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Comparative Analysis of Systemic Lupus Erythematosus Support Group Type on Quality of Life

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Abstract

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MS, Walden University 2014

BS, Lander University 2010

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

When individuals are diagnosed with systemic lupus erythematosus (SLE), they tend to go through emotional, psychological, and physical anguish that requires support. Studies have shown that a support group can provide SLE patients with an outlet in which they can share firsthand feelings and experiences and receive emotional support but it is not known if how the individual with SLE accesses online or face to face support makes a difference. The purpose of this study, guided by the Chronic Care Model, was to determine if there were differences in quality of life (QoL) for persons with SLE participating in an online versus traditional face-to-face support group. One hundred five participants were recruited via email who were diagnosed with SLE and were 18 years of age or older. All participants were members of an online (n = 53) or face-to-face (n = 52) support group and completed a 20-item short-form health survey (SF-20). Data were analyzed using an independent t-test and responses to the SF-20 responses were used to show descriptive differences. Results showed there were no significant difference in overall QoL between online and traditional face-to-face support group participants. Positive social change may result as patients with SLE consistently attend support groups and find support from their peers. Future studies might include a larger sample size and consider QoL comparisons across patients who do or do not attend online or face-to-face support groups.

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Dedication

In dedication to my beloved parents Rufus and Bessie Giles who have always supported and encouraged me through all of my educational goals. To my three children, Reginald Jr., Myles and ReMari and my three grand-children, Naomi, Robyn and Zion, I took this journey to prove to you that anything worth having is worth the time and sacrificial work it takes to achieve it. Also, in dedication to all patients battling the mysterious chronic illness called Lupus.

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Chapter 1: Nature of Study

Introduction

A chronic illness is a long-term condition that often progresses slowly and can seldom be completely cured (Eriksson et al., 2019). This warrants the expansion of the scope for therapies that are instituted to combat the enormous stress that chronic illnesses may exert on individuals as well as families. The stressors can be from the dynamics of inadequate information regarding the pertinent progression of the disease to the unsettling feelings of depression or palliative care in instances where there is no intervention available. These dynamics contribute to the need for social support.

According to the American College of Rheumatology (2019), systemic lupus erythematosus, referred to as SLE or lupus, is a chronic (long-term) disease that causes systemic inflammation that can affect multiple organs. In addition to affecting the skin and joints, it can affect other organs in the body such as the kidneys, the tissue lining the lungs (pleura), heart (pericardium), and brain. This study is important in the advancement of lupus care because patients become depressed, withdrawn, confused or afraid after receiving a lupus diagnosis. Learning to cope may not be an easy task when trying to do it alone. The need to talk, interact and share with others who share common conditions is the reason support groups exist. Participation in a support group can have a significant impact on a patient’s quality of life (QoL; Breitbart et al. 2015). This impact on QOL can provide positive social change in the lives of SLE patients who have lost hope in achieving or maintaining an acceptable quality of life.

According to Olesińska and Saletra (2018), the World Health Organization (WHO) defined the quality of life as an individuals' perception of their position in life in relation to their culture and value systems and in relation to their goals, expectations, standards and concerns. It includes all aspects of human life; somatic state, mental wellbeing, social relationships and physical fitness. The focus of this study was on uncovering the difference in QoL for persons with SLE participating in an online versus traditional face-to-face support group.

Background

Raising awareness about SLE is a continual priority for medical professionals and patients. One initiative to raise awareness was the designation of the month of May as Lupus Awareness Month in an effort to inform patients, physicians, health care workers and the general population about best practices when diagnosing, caring for, and living with lupus. In the exploration of the benefits of support groups to patients with SLE, various researchers have conducted studies to ascertain the benefits of lupus support groups. Mazzoni and Cicognani (2014) studied patient experiences and social support requests in internet forums with SLE, they evaluated the benefits and impacts the internet-based programs have on the patients. Internet-based communication has continually gained popularity in patients suffering from various health conditions due to the ease of access and reduced costs. Also, the rise of online platforms can be attributed to increased internet connectivity and anonymity that may be associated with online platforms. Unlike traditional support groups where patients have to meet physically, internet-based platforms can be accessed from the comfort of home. Therefore, patients suffering from physical challenges such as walking for long distances can engage in online support groups. According to Mazzoni and Cicognani (2014), patients can share experiences and social support among chronic patients, such as SLE, through posted message conversations.

Mazzoni and Cicognani qualitatively analyzed 145 posts from Italian internet forums for SLE patients and reported how the patients in online forums express their emotions and seek others for support by sharing their stories. Additionally, the researchers emphasized the need for support groups for SLE patients, which can help them cope with the long-term psychological effects of the disease. Mazzoni and Cicognani asserted that adequate professional supervision is essential to ensure all interactions are done in an effective manner, to avoid negativity. Therefore, an online support group has a significant impact on the quality of life of the patients living with SLE (Mazzoni & Cicognani, 2014).

Scholars have yet to research the differences between traditional and online support groups for persons with SLE in terms of whether one format is more effective than another for contributing to the QoL. Consequently, this study was beneficial for SLE patients and health professionals. The results of this study provided evidence of the benefits of online support groups for SLE patients who have limited support options that address their concerns. The results of this study provided evidence to health professions that have been reluctant to encourage online support for their SLE patients (Mazzoni & Cicognani, 2014).

Problem Statement

The research problem is the indeterminate effect on QoL relating to SLE support groups (Huber et al., 2018; Mazzoni & Cicognani, 2014). A preliminary review of literature revealed multiple sources about chronic illnesses and the general well-being of patients who participate in traditional support groups (Huber et al., 2018). Social support systems are purported to mask the feelings of isolation that could result from feelings of denial. There is a positive correlation between social support and patients' QoL (Brennan & Craven, 2016). However, there is a dearth of research that indicates whether SLE patients will benefit from participation in online or traditional support groups.

The results of the study filled a gap in the literature specific to whether online support groups are just as effective to maintain quality of life as traditional face-to-face support groups for SLE patients. This study is relevant and significant to the nursing discipline because nurses are advocates for patients. In their advocacy efforts, nurses should recommend support groups to patients as a type of personal healing process of coming to terms with an illness, aid in coping with an illness and resulting in a better QoL.

When individuals are diagnosed with new conditions or sicknesses, especially those that cannot be cured, they tend to go through emotional, psychological, and physical anguish that requires support. The normal realm of friends and family members may not be the best to offer support in such scenarios, as patients often feel friends and family do not understand their condition because they have never been in such situations (Kodatt et al., 2014). SLE is an incurable condition that can only be managed by controlling the symptoms, which have a significant impact on the patients mental and physical state. Therefore, SLE patients benefit from the support provided by individuals who have the same experiences (Mazzoni & Cicognani, 2014). Due to the impact of advances in technology on every sector, lupus support groups have adopted online platforms, where patients can interact with each other, if they cannot access the physical platforms. The need to talk, interact and share with others who share common conditions is the reason that support groups exist. Kodatt et al. (2014) found that online peer-to-peer groups were useful for persons dealing with long-term illness as they could share strategies for improving their health and receive emotional support from others. Support groups provide a plethora of educational resources for persons with chronic illnesses and these services are often extended to caregivers of persons with SLE

Purpose

The purpose of this quantitative study was to determine if there were difference in QoL for persons with SLE participating in an online versus traditional face-to-face support group. The variables analyzed in this quantitative study were QoL of SLE patients and the type of support received (online support groups or traditional face-to-face support groups).

Research Question and Hypotheses

A prospective, quantitative method of comparison analysis was used to answer the following research question:

Research Question

What is the difference in the general QoL score for SLE patients who participated in an online support group versus those who participated in a traditional in-person support group?

Hypotheses

The generated hypotheses based on preliminary literature review is that there is no difference in QoL for SLE patients participating in an online versus traditional face-to-face support group. The difference in QoL will be examined by analyzing survey data.

$H_0$1: There will be no difference in QoL for SLE patients participating in an online versus traditional face-to-face support group.

H_A1: There will be a difference in QoL for SLE patients participating in an online versus traditional face-to-face support group.

The difference in QoL was examined by analyzing data from individuals in support groups. Participants from traditional face-to-face and on-line support groups completed QoL surveys. All identifying patient information was de-identified for this research study. The variables were tested and measured using the statistical *t*-test method after the data were collected.

Theoretical Framework

The Chronic Care Model (CCM) is an essential framework for improving chronic disease care at the patient level (National Institute of Diabetes and Digestive and Kidney Diseases, 2019). The model is based on six interrelated system changes meant to ensure that the care involves patient-centered practices and is oriented towards evidence-based practices. CCM aims at a transformation of care provided to patients with increased attention on delivery of care and primary care (Golder & Morand, 2017). The model is based on a variety of approaches such as planned interactions, effective team care, integrated decision making and self-management support brought about by effective utilization of community resources (Golder & Morand, 2017). The CCM model supports improvements that are geared toward the resources in the community and how their usage can be maximized. CCM model has been used with a number of populations and has shown effectiveness in caring as well as treating chronically ill patients.

The management of chronic disease often overwhelms patients. The CCM element relative to this study is patient self-management support, which is designed to empower patients to manage health and be active participants in health care. When SLE patients participate and engage in support groups, they are empowering themselves with the available resources to better manage the condition in hope of maintaining a positive QoL. Literature review revealed that the CCM framework is grounded in a study conducted by Aria and Archer (2018) who compared patients’ perception and understanding of an online healthcare support system in two groups: internet-panel group and in-person group. The researchers concluded that the use of an online healthcare support system is as effective as in-person support. More detail on CCM is presented in Chapter 2.

Nature of Study

Online SLE support groups are becoming a valuable alternative to traditional SLE support groups (Zheng et al., 2009). Evidence to answer the research question for this study was gathered from online and traditional support group participants. To address the research question, a prospective, quantitative method of comparison analysis was used to determine whether there was a difference in QoL for SLE patients participating in an online versus traditional face-to-face support group.

The independent samples *t*-test, which is an inferential statistical tool, was used to determine if there was a significant difference between online versus traditional face-to-face support groups on QoL. The independent samples *t*-test is highly valid and reliable in determining whether two independent variables are equal to each other in terms of QoL, assuming that both variables have equal variances. The Short Form-20 (SF-20) is a widely used tool for monitoring population health, comparing and analyzing disease burden and predicting medical expenses (SF-20 Health Survey, 2019). SF-20 is the tool that was utilized in this study to capture SLE patients' survey responses as primary data. Surveys were completed by online support group members and traditional face-to-face support group members respectively. Online consents were obtained from all participants and personal patient information was de-identified for the research study. The descriptive, comparative quantitative methodology included the independent variables:

online support groups and traditional face-to-face support groups and the dependent variable of overall QoL which is the first question on the SF-20.

Definitions

The following terms are used throughout this study and are defined below for better comprehension for the reader.

Systemic Lupus Erythematosus: According to *Centers for Disease Control and Prevention*, SLE, is the most common type of lupus. SLE is an autoimmune disease in which the immune system attacks its own tissues, causing widespread inflammation and tissue damage in the affected organs. It can affect the joints, skin, brain, lungs, kidneys, and blood vessels. There is no cure for lupus, but medical interventions and lifestyle changes can help control it. SLE and lupus are used interchangeably in this study.

Quality of Life: CDC defines Health-related Quality of Life (HRQoL) as an individual's or group's perceived physical and mental health over time. Health means more than the absence of having a disease; health is a resource that allows people to satisfy basic needs, realize their goals and cope with the environment to live a long, productive and quality life (CDC, n.d.). The QoL of an individual refers to the individual's subjective perception of having to live life under the condition (Kusnanto et al., 2018).

Support Groups: National Cancer Institute (NIH) defines online support groups as "meetings" that take place online. People meet through chat rooms, listservs, webinars, social media (such as Twitter or Facebook), or moderated discussion groups.

Assumptions

Additionally, there was the assumption that this study's participants would answer the survey questions truthfully ensuring an unbiased and accurate analysis. Another assumption is that individuals with SLE desire the best level of QoL that they can achieve.

Scope and Delimitations

The scope of this study was to determine whether there are differences in QoL for persons with SLE participating in an online versus traditional face-to-face support group. As such, two groups of participants were recruited in the study and were compared. The independent variable was the type of support group that the participants received – online or traditional face-to-face. The dependent variable was the QoL. This study employs a quantitative method and causal comparative research design to address the research question and test the hypothesis.

The results of this study were generalizable to SLE patients who (a) participated in an online support group, (b) participated in a traditional support group, and (c) had participated in either type of group at least monthly for a twelve-month period. The study was limited to adults 18 or older who have been diagnosed with SLE for more than 6 months. QoL in SLE patients is a specific aspect of the study with the CCM framework as the blueprint for empowering patients in health self-management

Limitations

One of this study’s limitation was that traditional face-to-face support group participation could have been sporadic causing meeting attendance to vary, which would limit the opportunity for me to distribute surveys to this study’s potential participants in an efficient manner and may have influenced the effect of the study. Data contamination was another limitation that could have occurred if participants took the survey multiple times. Also, in the era of stolen identities, the reluctancy to participate in the survey with the belief that disclosure of personal identifying information is needed threatened to be a possible barrier. Last, limitations could have included financial challenges of fees associated with instrumentation usage and insufficient time to conduct the study. I took measures to reduce limitations including, ongoing communication with main contact individual and thorough explanations and instructions to participants regarding the study’s scope and purpose.

Significance

SLE has an unpredictable disease course and is documented to cause an existential rearrangement of life (Larsen et al., 2018). SLE patients’ QoL may be jeopardized. More specifically, there may be limitations due to the various accompanying symptoms of SLE that appear with disease flares. Many patients experience fatigue, weight loss, and fever (American College of Rheumatology, 2019) and some symptoms may make it difficult and/or impossible for persons with SLE to leave their homes.

According to Bennett (2018), an estimated one and a half a million Americans have been diagnosed with lupus, with 1,600 patients being diagnosed annually.

Therefore, the number of SLE patients continues to increase requiring the development of strategies to enhance patient’s QoL. Bennett (2018) evaluated the impacts of self-efficacy, positive social support, as well as problematic social support and race on the QoL of SLE patients. The study demonstrated that self-efficacy, problematic social support and positive social support had a variance of 38% of the QoL for SLE patients.

Significance to Theory

This research is significant in theory because it will lead to positive change in the lives of SLE patients if the study’s results support a higher level of QoL as a result of support group participation (Kulczycka et al., 2010; Zheng et al., 2009). Specifically, the insights of this study add to the existing literature about the use and application of the CCM which deals with the management of chronic diseases such as SLE. Moreover, the insights of this study with the regards to the QoL of SLE patients attending traditional face-to-face support group and online support group enhances the understanding of both researchers and practitioners alike as to how support groups impact QoL of SLE patients (Mazzoni & Cicognani, 2014; Zhang et al., 2009).

Significance to Practice

The findings suggest positive social support, self-efficacy, and problematic social support have an independent impact on the health-related QoL and non-health related QoL. More so, the findings of this study suggest the importance of conducting online support groups for SLE patients if traditional face-to-face support groups is not possible (Mazzoni & Cicognani, 2014). Therefore, the impact of health practitioners and psychologists cannot be overlooked in the positive social support for patients with SLE as they assist their patients in support groups.

Significance to Social Change

A potential implication for positive social change that is consistent with and bounded by the scope of the study is that due to the efforts of regular participation in support groups, patient QoL is improved. Regardless of support group type, benefits include emotional support, healthcare advocacy and most importantly, a greater QoL (Kulczycka et al., 2010; Zheng et al., 2009). The findings of this study may help health care providers to increase the availability of support groups for SLE patients and review existing support group programs to enhance the QoL of SLE patients.

Summary

SLE is a chronic inflammatory autoimmune disease with a varied clinical perspective. The disease may come with little or no significant impact on the everyday life of the suffering individual, such as situation is referred to as oligosymptomatic (Fava & Petri, 2019). Conversely, the disease may spread to vital organs of the body eventually resulting in disability or loss of life. Recent advancement in healthcare system has led to the development of better methods for diagnosis, treatment and support available to patients with the condition. In the exploration of the benefits of support groups to patients with SLE, researchers conducted studies to ascertain the benefits of lupus support groups, but had yet to research the differences between traditional and online support groups for persons with SLE in terms of whether one format is more effective than another for contributing to the QoL. Chapter 2 contains a detailed literature review and review of the theory on support groups of QoL in individuals with SLE.

Chapter 2: Literature Review

Introduction

The research problem was the indeterminate effect on QoL relating to types of SLE support groups. The purpose of this study was to explore if there are differences in QoL for persons with SLE participating in an online versus traditional face-to-face support group. According to the American College of Rheumatology (2019), SLE is a chronic (long-term) disease that causes systemic inflammation that can affect multiple organs. After receiving a SLE diagnosis, patients may become depressed, withdrawn, confused or afraid. Learning to cope may not be an easy task when trying to do it alone. The need to talk, interact, and share with others who have common conditions is the reason that support groups exist. Participation in a support group can have a significant impact on SLE patients' QoL (Breitbart et al., 2015).

As a result of the generalized and the chronic nature of SLE, it highly influences the QoL of a patient in many ways. The QoL of an individual refers to the individual's subjective perception of having to live life under the condition (Kusnanto et al., 2018). For this research project, the comparison of traditional SLE support groups and online support groups participation regarding QoL was analyzed. The purpose of this quantitative study was to determine if there were difference in QoL for persons with SLE participating in an online versus traditional face-to-face support group.

Literature Search Strategy

The following section discusses the strategies and databases used to guide the review of the literature on QoL of people living with SLE and the impact that social support groups online or face-to-face have on QoL of individuals with SLE. For this research, I searched the Cochrane Online library, Google Scholar, PubMed, and EBSCO. Keywords used were: *Quality of life and SLE, systemic lupus erythematosus and supportive therapy, SLE and support groups, and Support groups and online*. Several articles were targeted to provide background for this study. The literature was conducted utilizing the Walden Library, Internet Searches and the Community Library. The literature research commenced in the Fall of 2018 and included searches of peer reviewed articles as well as internet searches.

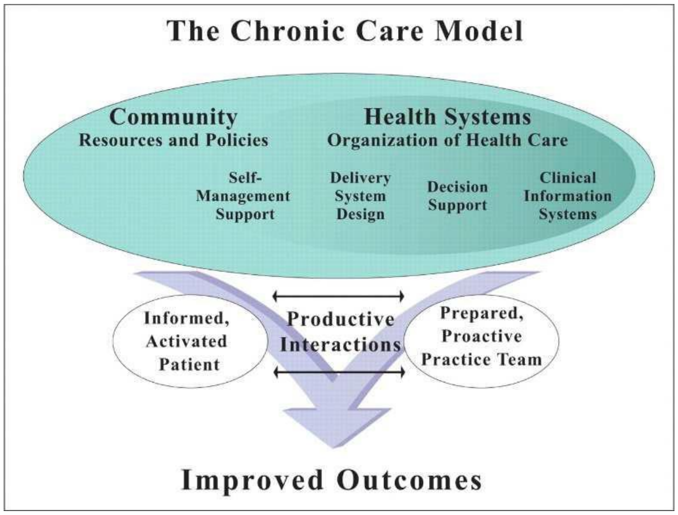
Theoretical Foundation

The theoretical foundation for this study is the CCM. The initial evidence upon which the CCM was based came from a review of interventions to improve care for various chronically ill populations (Wagner et al., 1996). These evaluations showed—and a subsequent Cochrane Collaboration review confirmed— that multicomponent practice changes in four categories led to the greatest improvements in health outcomes: increasing providers’ expertise and skill, educating and supporting patients, making care delivery more team-based and planned, and making better use of registry-based information systems (Renders et al., 2001). These changes formed the basis of the CCM. Today the CCM is a widely adopted approach to ambulatory care improvement. It guides national quality improvement initiatives involving groups of primary care practices, such as the Health Disparities Collaboratives (HDCs), as well as state-based and regional efforts that, combined, have worked with more than 1,500 physician practices in the United States and internationally. The CCM is also an integral part of current patient-centered medical home models (Berenson et al., 2008).

The management of chronic disease is continuing to overwhelm patients and be a burden on individuals and society; almost half of the America population has at least one chronic illness resulting in more than three-fourths of America's health care spending (Gee et al., 2015). The CCM is a well-established and validated framework that provides a holistic approach to caring for the chronically ill that supports increased functional and clinical outcomes such as SLE (see Figure 1). The chronic care model consists of six components of healthcare delivery. They are health system, clinical information systems, delivery system design, decision support, self-management support, and community resources.

Figure 1

The Chronic Care Model



Williams et al. (2014) used CCM to understand how community-level factors may exacerbate disparities explored within social determinant frameworks or facilitate better delivery of care for SLE patients. The CCM is designed to help practices improve patient health outcomes by changing the routine delivery of ambulatory care through six interrelated system changes meant to make patient-centered, evidence-based care easier to accomplish. Specifically, the aspect of CCM that is relevant to this study is patient self-management support, which is designed to empower patients to manage health and be an active participant in health care. The CCM has been used for diabetes care in primary care settings, and positive outcomes have been reported (Stellefson et al., 2013). Similarly, Stuckey and colleagues (2011) concluded that the CCM provides the best evidence-based framework for organizing and improving the delivery of chronic care ensuring productive interactions between an informed, activated patient and a proactive prepared medical team. The CCM model is an effective holistic approach to revamping medical care through partnerships between healthcare systems and communities, and is the best choice to use to evaluate SLE as a chronic illness managed by patients through support group participation.

Literature Review Related to Key Variables

SLE is an autoimmune condition essentially of unknown etiology, which can present through a host of manifestations. One cardinal feature is that the condition has episodes of flares where the symptoms are active as well as other instances of remission where the symptoms are more controlled (Bengtsson & Rönnblom, 2017). The focus of this literature review was on one of the cardinal aspects of the condition, the social support network, and its effect on the QoL of all those affected by the condition. A number of studies show that the activities of the disease fail to correlate with the QoL of the patients because the symptoms vary significantly from patient to patient (Izadi, 2020; Mousavi et al., 2017; Thong & Oslen, 2017). The following review of the literature will cover the key variables examined over the course of this current study through the review of the literature. The key variables presented below are: *quality of life and SLE*, *SLE and supportive therapy, SLE and support groups,* and *Support groups and online*.

Quality of Life and SLE

SLE affects the QoL of those who live with the condition. Not only are they faced with the physical limitation of the disease, but emotional health is also a challenge. One investigation that examined the epidemiology and the disproportionate prevalence of SLE among African Americans noted that the condition had a negative correlation with the QoL as well as coping capabilities of those affected (Williams et al., 2017). Conceicao et al. (2019) studied the impact of psychoanalytic psychotherapy on QoL, depression, anxiety, and coping in patients with SLE and found that the eighty females in the study had improvements in vitality and pain reduction but no change in the disease activity score was observed significantly impacting the participants QoL. Patients who live with SLE therefore are in need of ongoing support medically and emotionally.

SLE and Supportive Therapy

Jordan and colleagues (2019) conducted a study to determine whether there is a relationship between organ damage, symptoms of depression in African American women diagnosed with SLE, and the impact of social support relative to their condition.

Findings of the study suggested that symptoms of depression or even organ damage were linearly related to social support from family members. However, many SLE patients lack family support because family members do not completely understand the diagnosis or the support needed to help their family member cope with SLE.

According to Williams et al. (2016), self-management web-based programs have demonstrated improvements in health distress, self-reported global health and activity limitations with individuals with SLE. The researchers examined the interventional impacts on QoL indicators for patients living with SLE such as stress and depression. In three different randomized wait-list controlled trials, the researchers evaluated patient-centered interactions on web-based forums. Even though the interventions were web-based, the participants had the option of receiving emails, and access to online messages board, participation in a support group, and enrolment in a local management program. The participants who chose to attend local support groups were referred to the Lupus Listening and Learning Group, which is affiliated with the Lupus Foundation of America. Also, there were outreach activities that included communication with a network of local churches and community-based organizations that would offer additional support group participants. Results showed that health-based programs helped people improve stress management and their health conditions. Therefore, the researchers concluded that therapeutic support interventions significantly impact the QoL and possibly moderate the evolution of chronic and unpredictable conditions, including SLE. Psychoanalytic psychotherapy assists patients in understanding and resolving their problems by increasing awareness of a particular condition. The sessions are given to patients having some conditions such as SLE to help them cope with challenges including depression and anxiety, with the primary objective of improving QoL.

Conceicao et al. (2019) studied the impact of psychoanalytic psychotherapy on QoL, depression, anxiety, and coping patients with SLE. In a randomized clinical trial of eighty females with SLE, participants were placed in two support groups, one therapeutic and the other a control group. The support groups were organized and coordinated by professionals to ensure proper dialogue, the sessions were held for 20 weeks, and the two groups' variables were analyzed and compared over the period. In the beginning, both groups were homogeneous in all variables, including medications. However, after the 20 weeks sessions, the therapy group had significant differences from the control group with a lower frequency of symptoms, lower anxiety levels, and other factors used to evaluate QoL. Even though no change in the disease activity score was observed in both groups, therapy support groups significantly impacted the QoL of the SLE patients.

SLE and Support Groups

Online Support Groups

Online platforms are a useful resource as social support for SLE patients of all ages. Adults with SLE and adolescents with the disease face similar challenges although the approach to supportive therapy may differ.

Support groups for Adults with SLE.

Online healthcare support groups have been shown to be effective as a means of sharing experiences and strategies for improving health and emotional support for patients who live with chronic diseases such as SLE (Kodatt et al., 2014). Aria and

Archer (2018) compared patients’ perception and understanding of online healthcare support systems and found that patients in internet-panel groups and in-person groups perceived the online healthcare support system equally effective.

Mazzoni and Cicognani (2014) described the psychosocial support and insight that could be obtained from the online modalities such as the internet. Posts from an Italian online forum from SLE patients were collected and analyzed utilizing a qualitative content and statistical textual analysis. The results showed different purposes for patients’ posts: starting new relationships, seeking information, receiving emotional support, and giving a contribution. The discussion generally focused on the relationship between the requested/offered support and SLE experiences. Mazzoni and Cicognani contended that online platforms also bridge geographical gaps and seamlessly offer a more diverse patient pool to obtain insight and knowledge

Support Groups for Adolescents with SLE.

Not only do adults face many challenges related to SLE and the continuous management of the condition, youth who live with SLE are may face even greater challenges. Based on their relatively young age and lack of maturity, adolescents diagnosed with SLE may respond more to online types of media and support. In this age of advanced technology, tele-medicine and online social interactions, younger patients may be more motivated to manage their condition, if online support is available. Scalzi et al. (2018) emphasized the need for online modalities through which adolescents are provided information and support that would guide them in managing their condition, resulting in improvements of adherence to medication regimens, subsequently, improving

QoL. In fact, web-based SLE forums were more effective in helping adolescents adhere to medication and as a result improved QoL (Scalzi et al., 2018). Scalzi et al. findings indicated significant improvements in education adherence in adolescents and young adults with SLE using web-based educational and support interventions enhanced by the use of social media. The adherence to medication in the sample improved from 63% to 93% after engaging in the online-based support groups. Adherence to medication is a sign of acceptance and realization of the benefits of compliance with the physician's advice. All the subjects examined in the study revealed significant improvements due to social media and empowerment. Improving medication compliance behaviors and symptoms management techniques significantly impacts the patient’s QoL. Additionally, adolescents and young adults tend to be more aligned with technology and social media, making it an ideal option for seeking social and educational support.

Dealing with a chronic illness as a younger individual and feeling alone is not easy and can make disease management more difficult. Support is one of the most important elements of dealing with any chronic disease, including SLE. Family and friends can be a necessary part of a support system, as it helps to seek advice from others not involved in your immediate patient circle. Daly and colleagues (2014) provided insight into the experiences of young people regarding how well they cope with SLE and the desires they have as they seek support groups in hopes of meeting other patients with whom they can communicate and easily relate. Daly’s et al. was a precursor for the initiation of an online platform for young people in the UK, so that they could have access and opportunities to freely express themselves as they interact with other patients.

Traditional Face-to-Face Support Groups

In traditional, face-to-face support groups, patients engage in various physical activities such as team building and behavioral interactions with the oversight of a professional. Huber et al. (2018) reported that members of traditional support groups reported a high physical symptom burden although a high overall QoL. Da Hora et al. (2019) studied the effect of therapies on the QoL of patients with SLE. The researchers assessed the conventional SLE support groups, having looked at cognitive behavioral therapy, pharmacological treatment, and physical activities in the support groups. Various activities were assessed in which the patients engaged when they met in the support groups. Da Hora et al. affirmed that treatment therapies are associated with statistically significant development in the QoL for patients with SLE. In addition, the researchers determined that changes in the perception of the SLE patients about their condition enhances their ability to perform activities and achievement of satisfactory levels of health. Patients that were observed within the study who were part of the intervention groups, exceeded average values in mental health, pain scores, emotional, and vitality scores. However, no improvements were noted in the general aspects of health. SLE is a condition that is managed by controlling and dealing with the symptoms and side effects, and the support group interventions significantly impact the QoL of the patients.

Undoubtedly, social support is one of the most important factors in predicting physical health and well- being. Physical and emotional stress in SLE patients should be avoided as it can be detrimental to overall physical health. In an already dysfunctional immune system, stress in SLE patients can trigger an exacerbation or flare. Williams et al. (2015) asserted that there is a relationship between the presence of a social support system and the deterioration in QoL of patients with SLE. The absence of social support has many disadvantages and, in most cases, can predict the deterioration of physical and mental health. Conversely, the presence of effective social support structures enables patients to more effectively cope and lead more fulfilling lives.

Brennan and Creaven (2016) investigated support that patients receive from medical personnel and from the other formal support groups regarding QoL. The researchers explained that SLE patients often feel isolated from society due to the lack of societal understanding, and support groups bridge the emotional isolation gap and provide emotional coping. Additionally, they suggested that support groups may also have limitations on the QoL of patients with respect to the severity of individual symptoms. Brennan and Creaven’s results indicated that many physicians may not necessarily be well equipped to offer support to patients and as such, there is a need to reinforce their competency to do so.

To determine the benefits and effects of peer mentoring in patients diagnosed with SLE, Williams et al. (2017) studied the epidemiology and the disproportionate prevalence of the condition, with African Americans bearing the brunt of the disease. The researchers noted that the condition has a negative correlation with the QoL as well as coping capabilities of those affected and advocated for the presence of peer mentors who would inadvertently augment the already existing support groups in the society. Peer mentors could be beneficial as they would provide more personalized care and hence would cater more towards the overall welfare of the individual, resulting in a better QoL for the patient.

Quality of Life and Support Groups

QoL has been shown to improve when patients with SLE interact with others with SLE or other similar chronic diseases. Da Hora and colleagues (2019) found that QoL of patients with SLE was enhanced as patient participants in support groups perceptions of their ability to perform activities and achieve satisfactory levels of health improved. Patients exceeded average values in mental health, pain scores, emotional, and vitality scores. However, no improvements were noted in the general aspects of health. Because SLE is a condition that is managed by controlling and dealing with the symptoms and side effects, the support group interventions significantly impacted the QoL of the patients.

While support groups may have limitations on the QoL of patients with respect to the severity of individual symptoms, patients with SLE often feel isolated from society due to the lack of societal understanding, and support groups bridge the emotional isolation gap and provide emotional coping (Brennan & Creaven, 2016).

The research gap is the indeterminate effect of the type of SLE support groups on QoL (Huber et al., 2018; Mazzoni & Cicognani, 2014). A preliminary review of literature revealed multiple sources about chronic illnesses and the general well-being of patients who participate in traditional support groups (Huber et al., 2018). Social support systems are purported to mask the feelings of isolation that could result from feelings of denial. There is a positive correlation between social support and patients’ QoL (Brennan &

Craven, 2016). However, there is a dearth of research that indicates whether SLE patients will benefit from participation in online or traditional support groups.

Support groups are available for patients to share feelings, fears and have conversations about the many aspects of the condition, including different treatment regimens in traditional and online formats. However, this study addressed the gap in the literature specific to SLE patients to discover if online support groups are just as effective to maintain QoL as traditional face-to-face support groups

Summary and Conclusion

The focus of Chapter 2 was on concepts, models and theories related SLE support groups. SLE is a multisystem, chronic, and clinically heterogeneous condition that is characterized by pain and inflammation in different parts of the body. There are no specific tests to diagnose SLE, and the diagnoses are based on patient history, symptoms exhibited, the examination of patients, and multiple medical tests that rule out other diseases such as damage to the liver, kidney, heart, and disorders in the blood clotting cascade (Brennan & Creaven, 2016; Kodatt et al., 2014). As such, the lupus diagnosis is delayed or missed, and during the waiting times, patients are given treatments to manage the symptoms (Huber et al., 2018; Mazzoni & Cicognani, 2014). This leads to increased healthcare costs and prolonged hospital stays for the patients and thus affecting the quality of life of patients (Huber et al., 2018). This research project is significant to the nursing profession because scholars have yet to research the differences between traditional and online support groups for persons with SLE in terms of whether one format is more effective than another for contributing to the QoL. Support groups are available for patients to share feelings, fears and have conversations about the many aspects of the condition, including different treatment regimens (Kodatt et al., 2014). It is not known if one modality of support group enhances QoL to a higher level than the other. This study addressed the gap in the literature specific to SLE patients to discover if online support groups are just as effective to maintain QoL as traditional face-to-face support groups. Chapter 3 contains the research design, rationale and methodology as essential components to the study.

Chapter 3: Research Method

Introduction

The purpose of this quantitative study was to determine if there were difference in QoL for persons with SLE participating in an online versus traditional face-to-face support group. This chapter contains a discussion of essential research components in conducting this study. The research design and independent and dependent variables will be discussed. The chapter also includes the research methodology, the specific research processes, procedures and techniques used for analysis.

Research Design and Rationale

A comparative research design was employed for this study. Comparative studies aim to investigate differences between two or more categorical groups based on a dependent variable or set of dependent variables (Babones, 2014; Della Porta & Keating, 2008). Comparative research is used for studies aiming to determine the cause for or consequences of existing differences in groups of individuals (Della Porta & Keating, 2008). The purpose of this study was to examine the difference of a dependent variable (i.e., QoL) between two groups (SLE patients participating on online versus traditional in-person support group) in a situation in which the researcher has no influence on the groupings nor the support group conducted (Hoe & Hoare, 2012; Ingham-Broomfield, 2014). The identified groups lack random assignment and cannot be manipulated like the SLE patients who went for an online and traditional in-person support group (Trochim & Donnelly, 2008), which makes a comparative design suitable for the study.

This post-intervention comparative quantitative design evaluated the method of support group delivery as the independent variable: online and traditional in-person. I analyzed for a significant difference between the two independent samples on the outcome of QoL as assessed by an overall general QoL rating. The problem was examined using the following research question: what is the difference in the general QoL score for SLE patients who participated in an online support group versus those who participated in a traditional in-person support group?

$H_0 1$: There is no difference in the general QoL score for SLE patients who participated in an online support group versus those who participated in a traditional in-person support group.

$H_A 1$: There is a difference in the general QoL score for SLE patients who participated in an online support group versus those who participated in a traditional in-person support group.

I used a descriptive comparative quantitative methodology to determine if the general QoL score was higher for participants in a particular method of support group delivery versus another. The inclusion criteria for the study were that the participants had a diagnosis of SLE and had actively participated for at least 12 months in an 18-month time-frame in an online or traditional in-person SLE support group. The results offered guidance on the usefulness of innovative methods of delivery for support groups to effectively reach a larger population of SLE patients.

Methodology

The post-intervention independent groups comparative analysis was used to evaluate both traditional in-person and online SLE support group interventions on the outcome of general QoL rating for SLE participants. In traditional in-person support groups, participants are engaged with health professionals and other SLE patients from the community (Da Hora et al., 2019; Zheng et al., 2009). Similarly, the online support programs engage participants with health professionals and other patients with SLE. The online support group offers greater potential for participation, especially for the patients with physical challenges as they can participate in the SLE support group from the comfort of home (Mazzoni & Cicognani, 2014). The selected population for this project were patients with a SLE diagnosis who have been actively participating in either a traditional or online SLE support group for 12 consecutive months during an 18-month time frame. Prior to initiation of the study and recruitment of participants, the study received approval from Walden University’s Institutional Review Board for human participants’ protection on October 05, 2020.

Sample Size

The required sample size was determined through conducting a power analysis using G*Power software (Faul et al., 2013). Four factors considered in the power analysis were significance level, effect size, power of test, and statistical test. Significance level refers to the probability of rejecting a true null hypothesis, also commonly called as Type I error (Haas, 2012). On the other hand, the power of test refers to the probability of rejecting a false null hypothesis (Haas, 2012). In most quantitative studies, significance level is set at 95% and power of test is set at 80% (Koran, 2016). I used the same factors for this study: 95% significance level and 80% power of test. The effect size indicated the estimated degree of relationship between predictor and criterion variables (Cohen, 1988). Effect size are normally categorized into: small, medium, and large. Medium effect size is commonly used for quantitative studies as it strikes a balance between being too strict and lenient in estimating the degree of relationship between the variables (Berger et al., 2013). Lastly, I used independent samples *t*-test to address the research questions and test the hypotheses. Using 95% significance level, 80% power of test, medium effect size (f = .50), and independent samples *t*-test with two-tailed test, the minimum required sample size was 128 (see Appendix A). That is, 64 participants were needed from traditional face-to-face support group and 64 participants from online support group.

Selection and Recruitment Process

The selection and recruitment process began after the IRB approval was received (10-05-20-0418283). The selection process for potential participants was conducted using convenience sampling. Convenience sampling is defined as a method adopted by researchers where they collect data from a conveniently available pool of respondents (Della Porta & Keating, 2008). The recruitment process was conducted via a series of emails I forwarded to the organization contact to be sent to potential participants. The content of the first email included an invitation to participate and an explanation of the purpose of study and the research question it aimed to answer. The email also requested that only those who participated in at least 12 months of the support group be included for survey completion. The second email contained the important factors of the study including the nature of the SF-20 Health Survey and the timeframe for survey completion.

The CCM was explained with emphasis on the promotion of self-management techniques which includes support group participation. I included my contact information on all emails, in case of additional questions. Instructions were given on the process for exiting the study if participants decided not to participate and a statement of consent to participate was included at the beginning of the survey. When the participants agreed to complete the survey, the survey began with the established survey questions and indication of the average time for completion.

Participants were asked about lupus management, self-care management and complications related to the condition, and their participation in support groups by type. Demographic information was not collected and participants were advised of confidentiality of their survey participation and survey responses. In this case, there was no need for data de-identification as the survey was completed anonymously via Survey Monkey. When the completed surveys were returned, a final email was sent to the main contact individual to share with participants and thank them for their participation with a debrief on the completion of the study and how the results would be used in promotion of support groups. There was no further follow up conducted after the final email.

Instrumentation and Operationalization of Constructs

The Short-Form Health Survey (SF-20) is the result of a multi-year Medical Outcomes Study (MOS) of patients diagnosed with chronic diseases or conditions. This 20-item survey measures six aspects of health status: physical functioning (6 items), role functioning (1 item), mental health (5 items), general health perceptions (5 items), and bodily pain (1 item). Scores of this instrument are specifically coded and calibrated so that each of the six dimensions is equally weighted. Each parameter score is transformed to a scale from 0 to 100, higher values indicating better status.

Operationalization

There were two variables for this study. The independent variable was the support group type. The support group type was operationalized as a categorical variable – either traditional face-to-face support group or online support group. Each participant could only be included in one and only one support group type. The dependent variable was the QoL. For the purposes of this study, the QoL of an individual referred to the individual's subjective perception of having to live life under the condition (Kusnanto et al., 2018). The QoL was operationalized as an interval (continuous) variable through the use of Likert-type scale of SF-20.

Threats to Validity

External Validity

External validity is intended to ensure the generalizability of results, and by selecting a population that represents the general population being studied, my study addressed external validity (Bernard, 2013). However, because my sample was a group of participants in two separate support groups in a single geographic location, external validity was threatened in that generalizations to other populations or areas may be limited. The sample size can also serve as a threat to external validity if the population is not large enough to have meaningful results. In the case of my study, I used G*Power to calculate the sample size needed to provide significant results if significance could be achieved. Furthermore, to ensure the study had external validity, I encouraged the participants attending face-to-face support groups to complete the survey independently at home and not while attending a support group meeting with other possible participants. This act could potentially cause data contamination or biases if survey answers are shared and discussed among participants. Maintaining confidentiality was related as a priority to participants.

Internal Validity

Data contamination was a limitation that could occur if participants take the survey multiple times (Johnson et al., 2019). Reluctancy to participate in the survey with the fear of disclosing personal identifying information threatened to be a possible barrier. Due to the threat of identity theft, participants could have been fearful that participation posed a threat to privacy.

Ethical Procedures

This study followed all ethical considerations governed by Walden University. The study received an IRB approval from the university (10-05-20-0418283). The research did not pose any harm to participants for several reasons. The nature of anonymous quantitative data collection was such that no identifying information was collected that can be linked back to the cases. Pseudo codes were used to designate each participant, i.e., P01 for participant number one and so on. Secondly, the data collected in this study were not in any way confidential, meaning that were anonymity somehow compromised, the risk of harm would remain minimal. The priority, above all others in this study, was that there will be no harm to the participants.

Hard copies of raw data and other documents pertinent to the study were securely kept in a locked filing cabinet inside the personal office of the researcher. Soft copies of raw data and other documents were r saved in a password-protected flash drive. All data and documents related to the study will be destroyed five years after completion according to Walden IRB policies.

Summary

In summary, the research design and methodology included the research process, procedures and methods for conducting a trustworthy study. The study results were analyzed to determine how QoL could have a positive impact in the lives of SLE patients who participated in either traditional or online support groups. Participants were chosen by convenience sampling and completed and return surveys via survey monkey process. The final sample size was 105 participants and included 52 from the traditional face-to-face support group and 53 from the online support group. Chapter 4 will detail the data collections process and statistical analysis of results.

Chapter 4: Results

Introduction

The purpose of this quantitative study was to determine if there were difference in QoL for persons with SLE participating in an online versus traditional face-to-face support group.

The research question was: What is the difference in the general QoL score for SLE patients who participated in an online support group versus those who participated in a traditional in-person support group?

The hypothesis was:

$H_0$1: There is no difference in QoL for SLE patients participating in an online versus traditional face-to-face support group.

H_A1: There is a difference in QoL for SLE patients participating in an online versus traditional face-to-face support group.

Research Question and Hypotheses

Research Question

A quantitative, descriptive method of comparison analysis was used to answer the following research question: What is the difference in the general QoL score for SLE patients who participated in an online support group versus those who participated in a traditional in-person support group?

Hypotheses

The generated hypotheses based on preliminary literature review was that there is no difference in QoL for SLE patients participating in an online versus traditional face-to-face support group. The difference in QoL was examined by analyzing survey data obtained using the SF-20 QOL survey.

$H_0$1: There is no difference in QoL for SLE patients participating in an online versus traditional face-to-face support group.

H_A1: There is a difference in QoL for SLE patients participating in an online versus traditional face-to-face support group.

The difference in QoL was examined by analyzing data from individuals in support groups. Participants from traditional face-to-face and on-line support groups completed the SF-20 QOL survey by following a link provided in the invitation to participate. All identifying patient information was de-identified for this research study. The variables were tested and measured using the statistical *t*-test method after the data were collected.

Data Collection

Participants completed the survey online via Survey Monkey. The data collection began on October 6, 2021 and ended on February 14, 2021. I received a notification email from Survey Monkey every time a participant completed the survey. At the conclusion of the data collection, I received a total of 106 completed surveys. However, there is three participants that did not meet the inclusion criteria and did not provide consent to participate. As such, a total of 103 participants were included in the data analysis. Specifically, the final participants belonged in the traditional group was 52 while in the online group was 53. Post hoc analysis using G*Power, with alpha .05, medium effect size *d* = 0.05 with the known group sizes *df* = 103, yielded an actual power of 71.83% which fell slightly short of the desired power of 80% (see Appendix B).

The data were collected using the Short Form-20 (SF-20) tool which consisted of 20 questions using 3-point, 5-point, and 6-point Likert scales. Responses from Survey Monkey were exported to Microsoft Excel for data pre-processing. The responses were re-coded based on the scoring instructions of the SF-20 tool. After data pre-processing, data were analyzed using SPSS Version 26.

Demographic Characteristics of Sample

Participants were SLE diagnosed patients 18 years of age or older who have participated in an online or face-to-face support group for a minimum of 12 consecutive months. Gender nor ethnicity were revealed in the study.

External Validity Representativeness of the population of SLE patients

The participants represented SLE patients at various stages of lupus and therefore the sample of participants were a total representation of the larger lupus population.

Results

Descriptive Analysis

This section presents the descriptive responses from the two groups on each of the questions and will conclude with the results of the independent sample *t*-test comparing the two groups by their scores on the overall QoL question.

Q-1: In general, would you say your health is:

In the traditional face-to-face support group, 30.2% of participants were fair and 28.3% were very good, while 18.9% were good and 1.9% were excellent. Only 20.8%

declared that their health was poor. While in the online support group, 35.8% of participants responded their health is fair and 26.4% responded as good while 20.8% responded as very good and none as an excellent. Only 17.0 % stated their health as poor.

Q2: **For how long (if at all) has your health limited you in each of the following activities?**

a. Vigorous health activities

In traditional face-to-face support groups, most participants (47.2%) responded that they can perform such activities for a period of 3 months or less without any limitations, and 26.4% said they can do the same for more than 3 months, while 26.4% said they can perform such activities without any health limitations. In online support groups, majority of the participants (50.9%) replied that they can do such activities without any health limitations for a period of 3 months or less and 28.3% of participants said that they can do the same for more than 3 months while 20.8% of members expressed that they can perform such exertions without any health limitations).

b. Moderate health activities

For traditional face-to-face support group, majority of participants (49.1%) said that they felt these stresses limited for 3 months or less and 18.9% said that they were limited for longer than 3 months while 32.3% of participants said that they were not limited at all. On the other hand, majority of the participants (54.7%) in the online support group said that feel limited for 3 months or less and 22.6% of participants said that limitations exists for more than 3 months while 22.6% of members said it did not limit at all.

c. Walking uphill or climbing a few flights of stairs

In the traditional face-to-face support group, a strong majority of participants (52.8%) responded that they can perform such activities for a period of 3 months or less and 18.9% said they can do the same for more than 3 months, while 28.3% of participants said they can perform such activities without any limitations at all. In online support groups, a vast majority of the participants (49.1%) replied that they can do such activities for a period of 3 months or less and 18.9% of participants said that they can do the same for more than 3 months while 32.1% of members expressed that they can perform such exertions not limited at all.

d: Bending, lifting, or stooping

In traditional face-to-face support groups, a vast majority of participants (54.7 percent) said they were limited for 3 months or less and 13.2% limitations extended to more than 3 months while 32.1% of participants said that it was not limited at all. In online support groups, a fair majority of the participants (41.5%) said that they were limited for 3 months or less and 17.0% of participants said that limitations occurred more than 3 months while 39.6 % of members said not limited at all.

e. Walking one block

In traditional face-to-face support groups, most participants (50.9%) responded that limitations exists for 3 months or less, and 22.6% said that they were limited for longer than 3 months, while 26.4% of participants said that this caused no limitations in walking one block at all. In online support groups, a majority of the participants (52.8%) said that they were limited for 3 months or less and 18.9 % of participants said that limitations lasted more than 3 months while 28.3% of members said that this is not limited at all.

f. Eating, dressing, bathing, or using the toilet

In traditional face-to-face support groups, a strong number of participants (47.2%) said there were limitations in performing these activities for 3 months or less and 5.7% of participants said that the time period could limitations lasted longer than 3 months while 47.2% of participants said these activities were not limited at all. In online support groups, a majority of the participants (35.8%) said that they feel performing these activities were limited for 3 months or less and 9.4 % of participants said that limitations lasted more than 3 months while 54.7% of members said these activities are not limited at all.

Q3: How much bodily pain have you had during the past 4 weeks:

In traditional face-to-face support groups, a reasonable proportion of research participants (34.0 %) said it as moderate, 18.9% of discomfort reported as very mild, 15.1% as mild and 18.9% as severe, while 1.9% as very severe. While 11.3% responded that no bodily discomfort was experienced. In online support groups, a fair number of study participants (41.5%) said it as moderate discomfort, 22.26% as mild, 13.2% as very mild and 13,.2% as severe. Meanwhile, 7.5% responded as experiencing very severe discomfort and 1.9% responded to having experienced no discomfort.

Q4: Does your health keep you from working at a job, doing work around the house, or going to school?

In traditional face-to-face support groups, 24.5% of participants answered to this question that they were unable to work a job, do housework or go to school for longer than 3 months and 39.6% said that these activities were limited for 3 months or less, while 35.8% responded that their health did not limit working or going to school. In online support groups, 28.3% of participants replied they were not able to work or go to school for more than 3 months and 28.3% expressed that limitations lasted for 3 months or less while 43.4% said that there were no limitations to going to work or school at all.

Q5: Have you been unable to do certain kinds or amounts of work, housework, or schoolwork because of your health?

In traditional face-to-face support groups, about 37.7% of participants responded that they were unable to perform certain kinds of work, housework or school work for longer than 3 months, 26.4% said that work/school limitations were present for 3 months or less, while 35.8% said that they had no limitations with work/school activities). In online support groups, 26.4% of participants responded that they were not able to attend work/school for more than 3 months and 50.9% expressed that they were limited in work/school activities for 3 months or less while 22.6% said that no limitations in work/school activities at all.

Q6: How much of the time, during the past month, has your health limited your social activities (like visiting with friends or close relatives)?

In traditional face-to-face support groups, 24.5% of participants answered that most of the time health limited social interactions, 22.6% said a good bit of the time social interactions were limited, 20.8% there were no limitations in social interactions, while 22.6% said they were limited only for a little bit of the time. 9.4% said that social interactions were limited all of the time. In online support groups, 18.9% of participants replied that a good bit of the time they limited social interactions, 18.9% responded that they spent most of the time limiting social contacts, 24.5% spent some of the time limiting social interactions, while 17.0% expressed that limited social interactions just for a little of the time. About 13.2% responded that they did not limit social interactions at all.

Q7: How much of the time, during the past month, have you been a very nervous person?

In traditional face-to-face support groups, 30.2% of participants responded that they were nervous a good bit of the time, 9.4% said they were nervous most of the time, 24.5% admitted to being nervous some of the time, while 22.6% reported that they were nervous only for a little of the time and approximately 1.9% said they were nervous none of the time. In online support groups, 18.9% of participants replied that a good bit of the time they remained nervous, 11.3% said that they remained most of the time being a nervous person, 26.4% remained nervous some of the time in strain while 28.3% expressed that they remained nervous just for a little of the time. About 5.7% said that they were not nervous at all.

Q8: During the past month, how much of the time have you felt calm and peaceful?

In traditional face-to-face support groups, 20.8% of participants responded that a good bit of the time they feel calm and peaceful, 18.9% said they felt calm and peaceful most of the time, 30.2% felt this way some of the time, while 20.8% said they felt calm and peaceful for a little of the time. Around 1.9% said they were calm and peaceful none of the time. In online support groups, 15.1% participants replied that a good bit of the time they felt calm and peaceful, the same percentage said that they felt calm and peaceful most of the time, 39.6% remained calm and peaceful some of the time, while 26.4% expressed that they remained calm and peaceful just for a little of the time. About 1.9% said that were calm and peaceful none of the time.

Q9: How much of the time, during the past month, have you felt downhearted and blue?*”*

In traditional face-to-face support groups, 20.8% of participants responded that they feel downhearted and blue a good bit of the time, 11.3% said they felt downhearted and blue most of the time, 20.8% felt some of the time, while 34.0% said they only felt downhearted and blue a little bit of the time. There were 3.8% of participants who said that they felt downhearted and blue all the time. In online support groups, 13.2% of participants replied that a good bit of the time they felt downhearted and blue, 9.4% said that they felt downhearted and blue most of the time, 22.6% felt some of the time while 43.4% expressed that felt downhearted and blue little of the time. About 7.5% said that they felt downhearted and blue all of the time.

Q10: “During the past month, how much of the time have you been a happy person?”

In traditional face-to-face support groups, the participants were asked to respond to the question, "How long have you been a happy person over the past month?" 24.5% participants replied that a good bit of the time they have been happy, 22.6 percent said they were happy for most of the time, 28.3 percent responded some of the time, while 15.1 percent said they had been a happy person a little of the time, 1.9 percent all of the time and none of the time, 7.5 percent.

In online support groups, 22.6% participants replied that a good bit of the time they had been a happy person, 13.2% said that they have been happy most of the time, 35.8%

responded some of the time while 20.8% responded a little of the time, 1.9% for all of the time and 5.7% for none of the time.

Q11: How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?

In traditional face-to-face support groups, the participants were invited to respond to the question, 9.4% of participants responded that a good bit of the time they feel so down in the dumps that nothing could cheer them up, 15.1% said they felt so down in the dumps that nothing could cheer them up for much of the time, 5.7% responded some of the time, and 22.6% said they only felt this way for a little of the time. For all the time, 0% and 47.2% for none of the time. In online support groups, 7.5% participants replied that a good bit of the time they have felt so down in the dumps that nothing could cheer them up, 7.5% said that they have felt so down in the dumps that nothing could cheer them up for most of the time, 18.9% felt some of the time while 22.6% expressed that they felt so down that nothing could cheer them up a little of the time, 1.9% responded all of the time and 41.5% responded none of the time.

Q12: Please mark the circle that best describes whether each of the following statements is true or false for you

In traditional face-to-face support groups, the participants were asked to respond to the question, "I am somewhat ill". The majority of participants (50.9%) said it was definitely true, 37.7% certainly considered it to be mostly true, 9.4% considered it to be mostly false, 1.9% unsure, and none of the participants definitely identified it as false. In online support groups, a majority of the participants (41.5%) said it to be mostly true, 52.8% regarded it to be definitely true, 3.8% considered it to be mostly false,1.9% considered it to be not sure, and none of the participants described it to be definitely false.

In traditional face-to-face support groups, the participants were asked to affirm or deny the statement, "I am as healthy as anyone I know”. A strong number of participants (52.8%) claimed it was mostly false, 22.6% of participants certainly identified it as definitely false, 22.6% definitely found it to be true, 1.9% considered it to be questionable, and none of the participants said it was definitely true. In online support groups, a majority of participants 41.5 percent definitely identified it as false, (37.7%) said it was mostly false 9.4% felt it was not clear, and none of the participants said it was definitely true.

In traditional face-to-face support groups, the participants were asked to respond to the statement, "My health is excellent". The majority of participants (47.2%) said it was mainly false, 34.0% of participants definitely identified it as false, 17.0% considered it to be mostly true, 1.9% considered it to be unknown, and none of the participants said that this was definitely true. In online support groups, a vast majority of the participants (41.5%) said it to be mostly false, 41.5% of the participants described it to be definitely false, 5.7% considered it to be not sure, and none of the participants said it to be definitely true.

In traditional face-to-face support groups, the participants were asked to respond to the sentence "I have been feeling bad lately”. The majority of participants (45.3%) said it was mostly true, 32.1% of participants identified it as mostly fake, 11.3% definitely considered it to be true, 9.4% considered it to be questionable, and 1.9% said it was definitely false. In online support groups, a vast majority of the participants (45.3%) said it to be mostly true, 22.6% of the participants described it to be mostly false, 17.0% regarded it to be definitely true, 45.3% regarded it to be mostly true, 13.2% considered it to be not sure, and 1.9% of the participants said it to be definitely false.

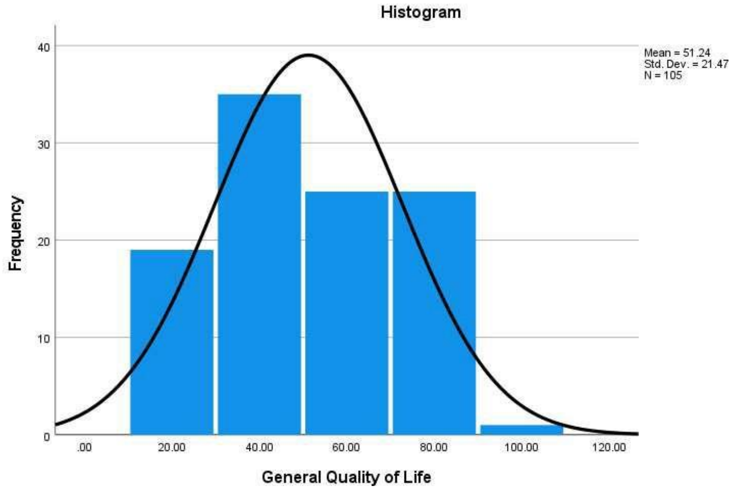
Statistical Analysis of Overall QoL using *t* test

An independent samples *t*-test is an inferential statistic that is used to determine if there is a significant difference between the means of two groups that are similar in some ways. The assumptions of the independent *t*-test are that the independent variable must be bivariate and in the case of my study, the independent variable was the type of support group either online or face-to-face so it met the requirement.

The dependent variable must be continuous data and the QoL results were ordinal with five levels providing for continuous level of measurement. The next assumption is that there must be independence of observations and in my study the participants in the face-to-face group were independent of those in the online group, the dependent variable must also be normally distributed and in my study, a histograms of the continuous data from the dependent variable met the requirement of normal distribution with a skewness and kurtosis within the range of normal distributions (see Figure 1). Homogeneity of variances was also met with a $p > .05$. Therefore, the assumptions of the independent samples *t*-test were all met and the analysis could be supported for use.

Figure 1.

Histogram of Dependent Variable



An independent samples *t*-test was then conducted to answer the research question of whether there were statistically significant differences between the self-reported QoL of participants who attended the online support group compared to those who attended the face-to-face groups. Results of the analysis indicated that the traditional face-to-face group had a slightly higher QoL (*M* =52.31, *SD* = 22.80) than the online group (*M* =50.19, SD = 20.24) (see Table 1). However, there was no statistically significant difference (*t* = 0.50, 104, *p* = 0.62; 95% CI = – 6.22, 10.46) across the two groups' overall QoL scores (see Table 2). Therefore, the null hypothesis was accepted and can be concluded that there was no difference in QoL for SLE patients participating in an online versus traditional face-to-face support group.

Table 1

Descriptive Statistics of QoL by Group Type

	Support Group Type	N	Mean	SD	Std. Error Mean
General Health Quality	Traditional	52	52.31	22.80	3.16
	Online	53	50.19	20.24	2.78

Table 2

Independent t-Test for General QoL

		Levene's Test		t-test for Equality of Means					
		F	Sig.	*t*	*Df*	Sig. (2 tailed)	Mean difference	95% CI of the difference	
								Lower	Upper
General QoL	Equal variances assumed	1.51	.22	.51	103	.62	2.12	-6.22	10.46
	Equal variances not assumed			.50	101.077	.62	2.12	-6.23	10.47

Summary

The purpose of this quantitative study was to determine if there were difference in QoL for persons with SLE participating in an online versus traditional face-to-face support group. A total of 105 participants were recruited to participate for the study. Specifically, there were 52 SLE patients from the traditional face-to-face support group and 53 SLE patients from the online support group. An independent samples *t*-test was conducted and the results showed that there was no statistically significant difference (t = 0.50, 104, p = 0.62; 95% CI = – 6.22, 10.46) across the two groups' overall QoL scores. Therefore, the null hypothesis was accepted and can be concluded that there was no difference in QoL for SLE patients participating in an online versus traditional face-to-face support group. Chapter 5 discusses the conclusion and recommendations for future research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this quantitative study was to determine if there were difference in QoL for persons with SLE participating in an online versus traditional face-to-face support group.

This study was conducted because it was important to important in the advancement of lupus care because patients become depressed, withdrawn, confused or afraid after receiving a lupus diagnosis. Participation in a support group can have a significant impact on a patient's QoL (Breitbart et al. 2015). According to Olesińska and Saletra (2018), the WHO defined the QoL as an individuals' perception of their position in life in relation to their culture and value systems and in relation to their goals, expectations, standards, and concerns. The findings suggested the method that individuals with SLE pursue support, on-line or in person did not make a difference in how positive social support, self-efficacy, and problematic social support have an independent impact on the health-related and non-health related QoL provided by health practitioners and psychologists and has a positive social impact for patients with SLE. Descriptive data suggested that the online method was more convenient for participants.

Interpretation of Findings

Scholars have yet to research the differences between traditional and online support groups for persons with SLE in terms of whether one format is more effective than another for contributing to the QoL. Consequently, this study will be beneficial for SLE patients and health professionals.

Whereas findings from this study indicated there was no difference in QoL for both the online and face-to-face support groups for people diagnosed with SLE infections, more studies need to be carried out where other factors such as disease severity, living conditions, and economic conditions are considered. Patients attending either support group type with consistent attendance and participation can expect to enjoy and maintain the same level in their QoL.

The results of my study were similar to previous studies that compared patients' perceptions and understanding of online healthcare support system in two different groups concluded that internet-panel group and in-person group use, that the online healthcare support system is as effective as in-person support (Aria & Archer, 2018; Huber et al., 2018; Mazzoni & Cicognani, 2014). Additionally, Kodatt et al. (2014) found that online peer-to-peer groups were useful for persons dealing with long-term illness as they could share strategies for improving their health and receive emotional support from others. Both traditional face-to-face and online support groups provide a plethora of educational resources for persons with chronic illnesses and these services are often extended to caregivers of persons with SLE.

The theoretical framework in this study was the CCM, discussed as an essential framework for improving chronic disease care at the patient level (National Institute of Diabetes and Digestive and Kidney Diseases, 2019). The model, based on six interrelated system changes meant to ensure that the care involves patient-centered practices oriented towards evidence-based practices with the goal of transformation of care with increased attention on delivery of and primary care (Golder & Morand, 2017). The CCM element alignment to this study is patient self-management support designed to empower patients to manage health and be active participants in health care. The results of this study supported CCM in that when SLE patients participate and engage in support groups, they empower themselves with the available resources to better manage the condition in hope of maintaining a positive QoL.

The results of my study suggest evidence of the benefits of online support groups for SLE patients who may find limited support options to address their concerns, as well as provide evidence to health professions who have been reluctant to encourage use of online care. This aligns with similar results found in other studies (Aria & Archer, 2018; Huber et al., 2018; Mazzoni & Cicognani, 2014). While this study did not produce significant results regarding online vs. traditional face-to face support group participation to draw conclusion of which might be more beneficial for the patients. Additionally, consideration of the comparative analysis, patients noted that the online method was more convenient. The potential implication for positive social change is consistent with efforts for regular participation in support groups. Regardless of support group type, benefits include emotional support, healthcare advocacy and most importantly, a greater QoL. Ppeer reviewed articles and supported by statistical data, it was revealed that participation in either support group types by patients had similar or the same impact in maintaining QoL. As a result of my research, health professions should be motivated to introduce online and traditional face-to-face support group options to their patients. They may offer researched evidence that the QoL can be maintained with consistent participation in either online or traditional face-to-face support group types.

Limitations of the Study

One of the major limitations of this study was the use of convenience sampling technique to determine participants of the analysis. Outcomes of a convenience sampling survey cannot be comprehensive to the target population because of possible bias associated with the technique. Underrepresentation of subgroups in the sample in comparison to the population interest contributes to the bias associated with the technique. Also, studies carried out on a convenience sample is prone to limited external validity. With participants having varied degrees of attendance, the results of the support group QOL may be limited for those who had only attended a few support group meetings compared to those who attended many. This variation in attendance for those who completed the surveys may have influenced the results and leave the significance or lack of significant findings in question. Due to the current health pandemic, traditional support groups during April to May 2020 were not engaging in face-to-face meetings. Another limitation experienced in the study during its inception period was the slow response in completing and submitting surveys caused by the ongoing COVID19 pandemic. Additionally, the desired sample size was not achieved. I hoped to include 128 participants, 64 participants each for the two support groups. Unfortunately, due to various factors, only 105 agreed to participate in the study. Given the small sample size associated with the current study, the generalizability of the outcomes from the study is limited.

Recommendations

From the study outcomes, I recommend the following be undertaken in further studies; First, there is a need to be more involved in the recruitment process of participants. The involvement can be achieved by personally making a list of requirements that each participant should meet, including gender, age, or religion. Additionally, I may directly contact study participants through written or verbal communication while adopting mechanisms to keep in touch. I should also strive to make the study experience positive to encourage potential respondents to participate. Also, the incentives could be provided to encourage uptake of the study by the right audience. In addition, screening of participants to ensure only reliable individuals are recruited in an unbiased way can be done.

I could also use multiple social media platforms such as Facebook, Instagram, Twitter, WhatsApp, and TikTok to recruit respondents for the research study. Here, I would provide my contact information directly on the advertisement post message to be contacted by respondents. I could then use screening questions to determine eligible participants. Social media recruitment would accelerate the recruitment process because it is easy to reach potential participants. Additionally, social media platforms forms provide a wide range of respondents to choose from. Consequently, this recruitment method could improve response time and ultimately reduce the time and resources needed to complete the required surveys.

Further recommendations include offering incentives such as gift cards or to a further extent, money as a token of appreciation to potential participants during the recruitment process. In addition, incentives encourage participants to contribute to study surveys because it serves as an appreciation for their contributions, efforts, and dedication towards the survey/study. Also recommended for future studies is the use of control groups, those patients who do not attend any support group, neither the face-face groups nor the online-based support groups. These support groups would establish a cause-and-effect association by isolating the effects of an independent variable. Results from both sets of groups (those who attend support groups and those who do not participate in support groups) can then be compared to determine the exact impact of support groups on Systemic Lupus Erythematosus patients' QoL.

Additional recommendations for further studies include expanding the geographical areas from where study participants are recruited. Further recommendations include churches that could be utilized to provide a recruitment base for respondents in the study survey. Other recommendations for future studies include using the snowball sampling technique because it is rare to find respondents with Systemic Lupus Erythematosus disease. The method will enable existing respondents to refer other individuals suffering from the same condition. In addition, the technique will provide enough data to analyze and draw conclusions on the impact of support groups (online-based and face-to-face) on the quality of life of people living with Systemic Lupus Erythematosus disease. If adopted in future studies, the snowball sampling technique will be economical on time as it is quicker to find respondents. It is also cost-effective as respondents will be drawn from a primary source and therefore not so expensive. Moreover, the technique would help solve issues concerning the unwillingness of potential respondents taking part in the survey/study because they will be known to each other before the examination.

Implications

Implications to Individual Patients

The dynamics of living with SLE bring forth the need for support options. These options are aimed at helping patients coming to terms with their illness and utilizing appropriate resources to help manage their situations and maintain a better QoL. The potential impact of social change could be evident at various levels, including individual, organizational, societal, and family levels. Social change can be impacted at the individual patient level because patients achieve a greater QoL by participating in support groups that best fit their lifestyles (Kodatt et al., 2014). In doing so, patients may no longer misunderstand the implications and benefits of support groups based on the type of support group and understanding how beneficial these groups can be (Mazzoni & Cicognani, 2014). To ensure patients have a good understanding of the requirements of a particular support group, health workers can carry out awareness campaigns and education to patients on how best they can utilize support groups to improve their quality of life.

The type of education provided can be in special pullouts in newspapers, blog posts, community-based campaigns, and even posters around residential settlements (Scalzi et al., 2018). Additionally, the education can be provided through specific departments and customer care desks in medical centers where patients are taught the basics of support groups, how they work and the benefits they provide (Huber et al., 2018). This method of persuasion can be successful in convincing patients because it is carried out in a hospital setting and done by medical practitioners (Daly et al., 2014). This critical feature would easily convince patients to join. Besides medical facilities and medical practitioners, education on joining support groups can be carried out by community-based organizations and state or government institutions concerned with community health or societal members who can volunteer to provide civic education (Huber et al., 2018; Mazzoni & Cicognani, 2014).

Implications at Family Level

Families are the backbone of society and can easily influence societal change. Families' involvement in support groups concerned with patient care will encourage more people in the community to take up the challenge and get involved in these groups (Huber et al., 2018; Mazzoni & Cicognani, 2014). In addition, families can directly or indirectly be involved in support group sessions to provide moral and mental support to patients in these groups. By attending these sessions, family members get equipped with knowledge on how to improve their individual quality of life or that of their neighbors or friends having SLE (Huber et al., 2018).

Implications at Organizational Level

At the organizational level, health practitioners need further education and training to equip them with skills and knowledge of how support groups operate. However, healthcare providers can take comfort in sharing the benefits regarding QoL concerning support group participation (Huber et al., 2018). They can do so when carrying out medical consultations with Systemic Lupus Erythematosus patients and giving them hope in their fight against the disease (Mazzoni & Cicognani, 2014). Furthermore, healthcare practitioners can provide reassurances to patients who may not have been convinced on how support groups work and the different support group options available, which result in the same QoL benefits (Zhang et al., 2009). Additionally, healthcare providers and medical centers should incorporate encouragement policies and plans which encourage patients to join support groups (Mazzoni & Cicognani, 2014). Consequently, new and existing patients visiting the health facilities should be provided with occasional reminders and follow-ups on how they are faring with their support groups, challenges they face, and how best they can be helped to overcome the obstacles.

Implications at Societal and Policy Levels

These study findings can be presented to leaders in various political platforms and events at the societal and policy formulation levels. Usually, politicians and people in power have massive support bases from which a good number suffer SLE disorders (Zhang et al., 2009). These leaders can use their influence to educate the masses on the benefits of joining support groups and positively impact their quality of life (Mazzoni & Cicognani, 2014). Churches and news events can also be used as forums to encourage participation in support groups, a move that can boost funding and material support to initiatives and organizations involved in the treatment of SLE diseases. Additionally, letters to the political leadership to support various healthcare programs can positively impact patients' quality of life.

Empirical Implications

From the study outcomes, healthcare practitioners involved in diagnosing and treating SLE disorders should be persuaded to incorporate policies that encourage new SLE patients to join support groups. Still, healthcare practitioners should provide occasional reminders to patients on how they how support groups they joined are progressing and any possible need for expert support (Mazzoni & Cicognani, 2014; Zhang et al., 2009).

Summary Recommendations for Practice Change

Recommendations for practice change deduced from this study include carrying out campaigns in communities to encourage patients to join support groups of their choices, either those online-based or the traditional face-to-face groups (Larsen et al., 2018). Also, political leaders and those in power are encouraged to support these initiatives, both financially and through legislations, to ensure success of health care initiatives that improve the quality of life (American College of Rheumatology, 2019). For future investigations, this analysis recommended the use the snowball sampling technique to increase the accuracy of results obtained from the study

Conclusion

Many SLE patients suffer through their diagnosis due to the lack of having some type of social support relative to coping with their condition. Online and traditional face-to-face support groups may help patients cope with their illness and maintain a better QoL. Online support groups are offered on various online platforms where patients participate without leaving their homes. Traditional face-to face support groups can be assembled in various locations outside of patient's homes. Studies have shown that support groups are a great way for patients to connect, share experiences and learn about their conditions (Brennan & Craven, 2016; Huber et al., 2018; Mazzoni & Cicognani, 2014). Individuals with SLE who seek support may access support groups either in the traditional face-to-face format or online because it has been proven that any type of support group increases QoL. That is, with provider-education and engagement in care for patients with SLE then with the assistance of healthcare providers in encouraging these options, SLE patients will continue to thrive and live better, longer, healthier lives.

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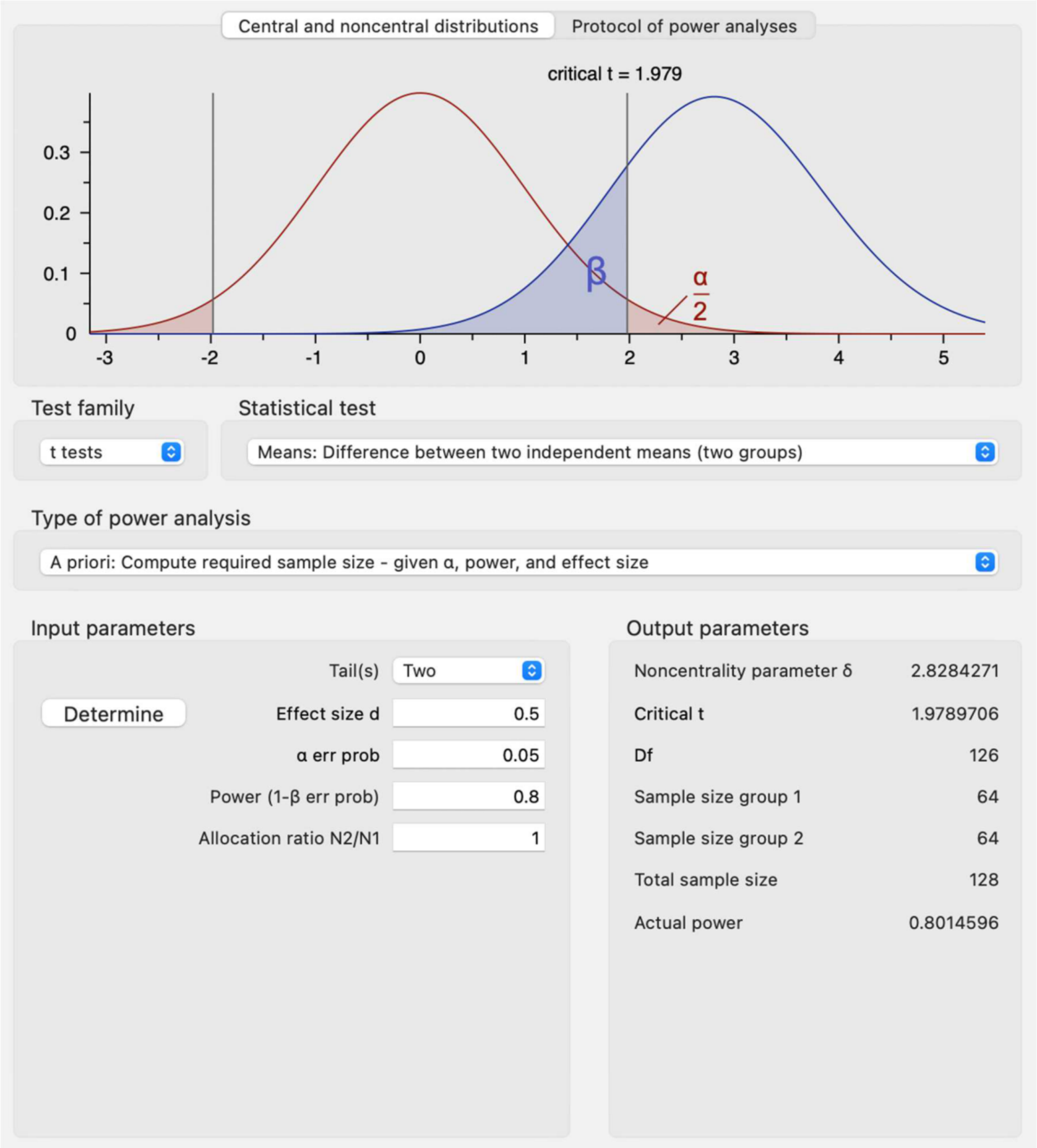
Appendix A: A Priori Power Analysis



Test family: t tests

Statistical test: Means: Difference between two independent means (two groups)

Type of power analysis: A priori: Compute required sample size - given α, power, and effect size

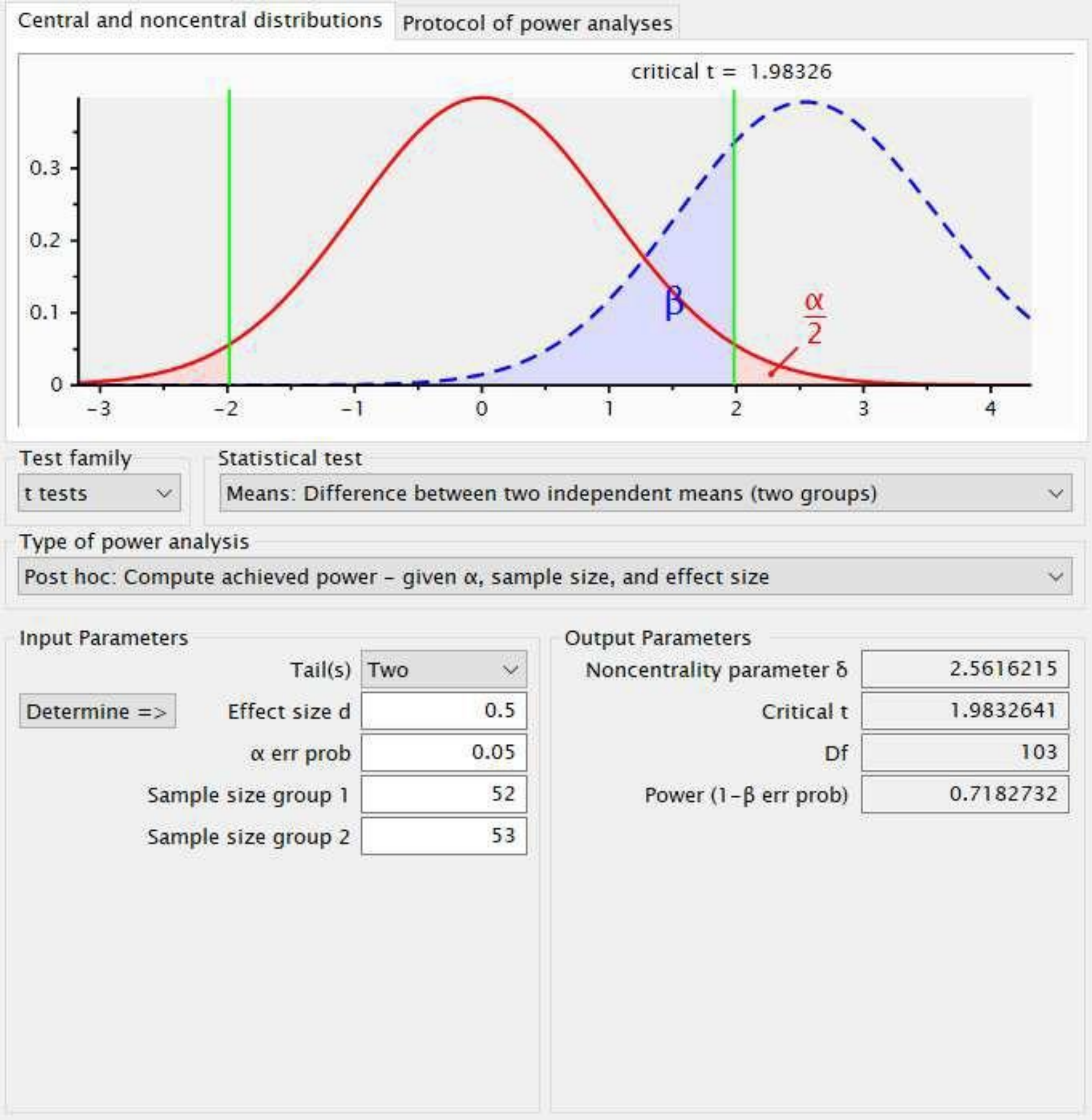
Input parameters

Tail(s)	Two
Effect size d	0.5
α err prob	0.05
Power (1-β err prob)	0.8
Allocation ratio N2/N1	1

Output parameters

Noncentrality parameter δ	2.8284271
Critical t	1.9789706
Df	126
Sample size group 1	64
Sample size group 2	64
Total sample size	128
Actual power	0.8014596

Appendix B: Post Hoc Power Analysis



critical t = 1.98326

Test family: t tests

Statistical test: Means: Difference between two independent means (two groups)

Type of power analysis: Post hoc: Compute achieved power – given α, sample size, and effect size

Input Parameters

Tail(s): Two

Effect size d: 0.5

α err prob: 0.05

Sample size group 1: 52

Sample size group 2: 53

Output Parameters

Noncentrality parameter δ: 2.5616215

Critical t: 1.9832641

Df: 103

Power (1−β err prob): 0.7182732