. By conducting a comprehensive position of describing the investigation and the assumptions that stayed fundamental to the research, transferability is improved. This qualitative research intended to provide to a better understanding of learning and instruction in online social support groups (Koos, Mouret, & Doncieux, 2013). Additionally, transferability of this study allows others to gather comparable data and related inquiries (Smart & Paulsen, 2011). More research with online social support groups will be vital to consider the strength of the conclusions.

Dependability

The appreciation of dependability stresses the necessity for the researcher to justify the evolving setting in which the study transpires. The investigator is accountable for telling the deviations that happened and in what way these variations affected the manner research managed the investigation (Koos, Mouret, & Doncieux, 2013). Descriptive narratives were used expending raw data and thematic organizing which assisted to lead to expand credibility, transferability, and confirmability (Merriam, 2009, p. 229). Trustworthiness is recognized when the members legitimize the reliability of the background as deciphered by the researcher (Koos, Mouret, & Doncieux, 2013).

Confirmability

Qualitative research generally acknowledges that each researcher carries a distinctive perception to the study. Confirmability suggests that the studies outcomes can be established or supported by others (Koos, Mouret, & Doncieux, 2013). There are continuously various kinds of approaches to improve confirmability. It is central that the researcher, keep documentations of each method for confirming the data during the study. Additionally, the researcher may perform a data review that inspects the data collection and evaluation methods and builds conclusions concerning the possibility for bias (Koos, Mouret, & Doncieux, 2013). Data gathered from the interviews and Facebook support group were used and compared with the evaluation, interpretation, and results of all members' responses. The purpose was to accomplish an increased amount of confirmability that ultimately raises the trustworthiness and validity of the research.

Summary

In Chapter 3, I explained the methodology that was used to examine learning and instruction in online social networking support groups. The research design for this case study was qualitative and a purposeful sampling was used as a sampling approach to choose members. I was the key instrument for collecting, dissecting, and translating the data gathered. Triangulation, daily group observation, and spending extended time in the field were the anticipated tactics expended to warrant the value of the research study. All ethical principles and parameters that are defined by Walden University were maintained. Section 4 presents a discussion concerning the research outcomes.

Chapter 4: Results

The purpose of this study was to explore the learning and instruction that occurs among members in a virtual social networking Reflex Sympathetic Dystrophy (RSD) support group using Facebook. The following three research questions guided my study:

1. How does social networking enable learning in an online support group?
2. How does social networking enable instruction in an online support group?
3. What are the perceptions of the RSD participants regarding learning and instruction in online social networking?

The first section of this chapter includes descriptions of the study's setting, participants' demographic information, and my data collection methods. In the second section, I offer data analysis and provide evidence of research trustworthiness. I have organized research findings under the themes and patterns that emerged from the participant interviews and my observation of the Facebook support group RSD/CRPS Fighting Warriors group.

Setting

The setting for this research had two levels: (a) participants' digital world and digital footprints of the public Facebook support group RSD/CRPS Fighting Warriors, and (b) the physical locations where participants participated in recorded and transcribed telephone interviews. My research focused on the digital rather than the physical setting. The themes I extracted from the data were developed in the context of the Facebook support group RSD/CRPS Fighting Warriors and were influenced by the participants.

Demographics

The 10 RSD group participants lived in the United States. Each group participant was a member who has RSD, caregiver, or medical professional. Participants were designated “Participant 1,” “Participant 2,” and so on to protect their confidentiality. Participants 1-6 have RSD. Participants 7 and 8 are RSD caregivers, and participants 9 and 10 are RSD patients and nurses. Out of the 10 participants, only two were male while the others were female. All ten participants had used Facebook RSD support groups for periods ranging from 1-8 years. Each RSD participant had been diagnosed between 3-33 years ago. Each caregiver had been a caregiver for 3-4 years. Each medical professional was a nurse who also had RSD. They each had never heard of RSD until they were diagnosed and began treatment for RSD between 3-7 years ago. Table 2 provides the participants’ demographic information.

Table 2

Demographics: 10 RSD/CRPS Fighting Warrior Members

	Pseudonym	Gender	Years of diagnosis/care	Years participated in online social support groups
Participant 1	Ron	M	3	3
Participant 2	Rosemary	F	4	3
Participant 3	Rudy	M	3	2
Participant 4	River	F	3	3
Participant 5	Reese	F	33	4
Participant 6	Rhonda	F	12	8
Participant 7	Catherine	F	4	4
Participant 8	Casey	F	3	3
Participant 9	Nicole	F	3	3
Participant 10	Nikki	F	7	6

I used the following codes throughout the study to track which participant had RSD, a caregiver, and a medical professional. I assigned a pseudonym beginning with an "R" to all participants with RSD. All the pseudonyms beginning with "C" are the caregivers. Last, each "N" reflects the medical professionals working as nurses. I have not used participants' real names in order to protect their confidentiality. Throughout this chapter, an R, C, or N will appear beside the participant number. However, I also use the pseudonyms in conjunction with the participant number.

Data Collection

Yin (2014) suggested that the use of qualitative data helps one "gain in-depth examination of a case within its real-world context" (2014, p. 220). In this section, I present details about how I collected the data and then offer the data analysis. I interviewed ten participants. Each interview lasted no longer than an hour, and I conducted the interviews over a period of two weeks. During those two weeks, I also collected data through observation of the Facebook RSD/CRPS Fighting Warriors group. The data collection methods occurred congruently.

I conducted focused, semi-structured interviews with ten participants from the Facebook support group RSD/CRPS Fighting Warriors. I developed seven interview questions (Appendix A) to draw data from the members. The interview questions focused on how and why members used social media support groups rather than traditional face-to-face support groups. Each participant signed an Informed Consent Form (Appendix B) prior to the interview. One-hour interviews produced the main data, and I conducted all ten interviews via telephone.

I audio-recorded all interviews using GarageBand software, and transcribed them using Microsoft Word software. Files were kept secure in my password-protected laptop and locked in my home office. The analysis of the data took place in my home office, and the data were kept in my password-protected locked personal computer. The only variation in data collection was that each interview was allotted a 1-hour period, however seven of the ten interviews lasted less than 45-minutes.

I did not need to gain permission to explore the public (open) Facebook support group, RSD/CRPS Fighting Warriors for the purpose of the research. I used digital data mining to obtain records from online documentation. The data that I collected were posts from members, posts from the participants, photographs, emoticons, upcoming events, comments to initial posts, and linked research studies. Digital data mining is a technique that looks for patterns or clustering of similar kind of words. Frequently-used terms to show similarities between stories, news, emails, status updates, and information sharing (Agnihotri, Verma, & Tripathi, 2014). I Observed the group during the same 2-week period that I conducted the interviews. My observations took place in my private home office from my computer. Additionally, during this 2-week period, I would use my mobile devices to observe the group when I was away from my computer. I observed the group each day during the 2-week period for 3 hours each day, totaling 42 hours of observation. I then analyzed data for themes and patterns. I compared and contrasted data collected from interviews and Facebook postings to identify themes and patterns. I treated and coded data gathered from Facebook using the same approach as that used for the interview data.

There were no prominent or abnormal situations encountered during data collection. Synchronous interviews required careful scheduling. Even though I considered schedules, one interviewer placed me on hold for twenty-minutes while she took care of her duties. All interviews were successfully recorded during the initial attempt.

Data Analysis

In this section, I describe the data analysis process and coding in detail to support research replication. Miles, Huberman, and Saldaña (2013) have stated, "coding is analysis" (p. 45). Silverman (2005) has noted that the investigator engages a reflective rewriting of the past with an unidentified attitude on the contributing difficulties with which the inquiry is concerned. To understand this unidentified outlook, I focused on what the collected data implied about the learning and instruction of members who belonged to an online social support group. The coding and theming method occurred organically.

Manual Coding

Manual coding focused on identifying commonalities in the raw interview data. My data analysis facilitated the inductive emergence of coding categories. First, I manually coded the transcribed interview texts and linked associated categories to text strings, phrases, words, or paragraphs for each of the ten interviews. Second, I manually coded the raw data from the Facebook RSD/Warrior Fighting Warriors support group. This allowed me to create themes, subthemes, and associated categories. Initial and emerging themes are presented in Appendix C. Third, patterns emerged and linked back to the main research questions. I used a similar process to analyze data gathered from both interviews and social media group observation. Based on the data analysis, four distinct themes emerged that represented the perceptions shared by participants: (a) knowledge, (b) persuasion, (c) learning, (d) underlying results.

Themes

Theme 1: Knowledge

Participants described a sense of being more informed from the support forum than from their medical providers. Siemens (2005) noted that informal learning is an important feature of twenty-first century learning experiences. He additionally explained that learning today happens in an assortment of means within groups, personal networks, and technology. Technology and connection moves learning out of formal educational settings to situations where individuals learn through individual competence and personal experiences. The interviews resonated with Siemen's theory when participants expressed how much information they gained about RSD through their connections in the virtual RSD support group. Thus, the foundations of Siemen's connectivism theory, described in Chapters 2 and 3 confirmed that personal knowledge is comprised of a network, which in turn feed backs into that network. This kind of information-sharing concerning Reflex Sympathetic Dystrophy individuals, caregivers, and medical professionals increases because of the exchanges and interactions in the social media support-group environment. The statements below are some of the interview responses from the question "Why did you decide to join a Reflex Sympathetic Dystrophy (RSD) Facebook support group?"

Ron: I was lost and never heard of it. I gained more information in the support group than I did using Google or seeing my doctors.

Rosemary: I needed more information. I needed more support than what I was getting from home.

Rudy: I felt it was important so I could learn about others experiences and compare them with mine. I did not understand what was going on so I wanted to learn from others.

River: I was originally looking for a local face-to-face support group, but there wasn't one, so I did the next best thing. I needed someone to understand what I was going through and I need resources.

Reese: It was not until I joined the Facebook group that I found people with this condition. Finding others support, information continues to be a huge part of my life.

Rhonda: It is a way for me to connect with others like myself who are experiencing the same things. It's always informative because people will share doctors, treatment options, disability options, and particular types of insurance especially Medicare.

Catherine: Gain knowledge of the disorder and to find support for both my daughter and me as her caregiver.

Casey: Initially I joined to gain more information to assist my husband and the needs we have to combat the disease. Later on, it has turned into support and supporting others.

Nicole: I liked that it was anonymous and easy to travel great distances. I needed information about the disease too. I had never heard of it even as a nurse.

Nikki: It all came from me feeling isolated. Got tired of being alone. Never had a full grasp of what was happening to my body and I wanted information about it.

Each participant shared their feelings as to why they chose to join the Facebook support group. It was expressed through the sharing of joining the group that each participant also realized how informative the group was. They expressed that they would look for specific information regarding certain treatments, medications, surgeries, protocols, specialists, and relationships. The yearning for information was abundantly clear from each participant. The support group helped the members gain information for themselves that was lacking before joining the group. Although the mood and tone of the group was mostly positive, there was negativity spoken directly from each participant. However, the negativity was not based on the information that was gained; rather the participants had gained positive information that increased over time belonging to the group.

Theme 2: Persuasion

Participants had numerous opinions and described different experiences as enriching their knowledge and learning experience. Phrases such as, “Sign this petition,” “Scare tactics,” “Good doctors versus bad doctors,” “Standard or non-standard treatments,” “Current research articles” “Motivational,” “Inspirational,” “One should do…” were communicated repeatedly during the interviews. In the literature review, I indicated that extensive research has supported the use of traditional support groups as a desirable practice in feeling respected and supported (Booth, 2012). Therefore, online support groups stimulated disclosure and offered interaction with comparable others (Anderson, 2013) which was shared by these ten participants. The following responses were prompted by the interview question, "What types of information is shared?"

Ron: I would say that treatment information is shared on a daily basis.

> Questions are always being asked and there are many different opinions given especially about a doctor or particular treatments.

Rosemary: People tend to share their story of how they got RSD and they

> share good and bad information from personal experience. They share different treatments, meds, ideas, motivation, and never giving up hope.

Rudy: I appreciate the shared motivational quotes and inspirational photos.

> Particularly people who I know suffer worse than me and are traveling and smiling. This is so helpful because it brings my spirits up. Also, in the "Man Cave" group people bring up what treatments, doctors, and how to go about things are shared. Often times you will get someone in there that thinks they know everything and attempt to take over the group.

River: Treatments, emotional feelings, a lot of feelings, medication types,

> how their pain levels are, how they are feeling, how their coping and what works, and current stressors are shared which sometimes comes across as pushy or persuasive.

Reese: One of my concerns that happens a lot is that I don't respond to popularity contests. I don’t think organizations should have figureheads. There would be fewer power problems if people just wanted to collaborate and not attack others because they didn’t follow their particular treatment or go to their particular doctor that stuff creeps me out.

Rhonda: Online petitions for certain drugs to be accepted by FDA to help people with chronic pain are often shared. New medical articles are shared and we are told that we should try these options. We are persuaded by the passion behind people on which doctors to see and what treatments have worked for them even though we are all very different.

Catherine: Coping skills are very important and often times shared on a daily basis. Medications, treatments, and what professionals who you should and should not see are heavily suggested.

Casey: Someone will share a research article about a particular procedure and push that everyone read the article and that it is the next new cure. Treatments and medications are shoved down our throats at times and sometimes it’s not warranted. Often times, especially as a caregiver counseling is involved but it is not asked for rather just given. Bad advice like placing ice on the affected limb scares me because that can make the RSD spread.

Nicole: People are looking for the answer and sharing their daily struggles. RSD has no logarithm but you hear about treatments that work and don’t work for others. It’s challenging sharing medical information and being so hopeful, you want the same feeling if the outcome is positive for one.

Nikki: I think people are careful not to give medical opinions even if we are medical professionals ourselves. They will say this is what worked for me and I urge you to try this, even if our bodies react differently.

While persuasion is occurring in the online social support group, it is difficult at times to decipher between persuasive or informative. However, the participants in the group and I both could clearly see the difference. For instance, when the participants used the words, “urge”, “go to ____”, “he’s the best”, “don’t go there” and “don’t do that”, it becomes evident from the participants perception that individuals feel strongly about particular topics brought up and they will express it, even multiple times. It is with this theme of persuasion that the participants agree and through the observation of the group, that persuasion is another layer that is occurring within the support group.

Theme 3: Learning

Participants revealed several recurring themes during the interview such as different treatment options, doctors, different social security processes, worker’s compensation hearings, claims, settlements, new research, and experimental treatments, from being part of an RSD-support group. Participants shared that the experiences of others in the group helped them address many of the same issues and concerns they had about the illness. The participants concurred that they learned more from the online social networking group than from their medical professionals. The theory of connectivism anticipated that within social networks, personal knowledge and development allows learners to remain current through the connections formed (Siemens, 2005). Participants noted that when learning about the disease and the medical community was absent with ideas, the RSD Facebook social support group was there to discuss or answer questions at any time of the day.

The literature review in Chapter 2 indicated that for many individuals who are a part of support group feel a sense of belonging and find their identity, but learning has not been studied. Therefore, findings confirmed that group members, by giving the members information and knowledge that they were not getting elsewhere, substantiated learning from shared experiences. Additionally, the information given by support group members often helped in challenging times. Brown (2002) explained that the Internet influences the development of learning, knowledge and understanding within the extension of an individual's network is the personification of connectivism. Group members are able to offer information, suggestions, and recommendations, because several had inquired related questions at another time or another. The responses below were prompted by the interview question, "What have you gained and learned from belonging to an online social networking RSD support group?"

Ron: I have shared about my neck problems. I shared how I was feeling and dealing with the remodel of my home. I have posted about my most treatment of LDN and how I am doing on it. I have learned more about this disease in the Facebook group than from my doctors.

Rosemary: I have learned about different meds, and doctors. I have learned about some of the mini conferences that I've attended and ones that I wasn't aware of and people directed me to that I wasn't aware of.

Rudy: Talking and learning from others like myself I learned that these same people were still living their life that there was a light at the end of the tunnel and I could keep pushing on.

River: I have learned that I am not alone. I have learned different treatments, how to cope, gained an abundance of support. I've learned that we are stronger in numbers than we are alone.

Reese: I have learned that because of the experience of leading, part of my different information that I learned comes from different people because they find different approaches. I am able to find things more easily. Order comes out of chaos through collaborative efforts. "What we do online in Facebook support groups are on the front lines of mental healthcare because as you know and many of us aren't successful all the time but we keep people from killing themselves, we're doing some good!" (September 11, 2015).

Rhonda: I have learned that it is easier to be open because the connection and tremendous support. I have learned I am not the only one with particular symptoms. I have learned that there are others experiencing the same things. I am not alone.

Catherine: Biggest gain is the knowledge that you aren't alone in this. Also, we learned where to go, who to go to, and different treatments.

Casey: I have learned that there are more people out there than us suffering in. I have recognized that there are a lot of people in pain than I originally believed.

Nicole: I have definitely learned about treatment modalities than maybe

> what my doctors haven't shared with me. I have learned alternative treatments not surgical or typical treatment options but things like supplements, hypnosis, and cannabis.

Nikki: It's opened my mind significantly. I learned that I was not alone

> and not the only one with these symptoms.

Participants shared that through different conversations amongst members and advice given throughout the group, they have learned more from the group than they have from any of their specialists. As a member of the group, I saw first-hand the learning that was occurring throughout the group. It is uncommon for a question to be asked in the group and no one receive a response. Typically, it is quite the contrary. For example, a question was asked about Ketamine infusions. This is a new type of experimental treatment that many doctors and individuals with RSD are attempting. However, there is not much research or information out there about it. The question asked in the group was, "Has anyone ever had Ketamine infusions?" (observed, September 13, 2015)? Within 10-minutes, there were well over 25 responses with different information shared. Some people shared their personal experiences with it, while others shared local clinics, universities, and costs of this treatment. This question only shows a small glimpse into the learning that occurs in these support groups. As you can see from the responses of each participant, they have all learned something. They learned they were not alone, as well as they learned about different treatment modalities, physician information, and most of all more knowledge about Reflex Sympathetic Dystrophy.

Theme 4: Underlying Understanding

Participants stated they were very understanding with misunderstandings, negativity, and/or personal attacks from a comment made, photo shared, question(s) asked, and having different opinions regarding treatments such as spinal cord stimulators. They preferred positive shared experiences and each explained that they attempt to stay away from negativity, so they typically continue scrolling through news feeds or do not comment on a negative post. Nevertheless, there was a mutual understanding with why there were argumentative comments and negative posts. The underlying understanding was the negative attitudes shared. Negativity is often dismissed especially through text because each person understands that chronic pain is 24/7 and it can cause negativity, hostility, anger, irritation, quick to attack, and anxiety. The six participants who live with Reflex Sympathetic Dystrophy used these words to describe the disease, “hell,” “monster,” “torture,” “suffering,” “enemy,” and “brutal.” Hence, acknowledging and knowing that chronic pain is 24/7 with limited relief is understood.

I am fortunate enough to be a member of RSD/CRPS Fighting Warriors group. I was able, on a daily basis, to witness some negativity from other RSD members who were in high levels of pain and the exchanges between the other members. The experiences listed above validated the literature in Chapter 2 under the section Online/Virtual Support Groups. For example, Turnbull (2010) suggested that physical and psychological attitudes emerge when someone is obtaining social support. Similarly, the assertions in Chapter 2 confirmed that emotional support, understanding, and coping strategies includes the crucial need to join a support group especially with specific diseases once diagnosed (Wald, Dube, & Anthony, 2007). No specific question prompted these responses but during answers from the other interview questions, each participant expressed the negative attitude or behavior understanding.

Ron: People are in pain 24 hours a day; inevitably, you are going to have minor issues along the way with the way people do stuff since everyone is in chronic pain you have to give some slack. You just simply brush it under the rug.

Rosemary: A lot of people have workman's compensation issues but I feel that I am shunned because I don't. I know we are all fighting RSD and I certainly feel for those fighting extra battles but I understand how and why people can get frustrated.

Rudy: There are some groups where there is a lot of negativity, which brings people down as well as arguing occurs, but I understand because we live in hell.

River: Sometimes you can't tell the tone through the words on the page and it can be offensive. They may be screaming or yelling but it could be due to the pain so we have to take things with a grain of salt.

Reese: There are a lot of sufferers in anger. People are living with this horrendous and tear your life a part illness, but it's understandable. I do believe though it comes from immaturity.

Rhonda: Drama can occur because people are in constant pain and become passionate about their personal paths or doctors they feel strongly about and you feel like you are being lectured and schooled and they will be very negative towards you.

Catherine: Sometimes you hear treatments that go well for people or they have all these resources and you don't and you become resentful and angry. You feel like you're waiting for your turn for something positive to happen.

Casey: Within a post someone or many will thrash and send mean and insensitive comments toward that individual. I understand people are not thinking clearly because of the pain and medications. A lot of people in pain don't think clearly or rationally due to pain and meds and contributes even more and at time can be negative which is understandable

Nicole: Sometimes it is easy to fall into negativity and understand it because when you are in so much pain, all you want to do rant and rave. It's hard not to get negative with the 24/7 horrific pain.

Nikki: Words through text often times sounds harsh, accusatory, and mean. While I don't condone this I understand because chronic pain makes people on edge and angry.

Although the subject of an understanding of negative emotions was not addressed in the literature, it was an essential theme in the interviews and findings. Most RSD individuals, caregivers, and medical professionals have been through many different stages of the illness. Online support group participants corroborated that, in the age of the computer, smartphone devices, and the World Wide Web, they have a distinctive advantage over others with RSD who have had been living with this disease as far back as 10 years ago. Additionally, participants confirmed that even though there is negativity, most individuals are supportive and understanding at all hours of the day. For instance, for a member with RSD who was flaring and experiencing negative posts, the support group was able to offer reassurance and positive comments that empathized and validated their concerns.

Each theme and subject presented above validated the significance of conducting a case study on learning and instruction in online social support groups. Additionally, the study was essential because it exposed the complicated and overwhelming world of Reflex Sympathetic Dystrophy. Participants mutually averred that that belonging to an RSD Facebook support group impacted their lives markedly. Many participants thought that without the support of the group, they would have felt alone and uneducated about the illness. During the interviews, I realized that most participants recognized that the information given by medical professionals was very minimal from the experiences explained in the online social support group environment. However, many participants were quite open to the different opinions, asking questions and maintaining that the opportunity for successful information gaining depended on connectivism by being in a networked world, which is the very manner of information that is acquired.

Findings indicated that RSD Facebook support groups were a positive experience. Support-group members and participants developed unique bonds with people they would not otherwise have encountered. Participants also described that they had learned more from their RSD Facebook support groups than from their doctors. They did confirm what the literature already says about companionship, identity, and relationships that could only come from individuals in similar situations. Moreover, these experiences of learning and instruction in an online RSD social-networking group came from those members who are a part of numerous support groups both virtually and face-to-face.

Evidence of Trustworthiness

In using a qualitative case study approach, it was critical that the research investigates, assess, and establish accuracy and reliability in the study. Qualitative research was a journey of description and discovery that does not follow inflexible restrictions (Thomas & Magilvy, 2011). Researchers tend to carry past experiences and knowledge into the study setting, but as a qualitative researcher, it was imperative to set aside bias and truly listen to the perceptions of the participants in order to maintain credibility.

According to Yin (2014), qualitative thoroughness or research validity in qualitative research was established in the researchers using themselves as an instrument of exploration. Consequently, I was able to learn study participants' individual interpretations of their perceptions, experiences, and meanings. Qualitative researchers try to comprehend the experiences of members and use their skills of observation and quantifiable analysis to produce substantial results.

Trustworthiness of a study relies on the steadiness of results over time. This study was designed to meet demanding investigation applications. The data gathered, data analysis, and my interpretations remained connected to the initially transcribed records. The study did aspire to have high transferability to other support groups. A summary of trustworthiness categories follows.

Credibility

The interviews allowed me to have open communication with members of one Facebook support group. Semistructured interviews permitted me to have focus for each interview and to have a relaxed environment between each participant and me. Each interview assisted in the data collection process, which allowed me to gain rich and descriptive data. It was through taking pieces of what each participant said and then the observation of the group, that I was able to create personal understandings (Siemens, 2006). As projected in Chapter 3, each interview data was also verified from the online social support group. The observation data became another avenue to each participant as well as other members of the public and open Facebook support group. Triangulation did occur through the use of interviews and the support group data. That allowed my knowledge of virtual and interview data to develop and understand each RSD member. Virtual data were not quoted to certify confidentiality.

Transferability

The results could be transferable to other types of support groups. Future research is recommended because there are several different types of groups (open vs. closed, traditional vs. virtual). From the beginning, the study was not intended to be transferable to different populations, however after the results indicated that learning and instruction do occur in online social support groups, different groups may need to be considered. The purpose of the study was to understand through perceptions of participants and observations that learning and instruction do occur in online social media support groups. It is through this evaluation, the outcomes contributed to an understanding of learning and instruction in informal learning environments. Future research will generate depth in understanding that virtual support groups allow for collaboration and education. As proposed in Chapter 3, academia will also support the significance of the discoveries in time.

Dependability

The exploration of the data was meaningful and iterative. It included physical and virtual sequences. Since I performed each transcription of the audio-recorded interviews and typed observational notes, it could have been possible that manipulation occurred but not on purpose, but from human error. I did not use a software program to find codes, patterns, and themes. All coding was manually conducted. The support group information is dependable because this was a glimpse of virtual support group practices in time. Associated by my attentiveness in evaluation and interpretation of each Reflex Sympathetic Dystrophy participant.

Confirmability

As planned, I conducted an analysis of data. I conducted each interview and observation as planned prior to the study. I did not change anything as explained and approved in the IRB application. GarageBand allowed me record each interview and go back to listen if need be. Through each interview and observation, I was able to create different themes. As planned prior to the study, the researcher conducted a multilayered analysis of the data. The data analysis expressed in Chapter 4 encompassed literal quotes to provide evidence of applicable themes that increased confirmability.

In Chapter 3, I said that there would be follow up interviews. These follow up interviews were not completed. After the first interview that lasted approximately 45-

minutes, the participant was eager to get off the phone because the pain was beginning to rise. Additionally, since I also have RSD, I realized a few things: (a) I would be able to get all the information that I needed from each interview, and (b) My pain levels during and after each interview were high as well and I needed to lie down immediately after each interview. Understanding the disease on a personal level allowed me to decide that I did not need follow-up interviews, as I was able to get an abundance of information through each interview.

Results

This section discusses the findings of the study organized by the three research questions outlined in Chapters 1 and 3. The first research question examined the learning in online support groups. As discussed in Chapter 2, extensive research has supported the use of traditional support groups as a desirable practice in feeling respected and supported (Booth, 2012). Additionally, research has confirmed that face-to-face support groups positively influence learning (Booth, 2012). Traditional support groups provide opportunities to gain new information about their disability.

Research Question 1: How does the social networking site Facebook enable instruction in online support groups?

The participants in this study consistently expressed that without online support groups they would not know about RSD as much as they do because, they have learned more about the disease in the online groups than from their medical professionals. The participants have learned through information sharing of who (background), what (RSD), when (diagnosis), where (they live), why (they are in the group), and how (personal stories of how they got RSD). Additionally, in the learning section, all participants mentioned each of following regarding what they have learned from being a part of the online support group: coping, acceptance, treatments, doctors (nationally, regionally, and internationally), information about RSD (signs, symptoms, and diagnostic tests), events, and medications. Ron explained that it was not until he attended a face-to-face event that he had met anyone else with RSD. Furthermore, he was unfamiliar with Facebook RSD support groups and was told by this same individual about them. He immediately became a member of the RSD Facebook support group while at the event. Catherine lives in remote location that she was learning about medications and ketamine treatments that she would take the information she was learning about in the Facebook group to her primary care physician and ask for particular medications or treatments. She also learned about ketamine treatments and was able to get the care for her loved one. Rosemary shared, "if it was not for the Facebook support group, I would have never attended the fundraising event in Sonoma" (personal communication, September 7, 2015). Nikki recognized that although she does not condone sharing of medications she realizes that "people aren't looking for answers rather they are looking for different treatment modalities that they maybe are not getting from their providers" (personal communication, September 11, 2015).

Research Question 2: How does the social networking site Facebook enable learning in online support groups?

The second research question observed the instruction in online support groups. The analyzed data revealed participants perceptions concerning instruction occurs once questions, photographs, or events are shared initially in the group. It is inside the threads (initial posts) that instruction transpires. Instruction is very informative. Information shared through questions, photographs, procedures, research articles, treatments, events, petitions, and medications are discussed. Instruction was observed in the Facebook RSD/CRPS Fighting Warriors group rather than interview responses. There are several major instruction topics that are typical: worker's compensation, social security disability, event, and treatments. For instance, a member of the group will ask a question such as, "I am about to attend my first hearing for my case, and does anyone have information to share with me, thank you" (Participant5R, personal communication, September 12, 2015). In the threads you will see minimal comments but a majority will have approximately 20 comments about others sharing what they had went through and give advice and/or instruct the individual on how to prepare, what to expect, how to handle the anxiety of "taking the stand" (observation, September 17, 2015). Furthermore, instruction occurs during important times. Discussion about worker's compensation discusses claims, hearings, trials, names of lawyers, and settlements.

Additionally, a member will ask questions regarding social security disability. An initial learner will ask, "I am ready to sign up for social security disability, how do I get started?" within the thread of comments, other members of the group will respond with, "be prepared to appeal because we are often times denied our first time" (observation, September 13, 2015). Also, "I received SSDI but I don't know which Medicare program to choose, anyone have any ideas" and a common response is "you need to call a

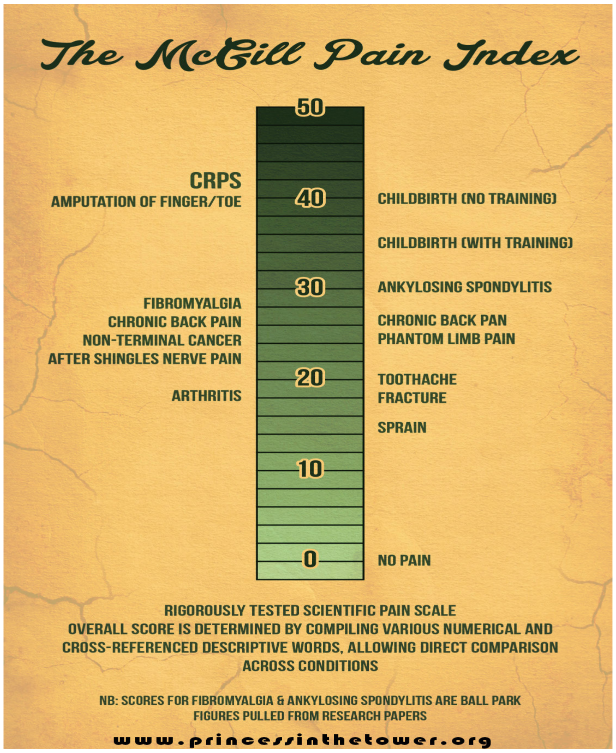
Medicare insurance agent and sit down to discuss all of your options because it can get quite confusing and overwhelming" (observation, September 20, 2015).

The most current primarily discussed treatment is ketamine. Within the group many members will discuss getting ketamine infusions, want information regarding ketamine, locations as to where ketamine infusion treatment is occurring, insurance coverage of ketamine, and overall satisfaction or dissatisfaction of ketamine. Some examples are, "I am going to Stanford for my initial ketamine infusion, what should I expect?" "Has anyone had hallucinations while going through ketamine treatment, because I did and I'd like to know how you got through it", "I'm excited to begin ketamine treatment, can you all please send me positive thoughts and prayers?" "I have been instructed to get a port for my infusions but what if they don't work? " "I am concerned I am not getting the correct protocol for ketamine, does anyone have any suggestions or can you share your experience with me?" (observation, September 4-20, 2015). It is from these initial questions from members that threads begin to expand. Individuals from the group will share their personal stories of ketamine, share photographs during and after ketamine treatment, instruct members to go to certain locations opposed to others. This was especially true with Ron. He shared that his doctor has told him he is a good candidate for ketamine. He is hesitant but said during the interview, "I am not opposed to ketamine, I just do not know if it's right for me now, but when I want information about it, I go through old threads about the topic and look to see what others experiences have shared" (September 4, 2015).

One of the more exciting and uplifting instruction that occurred were events. Members shared many events, set up teams, posted pictures from the events, which engaged other members. These instructional conversations were more inspirational. For example, “There is only 3 weeks left to sign up for QTF Run/Walk/Roll” and within the comments section members would ask, “how do I sign up”, “where is the event”, “is this just for people being treated at USC”, “I did this event for the past 9 years and it is an event that one cannot miss out on” (observations, September 11, 2015). Additionally, more walks were shared from all around the country, including but not limited to the RSDSA Annual Walk, Quench the Fire Run/Walk/Roll, and the San Diego November walk. Also, Paint the World Orange Day, RSD Awareness Months (September is Chronic Pain Awareness Month, and November or NERVember is RSD Awareness Month). Furthermore, face-to-face support group meet ups and times were shared, weekly conference calls, proclamations, conferences, and professional fundraising events are instructed. Members of who attend these events, such as a face-to-face support group will initially post the time and date of the group and then some comments will follow, “I can’t drive to get there but live close, is there anyway someone can drive me to the meet up?” “I attend this support group and you have to go as it’s so important for all of us to have interpersonal connections”, “I wouldn’t be able to get by without looking forward to my monthly support group meeting, it’s a must” (observation, September 15, 2015).

Lastly, photographs shared are instructional. Individuals will share photographs of his or her flare up photographs, informational RSD Warrior photos are shared, treatment photographs, as well as the McGill Pain Index is often shared. During observation, the

McGill Pain Index was shared and discussed 13 times (observation, September 4-20, 2015). Below is a photo of the McGill Pain Index. It’s a scale of rating pain developed at McGill University by Melzack and Togerson (1971) that yields a self-report survey that allows patients to provide their physician a depiction of the amount of pain that they are undergoing (Hawker, Mian, Kendzerska, and French, 2011).



RIGOROUSLY TESTED SCIENTIFIC PAIN SCALE
OVERALL SCORE IS DETERMINED BY COMPILING VARIOUS NUMERICAL AND CROSS-REFERENCED DESCRIPTIVE WORDS, ALLOWING DIRECT COMPARISON ACROSS CONDITIONS

NB: SCORES FOR FIBROMYALGIA & ANKYLOSING SPONDYLITIS ARE BALL PARK FIGURES PULLED FROM RESEARCH PAPERS

Figure 1: The McGill Pain Index.

As the figure shows, CRPS also known as RSD is at the top of the list. This image as stated above was shown and discussed 13 times in a two-week period. The figure is not only a visual aide to instruct members on the severity of the disease, but it is often an instructional guide that members will leave comments such as, “I showed this to my doctor and he finally took my pain seriously", "Make sure to share this with friends and family so that they can understand what you are going through", "Perfect visual so that others can learn and see our diseases severity" (observed, September 4-20, 2015).

Research Question 3: What are the perceptions of the group participants regarding learning and instruction in online social networking?

The third research question examined the perceptions of RSD members regarding learning and instruction in online social networking support groups. As stated in Chapter 2 limited research has shown how best to provide learning and instruction to chronic pain individuals with RSD in a social networking support group environments. Overall, the results indicated that members with RSD, caregivers, and medical professionals perceive that they learn more than they themselves instruct; however, they do find that what is instructed and shared is credible. Casey stated, "I think we are all credible because we are sharing from our hearts and our stories and that makes us as credible as anyone else" (personal communication, September 11, 2015). Additionally, Rhonda explained that "she shares a variety of things such as my personal struggles, accessing treatment, insurance issues, understanding, struggling with family members, because I want to help my other RSD warriors" (personal communication, September 12, 2015). However, in most cases each participant agreed that they had learned more about the disease than from their doctors by being in the Facebook group. Furthermore, each participant said verbatim, "The disease is real" (Participants 1-10, personal communication, September 4-12, 2015). Their perceptions shared that they have been able to make changes in their own treatments/care from learning about the different treatments and medications.

Rosemary shared, “I saw a post about a particular medication. I had not heard of it before but brought it up to my doctor and they put me on it. It has drastically changed my life and I am still on that medication” (personal communication, September 7, 2015). Each participant did share that they feel as though they are the first ones to know about innovations in treatments or trial studies because they would not know about them if they were not a part of the group, even if they themselves are not going to actively do it, they at least know about it. Moreover, each participant in their own way shared the perception that the online support group on Facebook was important and a vital part of their daily lives. They felt that the connectedness and ability to talk to anyone at any time of day (convenience) allowed them to feel as if they were not alone.

Through each interview, it was apparent that each person had some sort of emotion come through. These emotions were very raw and real. Some of the emotions shared over each telephone interview were both positive and negative. The topic is emotional in different ways for each participant group. For instance, caregivers were very angry and felt as if it was their responsibly to get awareness out there about the illness. Members with RSD however were more emotional by either getting choked, nearly crying, or cried. Lastly, the medical professionals were emotional but they were informed, professional, and surprised by what they were sharing. For instance, Nicole stated, “I have RSD so I am more compassionate and understanding when it comes to people overly sharing on Facebook and rather than get upset, I like to share a similar situation that I have lived than come from my nursing background” (personal communication, September 11, 2015). Overall, the results indicated that each participant learns from the group but through their perceptions of instruction during telephone interviews participants did not feel instruction had occurred because they did not share those perceptions. Instruction was in fact occurring, but when observed in the Facebook support group by the researcher.

Summary

The purpose of this qualitative case study was to explore and examine the lived experiences of Reflex Sympathetic Dystrophy individuals, caregivers, and medical professionals who were participants in Facebook's RSD/CRPS Fighting Warriors support group. In Chapter 4, I provided the results of the research, including relevant themes that emerged. This section provided participant demographics, data-collection procedures, data analysis, findings, interview and observation results, and results from participants by themes, categories, and evidence of trustworthiness. In Chapter 5, I conclude with the interpretation of the findings, limitations to the study, recommendations for future research, researcher's reflections, and implications for social change.

Chapter 5: Discussion, Conclusions, and Recommendations

This section presents the conclusions of my qualitative case study. The purpose of this study was to explore the learning and instruction that occurs among members in a virtual social networking Reflex Sympathetic Dystrophy (RSD) support group using Facebook. I conducted the study because current scholarship has not produced a clear understanding of what is learned and taught in online support groups. My analysis helped substantiate the fact that collaboration between members in the support group allows for them to learn and to recognize that instruction does occur. The findings were knowledge, persuasion, learning, and underlying results.

Interpretations of the Findings

This section describes themes that emerged from participant responses to the interview questions and my observation of the Facebook RSD/CRPS Fighting Warriors group. The participants responded to open-ended interview questions about their perceptions of learning and instruction in online social support groups. Siemen's (2004) theory of connectivism guided my development of the interview questions, observations, data collection, and analysis process. Furthermore, connectivism was apparent in the themes I found in the study. Several observations and excerpts from the interviews revealed that without the Facebook support group, participants would not have learned about Reflex Sympathetic Dystrophy by relying on just their medical professionals.

Previous studies have examined how or if traditional support groups aid in the participants' senses of identity, community, belonging, and personal growth. These included studies of diabetes, alcoholism, grief, and chronic conditions. The results from this study added to the limited knowledge base and body of research about chronic pain and online social support groups. Several themes emerged during the interview and observation process that helped explain the motivation behind joining an RSD Facebook support group. I analyzed the data separately and coded it by emerging themes. The themes that emerged from the data included knowledge, persuasion, learning, and underlying results for members in an RSD support group.

Participants described their experiences, communicating that they had learned more about the illness from other members than from their doctors. When specifically asked, "What have you gained and learned from belonging to an online social networking RSD support group?" each participant responded by sharing stories of how the group supports and offers resources. One member stated that belonging to a Facebook RSD support group was about "embracing real understanding" about an individual living with RSD and the issues that come up in the process (Participant4R, September 11, 2015). Perhaps Participant 5 (Reese) summed it up best:

> Well, one huge one is the embrace of understanding. I'm gonna cry because it happens when you don't expect it. When you spend decades alone with this condition having other people understand means the world because you know how it can be. The doctors have no clue, deny, don't pay attention to detail. They send you here and there, and you become a guinea pig for medications and treatments. I'm not going to be a guinea pig anymore. Family members don't believe you and neither do people. I spent a lot of years alone. So having the

> embrace of understanding and compassion that is real and living with this is a real life horror story.

It was evident that belonging to an online RSD social support group empowered the members who participated in the study to share their experiences so that others could learn from one another despite negativity, problems, obstacles, or issues. One participant described how the Facebook RSD group functions in society. She explained,

> Because I think a lot of people came to where they are and meds and treatments based on what their injuries are. I think a lot of times because there are all types of people they go back to the beginning and are able to share information and share treatments, meds, ideas, different forums and kind of lead you in a positive direction. Especially, when you have a group with caregivers and nurses who are people that came into a profession because they are people who want to help and help those in need. They are people with big hearts who are giving themselves and into a career where this is all they want to do each and every day to have an opportunity they want to help they want to listen and find info and talk to you to share what they know to have a group that includes people like this is a tremendous opportunity. Best group you could have is made up of all of them (Rosemary, September 7, 2015).

The literature I reviewed in Chapter 2 supported this perception that belonging to a group helps individuals overcome the feeling of isolation and provides emotional support. Additionally, participants typically feel a sense of belonging, acceptance, comfort, and trust. They also feel less alone. As the theory of connectivism suggests, learning here is a progression that transpires not exclusively by the individual, but through the group and the networks that help us to learn more.

Knowledge

Based on interview and observational data, the Facebook support group offered significant information for all members of the group. Members have the opportunity to interact with other people from all over the country and world. This study focused on an online social-networking RSD group that uses Facebook. In Chapter 2, I described how interactive support generates exploration of information, information sharing, and typically occurs to particular condition groups (Roustan, Rodriguez, & Argilaga, 2013). Most participants in the study understood the significance of sharing information about topics such as worker's compensation, social security disability, protocols for surgeries, published research articles, different treatments, doctors, medications, events, emotions, stories, and informational photographs. Members recognized experiences as part of learning development. In turn, support group members offered knowledge based on the same questions they once had (i.e., doctors, protocols, medications, signs, symptoms, spreading, and other such physical or emotional problems).

The online forum permitted members to intermingle with individuals from outside their neighborhoods, beliefs, and socioeconomic statuses. RSD support group members formed connections by sharing experiences and supporting each other during times of crisis, problems, events, or excitement. Siemen's (2005) described that learning and knowledge rests in the diversity of information. Additionally, members demonstrated a sense of understanding in the group forum where individuals with RSD, caregivers, and medical professionals exchanged pictures of treatments, flare-ups, the McGill Pain Index, and motivational/inspiration quotes. Participants in this study indicated that convenience, quick response time, and being able to get information at all hours directed solid connections, hope, and an enhanced understanding of their illness.

Persuasion

The communication of experiences provided group members a way to persuade one another by helping others on their journey's with RSD. The persuasive information gave participants knowledge that they would otherwise not know because of varying background and locations. The primary persuasive strategies I observed within the group were those regarding doctors, treatments, and photographs. For instance, two days after our initial interview, Participant 6 (Rhonda) shared information in the group about an upcoming experimental treatment, and she posted the study information and then shared the positive outcomes from the original study that happened in Italy. The post stated, "If you want to begin feeling better this study is very promising for all diagnosed with CRPS 1" (September 14, 2015). Moreover, members shared what doctors they had seen and noted upcoming appointments with a particular doctor. Many members would respond with comments such as: "I saw him and the staff was very professional but the doctor has no experience with RSD," "I loved that doctor", "That doctor is there to make money and that is why he does not see patients with insurance," "This doctor listens," and "You should go see my doctor, pm for info" (observation, September 4-20, 2015).

Additionally, September was Chronic Pain Awareness month. The U.S. Pain Foundation was promoting a photo challenge. Within the challenges, they had several different daily activities that they wanted you to be a part of. Many members of the group would not only share the challenge but they would also urge members to first, do the challenge, and then second, join U.S. Pain Foundation as an ambassador. Through the two-week observation period in September three members were sharing the challenge and by the end of the observation, over 20 members were promoting the challenge as well as promoting that all RSD members "should like U.S. Pain Foundation page and become an ambassador" (observation, September 20, 2015).

Members of the group would also share photographs such as them going into treatments, during treatments, and after treatments. These photographs were persuasive because the member would have a caption that would say, "After my second day of ketamine, my pain is beginning to decrease" (observation, September 13, 2015). Following the caption, the photograph that was shared either showed the members smiling, out of a wheelchair, standing, with their family, or shared attending activities that they could not have been to without the treatment they received. Participant 8 (Casey) summed up positive treatments and shared photographs precisely,

> "Sometimes you hear treatments that go well for people or they have all these resources and you don't want to feel resentful cause sometimes you do. You still are trying to figure your way through things. All right, I'll deal with my issues tomorrow. You feel like you're waiting for your turn for something positive to happen" (Participant8C, September 10, 2015).

Members' experiences were focused on shared know-hows and persons who generated experiences rather than difficulties allowed for persuasion to occur in the group between most members. The participants portrayed the exchanges between the RSD members were more concerned with medical treatments and physicians' concerns and interests rather than focusing on non-related RSD issues. The RSD differences discussed revolved around the similar experiences (i.e. pain, treatments, clinical trials, doctors, signs, symptoms, or assistive devices).

Learning

Based on interview and observation data, the RSD support group offered significant learning benefits for all RSD members (individuals with RSD, caregivers, and medical professionals). Participants shared their perceptions of what they feel they have learned from being a member of the RSD support group. Each participant explained that they had learned coping skills, acceptance, medical treatments, doctors (nationally, regionally, and internationally), and information about Reflex Sympathetic Dystrophy, events, and medications. However, there were quite a few other great perceptions that participants shared. Each participant perceived, "I have learned more about the disease than from my doctors" (Participants 1-10, personal communication, September 4-12, 2015).

Participants shared the same sentiment that if it were not for the Facebook support group the disease was not real until they met others with it. Participant 3 (Rudy) summed it up eloquently, "The disease is real" (September 10, 2015). Furthermore, each member perceived that they were never alone. Participant 10 (Nikki) shared,

> "I could no longer tolerate how I felt. Not fully understanding it. I'm a healthcare provider and I had never heard of it. I never had a full grasp of what was

> happening to my body. I got tired of being alone. What's the harm to talking to someone online? I realized I was not alone" (September 11, 2015).

Additionally, participants felt confident that the members shared experiences inside the Facebook group were for the most part credible and helpful. When the participants defined credibility, they thought each member's personal experiences made them credible for information, but credible as a medical professional no. Participant 2 (Rosemary) shared, "I think credibility would go to something that my father-in-law said, that you don't know what you don't know" (September 7, 2015). Whereas Participant 4 (River) stated,

> "I do, most of the time the information shared is fairly credible. Occasionally information is questionable and it seems credible. Most individuals that do share it's backed up by others as well it tends to be information we can find through research studies of journal article or through presentations from well renowned physicians that are well known in our medical community that treats our medical condition" (September 11, 2015).

As far as the Facebook support group being helpful, every participant established that the group was helpful. Participants shared similar views how the Facebook group is a great tool and guide. Participants shared that they typically go on to the Facebook group first, prior to doctor appointments or medical treatments. Participants will go online and look up old threads, post something for them, to gain information they do not have, and learn anything that they are particularly looking for.

Participants felt that the RSD Facebook group is a big part of their daily lives. They appreciate that they can connect at all hours of the day and learn new information. One of the main principles of connectivism is decision-making. Siemen's (2005) rationalizes that decision-making is itself a learning practice. Selecting what to learn and the connotation of received information is perceived within the lens of ever-changing reality. Although there is an accurate response today, it could be inaccurate tomorrow due to changes in the information environment affecting the decision. For example, Participant 6 (Rhonda) said, "I have not done Ketamine infusions because the protocols keep changing which I have learned from this group. I have learned that it is still considered experimental and it's not worth it for me until Ketamine is a proven treatment for CRPS" (September 12, 2015).

Lastly, participants explained that even though they have learned more about the disease than their medical professional, they realize and accept that even though they share the same illness, each person with RSD is different. For example, some treatments like lumbar sympathetic blocks, ketamine infusions, and spinal cord stimulators work for many, but they do not work for everyone. When individuals ask questions about medications through the support group, "My doctor placed me on Cymbalta, can anyone share with me their experience?" (observation, September 10, 2015). Responses from participants consistently shared a similar perception: that even though a medication works for them, it may not work for another person. Lastly, they have learned that the disease does not have standard treatment protocols, because everyone is so different. Some individuals feel the intense burning pain while others feel extreme cold type of burning. Each participant got the illness after different situations. Some of the RSD participants got it from an injury, some woke up with it, and others still have no conclusive evidence of how they got the syndrome. Lastly, it is each participant's perception that they are far from a cure because even though each person has RSD, they are all so different. However, participants followed up their negative thought about a possible cure by expressing they are hopeful because of the RSD Facebook group.

Underlying Results

Surprising results came from both the interviews and observations. During the interviews, I was surprised that each participant shared they are a part of multiple RSD Facebook groups. They shared they are part of these different groups because each group has different characteristics. For example, Participant 5 (Reese) expressed,

> "I appreciate the integration of diverse groups. There are some groups that are open and it's like an arms are wide open which is good for people who are first diagnosed. Then, some that are broad and general, and some are much more focused, and people respond to what is calling them at that time. It's part of what I have appreciated that is has happened organically. You have the broad more large groups and then there are specific region or interest and people have the opportunity to decide which is the best for them at the time of the illness" (September 11, 2015).

Participants shared that they are a part of multiple Facebook groups that include but are not limited to demographics (gender, states, cities, age, faiths, etc.), organizations such as RSDSA, Power of Pain Foundation, and U.S. Pain Foundation, private, closed, and open.

Furthermore, most participants interviewed are a part of traditional face-to-face support groups. They did explain that there is a definite difference. What was surprising was not that they were a part of traditional support groups, but that they met individuals first from the Facebook support group(s) and then they would decide to either meet face-to-face and/or create a support group in their area when they saw that there were enough people in their area. Members of the group would post a meet-up time and place and members comment if they were attending or not. This connected connectivism that learning today is from changes in society where knowledge is no longer an inner, personal endeavor. People function when innovative instruments such as online social support groups are applied.

Lastly, another surprising result was the mere acceptability of a negative attitude. As stated previously, negativity was given a “hall pass” at most times because each participant understands that this pain is so horrendous that it is only natural for individuals to post or comment in an attacking tone and/or negatively. I observed this in the forum as well. An example was from a member of the group who posted the following, “This disease has sucked the life out of me. I can’t go on. I don’t know how I can keep living with this pain. Sorry for being so sad and negative but I’m having a bad flared up day and I just wish I wasn’t in this pain anymore” (observation, September 18, 2015). The amount of comments from members in this group was at 65 when I had observed this post. The most compassionate, understanding, positive, and helpful comments were given to this member. For example, “I understand what you’re going through, if you need to talk to someone please feel free to pm me”, “Have you tried taking more of your medications", "What can I do to help you", and "You are not alone" (observation, September 18, 2015). I do not know if the comments were from just members with RSD, caregivers, or medical professionals, but many people gathered together to support this individual in need. This negativity was understood. Participants expressed that they dismissed negative attitudes especially through text because each person understands that chronic pain is 24/7 and it can cause negativity, hostility, anger, quick to attack, anxiety, and suicidal thoughts. They have learned through the years of living with the disease or taking care of someone with RSD that they do not take is personally, rather they are more understanding and compassionate. They did share that negativity is tough and that if they too are feeling negative, they sift through those posts because they cannot endure more negativity. However, for the most part, each participant was understanding and took negativity with "a grain of salt" (Participant9N, September 11, 2015).

Limitations of the Study

The study was limited in scope to RSD members who are current members of the public RSD/CRPS Fighting Warriors group. Additionally, besides two members, all members lived in California. A major limitation included response bias because even though I did not have personal relationships with some of the participants, they know who I am as an active RSD community member. So, it was possible that some of the answers were based on what the participants thought I wanted to hear, rather than answering truthfully. To overcome researcher bias, after each interview I wrote in a reflexive journal that I shared how I was feeling at the time of the interview and then I was able to be objective by being truthful with my feelings and then used strategies on how to remain objective.

I assumed participants would be willing to share honest examples/stories, of self-experiences. To overcome this limitation, I tried to create understanding with each member by reassuring sincerity and clarified that his or her names would not be used in the study. I described that demographics in the first portion of the interview were confidential and used in Table 1 with participant number.

Lastly, I feel as though a few of the interview questions could be changed because each participant shared about what they had learned but when it came to discussing instruction, I do not think they understood the questions regarding instruction. Therefore, it was during observation that instruction was apparently occurring. Therefore, the perceptions of instruction from the interviewed participants were not fully discussed, like it was with the topic of learning.

Recommendations

This qualitative case study used a small participant sample. The recommendation for additional research and participant recommendations are included in this section. One suggestion is that Reflex Sympathetic Dystrophy research be continued on a larger scale. For example, a quantitative study could use a much larger sample, including traditional RSD groups. Additionally, all participants live in the United States. It would be vital to get different perspectives from individuals with RSD, caregivers, and medical professionals from all over the country and the world.

Since social networking reaches globally, a study between different cultures, countries, and beliefs would be crucial for further studies. In many countries, treatments are different. “In most cases, treatments are first completed and accepted from Europe and Australia” (Dr. Stephen Barkow, personal communication, September 20, 2015). Additionally, a comparison of RSD men and women should also be studied. We know that Reflex Sympathetic Dystrophy can attack anybody and at any age, but it is abundantly more common in women (Complex Regional Pain Syndrome: Fact Sheet, 2015). It would be recommended to study men’s perceptions of learning and instruction because men and women perceive things differently and are also affected by the disease differently.

Lastly, I would also recommend doing a comparison study between traditional and social networking support groups. This would be significant, because as it was explained in Chapter 2, traditional support groups have found that face-to-face support group members gain: networking, identity, feeling of respect and support; but there is still limited research about the learning and instruction in traditional support groups.

Implications

Today, individuals are learning through different connections that are provided through the World Wide Web, social networking sites such as Facebook, Instagram, and Twitter for instance. Additionally, Americans are pursuing their healthcare information through social networking sites (Fox & Jones, 2009). Individuals are no longer calling medical professionals or friends; rather they read blogs, update their social-networking profiles, as well as search the Internet for information regarding their condition.

However, there is limited information about the types of learning and instruction that occur within these social networking platforms.

Furthermore, there is controversy over chronic pain individuals concerning societal and medical views of recreational prescription drug use. The importance of discussing medical treatments, medications, coping strategies, surgeries, protocols, events, workman’s compensation, and social security disability of people with RSD, caregivers, and medical professionals were reflected in their viewpoints. Educating individuals with RSD, caregivers, and medical professionals on how significant being a part of an online social support group, should be discussed between individuals and their medical providers immediately after diagnosis would be a true sign of social change. The responsibility of having such important knowledge about ones illness is invaluable. “A chronic pain patient’s greatest advocates are themselves” (Dr. Devon Glazer, personal communication, September 19, 2015). Sharing Reflex Sympathetic Dystrophy social networking support groups, each pain management doctor, nurse, home healthcare provider, neurologist, neurosurgeon, physical therapist, orthopedic surgeon, and psychologist should be recommending that individuals and caregivers of this illness join a social networking support group. Social change is inevitable when individuals with RSD, caregivers, and medical professionals are knowledgeable and well educated about social support groups because it is in these groups that trends, issues, new information, are learned.

Professionals in medical and mental health backgrounds view social networking support groups as a powerful instrument of social change, due to shared peer experiences.

The information from this study connects the gap between traditional and online social support groups. The information from RSD Facebook support group in the study promoted learning and instruction for all members actively engaged within the group.

Social support groups, like RSD/CRPS Fighting Warriors group provide information and understanding, “mainly through others living with RSD personally help all who are affected by this disease” (Participant4R, September 11, 2015). Participants in this study emphatically advocated that anyone affected by RSD join an online social networking support group, because they will learn more about the disease than they will get from their medical provider. However, most medical professionals know so little about the illness that, without their advocacy, the individuals with RSD and caregivers will continue to find their own path, because not having the information of these groups, is still not a common practice.

In Chapter 1, I discussed the considerable social implications for future RSD individuals, caregivers, and medical professionals who join an RSD Facebook support group. I pointed out the relevance for social change by providing different interactions between individuals in online support groups. Also, being able to identify educational material has the potential to create a supportive culture for Reflex Sympathetic Dystrophy individuals, caregivers, and medical providers. The results indicated that the learning and instruction that occurs in these social support groups could be seen as a proven and effective method to guide other support groups. The development of more virtual RSD/CRPS support groups allows for further understanding of RSD.

Similarly, through participants' perceptions and observation of the group, being an active member has the most impact to help members. Individuals can become their own advocate, but also help educate their medical practitioner about the information that they have learned that the doctor may not have known. An RSD handbook could be made from the learning and instruction that continuously occurs in the virtual support group, which can positively change the understanding of RSD. The implications for this handbook could provide social change by encouraging healthy development of educational material in the Reflex Sympathetic Dystrophy limited medical community. This type of educational material, circulated by support groups like RSD/CRPS Fighting Warriors group facilitates and assists in promoting the social understanding of Reflex Sympathetic Dystrophy.

Participants agreed that society and medical professionals should be required to be educated on the new studies and trends discussed in this study. Additionally, I asked, "what have you gained and learned from belonging to an online social networking RSD support group". The findings from the responses described that learning, instruction, and understanding impacted an RSD member, caregiver, and medical provider decision to be a member of a Facebook support group. I found that social implication of using the real-life experiences of RSD members was substantial and valuable to explore.

Conclusion

This study was conducted to examine the learning and instruction that occurs in virtual social networking support groups. The study investigated the perceptions of learning and instruction by researching the shared information provided by belonging to an RSD Facebook support group through a case study research design. Results from the study yielded information that learning and instruction both occur in these social networking support groups through shared experiences and information sharing that prompted members of the RSD support group to use this forum continuously as their guide for understanding the illness.

The research contributed to the limited literature and validated the conceptual framework of Siemen’s (2004) connectivism theory by providing insight to the support and experiences found in the Facebook RSD/CRPS Fighting Warriors group. Participants highlighted that belonging to an online social support group provided learning and instruction that would not have been experienced alone. The support group included immediate information, wide-ranging RSD experiences due to online social networking, and a sense of understanding that it is through an individual’s network that they continuously learn, gain knowledge, and foster instruction effectively by the cycle of knowledge development. A social support group, as outlined by Siemen’s, allows the learner to remain up-to-date through the connections they have formed.

The findings conveyed that most learning and instruction occurs after a member of the support group asks a question, shares a photograph, expresses emotion, shares symptom(s), shares his or her feelings, or an event attended. It is inside the threads of the initial post that learning and instruction occurs. The research results have the potential to educate not only the members of the group, but have the social implications for the field of education particularly learning and instruction by promoting community-based instruction for RSD healthcare providers. Additionally, this study sought to identify what information was being learned and how it was being instructed. It was through individual experiences of individuals with RSD, caregivers, and medical professionals by understanding the level of RSD knowledge, using a case study research design.

Results from the study provided information on how learning and instruction is shared through members who have RSD, caregivers, and medical professionals' personal experiences and observations of the group. These types of experiences and observations encourage that social support groups are informative, persuasive, a learning center, and a place of mutual understanding during negative situations that may sometimes be considered hurtful and uncomfortable. The in-depth interviews validated the conceptual framework of Siemen's (2004) connectivism theory by offering understanding to the maintenance and experiences discovered in the online RSD support group atmosphere.

The participants emphasized that belonging to a Facebook RSD support group provided them with knowledge they would not have experienced alone. The situations included convenient information, comprehensive RSD experiences due to online social networking, generating persuasive treatment modalities, learning information they may have never known, and mutual understanding during times of negativity. Learning and instruction for people with RSD, caregivers, and medical professionals may not have coexisted if unaccompanied by a support organization. Nash (2014) suggested, "Support in any facet of life's journeys can be influenced by similar outcomes." The study's findings conveyed that all active RSD members would learn and instruct by being involved in a Facebook RSD support group. The implications of this research had the potential to educate not only diagnosed RSD individuals, caregivers, and medical and mental health professionals, but also to impact the field of education by understanding that learning and instruction do not just occur in the traditional classroom environment, rather in today’s society it is primarily through one’s networks. With more individuals taking control of their learning through technology, informal learning occurs with the increased digital skills, especially within a person’s virtual support networks.

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Appendix A: Interview Questions

1. Why did you decide to join a Reflex Sympathetic Dystrophy (RSD) Facebook support group?

2. How is an online social networking RSD group different than a traditional Face-to-Face support group?

3. What have you gained from belonging to an online social networking RSD support group?

4. What are the overall effects, positive and negative, you experience from belonging to an online support group?

5. Who makes up the RSD Facebook support group? (Patients, Physicians, Nurses, or Clinicians?) What type of information does each group share?

6. Of those members who give information and instruction in the support group, do you feel as though they are credible and/or helpful? Why or why not?

7. What types of information do you share with the RSD Facebook support group?

Appendix B: Consent Letter

Dear RSD Support Group Member Name (TBA):

The following information is provided to you to decide whether you wish to participate in the present research study. Participation in this study is voluntary. The researcher is a doctoral student at Walden University who has an interest in the interpretations of the learning and instruction in RSD virtual support groups who belong to an open virtual RSD group via Facebook. This research is being conducted to complete the requirements of the Ph.D. degree in Education at Walden University. You should be aware that you are free to decide not to participate or to withdraw at any time without affecting your relationship with your fellow group members, group leader, or the researcher.

You were selected to participate in this study because of your attendance in RSD virtual support group at least once a week and that you have had been diagnosed for 6 months and active in the group for a month or have taken care of an RSD patient for a year. The purpose of this study is to present individual interpretations of what learning and instruction in virtual support groups occurs.

All support group members will receive a Consent to Participate, which contains my contact information. Participants can contact me via email at xxxxx or by telephone at xxxxx. In turn, I will send a follow-up email that will serve as a confirmation of interest and suggest a date/time/ for phone or Skype interview sessions.

I will request Online Social Network participants to email me at xxxxx or call me at xxxxx to express an interest in the study. I will request the potential Online Social Network participants to contact me directly via email or phone; please do not post it on the general group chat forum (to protect anonymity and ethical standards of confidentiality). I will send a Consent to Participate Form as a confirmation of interest in participating in the study and ask for a scanned signature on the Consent to Participate prior to the interview along with possible dates/times/ to SKYPE. A second email will confirm date/time/ telephone or SKYPE interview session to ALL participants.

Data will be collected through one approximate 30-minute interview via SKYPE or telephone. This study is being conducted by, interviewed by, and transcribed by a researcher Heather R. Gilmore-Dooley, Doctoral Student at Walden University. Heather Gilmore-Dooley will select a transcriber through the office of Disability Services. The interview will be audiotaped and Heather R. Gilmore-Dooley will be the one conducting the interview. The interviews will be scheduled at a time agreed upon by the participant and the researcher.

Interviews will be conducted in a private room. A SKYPE or telephone interview can also be requested in where interviews will be conducted in the privacy of the participants and researcher home. The participant will be asked for input and corrections to the textural and structural descriptions.

Risks and Benefits of Being in the Study Being in this type of study may involve some risk of the minor discomforts that can be encountered in daily life, such as reviewing psychological well-being and emotions that are “normal” for patients, caregivers, and medical professionals handling chronic pain. You may experience feelings such as fatigue, stress and/or physical feelings such as additional pain. Being in this study would not pose risk to your safety or well-being. The anticipated benefit to the participant is to present a non- judgmental and safe forum to discuss the learning and instruction in a virtual support group

Questions and Concerns

Please do not hesitate to ask any questions about the study either before participating or during the time that you are participating. I will share the findings of the research study with the participant once it has been completed. Your name will not be associated with the research findings in any way. Confidentiality will be maintained through the use of your initials instead of your name. The researcher, the university board and review bodies, and the transcriptionist (who will sign a confidentiality agreement) will be the only ones who know your identity. The researcher will not use your information for any purposes outside this research study. Data will be kept for a period of at least 5 years, as required by the university. Participants will not be given any type of monetary compensation will be given in the form of gift(s) or reimbursement (for travel costs, etc.).

If you wish to talk privately about your rights as a participant, you can call the Walden representative or email irb@waldenu.edu You should keep/print a copy of this informed consent form. If you have any questions for the researcher please feel free to contact me at any time [redacted].

By signing this Consent Form, you agree:

To participate in the one-to-interview, which includes a personal inquiry that will remain confidential

that you are age 18+

that you have been diagnosed, cared for, or treated RSD for over 6 months, and have been an active participant in the RSD Fighting Warriors Group for over a month.

Statement of Consent: I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I am agreeing to the terms described above.

Printed Name of Participant____

Email of Participant____

Date of consent____

Participant's Written or Electronic* Signature________________________________

Researcher's Written or Electronic* Signature_______________________________

Walden University IRB approval # is 08-20-15-0316006

Appendix C: Interview Questions and Emerging Themes

Question	Emerging themes
IQ1: Reasons for joining RSD support group	• Lost/Alone • Real Experiences • Information • Support • Education
IQ2: Differences between online or traditional RSD support groups	• Always there • Convenient • Meet others from all over the world • More open to share information • Flexible
IQ3: Gains and learning from belonging to Facebook support group	• Friendship • Support • Informative • Persuasive • Not all share similarities except the illness
IQ4: Negative and positive sides of belonging to an online support group	• Misread or misunderstood wording in forum • Negative attitudes • Lack of social norm filters • Too much sharing • More positive than negative • Compassion • Real bonds • Understanding
IQ5: Information each group of professionals share	• Who • What • When • Where • Why • How
IQ6: Information shared and instruction in support group is it helpful or credible	• Helpful • Credible through each personal experience • Didn't speak of

		instruction
IQ7: Information that you share		• Treatments • Feeling physically • Inspiration • Doctors • Feeling emotionally • Medications • Events • Petitions • Not always RSD related • Social Security Disability • Insurance • Workman’s Compensation • Published Journal Articles