USING THE *LUPUSOHIO* MOBILE DEVICE APPLICATION AS A STRATEGY TO INCREASE KNOWLEDGE AND IMPROVE SELF-MANAGEMENT IN LUPUS PATIENTS: A MIXED METHODS STUDY

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by

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ABSTRACT

Background: People living with lupus (PLWL) face a difficult and uncertain disease that includes both exacerbations and remissions. Symptom knowledge and self-management are key to preventing complications. The *LupusOhio* mobile device application assists with education and management of lupus, but it has yet to be evaluated.

Objective: The aims of this exploratory, concurrent mixed methods study include: 1) understanding existing users' perceptions of the *LupusOhio* mobile application in terms of usability and value; and 2) assessing new users' lupus knowledge and self-management before and after using the *LupusOhio* mobile application.

Methods: Recruitment was determined based on responses to an email sent to PLWL living in Ohio (*n*=1,399). Of 102 respondents to the link, 94 (92.2%) completed the preliminary survey. Sixty-two (65.9%) had never used the *LupusOhio* mobile application. These respondents were asked to download, use the *LupusOhio* mobile application, and log perceptions for one month. Previous users were invited to participate in face-face interviews (*n*=7), centered on eliciting their perceptions of app usability and value.

Results: Feedback from the interviews were similar to findings of the intervention. Interviewees revealed that the *LupusOhio* mobile application was an effective tool for providing basic material. Half of new users rated the *LupusOhio* mobile application as very helpful or helpful (50.0%) and very valuable or valuable (50.0%). Pretest/posttest lupus knowledge scores did not improve (*M*=9.00, *SD*=1.09; *M*=8.06, *SD* 3.04), which may indicate there was not enough time for change to occur. There were two significant findings for self-management for new users. Top three areas opened in the app included: *My Lupus Answers* (83.3%); *Events* (61.1%); and *News* (50%). These findings are consistent with feedback from the interviews.

Conclusions: This study revealed that PLWL who used the *LupusOhio* mobile application agreed that the app was a useful tool for obtaining basic knowledge about lupus and lupus-related events in which to participate. Participants from both groups indicated similar responses regarding areas liked and in need of improvement. Results from this study can be used to improve the *LupusOhio* mobile device application to better educate PLWL.

***Keywords*:** systemic lupus erythematosus, disease self-management, patient education, strategies for patient education, mobile application

Dedication

I would like to dedicate this dissertation to my family, friends, and co-workers for all their support and encouragement throughout this journey.

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I would like to thank my dissertation committee, Drs. Mary Step, Eric Jefferis, Margaret Stephens, and Joel Hughes for their guidance and contribution to the successful completion of my dissertation. I would also like to thank Karen Baker for her support and encouragement throughout the dissertation project. I would like to extend my gratitude to the Lupus Foundation of America, Greater Ohio Chapter for their assistance in conducting this research project, as well as all participants of the study.

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Diana L. Fleming, May 2020, Kent. Ohio.

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Chapter I

Introduction

Lupus is a chronic disease that may appear in many different forms – systemic lupus erythematosus (SLE), discoid lupus (DL), drug-induced lupus (DIL), and neonatal lupus (NL). Approximately 1.5 million people in the United States suffer from the effects of some form of lupus (CDC, 2015; LFA, 2015) which presents with periods of exacerbations (flares) and remissions. Lupus affects primarily women between the ages of 15-44 years with a ratio of 9:1 when compared to men. Lupus can also affect older adults, men, and young children (CDC, 2015; LFA, 2015). There is a higher prevalence of the disease among people of color such as African Americans, American Indians, and Hispanics (CDC, 2015; LFA, 2015). People of color have a shorter lifespan with more complications and worse health outcomes. Lupus results in financial, physical, and emotional burdens, not only for PLWL, but for society and the health care system, as well (Drenkard et al., 2014; Oglesby, Durden, Narayanan, Juneau, & Wilson, 2013; Garris et al., 2013).

The *LupusOhio* Application

LupusOhio is an application for mobile devices designed specifically for lupus patients. The family of Rita Dennis donated money to the Lupus Foundation of America, Greater Ohio Chapter, LLC (LFAGOC) in memory of Ms. Dennis who suffered from complications of lupus. The family wanted other lupus patients to be better equipped to manage their disease. The LFAGOC used this donation to fund the development of *LupusOhio*. The family then donated the application back to the LFAGOC to be dispersed to lupus patients. The *LupusOhio* application was designed by Todd Sullivan and Caleb Lichty in 2014 and is currently managed by Mark and Caleb Lichty. The application was developed based on a template used by the developers. The developers worked with the LFAGOC to build the platform of the application to make the application specific to lupus patients. The LFAGOC contributed to the development of the application by providing the educational information and other items of support for lupus patients. The LFAGOC is responsible for all content within the application and has complete access to update *LupusOhio,* which is done regularly on a monthly and as needed basis by administrative staff. No metadata is available with the application, which presents a limitation when evaluating the usability of the application. Lupus Foundation of America, Greater Ohio Chapter adopted *LupusOhio* as the official application of the chapter.

LupusOhio is under the license of Open App Marketing, LLC and managed under the agreement of the Open App Marketing, LLC and the Lupus Foundation of America, Greater Ohio Chapter. *LupusOhio* is a free application for both Android and Apple users, requiring either Android version 4.1 and up, or iOS 8.0 or later for iPhone, iPad, or iPod touch. The approximate size of the application is 15 M for Android users and 34.7 MB for iPhone / iPad / iPod touch users. The application is available in 32 different languages and is available in the greater Ohio area.

The home page is primarily informative, offering ten tabs that provide a diverse range of lupus relevant information. Descriptions of each page of the *LupusOhio* mobile application were summarized (see Table 1), along with screenshots of the *LupusOhio* application (see Figure 1).

Table 1

Display of LupusOhio Application Tab Descriptions

Primary Tabs	Descriptions	Secondary Tabs	Description
Call us	Contains contact information for patients to call the LFAGOC to obtain information		
Directions	Contains a Google Map page with directions to the LFAGOC office		
Share	Provides five options to share	Share by Email	Connects to personal Email
		Share on Facebook	Connects to LFAGOC Facebook site
		Share on Twitter	Connects to Twitter site
		Share by SMS	Connects to personal SMS on phone
		Share on Google+	Connects to Google+ site
Events	Contains links to both upcoming and past events.	Upcoming Events	Contains links to upcoming events. Click on the preferred event to get information including date, time, directions, Google Map, and registration information
		Past Events	Contains information and photos of past events
About	Contains six links with descriptions of each.	About Us	Describes the lupus foundation and services. Has a tab for the description and to post comments?
		Our Mission	Describes the Mission statement of the LFAGOC
		Our History	Describes the history of the LFAGOC
		Our Staff	Describes the services of the staff
		Our Board	Describes the role of the Board of Directors of the LFAGOC. Has an embedded “click here” link to see photos and bios of each board member
		Our Brand	Describes the Brand of the LFA. Has an embedded “Click here” link to watch a video clip about lupus and description of the disease.
Rita Dennis	Contains information about the patient to whom the application was dedicated		
Walk 2019	Contains information on each of the fundraising walks: Cincinnati, Columbus, and Cleveland.	Join the Fight. Register Now	Links to “Register”, “Sponsor Participant”, Login”, & “Event Information”
		Register to Volunteer	Provides a form to register as a volunteer for the event
		Walk Tools	Links the walker to 12 further links for Walk Materials including “Walk Team Captain Guide”, “Corporate Giving Guide”, “How to raise $250”, and more.
		Why I Walk	Link for the patient to share their story and select the location of the walk at which they want their story shared.

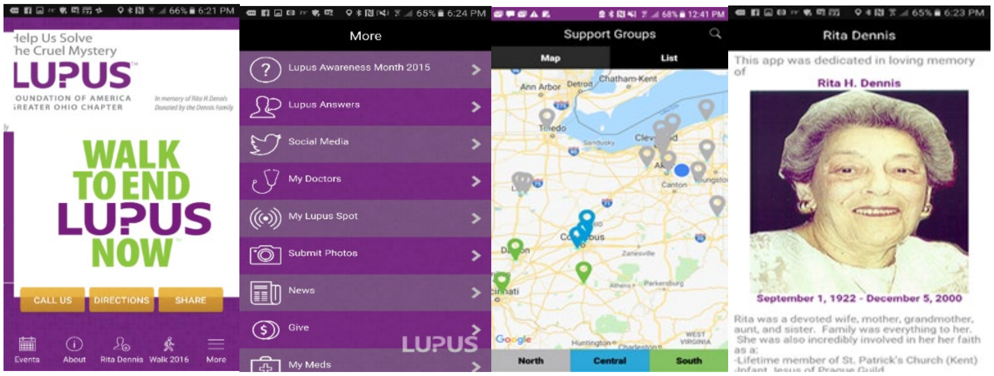
Table 1

Continued

Primary Tabs	Descriptions	Secondary Tabs	Description
More	Contains 13 additional tabs.	Lupus Awareness Month	Provides 3 links describing events to promote lupus awareness
		Lupus Answers	Contains frequently asked questions, resources, and a Physicians' Directory.
		Social Media	Provides Links to Facebook, Twitter, Instagram, Pinterest, LinkedIn, Snapchat, and YouTube where users can find lupus information
		My Doctors	Blank page to add physicians and appointments
		My Lupus Spot	Contains 10 additional links to "Living with Lupus Tips", inspirational messages, and support group facilitators.
		Submit Photos	Site for PLWL to submit photos of events
		News	Contains up-to-date news on research, National Public Agenda, Grants, and current medications, and Congressional reports.
		Give	Contains links on how to give to the LFAGOC or how to donate to a Walk.
		My Meds	Contains a blank page where PLWL may add medications and dosages to have a list readily available when seeking medical treatment
		Support Groups	Contains 2 links: "Map" with directions to the support groups divided by regions throughout Ohio (North, Central, South); and the "List" contains a list of support groups throughout Ohio with addresses, date and time of meetings, and comment section
		Mailing List	Provides a form to sign-up for the lupus newsletter
		Credits	Contains information of who designed and managed the application. Copyright 2015 Lupus Foundation of America Greater Ohio
		Lupus Store	Contains a variety of items to be purchased that show support for lupus and increase lupus awareness. Proceeds obtained support the LFAGOC for services and programs.

Figure 1

Screenshots of LupusOhio



This app was dedicated in loving memory of

Rita H. Dennis

September 1, 1922 - December 5, 2000

Rita was a devoted wife, mother, grandmother, aunt, and sister. Family was everything to her. She was also incredibly involved in her her faith as a:

-Lifetime member of St. Patrick's Church (Kent)

-Infant Jesus of Prague Guild

Note. Screen shots of main pages *LupusOhio* - Home page, More page, Support Groups, and Rita Dennis Story

Purpose

This dissertation describes a concurrent mixed methods study design investigating perceptions of PLWL in Ohio who used the *LupusOhio* mobile application, while concurrently assessing PLWL who had not used *LupusOhio* mobile application and measuring lupus knowledge and self-management before and after using the *LupusOhio* mobile application.

Specific research questions developed for this study were:

1. Does using the *LupusOhio* mobile application benefit PLWL?
2. Do people diagnosed with lupus perceive the *LupusOhio* application as a usable and valuable tool for living with the disease?
3. Does using the *LupusOhio* mobile application increase the disease knowledge among PLWL in Ohio?
4. Does using the *LupusOhio* mobile application improve self-management among PLWL in Ohio?

Concurrent qualitative and quantitative inquiry explored perceptions of the application usability and value and investigated the feasibility of using this application as a strategy to improve patient outcomes.

The guiding research question for the qualitative strand of the study was: Do people diagnosed with lupus perceive the *LupusOhio* application as a usable and valuable tool for living with the disease? Qualitative interviews identified participants' perceptions of the usability and value of the *LupusOhio* application. Results of the qualitative strand of the study will be used to potentially improve the *LupusOhio* application.

The guiding question for the quantitative strand of the study was: Does using the *LupusOhio* mobile application increase the disease knowledge and improve self-management among PLWL in Ohio? The quantitative strand of the study, a one-group quasi-experimental pretest-posttest design, was implemented to assess participants' lupus knowledge and self-management scores before and after using the *LupusOhio* application.

The following hypotheses were developed for this study:

1. H^1: Using the *LupusOhio* application for a mobile device for one month will increase patients' knowledge of lupus symptoms and complications.
2. H^2: Using the *LupusOhio* application for a mobile device for one month will improve self-management of lupus symptoms and complications.

Chapter II

Literature Review

An extensive database search identified studies of strategies for improving patient education and self-management of chronic diseases. The databases searched included: CINAHL, Cochrane Library, EBSCOhost, Medline Complete, and PubMed. The key terms included: systemic lupus erythematosus, self-management, chronic diseases, patient education, strategies for patient education, mobile applications, mobile apps, smartphones, health outcomes, Internet-based programs, systematic reviews, and quality of life. Fifty-six (56) studies that included at least two keys words were found. Inclusion criteria were studies that used mobile applications or computer-based programs as strategies for patient education and self-management of patients with chronic diseases. Thirty-six (36) studies used mobile applications for self-management of chronic diseases such as diabetes, mental illness, cardiac disease, chronic lung disease, and exercise/physical activity. Studies were excluded if they did not use mobile applications, social media, or Internet as an intervention or support strategy, or that included mobile applications geared toward health care professionals' use only. Only one study was found that discussed the development of an application for lupus patients but did not include evaluation of the application on outcomes. However, 11 studies revealed other strategies for educating lupus patients such as support groups, Internet programs, mail-delivered kits, and face-to-face classes, which could provide useful information in mobile application development or improvement.

Patient education is key to managing chronic illness (Epping-Jordan, 2001)**.** Empowering patients to take responsibility and control of their health is an important part of self-management. The literature review discussed the definition of self-management and reviewed studies of self-management of chronic diseases using variety of strategies such as mobile applications, social media, or Internet.

Self-Management

Self-management is a term used to describe health promotion and patient education needed to manage symptoms of chronic diseases and prevention of complications. Self-management has been used to manage chronic illnesses such as asthma, diabetes, cardiovascular diseases, and arthritis to name a few (Lorig et al., 1999). One must take responsibility for his or her health decisions and day-to-day care, which may be a lifelong endeavor (Lorig & Holman, 2003). Self-management differs from traditional patient education in that people are not just receiving knowledge-based patient education, but are given the tools needed to develop problem-solving skills, improve self-efficacy, and the support to apply the knowledge to their individual chronic illness (Coleman & Newton, 2005).

Self-management of chronic disease. Chronic disease affects over 30% of the worldwide population and is increasing at a rate of 17% per year. Furthermore, the cost of chronic disease comprises 70% of health care costs in developed economies (Gill, 2015). As chronic diseases continue to increase, the World Health Organization Non-Communicable Diseases and Mental Health Cluster has developed an Internet-based resource center as a means of alerting leaders of the changes of global health issues and providing health care solutions for management of this surmounting burden (Bengoa, 2003; Gill, 2015). Self-management is a key factor in effectively caring for those with chronic illness and improving patient outcomes (Coleman & Newton, 2005).

As new technologies continue to evolve, health professionals are developing more strategies to assist people in managing health and chronic illnesses (Lorig et al., 1999). Internet-based programs, including those that can be accessed through mobile devices, have the potential to increase patient communication and education with their health care providers. Physicians can provide patients with an “information prescription” to guide patients to accurate web sites that provide education specific to the patient’s condition (Coberly et al., 2010; Lorig et al., 1999). Internet-based programs can reach a wide array of public health populations, which is another advantage for patient education. Disadvantages to Internet-based learning include breaches of privacy and security, inferior quality websites, irrelevant and inaccurate information, and failure of websites to use newer online technologies (McDaniel & Stratton, 2006; Crocco, Villasis-Keever, & Jadad, 2002).

Self-management programs can improve quality of life, lower hospitalizations or use of other health care services, delay the progression of the disease, and avoid complications (National Center for Chronic Disease Prevention & Health Promotion, 2015). Stanford University College of Medicine developed many self-management programs for a variety of chronic diseases including arthritis, diabetes, chronic pain, cancer, and HIV/AIDS which have been found to be very effective (Lorig et al., 1999; Lorig et al., 2001; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). These programs were developed to assist patients who had one or more chronic conditions to learn: 1) techniques to deal with problems such as frustration, fatigue, pain, and isolation; 2) appropriate exercise for maintaining and improving strength, flexibility, and endurance; 3) appropriate use of medications; 4) communicating effectively with family, friends, and health professionals; 5) nutrition; 6) decision making; and 7) how to evaluate new treatments (Lorig et al., 1999; Lorig et al., 2001; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). The programs offered a variety of venues for participants: small community group programs, Internet programs, and mailed programs. The Internet programs consisted of online workshops facilitated by two moderators, usually one of which had the chronic disease of interest (Lorig et al., 1999; Lorig et al., 2001; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001).

Tasks for self-management. There are three tasks that one might encounter to assist patients in managing their illness and maintaining wellness. The first task is medical management, which entails medications, special diets, and special exercises. The second task is maintaining, changing, or creating new behaviors to manage disease symptoms such as decreasing the amount of work, changing positions, and avoiding certain foods. Lastly, the third task deals with the emotional aspect of chronic disease such as anger, depression, fear, and frustration (Lorig & Holman, 2003; Schulman-Green et al., 2012).

Self-management as a problem-based concept. Self-management education must be individualized to each person's specific needs (Lorig & Holman, 2003; Coleman & Newton, 2005). For example, though people living with lupus may have some similar symptoms, (e.g. fatigue), others may experience fewer common symptoms such as cosmetic defects, or kidney issues (Macejova, Zarikova, & Oetterova, 2013; Meacock, Dale, & Harrison, 2013). For this reason, it is important to complete a needs assessment to identify each person's specific needs (Lorig & Holman, 2003; Coleman & Newton, 2005). Addressing individual problems is the foundation of self-management. Through self-management programs, people can have improved quality of life, fewer hospitalizations or use of other health care services, delay the progression of the disease, and avoid complications (National Center for Chronic Disease Prevention & Health Promotion, 2015).

Self-management skills. Researchers of self-management programs have identified five skills that are important to self-management: problem solving, decision making, resource utilization, formation of a patient / health care provider partnership, and acting (Lorig & Holman, 2003). Many of these same skills are used in the design and development of applications for mobile devices. For example, features for development of an application for self-management of chronic disease included a system to support self-care tasks, continuous adherence to regimens, monitoring of adherence, and secure two-way communication between patients and clinicians (Parmanto et al., 2013; Herschman et al., 2014). These features allowed support of self-care, adherence to regimens and monitoring, support of clinician-patient engagement, and was well-utilized (Parmanto et al., 2013). Another skill that is important in self-management is goal setting. Adults that set goals when dealing with health issues have been found to have improved recovery and rehabilitation. These goals drive individuals to achieve their goals and thus may improve the performance of self-management behaviors (Zaldonis et al., 2015).

Self-management and the constructs of Social Cognitive Theory. The study is rooted in the constructs of the Social Cognitive Theory (SCT), which are used to provide a rationale for predicted effects. The key elements of SCT include personal factors, behavioral factors, and environmental factors. The concepts of interest for this study included self-efficacy, observational learning (modeling), facilitation, and self-regulation (Glanz, Rimer, & Viswanath, 2008; Bandura, 1986).

Self-efficacy/observational learning. Bandura (1986) defined self-efficacy as one's confidence toward performing a task. Enabling PLWL to observe their peers via application information may result in better self-management of the disease and its complications. Multiple studies found that using digital forms of consumer health information (e.g. mobile applications, Internet, social media) resulted in improved patient knowledge, self-management, and health outcomes (Abogunrin & Martin, 2013). Chronic diseases studied included diabetes (Chomutare et al., 2013; Or & Tao, 2014; Chen et al., 2013; De Jongh et al., 2012; Pulman et al., 2013; Ristau, Yang, & White, 2013; Peeples, Iyer, & Cohen, 2013; Blake, 2008a; Blake, 2008b; Torbjornsen, 2014; Trudel, 2007), cardiovascular disease (heart failure and hypertension) (Nundy et al., 2013; Cano-Martin, Martinez-Perez, de la Torre-Diez, & Lopez-Coronado, 2014; Widmer et al., 2014; Leeman-Castillo, Beatty, Raghunath, Steiner, & Bull, 2010), chronic respiratory disease such as asthma and COPD (Belisario et al., 2013; Trivedi, 2015; Cruz, Brooks, & Marques, 2014; De Jongh et al., 2012; Zhang, Song, & Bai, 2013), mental illness (Donker et al., 2013; Karasouli & Adamas, 2014; Trivedi, 2015; Watts et al., 2013), and unspecified chronic diseases (Mattila et al., 2009; Parmanto et al., 2013; Mosa, Yoo, & Sheets, 2012; Wang et al., 2014; Blake, 2008a; Blake 2008b; Lau et al., 2011). Other studies looked at physical activity (Leeman-Castillo et al., 2010; Lau et al., 2011; Segerstahl & Oinas-Kukkonen, 2011; Glynn, 2011), eating disorders and weight loss (Loucas et al., 2014; Turner-McGrievy & Tate, 2011), and medication management (Bailey et al., 2014; Grindrod, Li, & Gates, 2014; De Jongh et al., 2012).

Relationship between knowledge and self-management. Multiple studies have observed the relationship between knowledge and self-management. Researchers found knowledge to have a direct relationship on self-management for a variety of chronic diseases such as heart failure, hypertension, hyperlipidemia, diabetes, lupus, and chronic kidney disease (Sahebalzamani et al., 2016; Ghannadi et al., 2016; Long, Ponder, & Bernard, 2017; Hayward et al., 2017; Kueh, Morris, & Ismail, 2017; Young, Hupzyk, & Barnason, 2017). For example, Kueh, Morris, and Ismail (2017) examined the effects of knowledge on self-management for people (*n*=266) with type 2 diabetes. Diabetes knowledge and self-management were measured using the diabetes knowledge scale and Summary of Diabetes Self-care Activities scale, respectively (Kueh, Morris, & Ismail, 2017). Kueh, Morris, & Ismail (2017) found that diabetes knowledge was a significant predictor of self-management for monitoring blood glucose and foot care. Researchers also found that there was an indirect relationship between self-management and quality of life (Kueh, Morris, & Ismail, 2017). Among all the studies reviewed, there were mixed results as to whether mobile applications were effective for self-management of chronic diseases.

Self-management using mobile applications on mobile devices. Mobile devices are widely used and a part of everyday life. Mobile devices can provide users capabilities and accessibility to a broad scope of information including multiple health related applications to assist users to manage their health (Boulos, Brewer, Karimkhani, Buller, & Dellavalle, 2014).

Multiple studies have investigated the use of mobile applications as a strategy for self-management of chronic diseases such as chronic obstructive pulmonary disease, congestive heart failure, hypertension, depression, diabetes, medication self-administration, eating disorders, and physical activity (Lorig et al., 1999; Bailey et al., 2014; Grindrod, Li, & Gates, 2014; Wang et al., 2014; Donker et al., 2013; Karasouli & Adams, 2014; Watts et al., 2013; Loucas et al., 2014; Turner-McGrievy & Tate, 2011; Segerstahl & Oinas-Kukkonen, 2011; Glynn, 2013; Cruz, Brooks, & Marques, 2014; Belisario, Huckvale, Greenfield, Car, & Gunn, 2013; Trivedi, 2015; Zhang, Song, & Bai, 2013; Nundy et al., 2013; Widmer et al., 2014; Leeman-Castillo, Beaty, Raghunath, Steiner, & Bull 2010; Lau et al., 2011; Abogunrin & Martin, 2013; Mosa, Yoo, & Sheets, 2012). These studies had mixed results and various health outcomes. Some studies revealed an improvement in self-management with positive health outcomes, while others showed no relationship between the use of the mobile applications and self-management or health outcomes.

Strengths of technology for self-management. Technology has brought about great advances in self-management for many chronic illnesses. Improved patient outcomes include blood glucose and hemoglobin A1c levels, smoking cessation behaviors, blood pressure levels, weight loss, and improved cardiac health. For example, Chomutare, Tatara, Arsand, and Hartvigsen (2013) tested a diabetes mHealth application to track blood glucose and self-efficacy. The researchers used a focus group of seven participants to test the impact of the application on blood sugar tracking and usability. Researchers measured the usability of the application with the System Usability Scale (SUS) (Chomutare et al., 2013).

The study was not powered, but the application scored an average 84.6, which represented a high usability score. People who used the application showed a significant decrease in glycosylated hemoglobin and a marginal increase in self-efficacy (i.e., confidence in self-management of disease) (Chomutare et al., 2013). Any SUS scores greater than 68 is considered above average usability on a scale of 0-100 (Sauro, 2011). Similar improvements were noted in other studies that evaluated self-management applications for diabetes (Blake, 2008a; Blake, 2008b; Chen et al., 2013; Torbjornsen, 2014; Or & Tao, 2014).

Gallagher, O'Donoghue, and Car (2015) described the need to use mobile device applications to fill the gap between health care professionals and patients with multiple specialty needs and patients who may be in different hospitals or different parts of the world. They also need to be able to access information "on the go" (Gallagher, O'Donoghue, & Car, 2015). Mobile applications or mobile health (mHealth) may provide improved communication between clinicians, as well as between clinicians and patients. Furthermore, response times and clinical decision-making can be greatly improved by using mobile applications as a means for accessing clinical resources (Gallagher, O'Donoghue, & Car, 2015; Parmanto et al., 2013).

Limitations of technology for self-management. Although technology has brought about great advances in self-management of chronic diseases, there are still barriers that interfere with the effectiveness of this strategy for delivery of knowledge. Identified barriers included: lack of regulatory guidelines and policies (Bradway, Arsand, & Grottland, 2015; McDaniel & Stratton, 2006; Crocco, Villasis-Keever, Jadad, 2002; Karasouli & Adams, 2014), risk of breach of individual privacy of health information (McDaniel & Stratton, 2006; Crocco, Villasis-Keever, Jadad, 2002; Lau et al., 2011; Tsalatsanis, Gil-Herrera, Yalcin, Djulbegovic, & Barnes, 2011), cognitive impairment and lack of understanding of technology (Archer, Keshavjee, Demers, & Lee, 2014; Tsalatsanis et al.,2011; Peek et al., 2014), lack of professional support and feedback (Turner-McGrievy &Tate, 2011), cost of applications (Caburnay et al., 2015; Sama, Eapen, Weinfurt, Sha, & Schulman, 2014), accuracy of information (McDaniel & Stratton, 2006; Crocco, Villasis-Keever, Jadad, 2002; Lau et al., 2011;

Tsalatsanis et al., 2011), maintaining user engagement without outside support (Mattila et al., 2009; Tsalatsanis et al.,2011; Baysari & Westbrook, 2015), and lack of access to mobile devices (Nundy et al., 2013). Three areas create a challenge to integrating self-management into the health care system: 1) payment mechanisms; 2); preparation of the health care system; and 3) preparation of the patients (Lorig & Holman, 2003).

Payment mechanisms. One challenge to self-management education is lack of financial resources for funding these programs. Health care providers want standardized programs that are effective, but due to the individualized needs of the patients, one size does not fit all (Lorig & Holman, 2003). A study example of potential cost savings was done by Cano Martin, Martinez-Perez, de la Torre-Diez, & Lopez-Coronado (2014). The economic impact of using the *CardioManager* application found that the application would potentially generate a 33% reduction in the cost management and treatment of heart disease, as well as increase quality of life and patient autonomy (Cano Martin et al., 2014).

Preparation of the healthcare system. Self-management programs are gaining popularity in some health care systems. Most are found in voluntary health care agencies and reach only a small population (Lorig & Holman, 2003). The public health system is another potential venue for self-management programs, but funding is lacking. Systematically, the health care system does not require documentation of self-management and many health care providers do not support that the self-management programs will be successful (Lorig & Holman, 2003). Recent studies suggest ongoing collaboration between patients and health care professionals may result in long-term benefits (Epping-Jordan, Pruitt, Bengoa, & Wagner, 2004, p. 299). Nevertheless, self-management is emerging as an important aspect of chronic disease management (Miller et al., 2011).

Preparation of patients. The third challenge on which this dissertation focused was preparing people to accept responsibility for their own health. Accepting responsibility for individual health is a significant shift from the current system in which patients are dependent on providers for treatment. Improved communication between patients and health care providers is imperative to the success of self-management of chronic illness (Trudel et al., 2007; Lorig & Holman, 2003; De Jongh et al., 2012).

Although researchers have found some indications that mobile phone messaging interventions may provide benefits in self-management of long-term illnesses, less is known about long-term effects, acceptability, costs, and risks of such interventions (De Jongh et al., 2012).

Cognitive impairment. Cognitive impairment of individuals with chronic illness can also create difficulties in self-management. For example, people living with lupus often experience “lupus brain fog” which is associated with symptoms of forgetfulness, depression, and mood disorders (Makay, 2015). Including caregivers in technology use, creating better technological designs, providing reminders and simple instructions, and attending to the adoption and sustainability of technologies have all been shown useful in dealing with the barriers of cognitive impairment and lack of understanding of the technologies (Archer et al., 2014).

Methods for lupus self-management. Eleven studies were found for educating lupus patients on the disease and methods for self-management. Methods of patient education specifically for lupus sufferers included: group education, journaling, support groups, cognitive mapping, pre-packaged instructional curriculum, a patient oriented website, and printed pamphlets (Brown, Somerset, McCabe, & McHugh, 2004; Lawson et al., 2011; Mendelson, 2006; Sutanto et al., 2013; Wiginton, 1999; Breland & Kamen, 2012; Brady, Kruger, Helmick, Callahan, & Boutaugh, 2003; Sohng, 2003; Young et al., 2002; Hirsh & Gardner, 2009). No studies that used an application for self-management of lupus were found.

Many of the studies reviewed above revealed positive results for improved self-management and other positive health outcomes when using mobile applications for other chronic diseases. People living with lupus may benefit from a mobile application designed specifically for them to assist them in monitoring symptoms, medications, health care provider appointments, and having access to lupus information that is readily available. Therefore, the *LupusOhio* mobile device application was tested to see what PLWL needed in an application to assist them in self-managing their disease and thus preventing complications. The next section will describe the study methodology.

Chapter III

Methods

Overview

A concurrent mixed methods study design was used to test research questions regarding the use and perceived value of the *LupusOhio* mobile application. Participants included a non-randomized set population of people diagnosed with lupus identified by the Lupus Foundation of America Greater Ohio Chapter (LFAGOC). An eligibility screening survey, which also served as a pretest measure, was used as a tool to identify participants that had not used the app, as well as current and past users. The PLWL who had not used the *LupusOhio* mobile application were invited to participate in a quasi-experimental study to evaluate lupus knowledge and self-management before and after using the *LupusOhio* mobile application. The remaining current and past users of the *LupusOhio* mobile application were interviewed to better understand their experience with the app. It was expected that greater application use would increase knowledge and improve self-management. Therefore, the study aimed to:

Aim 1: Assess new users' lupus knowledge and lupus self-management before and after using the *LupusOhio* mobile application.

Aim 2: Understand existing users' perceptions of the *LupusOhio* mobile application in terms of usability and value.

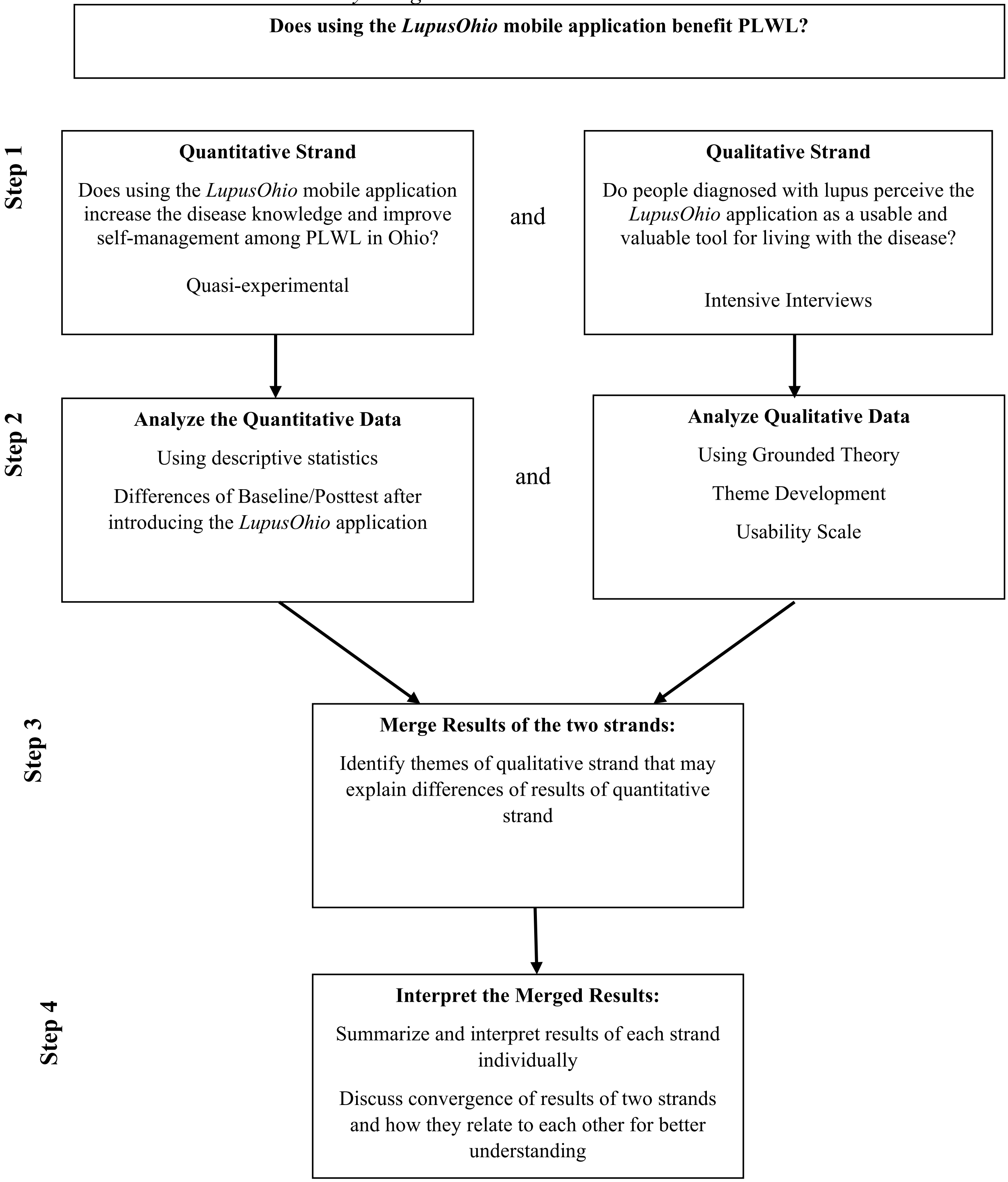
Research Design

Generally, this concurrent mixed methods study design explores the efficacy and usability of the *LupusOhio* mobile application by attempting to answer the overarching research question "Does the

LupusOhio mobile application benefit PLWL?" The rationale for using concurrent mixed methods in this study was that quantitative analysis addresses the predicted factors of increased knowledge and improved self-management, while the qualitative data analysis provides a better understanding of how PLWL used *LupusOhio* to improve knowledge and self-management (See Figure 2). A crossover study design was implemented, but due to the low number of responses, this was not feasible.

Figure 2

Concurrent Mixed Methods Study Design



Strengths of concurrent mixed methods. There are inherent strengths and weaknesses for both quantitative and qualitative methodologies when used alone. Using mixed methods can combine the strengths of both quantitative and qualitative methods resulting in a more meaningful interpretation of the data. One strength of mixed methods research is gaining a better understanding of the perspectives of a population such as values, beliefs, opinions, and behaviors (Creswell & Clark, 2011; Hughes, 2016; Essays, 2018). Another strength of mixed methods is that the combination of the strengths offsets the weaknesses when using either quantitative or qualitative individually (Creswell & Clark, 2011).

Mixed methods provide more evidence from different perspectives, which could not be discovered using the quantitative or qualitative alone (Creswell & Clark, 2011; Hughes, 2016; Essays, 2018). The gap in knowledge apparent when using quantitative and qualitative methods individually can be bridged by using mixed methods to provide stronger evidence through convergence of the results. Observations using narratives or pictures can expound on quantitative results. The numbers of the statistical analysis can be validated through the observations and narratives (Creswell & Clark, 2011; Hughes, 2016; Essays, 2018; Driscoll et al., 2007; Birt, et al, 2016). Mixed methods application can be advantageous when using quantitative results to add meaning to words, pictures, and narratives of the qualitative results by reducing personal biases (Creswell & Clark, 2011; Hughes, 2016; Essays, 2018; Driscoll et al., 2007).

Challenges of concurrent mixed methods. The primary challenges to a mixed methods study are the amount of skill, time, and resources necessary to complete the study. This can be particularly difficult for a single, novice researcher (Creswell & Clark, 2011; Hughes, 2016; Essays, 2018; Driscoll et al., 2007). A good understanding of the quantitative and qualitative methods and techniques for data collection, analysis, and interpretation of results individually is necessary. Ensuring that the researcher has adequate time to complete both strands of a mixed methods study, as well as enough resources to complete each strand of the study, can prove to be difficult (Creswell & Clark, 2011; Hughes, 2016; Essays, 2018). Attempting a mixed methods study as an individual researcher can present challenges, such as not having the expertise, input, and collaboration from diverse researchers (Creswell & Clark, 2011; Essays, 2018).

Although the use of mixed methods studies are becoming more popular, mixed methods research is still considered a fairly, new paradigm in which uncertainty in how to integrate and interpret results, as well as how to establish validity of results continues to exist (Creswell & Clark, 2011; Evans, Coon, & Ume, 2011; Hughes, 2016; Essays, 2018).

Characteristics of PLWL. Purposive sampling allowed the researcher to gather representative data from a specific group of people diagnosed with and treated for lupus. The target population for this study is PLWL who are members of the LFAGOC. The LFAGOC serves PLWL throughout the greater Ohio area. This population consists primarily of women at a ratio of 9:1 when compared to men (Lupus Foundation of America, 2020b). Blacks / African Americans, Hispanic / Latinos, and American Indians / Alaskan Natives are two to three times more likely to develop lupus than Caucasians and have more severe symptoms with worse outcomes (Womenshealth.gov., 2010; CDC, 2016; Lupus Foundation of America, 2020b). The majority of African Americans, as well as other ethnicities in Ohio, live in urban areas such as Cleveland, Cincinnati, and Columbus, with Cleveland having over one fourth of Ohio's African American population (Ohio Development Services Agency, 2015; United States Census Bureau, 2013).

Besides being members of the LFAGOC, eligibility for this study is PLWL who are at least 18 years of age and have been diagnosed with lupus. The sample population is primarily women between the ages of 18-64 years of age from diverse backgrounds including various education levels, races / ethnicities, relationship statuses, and from both rural and urban areas from all over Ohio (See Table 2 in Chapter IV).

Recruitment / enrollment procedures. As stated above, the general inclusion criteria for this study included PLWL diagnosed with lupus, who are at least 18 years of age that are members of the LFAGOC. The LFAGOC serves lupus patients throughout the greater Ohio area. These patients are listed on the LFAGOC's database which includes contact information. The database is linked to the LFAGOC website, to which the LFAGOC can disperse research updates, educational materials, and other pertinent lupus information to the constituents.

The Patient Navigator of the LFAGOC (liaison) sent an email to all members introducing the researcher and the study in a letter of support, along with a forthcoming invitation to participate in the study (See Appendix A). By working with the LFAGOC, we were able to reach out to lupus patients in Ohio to invite them to participate in the study via email through the LFAGOC website. One week later, a second email invitation letter was sent to all potential participants, which contained the invitation to participate in the study, an introduction of the researcher, and a more detailed description of the study along with a statement informing them to watch for another email containing a link to participate in the study (See Appendix B). A third participation email was sent the next week to the members of the LFAGOC which included the invitation for the study, the eligibility criteria and incentive eligibility, approximate time for completion of the screening survey, the link for the screening survey, and the contact information for the researcher (See Appendix C).

Screening Survey. Upon opening the screening survey, participants were presented the informed consent (See Appendix D), followed by demographic questions, a Systemic Lupus Erythematosus Quiz, and items from the Stanford Education Research Center Chronic Disease Self-Management Questionnaire adapted to the lupus population. These items were placed in a Qualtrics Survey format, which participants were able to complete via smart phones, tablets, or computers. The total number of recipients of the emails was 1,399. One hundred two participants opened the emails, of which 94 (92.2%) completed the screening survey.

At the end of the screening survey, participants were directed to the appropriate strand of the study based on their response to the question of whether they had used the *LupusOhio* mobile application. Those that reported using *LupusOhio* mobile application at least once prior to completing the screening survey were directed to the qualitative strand of the study, which included intensive interviewing. Exclusion criteria included people diagnosed with lupus who had not used the *LupusOhio* mobile application, who used a different lupus application, or family / caregivers of PLWL who used *LupusOhio* mobile application.

Those participants that had not used the *LupusOhio* application were directed to the quasi-experimental study. Exclusion criteria for the quasi-experimental group included people diagnosed with lupus who had used the *LupusOhio* application or family / caregivers of PLWL who used *LupusOhio* application. At the end of the screening survey, all participants were offered the chance to be placed in a drawing for a $50 gift card as an incentive for study participation.

Screening measures. As stated previously, the screening survey included demographic questions, the Systemic Lupus Erythematosus Quiz (SLEQ) to obtain the lupus knowledge score, and the Chronic Disease Self-Management Program Questionnaire (CDSMPQ) to obtain a score for disease self-management (Stanford Patient Education Research Center, 2007). These tests were completed for all PLWL in Ohio who opened the survey.

Systemic Lupus Erythematosus Quiz. The Systemic Lupus Erythematosus Quiz (SLEQ) is a ten question True/False quiz developed from information found on the CDC and LFA websites (see Appendix I) (CDC, 2016; LFA, 2015; Shiel, Diamond, Isherwood, & Witter, 2011). The SLEQ questions are general knowledge questions about a patient's general understanding of lupus. The scores are determined by summing the number of correct answers out of ten possible points. The screening scores were compared to the post app use scores to determine if using the *LupusOhio* application improves knowledge. These results will be discussed in the following section.

Validity and reliability of Systemic Lupus Erythematosus Quiz. No studies were found that measured validity and reliability for lupus knowledge. The information used to develop the questions was obtained from the LFA website and the CDC which displays content validity.

Chronic Disease Self-Management Program Questionnaire. The Chronic Disease Self-Management Program Questionnaire (CDSMPQ) is a 36-item questionnaire developed by Stanford University College of Medicine to increase self-efficacy, improve health behaviors, and improve health outcomes in people living with chronic diseases (Stanford Patient Education Research Center, 2007). This instrument has been used to reliably measure self-management interventions in a variety of chronic diseases including cardiovascular disease, mental illness, respiratory diseases, and arthritis with high test-retest reliability (Lorig et al., 1999; Lorig et al., 2001a; Lorig et al., 2001b). This questionnaire includes demographic items, as well as psychometric measures regarding health history, symptoms, physical activity, patient perceptions of confidence in performing daily tasks, and medical care (Stanford Patient Education Research Center, 2007). Psychometric measures were reported in the *Outcome Measures for Health Education and Other Health Care Interventions* (Lorig, et al., 1996). The entire CDSMQ questionnaire is eight pages in length and took approximately 20 minutes to complete. The CDSMQ sections predict future health; distress caused by chronic illness such as pain, shortness of breath, and fatigue; symptom control, role function, emotional functioning, and communication with health care providers. The CDSMQ has content validity. This instrument has been used successfully in a variety of other studies as stated previously.

The Chronic Disease Self-Management Questionnaire codebook describes how to score each of the five domains in the questionnaire. Domains include *General Health, Symptoms, Physical Activities, Self-Efficacy, Daily Activities,* and *Medical Care*. The questionnaire was adapted to fit the lupus population. Scoring of the items in the domains was done following the code book provided with the CDSMPQ. The scores will provide information on self-management and self-efficacy of PLWL (See Appendix F). Each of the domains will be described in detail.

The *General Health* domain is a single item, which identifies self-perception of current health condition and is a good predictor of future health (Stanford Patient Education Research Center, 2007). Participants rate their health on a scale from 1-5 with one (1) being excellent and five (5) being poor.

The *Symptoms* domain includes measures of health distress. The health distress measure is an average of four items that describe distress caused by lupus. These include discouragement, fearfulness, worry, and frustration. Participants rate each item on a scale from 0-5 with zero (0) being *None of the time* and five (5) being *All of the time*. In the Stanford Chronic Disease Management Study (2007), the Health Distress scale's internal consistency was good, $\alpha = .87$. Within the *Symptoms* domain are also three subsets of symptom scales which include fatigue, shortness of breath, and pain. Each of these brief measures are rated from 0-10 with zero (0) being *No Fatigue*, *no shortness of breath*, and *No pain* to ten (10) being *Severe fatigue*, *Severe shortness of breath*, and *Severe pain,* respectively. These scales use a visual analog scale with higher scores indicating worse symptoms over a two-week period. Each of these scores are rated separately and gives the researcher an idea of how lupus is affecting PLWL. There were no reported test-retest reliabilities on the fatigue and shortness of breath scale, however, the pain scale had a test-retest reliability of .92.

The *Physical Activity* domain contains six items for measuring exercise behavior, an important part of self-management The items are coded as numbers and then converted to the number of minutes of exercise according the number chosen with zero (0) being *None* and four (4) being *More than three hours per week* (180 minutes) (Stanford Patient Education Research Center, 2007). Item one (1) is scored individually for stretching / strengthening and items 2-6 are a sum of the values for each of these items. The physical activity scores give the researcher an understanding of PLWL exercise habits as part of self-management. Stanford Chronic Disease Management Study results revealed no internal consistency reliability for stretching and aerobic exercise but did report a test-retest reliability of .56 and .72 with N=51 for test-retest, respectively (Stanford Patient Education Research Center, 2007).

The *Self-Efficacy* domain is measured by the *Self-Efficacy for Managing Chronic Disease Scale*, a 6-item measure of self-efficacy. Self-efficacy is a critical concept in chronic disease management, which when measured can identify a patient’s understanding of the disease, plan how to manage the disease, evaluate patient education, and finally, indicate important health outcomes (Frei, Svarin, Steuer-Stey, & Puhan, 2009). Four of the six items in this domain measure one’s confidence in being able to perform certain activities without certain symptoms such as fatigue, pain, emotional distress, and other symptoms / health problems interfering with those activities. The other two items measure the ability to perform tasks or activities to reduce need to see a doctor and doing things to reduce illness effects other than medication. The items are scored on a 1-10 scale with one (1) indicating *Not at all confident* and ten (10) indicating *Totally confident*. The scale has a very good internal consistency ($\alpha = .91$). A higher score indicates higher self-efficacy (Stanford Patient Education Research Center, 2007). Perceived self-efficacy has been shown to be associated with improved self-management (Lorig & Holman, 2003; Bandura, 1986).

The *Daily Activities* section assesses the patient's ability to function. This measure contains the subcategory *Social/Role Activities Limitations* which has four items regarding how participants believed their health interfered with social / role activities such as activities with family, friends, neighbors or groups; hobbies or recreational activities; household chores, or errands and shopping within the past two weeks. The score ranges from 0-4 with zero (0) indicating *Not at all* interfering to four (4) indicating *Almost totally* interfering. The score is the mean of the four items with a higher score indicating greater activity limitations (Stanford Patient Education Research Center, 2007). The scale has a good reliability, $\alpha = .91$ (Stanford Patient Education Research Center, 2007).

The last section, *Medical Care,* contains two subcategories: *Communication with Physicians* with three items regarding communication when visiting physicians and *Health Care Utilization* which has four items regarding frequency of health care utilization in a six-month period. The three items in the *Communication with Physicians* subcategory included: preparing a list of questions for the physician; asking about things the patient wants to know or does not understand; and discussing personal problems related to the disease. Each item is scored on a scale of 0-5 with zero (0) indicating *Never* to five (5) indicating *Always*. The score is the mean of the three items with a higher score indicating better communication with physicians (Cronbach's $\alpha = .73$; test-retest = .89) (Stanford Patient Education Research Center, 2007). The four items in the *Health Care Utilization* subcategory measure the number of times the patient visited the physician, the hospital emergency room, stayed in the hospital, and / or the total number of nights spent in the hospital. These items are scored individually. For the purpose of this study, these items were not measured due to the short study period.

Application of the CDSMPQ to the Current Study. The domains of the CDSMPQ used in this study include: 1) *General Health, 2) Symptoms, 3) Physical Activities, 4) Self-Efficacy, 5) Daily*

Activities, and *6) Medical Care (Communication with Physicians).* These measures were used in the follow-up survey and compared to the screening survey results.

General Health domain measured PLWL self-rated perceptions of their overall health. *Symptoms* domain determined how PLWL perceived their current state of health. The health distress scale had a good reliability, Cronbach's $\alpha = 0.79$. The second subcategory measured fatigue, shortness of breath, and pain individually for PLWL, but there was no test-retest reliability completed.

Physical Activities were measured using the same method as described above by choosing a number from 0-4 (0 = no exercise; 1 = < 30 minutes/week; 2 = 30-60 minutes / week; 3 = 1-3 hours/week; and 4 = > 3 hours / week). These numbers were then converted into minutes (0= none; 1 = 15 minutes; 2 = 45; 3 = 120 minutes; and 4 = 180 minutes). As with the CDSMPQ described for the Stanford University study, stretching was a single item and the other five items were grouped together as aerobic exercises. The score for aerobics was the sum of the values of the five items. The reliability for the aerobic exercises was good, $\alpha = .85$.

Self-Efficacy was measured using the 6-item Likert scale ranging from 1-10 measuring one's confidence in completing the following six tasks: 1) keeping fatigue from interfering with things they want to do; 2) keeping physical discomfort from interfering with things they want to do; 3) keeping emotional distress from interfering with things they want to do; 4) keeping other symptoms from interfering with things they want to do; 5) doing different tasks needed to manage health to reduce the need to see the healthcare provider; and 6) doing things other than medications to reduce how much the illness affects their life. The score for self-efficacy was the mean of the six items with a higher score indicating higher self-efficacy. The reliability for this scale was good ($\alpha = .85$).

Daily Activities domain determined PLWL perceptions of their abilities / limitations to perform these activities while living with lupus over the past two weeks, which indicated self-management. Four items were measured on a scale from 0-4 (0 = not at all limiting; 4 = almost totally limiting). This scale is titled S*ocial and Role Activities Limitations*. The four items measured were normal social activities, hobbies / recreational activities, household chores, and errands / shopping. The score of this scale was the mean of the four items. This scale has a good reliability, Cronbach's α = .75.

The *Medical Care* domain displayed PLWL's communication behaviors with their physicians which is an indicator of self-efficacy. Three items measured included preparing a list of questions for the physician, asking about things not understood / treatment, and discussing personal problems related to the illness. The score was the mean of the three items measured. The scale had good reliability, α = .83.

Logging LupusOhio usage. Following screening and consent, participants used the application for 30 days. During this time, participants kept a log of how many times they used the application, how long they used the application at each opening, and what areas they used with each opening (see Appendix H). Weekly email reminders to log information were sent to the participants by the researcher. Other items on the log included whether they found *LupusOhio* app helpful or valuable, and a section to identify areas of likes and needed improvement. These items are also included on the posttest survey. As stated above, after using the application for 30 days, a link to the posttest survey was sent to participants, along with weekly email reminders to complete the posttest.

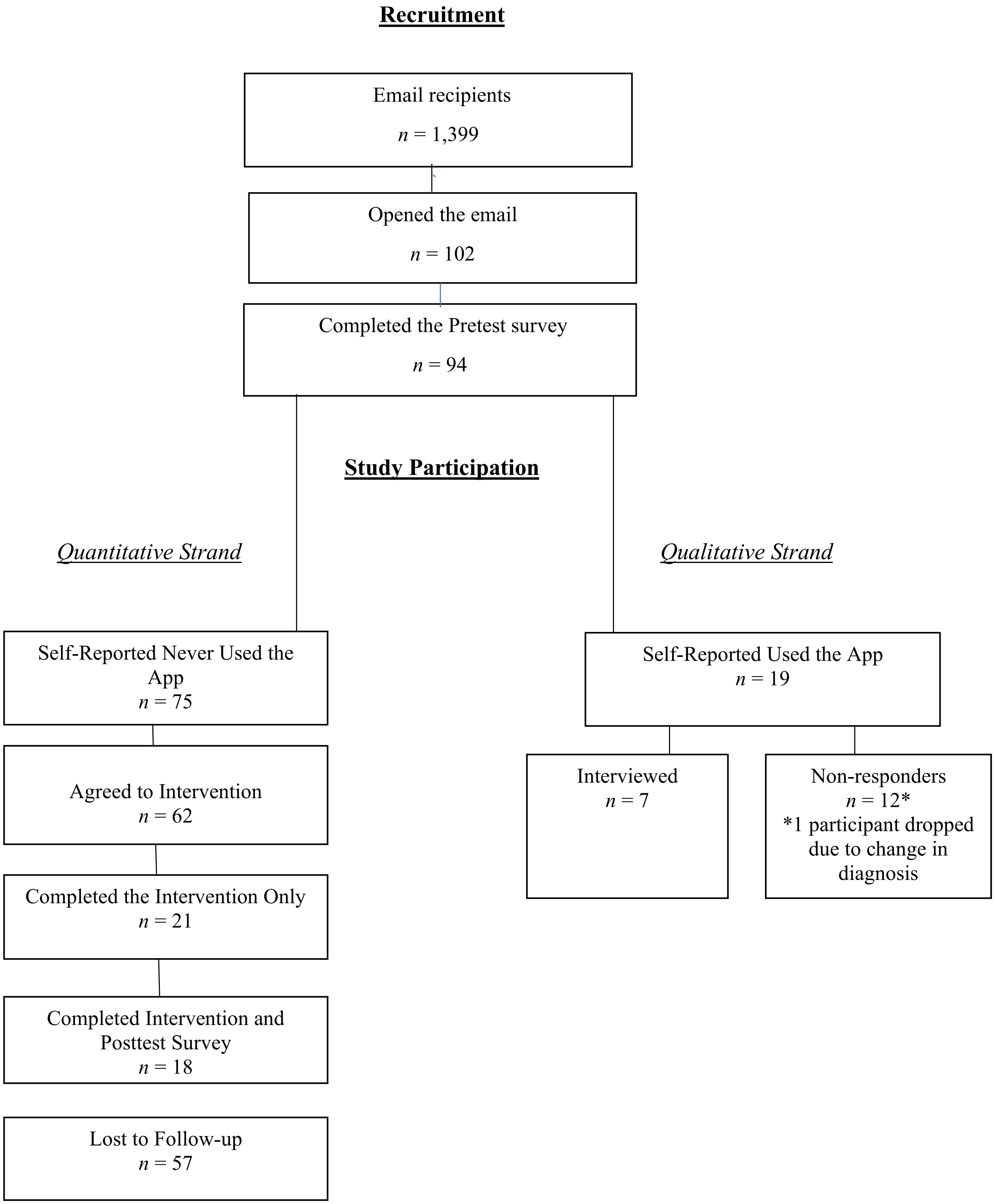
Assignment to study strands. After completion of the screening survey, the researcher reviewed and assigned participants to the appropriate strand of the study based on whether they had used the app before. Non-users of the *LupusOhio* mobile application were assigned to the quantitative strand of the study (quasi-experimental group) and current or past users of the *LupusOhio* mobile application were assigned to the qualitative strand of the study. A more detailed description of each strand assignment follows.

Quantitative Assignment. Seventy-five of the 94 (79.8%) participants that completed the screening survey never used the app and were assigned to the quasi-experimental group. Sixty-two (82.7%) of these potential participants agreed to participate in the study. Thirteen of 75 (17.3%) wanted to be placed only in the drawing for the incentive. An email was sent to each member that agreed to participate in the quantitative strand of the study, which thanked the participants for agreeing to participate; provided instructions on how to download the *LupusOhio* mobile application; and included the log sheet to document application use. This email was sent weekly for three consecutive weeks to recruit more participants. Of the 62 participants that agreed to participate in the quasi-experimental study, 21 (33.9%) used the *LupusOhio* app, but did not complete the posttest. Eighteen (29%) participants used the app for 30 days and completed the posttest survey (See Figure 3).

Qualitative Assignment. Eighteen of the 94 (19.1%) participants that completed the screening survey had previously used or were currently using *LupusOhio* mobile application. An email was sent to each of these potential participants inviting them to participate in face-to-face intensive interviews for three consecutive weeks. Eight interested participants agreed to complete face-to-face interviews. The researcher provided contact information as the next recruitment step, and set dates, times, and locations for the meetings. The following section will describe the procedures for each strand of the study (See Figure 3).

Figure 3

LupusOhio Recruitment & Participation Flow



Quantitative Procedures. As stated previously, the quantitative strand of the study was a pretest (screening) / posttest quasi-experimental design that tested lupus knowledge before and after using the *LupusOhio* mobile application for 30 days. The quantitative strand of the study aimed to answer the following research question:

> Does using the *LupusOhio* mobile application increase disease knowledge and improve self-management among PLWL in Ohio?
>
> The hypothesis for this portion of the analysis was:
>
> H^1: Using the *LupusOhio* application for a mobile device for 30 days will increase patient knowledge of lupus symptoms and complications.

The researcher also investigated the relationship between disease self-management and using the *LupusOhio* application among PLWL. The hypothesis for this part of the analysis was:

> H^2: Using the *LupusOhio* application for a mobile device for 30 days will improve self-management of lupus symptoms and complications.

A power analysis for conducting a t-test of mean differences between screening and posttest scores was performed with F test in a multiple linear regression model using a medium effect size of 0.15, a 0.95% confidence level ($\propto 0.05$) with a power of 0.8. The power analysis was performed using the two outcomes of interest, increased knowledge and improved self-management. Using these parameters, total sample size was estimated at 68 participants. To account for potential attrition (~33%), the total desired sample size was set to $n = 90$. It was expected that this proportion of respondents could be expected to drop out due to the unpredictable disease course of lupus. Members who had previously used the *LupusOhio* application were considered ineligible for this aspect of study participation.

Participants identified from the screening survey as non-users of *LupusOhio* mobile application ($n = 75$) were contacted by the researcher via their preferred contact method (email or phone) thanking them for agreeing to participate and that they were being divided into two group: A-L and M-Z. with different start dates for using the *LupusOhio* mobile application.

A detailed explanation of the procedure regarding events of the study was included. Those participants whose last names began with A-L were sent an email with detailed information on how to download the *LupusOhio* mobile application to either an Apple device or Android device, along with the log sheet to document their usage.

Participants used the application for 30 days. During this time, participants kept a log of how many times they used the application, how long they used the application at each opening, and what areas they used with each opening. Weekly email reminders to log information were sent to the participants by the researcher. Participants were reminded that participation was voluntary and that they may withdraw from the study at any time. Those participants whose last names began with M-Z (control group) were instructed to go about their normal activity during this time. A date was provided to the M-Z group for when to expect an email describing the download process, use, and logging of activity described above.

After the first 30 days, those whose names began with A-L were sent an email with the link to the posttest survey which took approximately 15 minutes to complete. A reminder email was sent for three consecutive weeks. Those participants whose last names began with M-Z were then sent the email with directions on how to download the *LupusOhio* application along with the log sheet for usage. The A-L participants were now considered the control group. As stated previously, an attempt to do a crossover study was made, but due to the small response rate, this was not feasible. After the 30-day period of using *LupusOhio* for the M-Z group, an email with the posttest survey link was sent, once again with three consecutive weekly reminders.

Qualitative Procedures. In the qualitative strand of the study, intensive interviews were used to answer the following research question:

> Do people diagnosed with lupus perceive the *LupusOhio* application as a usable and valuable tool for living with the disease?

The general characteristics of PLWL, described previously, were used to inform a potential sample quota for selecting interviewees. For instance, 90% of people diagnosed with lupus are women of childbearing years between the ages of 15-44. This demographic was the first sampling parameter. Next, a primary criterion for recruitment was that the participant must be at least 18 years of age. Therefore, the researcher aimed to recruit two females and one male in each of the two different age categories (18-44/45-64). Both men and women, between the ages of 50-64 years, had an equal risk of developing the disease, but experienced a more benign course than those between the ages of 15-44. There was no literature found that described the people between the ages of 45-49. As such, I included this age group with the 50-64 age group making the second group 45-64 years (Lupus Research Alliance, 2016; Shaikh & Wang, 1995; Rovensky & Tuchynova, 2007; Bertoli et al., 2006). It was also important to explore the experiences of people living in both rural and urban locations because the disease is more common in urban areas than rural areas (Justiz-Vaillant, Akpaka, & Poonking, 2015; Shaikh & Wang, 1995; Rovensky & Tuchynova, 2008; Bertoli et al., 2006). A question was included on the screening survey which asked from which location the participant resided (urban or rural).

Scholars of mixed methods studies have determined approximate sample sizes for a variety of qualitative types of studies (Creswell & Clark, 2011). For example, the sample size may be one to two cases for each observation – two females and one male from each age group and each residential location which was an approximate 12 participants (Creswell & Clark, 2011; Guetterman, 2015). Though an attempt was made to include members from each gender, age group (18-44 years, 45-64 years, or >64 years), and residential location (urban or rural), this was not achieved because only one male that completed the survey had used the app, but did not respond to the email invitations.

Interview procedures. Participants identified as currently using or having used the *LupusOhio* mobile application within three months prior to enrollment of the study (n = 18) were invited to participate in face-to-face intensive interviews. The 18 potential participants were contacted via their preferred contact (email or phone) as listed on the screening survey. Invitation emails were sent to these individuals for three consecutive weeks. A total of eight participants responded to the emails, but one declined due to seeing a new physician who informed her that she did not actually have lupus. Seven female participants (n = 7) responded to the invitations and scheduled an interview with the researcher.

The participants were contacted by the researcher via email and a meeting place was determined, along with a date and time. All participants agreed to meeting in their local libraries in a private study room, due to this being a quiet, public venue which was convenient and easily accessible to them.

Participants met with the investigator at their local library at the designated time and date set for the face-to-face interviews. Upon arrival to the library, the researcher obtained access to a private, enclosed study room from the librarian to ensure privacy and confidentiality for the interviews. After face-to-face introductions were made, the researcher described the interview process to the participant. Informed consent for audio recording was obtained at this time. The researcher then provided the participant with the System Usability Scale (SUS), which is a10-question tool used to measure usability of a variety of products including mobile device applications (Brooke, 1986). The SUS scale has been used in almost 500 different studies to measure perceptions of usability (Sauro, 2011). The score from this scale was later calculated to determine the participant's perception of the *LupusOhio* application usability and will be reported in the results section.

Interview questions. The researcher posed six introductory questions and eight open-ended questions about features of the *LupusOhio* application in the interview guide (see Appendix G). The introductory questions were intended to give the researcher a better understanding of each participants' experience over time with lupus. Information gleaned from these questions included the participant's length of illness, age at onset of symptoms and diagnosis, information provided at diagnosis, understanding of the illness, and methods used for disease management. This method of interviewing ensured, not only that the researcher understood the participant's responses, but also provided a means to allow the researcher to clarify answers provided. During the interview, the researcher recorded the interview while taking field notes of the participant's responses while noting both verbal and nonverbal behaviors (Mack, Woodsong, MacQueen, Guest, & Namey, 2011).

The researcher asked the eight open-ended questions from the interview guide regarding *LupusOhio* application features. These questions asked participants to expound on how long they have used the app, likes and dislikes of the app, the frequency of usage, the value and usability of the application., and areas of needed improvement, and finally, what they would share with others from the app. These questions were developed to gain a better understanding of the areas of the application that were working well for users and areas that needed improvement. Intensive interviewing allowed further questions to be developed from the responses to the previous questions gaining more detail from the responses. Upon completion of the interviews, the participants were asked again if they could be contacted for any clarification or additional questions.

Ethical Considerations. All recruitment materials and protocols were approved prior to the study start by the Kent State University Internal Review Board. An online informed consent was obtained from all participants that completed the screening survey. This process entailed sharing a complete description of the study purpose, participation, data management, an opportunity for questions, and electronic consent. Specifically, participation was voluntary and study participants were able to disengage from the study any time. A face-to-face audiotape / video consent form (see Appendix E) was provided to all participants in the qualitative strand who were interviewed. All interviews were face-to-face, recorded, and field notes taken throughout the interview. All study responses and recruitment data for both strands of the study were confidential, and efforts made to prevent disclosure. A random case identification number was assigned using the first initial of the participant’s last name and the last four digits of their cell phone number to protect identities of all participants. The key to the assignment of participants was kept separately from the collected data such as field notes and questionnaires and were destroyed after analysis.

Chapter IV

Results

Overview

This current mixed methods study attempted to answer the overarching research question: Does using the *LupusOhio* mobile application benefit PLWL? As stated previously, the study invitation went to 1,399 people living with lupus (PLWL) who were members of the Lupus Foundation of America Greater Ohio Chapter (LFAGOC). One hundred two people opened the link and 94 answered the questions of the screening survey. One person did not fully complete the survey and was unable to be identified as a user or non-user of *LupusOhio*. Seventy-five of the 94 (79.8%) were identified as not having used the *LupusOhio* mobile application (assigned to the quantitative strand) and 19 (19.6%) had used the *LupusOhio* mobile application (assigned to the qualitative strand). The quantitative strand results will be described below, followed by the qualitative results. Demographic descriptors, including gender, region, age, race / ethnicity, education, relationship status, and chronic illnesses are provided for all respondents, as well as for each strand of the study.

Quantitative Results

The quantitative arm of the study tested the differences between the screening survey results and the posttest results of individuals who never used the *LupusOhio* mobile application (See Figure 3). Sixty-two of the 75 (82.7%) participants that identified as never using the app agreed to use the *LupusOhio* application for 30 days and complete a posttest survey. Twenty-one participants completed the posttest; however, three of these participants did not have matching identification numbers between the screening survey results and posttest results. Consequently, it was not possible to compare pre and posttest scores for three participants who were then removed from the analysis.

Demographics. The sample of non-users identified females (94.4%) with approximately 2/3 residing in urban areas. Participants' ages were 18-44 years (50%), 45-64 years (38.9%), and older than 64 years (11.1%). Approximately 94.4% of the participants self-reported race / ethnicity as White/ Non-Hispanic. All participants self-reported as having at least a high school education with 44.4% having a college / university level education. Eleven of the 18 participants self-identified as being married or cohabitating. Participants reported having at least one chronic disease such as diabetes, asthma, other lung disease, heart disease, rheumatic disease / arthritis, or other chronic diseases not included in the list (See Table 2).

Table 2

Demographics of LupusOhio Mobile Application Study Participants

Variables	Quantitative Strand n=18 (24%)		Qualitative Strand n= 7 (38.8%)		Total n=94 (100%)	
	n	%	n	%	n	%
Gender						
Female	17	94.4	7	100	90	95.7
Male	1	5.6			4	4.3
Region						
Urban	12	66.7	6	85.7	66	70.2
Rural	6	33.3	1	14.3	28	29.8
Age						
18-44 years	9	50	4	57.1	55	58.5
45-64 years	7	38.9	3	42.9	32	34.0
>64 years	2	11.1			7	7.4
Race / Ethnicity						
White / Non-Hispanic	17	94.4	5	71.4	72	76.6
Black / Non-Hispanic	1	5.6	2	28.6	19	20.2
Hispanic					2	2.1
Not Reported					1	1.1
Education						
High School	10	55.6	3	42.9	29	30.9
College / University	8	44.4	2	28.6	46	48.9
Graduate / Professional			2	28.6	18	19.1
Not Reported					1	1.1
Relationship Status						
Married / Cohabitating	11	61.1	2	28.6	55	58.5
Single	3	16.7	3	42.9	24	25.5
Divorced	3	16.7	1	14.3	13	13.8
Separated			1	14.3	1	1.1
Widowed	1	5.6			1	1.1
Chronic Illnesses						
Diabetes	1	5.6	1	14.3	3	3.2
Asthma	5	27.8	2	28.6	28	29.8
Emphysema / COPD					1	1.1
Other Lung Disease	2	11.1			7	7.4
Heart Disease	1	5.6	1	14.3	12	12.8
Rheumatic Disease / Arthritis	9	50	3	42.9	53	56.4
Cancer					3	3.2
Other Chronic Disease	14	77.8	6	85.7	72	76.6
None	1	5.6	1	14.3	4	4.3

Participants were asked to rate the value and helpfulness of the *LupusOhio* app. Fifty percent of the participants rated *LupusOhio* application as both helpful to very helpful and valuable to very valuable, while 27.8% rated the app as a little helpful to not at all helpful and 33.3% rate the app as a little valuable to not at all valuable (See Table 3).

Table 3

Self-Reported Usability and Value of LupusOhio Percentages of Posttest Survey (n=18)

	Very helpful / valuable	Helpful / Valuable	Neither helpful / valuable	A little helpful / valuable	Not at All helpful / valuable
How Helpful was the App	16.7	33.3	22.2	5.6	22.2
How Valuable was the App	11.1	38.9	16.7	22.2	11.1

Note. Measures attitude

Systemic Lupus Erythematosus Quiz. Participants' results in the posttest survey revealed a lower score on the SLE quiz (*M* = 8.06, *SD* = 3.04) when compared to the pretest screening survey SLE quiz (*M* = 9.00, *SD* = .43). However, the results of the *t*-test revealed that this was not a significant difference in the SLE scores after using the *LupusOhio* application for 30 days [*t* (17) = 1.57, *p* = .14] (See Table 4).

Table 4

*Lupus Knowledge Mean Score Comparison for Intervention App Users**

	Pretest *M (SD)*	**Posttest *M (SD)***	***t*-value**	***df***	***p*-value**	**Min**	**Max**
SLE Quiz Score	9.00 (1.09)	8.06 (3.04)	1.57	17	0.135	0	10

*Note. *Completed Pre/Posttest Survey*

Chronic Disease Self-Management Questionnaire. The results of the CDSMPQ provided evidence for the research question:

1. Does using the *LupusOhio* mobile application benefit PLWL?
2. Does using the *LupusOhio* mobile application improve self-management among PLWL in Ohio?

The physical health outcomes variables on the CDSMPQ to answer the research question regarding benefits of using the *LupusOhio* application included: health status, health distress, fatigue, shortness of breath, and pain. Participants displayed no significant differences in physical health outcomes pre and post means after using the *LupusOhio* mobile application for 30 days. However, Social & Role activities limitations trended downward (See Table 5).

Table 5

Comparison of Means of Physical Health Outcomes of LupusOhio in Users Who Completed Pre/Posttest Survey

	Pretest	**Posttest**	***t*-value**	***df***	***p*-value**	**Min**	**Max**
	M (SD)	***M (SD)***					
Health Status	2.22 (0.73)	2.11 (1.02)	0.62	17	.542	0	4
Health Distress	3.19 (1.01)	2.74 (1.30)	1.18	17	.253	0	5
Lupus Symptoms							
Fatigue	7.83 (1.62)	6.61 (3.15)	1.52	17	.148	0	10
Shortness of Breath	4.44 (2.81)	3.44 (3.01)	1.40	17	.179	0	10
Pain	6.56 (2.41)	6.33 (3.13)	.242	17	.811	0	10

The variables, stretch and aerobic exercises, represent activities that PLWL can do to minimize the joint pain and fatigue. The self-efficacy score represents the confidence that PLWL can accomplish their daily activities without lupus symptoms interfering with those activities. The variable social and role activities limitations represent how lupus symptoms interfere with performing their daily social and role activities such as recreational activities, household chores, and doing errands. These variables measured whether there was any improvement in self-management after using the *LupusOhio* mobile application. There were no significant differences in pre and post means of the self-management variables; however, there was a trend toward slight improvement in the social and role activities limitations (*p*= 0.06) (See Table 6).

Table 6

Comparison of Means of Self-Management Scores and LupusOhio

Variables	**Pretest**	**Posttest**	***t*-value**	***df***	***p*-value**	**Min**	**Max**
	Mean (SD)	***Mean (SD)***					
Stretching	55.0 (60.9)	71.7 (77.44)	1.05	17	.308	0	180
Aerobics	110.83 (117.56)	127.50 (129.37)	.81	17	.431	0	180
Self-efficacy	4.91 (1.73)	5.21 (2.75)	.37	17	.717	1	10
Social & Role Activities Limitations	3.13 (0.92)	2.49 (1.22)	2.02	17	.060	0	4
Communication w/HCP	2.87 (1.10)	2.47 (1.62)	1.22	17	.241	0	5

Log Results of *LupusOhio* Usage. Participants were asked to log their *LupusOhio* application activity on the form provided (See Appendix H). Several types of activity were measured including the number of times the app was opened, the length of time at each opening, pages viewed on the app, information seeking success (yes/no). Results revealed that three participants opened the *LupusOhio* application > 5 times, seven opened the app 3-5 times, and 8 opened the app 0-2 times. Three participants viewed the app > 15 minutes, seven viewed the app 10-15 minutes, and 8 viewed the app 1-9 minutes.

Pages of the app most frequently visited by participants included pages that provided lupus information / education, events, and tools to manage their disease. Results of log information are listed in Table 7.

Participants identified several pages of the *LupusOhio* app that they "liked" in an open-ended response option on the survey. These included *My Lupus Spot* (27.8%), *News* (22.2%), *My Meds/My Doctors* (16.6%), *Events* (11.1%), *Support Groups* (11.1%), and As*k the Experts* (11.1%).

Six participants (33.3%) also documented items that they would like to see on the app, or that they felt needed improvement, such as making the app being more interactive between PLWL, as well as between users and activities on the app, ensuring the events calendar is updated, and ensuring all links are working. These items are can be found in Table 8. The next section will discuss the results of the qualitative strand of the study.

Table 7

LupusOhio Mobile Application Usage Percentages (n= 18)

Variable	**(n)**	**(%)**
Times Used within 30 Days		
>5 times	3	16.7
3-5 times	7	38.9
0-2 times	8	44.4
Minutes in App		
>15 minutes	3	16.7
10-15 minutes	7	38.9
1-9 minutes	8	44.4
Pages in App (Opened)		
Lupus Answers	15	83.3
Events	11	61.1
News	9	50.0
About	7	38.9
Lupus Store	7	38.9
My Lupus Spot	6	33.3
Walk	5	27.8
My Meds	5	27.8
More	4	22.2
My Doctors	4	22.2
Rita Dennis Story	3	16.7
Social Media	3	16.7
Photos	2	11.1
Directions	2	11.1
Share	2	11.1
Mailing List	1	5.6
Call Us	1	5.6
Found Information		
Yes	16	88.9
No	1	5.6
Not really	1	5.6

Table 8

Improvements / Changes Requests by Participants for LupusOhio Application

Improvements / Changes
• More interaction between patients
• Listing of lupus doctors by counties
• Improve the Lupus Store
• More information on support groups, lupus, news, community activities
• Some tabs not functioning
• Items for family use about lupus
• Disliked the color of the background
• Would like to see a not section to write down questions / answers for doctor visits
• Add a symptom tracker and lab tracker

Qualitative Results

The qualitative strand of this study interviewed participants that had previously used the *LupusOhio* mobile application. Interview analyses supported the results of the quantitative strand in many ways, as well as explained the results. Nineteen of the 94 (19.1%) participants that completed the screening survey were identified as having used the *LupusOhio* application. Initially, there were eight participants that agreed to intensive interviews, but one participant had recently visited a new rheumatologist that informed her that she did not have lupus; therefore, she removed herself from the study. All seven interviewees were females who ranged in age from 26-51 years ($M = 38.6$). The self-reported years of living with lupus ranged from 2.5 years – 20 years ($M = 7.9$). Five of the participants identified as Caucasian / Non-Hispanic and two identified as Black / Non-Hispanic. The participants were highly educated with educational levels reported as follows: two attended graduate school (28.6%), two attended college (28.6%), and three completed high school (42.9%). All demographic frequencies are listed in Table 2.

Recorded intensive interviews and field notes provided repeated mentions regarding diagnoses experiences, disease experiences, responses to lupus diagnoses (self-management techniques), and *LupusOhio* application usages. Self-management techniques identified were used for coping with physical and emotional symptoms. Participants are introduced in the following section which provides a better understanding of what PLWL deal with throughout the course of the disease - diagnosis, treatment, and management.

Introduction of interviewees. The following pseudonyms were given to the participants to protect their identities: Alicia, Bonnie, Connie, Debbie, Eva, Fran, and Grace. A brief introduction of each participant follows:

Alicia. Alicia, a 36-year-old Caucasian single woman, was diagnosed with lupus at age 16. She lives alone in an urban area. Alicia was unable to complete her college degree due to her lupus and its complications. She is a strong advocate for increasing lupus awareness.

Diagnosis narrative. At that time of her diagnosis, she was experiencing facial rash, joint pain, and difficulty walking or turning a doorknob. These symptoms began two years prior to her diagnosis. Her physician made the diagnosis based on her symptoms; however, the physician was not certain about her diagnosis. She was told that the diagnosis was “believed” to be lupus. Alicia described the path of her disease as follows:

> “Being diagnosed at my age [16 years old], they don’t really believe you. You look healthy from the outside, but they don’t know what’s going on in the inside. It has been very unpredictable.”

Disease experience. In addition to her lupus, Alicia has multiple other chronic diseases that affect her body daily – asthma, diabetes, fibromyalgia, chronic migraines, and postural orthostatic tachycardia syndrome (POTS). The effects of these conditions are compounded by the lupus. Alicia reported suffering from severe fatigue and joint pain which worsen during times of stress. As stated above, Alicia had to quit college due to lupus complications. She describes her experience as:

> "I have many ups and downs - good days and bad days. For every good day, I know it's going to follow with two or three bad days."

Response to lupus diagnosis and disease. When Alicia was diagnosed, she had never heard of lupus. She felt that she was not well educated about her disease upon diagnosis. She searched the Internet to find answers about what kind of symptoms to expect and how to avoid aggravating the symptoms.

Alicia describes some of the things that she learned through her research:

> "I found it would cause a lot of fatigue and then joint pain. Stressful situations can make it worse. I see all of this happening with me."

Alicia uses a variety of techniques to manage her lupus symptoms such as medications, support groups, rest, and mental health therapy. She reported that medications help to control the fatigue and pain along with taking "a lot of naps". Alicia describes fatigue as the symptom that she struggles with the most. When asked how she knows when her lupus is under control or managed, Alicia verbalized:

> "Under control? When I actually have a little bit of energy to get up. I can get out more to accomplish errands and whatever. I have no pain which is not very often. Let's say less pain… I take so many medications it's hard to know what's causing what."

Alicia attends monthly lupus support groups and receives mental health counselling to help her cope with the emotional symptoms of dealing with all her chronic diseases.

LupusOhio application use*.* Alicia began using the *LupusOhio* app when it first became available and uses it on a weekly basis to look up events such as support groups and other activities for PLWL. She also uses the app as a tool to recommend new patient education classes and support groups to new lupus patients and to increase awareness. Although she does not use the app for her own medications' or doctors' lists due to the vast amount of medications she takes and physicians she sees, she does point out these tabs to new patients.

Alicia verbalized frustration, especially for the new patients that are now facing the uncertainty that she herself had to experience. Even after 20 years of living with lupus, Alicia still does not understand how there is still no specific test to diagnose lupus.

> "Because I am in a lot of Facebook support groups, I am finding more and more people really have no idea [what lupus is]. It's very sad. I see people say online…I went to a new doctor and I was diagnosed with lupus. Then, I went to another doctor and he's saying, 'No [it's not lupus], it's something else. How is there still not a specific test so that you know if it's positive or negative?"

Bonnie. Bonnie is a 26-year old single, Caucasian female who currently lives in an urban region with her family. She is a college graduate with a degree in early childhood development and now teaches preschool. Bonnie experienced a variety of unexplained symptoms for many years but was not diagnosed until four years ago.

Diagnosis narrative. Bonnie suffered with joint pains and swelling since she was about five or six years old and the symptoms continued for many years. She was diagnosed with lupus at age 22 by a rheumatologist who had done blood work. Besides lupus, Bonnie also has rheumatoid arthritis (RA), juvenile arthritis, osteoarthritis, and anemia. She does experience severe fatigue, pain, and migraines. Bonnie has seen multiple rheumatologists over the years who gave her conflicting diagnoses. Bonnie discussed her experience as follows:

> "I had a lot of joint pain and a lot of swelling since I was really little. We were told they thought it was attributed to growing pains and just blew it off. They swept it under the rug. One rheumatologist said, 'Yes, you have it [lupus].' Another one said, 'No, I don't think you do because you're not tolerating the [lupus medication].' When I went to the next one, she said, 'Yes, you have lupus.' Then the next one said, 'I'm not sure.' It's so hard. It's definitely frustrating! It mimics so many other things."

Disease experience. Bonnie vividly remembers the Friday night that she received a call at work from her rheumatologist informing her that she had lupus. She reported that she was told that a medication was prescribed, and she needed to go pick up the medication.

“I had no idea what lupus was, no idea what the medication was. I was like, what is lupus?”

Bonnie was told by the rheumatologist not to look up lupus and to follow up with her in three months after starting the medication. Bonnie laughed as she talked about this encounter:

> “The first thing I did was go on the *My Chart* and confirm that’s what she said because I had no idea. I talked to my coworker and she asked, ‘What’s wrong?’ We confirmed [the diagnosis]. We looked it up a little bit. I was like oh my gosh! What the heck am I going to do now?”

Bonnie also sought information on Web MD and the LFAGOC website. When Bonnie found the LFAGOC website, she discovered the information classes for newly diagnosed patients to be helpful. At the LFAGOC information class, Bonnie received a list of rheumatologists and support groups near her, as well information on the various types of lupus. She also discovered that there are lots of PLWL, not only in her area, but throughout the world. Bonnie laughed again as she talked about information received at the new patient class:

> “We were told ‘Not to Google it’, which I had already done. [Laughed] Of course, we googled [lupus] which that was very scary. Googling anything you…you think you’re dying. So that’s always scary. That is obviously not a good option.”

Bonnie was the first person in her family to be diagnosed with lupus. She was not aware of any other relatives that had lupus but did have a family history of rheumatoid arthritis (RA), so she had no point of reference. Bonnie eventually had to switch rheumatologists, yet again, due to her current rheumatologist retiring. The search for a new rheumatologist took approximately two months.

Response to lupus diagnosis and disease. Although Bonnie has experienced many “bumps in the road”, she appears to be managing her lupus well. Many of her physicians have commented on how well she manages while still working fulltime.

She uses a variety of strategies to help her manage. Bonnie talked about how she manages:

> "I have to [manage] or I would be sitting in the corner crying because there's so many things going on in my body. You wouldn't know that I am dealing with a migraine and I think it's a lupus flareup migraine that I've been dealing with September 22nd [It is currently October 19th.]. I've been to the emergency room three times with it…I just deal with it. It also affects my joints. It hurts to get up and move. I just work through it."

Bonnie has a very good family support system. At this point, Bonnie does not attend support groups. She described her current state of support:

> "I'm in a good place and that's why I haven't needed the support groups. I know that if I would need to go to one, I could. Thankfully, I still live at home with my mom. She understands the fatigue just hits me so hard. My boyfriend is super supportive. The only one that doesn't seem to understand is my sister, but she's my sister."

Bonnie sees her physicians regularly and takes her medications as prescribed. She has tried many different medications to manage her lupus symptoms but has had a difficult time finding the right medication for her. The typical medications prescribed for lupus did not work for her.

> "The first medication we tried was [typical lupus medication] did not help. I'm allergic to it. So, prednisone absolutely helps. When I first went on prednisone, it controlled me. I cried every single day and thought I was going crazy! I tried [another medication] …for a few months and I had to stop that one because I was having foot surgery, but that one didn't help either. Then right now, we fought for 11 months for me to get on [infusion] and that's the one I'm on right now. That helps so much. So, I've done three rounds of infusions that helps amazingly! I've had flare-ups two weeks before every time [before the next scheduled dose]. I can tell when it's wearing off. We do it every four months."

Another strategy Bonnie uses to manage is exercise such as stretching and yoga to help with joint pain. She also attempted gluten-free dietary changes but saw no difference in her symptoms, so no longer follows these restrictions. When asked how she knew if her lupus was managed, she stated:

> “When I am able to move easily. I have less pain. I know when I am able to get out of bed easily…I can get up and put my clothes on by myself.”

Since her diagnosis, Bonnie is trying to increase awareness of lupus among her circle of friends. She talks about what she has learned and how she is increasing awareness:

> “One of my co-workers has lupus and I told my boss that next year, we should have a fundraiser…We should do a fundraiser and do the walk together.”

LupusOhio application use. Bonnie uses the *LupusOhio* app weekly. She describes the app as easy to navigate and readily available. She uses it as a resource to look up information on managing lupus:

> “I know there’s information in there. I can look up articles on ways to manage lupus. I can look up support groups and stuff [encouragements] on there when I’m having a bad time.”

Although she does think the app is a good tool, she generally takes her questions to her doctors. Bonnie does not use the app for her medications or doctors lists due to the complexity of her lupus. She prefers using a different app which gives her reminder alerts of when to take her medications. This feature is not available on the *LupusOhio* app.

Connie. Connie is a 38-year-old divorced Caucasian who was diagnosed with lupus 10 years ago. She is a high school graduate and a single mother of two children. She volunteers for the LFAGOC.

Diagnosis narrative. Connie discussed her medical history which started as a child. At that time, she had frequent illnesses attributed to sinus issues and asthma. Eighteen years ago, she developed a severe sinus infection that resulted in a need for a chest x-ray, which revealed a tumor “the size of an egg” on her thymus gland. Connie, accompanied by her mother and husband, went to see a surgeon about removing the tumor. By the time Connie saw the surgeon, her tumor was now the size of a tomato.

Connie was told by the surgeon that he was not sure whether this was cancer. He gave her the option to either wait six months to see if the tumor grew or to have it surgically removed. Connie opted to have the surgery. She reported being told by the surgeon:

> "If we wait, it's a 50/50 chance you could die, and operating is 50/50."

By the time that Connie received the surgery, the tumor had then grown to the size of a baseball and was "sitting on her heart" and "putting pressure" on her trachea. Connie displayed anger as she discussed the surgeon and the surgery. She continued to follow up with a "cancer doctor" even though the tumor was not cancerous. She was told by the oncologist that she needed to be tested for lupus and rheumatoid arthritis as a precaution because of the removal of her thymus gland. Six years after the surgery, Connie was diagnosed with lupus, myasthenia gravis (MG), fibromyalgia, seizures, and cardiovascular issues – venous pooling, sinus tachycardia, and hyperkinetic circulation. Connie reported that she had four blood tests that were positive for lupus.

Disease experience. Connie lived out of state when she was diagnosed. She reported not being given any information on any of the diagnoses she received. Connie said that she looked up the information herself on the Internet.

> "My cancer doctor in [previous location] didn't really have information and at least he was honest and said you have to be tested. After I was here, I joined the Lupus Foundation of America, which helped a lot."

She moved back home to be with family and had to find a new rheumatologist. Her mother assisted her in the search and went with her to see the new rheumatologist. Connie reported that the rheumatologist wanted to put her on medication for depression and told her that she did not have lupus. Connie became agitated as she talked about her visit with the rheumatologist. She said:

> "I told her I had four blood tests showed lupus. Help me!"

Due to the conflicting diagnoses, Connie changed all her physicians and went to a different hospital system. She displayed disgust in her voice when talking about the lack of communication between her previous physicians. Connie's new rheumatologist confirmed that she did, indeed, have lupus and myasthenia gravis. Connie was then referred to a neurologist for treatment of the myasthenia gravis. She sees multiple specialists for her various conditions. She stated her new physicians now communicate well with each other.

***Response to lupus diagnosis and disease**.* Connie manages her lupus by taking numerous medications, eating healthy, using daily prayer and meditation, and having self-determination to see her children grow. She is now on a chemotherapeutic drug which is ordered for her MG, but also helps with lupus symptoms. She takes nine other medications that often inhibit her ability to function due to the adverse effects. Connie stated:

> "The medication makes me sick…very nauseous. I can't get off the couch. I still have flares for both [MG and lupus], but it is not nearly as bad. My rheumatologist has been honest with me. He told me if the chemo stops working, there's nothing for my myasthenia gravis that would work for me. The medications I am on, I consider a band aid. It helps diminish the flares, but it's not the cure. Until they find the actual cure, it's helping me cope and function every day. I am just managing."

Another useful technique Connie revealed was daily meditation and prayer– "I thank God every day that I wake up and I have another day." Connie demonstrated self-determination through the many times that she verbalized wanting to see her children grow up.

> "I fight because I want to see my kids grow up. I must. My son looked all this stuff up and one day he said, 'You're going to leave us.' I said, 'No, I'm not. I don't plan on it.' You know when it's my time… He said that at 10 years old [He is now 15.]. He's very intelligent and he knows what can happen with both... I have a small goal to see them graduate high school and then go from there."

Connie knows her lupus is managed when she does not have "flares" (i.e., red palms, hands feel like they are "on fire", her fingers and toes get shiny and tight, bleeding in her mouth, and extreme fatigue). When these symptoms occur, she must lie down and rest. Connie denied ever having a break from the fatigue. She has good family support from her mother and children. She can ask her mother to take her children when she needs rest. Connie stated:

> "I just rest when I can. I try to fight through it. The kids are pretty good about it. When I need to rest, they know. If they want to do something, they can call grandma and she'll take them."

Connie also volunteers for the LFAGOC. She verbalized learning so much from the people there being a volunteer. Her children also volunteer with her.

LupusOhio application use. Connie has used the *LupusOhio* app weekly since its inception. She looks up symptoms and uses it for encouragement when she's struggling mentally. Connie stated:

> "I think it helps. It's a struggle sometimes like when you have more than one health issue. I look through the app to see if the symptoms I am experiencing are lupus."

She uses the *My Meds* and *My Doctors* tabs on the app to keep an updated list of her medications and doctors, as well as a paper list located on her refrigerator. Her children and her mother know where her medication lists are and have presented them to the emergency medical services when they called "911" for her in the past or when she needed to go to the hospital.

Debbie. Debbie is a 45-year-old Black / Non-Hispanic female from a rural area. She is a high school graduate and works full-time. She is separated from her husband and lives with her mother who has her own health problems. Debbie has several family members with lupus including two living cousins and one that passed away before she was born that they believed had lupus. She also has a grown son who is displaying symptoms of lupus. Debbie is a strong advocate for increasing lupus awareness.

Diagnosis narrative. Debbie was living out of state at the time of her diagnosis. She lived in a city that has a very large lupus population. Debbie believed this is one reason that she was given better care than most lupus patients living in other areas. Shortly before Debbie received the diagnosis of lupus, she had gone to her family physician with what she thought was heart problems. Her family physician sent her to a cardiologist who scheduled her for a balloon procedure to open a blockage in her arteries in her heart. While talking with the cardiologist, Debbie became very emotional. The cardiologist sat with Debbie and calmed her fears. He discussed with her the need for her family doctor to test her for lupus because she had many of the lupus markers. Her family physician did the blood work and confirmed that she had lupus. Debbie stated:

> "For many patients, it takes years for that diagnosis, but for me it was probably a total of six months."

Disease experience. Debbie was 35 years old when she was diagnosed. Upon diagnosis of her lupus, she was given an educational pamphlet printed by the LFA that included a brief description of what lupus is, symptoms, statistics about lupus, and the LFA website. She went to the LFA website and retrieved much more information on lupus including how it is diagnosed, symptoms, and possible treatments. Debbie primarily uses the LFA website when she has questions or concerns but will also use the Internet to research new symptoms or medications. Debbie discussed what she researched and learned about lupus:

> "Sometimes, I google symptoms. Sometimes, I'll google medications that my doctor wants to prescribe me before I actually agree to take them. I learned in the beginning, there was no cure and that there were different types of lupus and different treatments. Depending on which type of lupus I had… but there weren't very many medications specific to treat lupus."

She displayed a very positive attitude toward her disease and talked more about her fears for those in her family that were not accepting of their diagnosis of lupus and the fear of her son to get tested. She stated:

> "When I started getting sick, I lost so much weight…it was a scary time for me and my son, but I'm still here and doing better. It's in my family. My one cousin is in denial. Her doctor told her it was lupus and she said, 'No, I'm not accepting that.' She takes the same medications that I do. I guess you don't have to accept it, but we're on the same medication. We have a lot of the same symptoms. You have beat it! Don't let it win! You take charge! They want my son to get tested

> but he's afraid to. He has a lot of fatigue and pain in his joints. I'm working on him to get tested…I told him, 'I will go with you.' I'd rather know than not know. So hopefully, that'll convince him to get tested."

Response to lupus diagnosis and disease. Debbie takes multiple medications and must rest to alleviate her pain and fatigue. Debbie also visits her rheumatologist regularly and has email access to her physician to report her symptoms without delay. She learned through her research that eating a proper diet and staying active are important in managing her lupus. Debbie describes the changes she made in her life as follows:

> "I am mindful of what I put in my body and symptoms I am having. I think the most important thing is eating healthy. I'm trying to change my eating habits and trying to stay active which is sometimes easier said than done. I think those are the two most important things for me."

Debbie reported that she knows her lupus is managed:

> "When I feel pretty good and I'm not as tired. The pain and swelling that I normally have with my flare isn't as bad. So, I would say overall, just feeling better."

Debbie experiences many of the same symptoms as other PLWL when experiencing a flare. Debbie describes her experiences with her flares:

> "I get extreme fatigue where it feels like I can't wake up no matter what. I just sleep all the time. The swollen joints…I feel like I have the flu. I ache all over. Sometimes I get a low-grade fever and my migraines normally set in. I have a loss of appetite and I don't want to eat anything."

It is obvious that Debbie is an advocate for PLWL and their families with a desire to increase awareness.

> "We need more awareness because I know there's people out there living with lupus and they don't know they have lupus. It's a crazy disease. I always say it's cruel because sometimes I feel like I'm going crazy with it. Depression, symptoms, and not knowing what it is. Sometimes, I feel

> like a hypochondriac. There are the two things I would like to see…1) the cure and 2) increased awareness to get the information out there and make people aware."

***LupusOhio application use*.** Debbie uses the *LupusOhio* app approximately twice a month to look up details of events such as the symposiums that provide updated lupus information regarding new treatments and research, as well as other events that allow her to network with other PLWL. She registers for events through the registration site on the *LupusOhio* app. Debbie checks the *Ask the Experts* tab on the app each time she opens it for updated information. She also uses the app to search for a local support group. Unfortunately, her local support group dissolved due to lack of attendance and there are no other support groups close to her.

When asked if she would share the app with others and what areas of the *LupusOhio* app that she would point out, Debbie stated:

> "Probably the support. If there's any caregivers, they can find a support group in their area and especially the events. I love the lupus walk every year. I try to get as many people on my team as possible. Last year, my mom was my co-captain. We had our biggest team yet. My employer actually paid for the fees for any co-worker of mine that wanted to walk. I'm going to keep asking every year. We raised over $3,000 and it was the largest team that I've had. I wish they could find a cure."

Eva. Eva is a 46-year-old Black / Non-Hispanic female who is married with two children. She lives in an urban area and has her high school diploma. Eva displayed signs and symptoms of lupus since she was 16 years old but was not officially diagnosed with lupus until she was 32. Eva is now very active with the LFAGOC as a patient liaison who assists with educating newly diagnosed patients.

Diagnosis narrative. As stated above, Eva was 16 years old when she displayed signs and symptoms of lupus such as hair loss, skin lesions, rash, extreme fatigue, and proteinuria; however, her antinuclear antibody (ANA) blood test never came back positive. When she began planning her family, she experienced several miscarriages which is a complication of lupus; however, she eventually was able to have two healthy children. It was not until her last pregnancy that she had a positive ANA test and was "officially" diagnosed with lupus by her gynecologist.

Disease experience. After receiving this diagnosis, she became severely depressed due to frustration of not knowing how to manage the disease. Despite having symptoms of lupus for 20 years, Eva was never treated for lupus due to the negative ANA, nor was she given any information on it. Her physician kept telling her that he believed that she had lupus but could not be certain because of the negative ANA test. Eva was officially diagnosed with her last pregnancy. However, she was told "don't worry about it" because she would not be able to take the medications needed to treat her lupus. Eva recalls:

> "I was told you have lupus and that was it. My OB told me because she was the one who finally got the positive ANA results, but I didn't receive any information. My primary didn't have anything to give me either. He referred me to Dr. W. [rheumatologist]. She told me not to worry about it and said, 'I'm going to take care of you.' So, I didn't. I didn't feel any differently but after I delivered…I was like now what? I didn't know anybody lived with lupus. Everybody in my family that had it had passed. So, I went into a depression for three years."

After Eva delivered, she went to the rheumatologist who did blood work and started her on the usual lupus medication. She recalls:

> "He still didn't have anything to give me for a resource or even mention the Lupus Foundation. So, it was a big problem. I think that if I had that direction or if I…I really think that once I was diagnosed with lupus, they need to have a mental health person present and referrals need to be given for mental health immediately."

Response to lupus diagnosis and disease. When Eva was first diagnosed, she attempted to treat her lupus holistically. She went to a local health food store in search of answers. The clerk recommended several products for her to "cleanse" her body. Eva displayed frustration and anger as she described her experience with the store clerk:

> “The lady at the store told me ‘You don’t have lupus. You have candida. I told her, ‘No, I have lupus! I’ve been told by two doctors that I trust that I have it. I’m looking for things to help me manage it.’ She then told me, ‘Well, you just don’t want to listen to me. You’re going to die a slow, miserable death!’ I left there, went home, and cried. That began my depression.”

To help her daughter, Eva’s mother found a support group for Eva to attend. After attending the lupus support group, Eva found that she was able to live with lupus which changed her attitude toward positive. At one point, she stopped going to the support group because she thought she could manage on her own. She laughed as she described her experience:

> “I went and I started learning about lupus. I met ladies there who had been living with lupus for a long time and I saw that with lupus, I can do this. I can work! I can manage! You know what? My whole attitude changed. So, then I stopped going. I decided I didn’t need it anymore. So, [Support group facilitator] called me and said, ‘Hi, we missed you. Why didn’t you come?’ I said, ‘I didn’t go because I’m better now and I got my head together. I know what I’m doing. I got a plan.’ [Support group facilitator] replied, ‘We have other people that you might benefit from talking with or they might benefit from talking to you. So, I need you to come back.’ So, I started going back.”

When Eva realized that she needed others and others needed her, she returned to the lupus support groups and is now working for LFAGOC as a new patient liaison. Eva concluded that she manages the lupus and does not allow the lupus to control her. As part of her self-management, she sought out psychotherapy to help her cope with her lupus diagnosis and postpartum depression. Eva reported:

> “I just have a better perspective after talking it out with someone. I really think that once someone is diagnosed with lupus, they need to have a mental health person present and referrals need to be given for mental health immediately. Everybody thinks that a mental health professional just

> helps you if you're crazy, but they help. They are a neutral third party that's helping you to talk about how you feel, what you're going through, and life period. That's just my belief."

Eva believed that in order to cope with all her health changes, she needed to take better care of herself which included encompassing herself with positive people in her life. She changed her circle of friends to remove herself from any negative influences. As Eva stated above, she believes that all lupus patients should have some sort of mental health counselling offered in their treatment plan to assist them in coping with the uncertainty of lupus.

Other strategies Eva uses to manage her lupus include medications for symptom management, controlling stress, getting adequate rest, and changing her diet. She laughed as she talked about all her medications and changing her diet:

> "I take five pills a day. I used to take 22. I take [an infusion] every month. It's my friend. On the 26th or 27th day, I know that I'm starting to get a little sluggish and it's time for my infusion. It does wonders for me. Every other month, they give me a B12 shot. I also changed my diet. I try to eat less red meat and eat less sugar which is inflammatory, but I haven't been able to let sugar go totally. It's my friend."

Eva recognizes her lupus is flared when she experiences symptoms such as migraines, fatigue, hair loss, and her lupus rash. She describes her flares as follows:

> "If it's flared, I get a rash across my stomach and when I'm running the comb through my hair, it comes out a lot. I have days when I don't want to get out of my bed - not because I can't, but I just don't. I can feel it coming on, but it's not as bad as it used to be. I know I am under control when I am not having migraines and not having hair loss."

LupusOhio application use. Eva has used the *LupusOhio* app 3-4 times/month since its inception in 2014. She uses *My Meds* and *My Doctors* in the app to keep track of these items when visiting her various physicians and if her family needs the list if she must go to the hospital. She also uses the app as a tool for new patients to introduce them to the LFAGOC, support groups, and to guide them in finding information and events such as teleconferences, symposiums, walks, and other lupus information. Eva discusses the various tabs of the app and how she uses them:

> "I do use it for my meds. I put my meds in there so that my family members could have it. I told my kids… in case anything ever happened or if they had to take me to the ER. They need to know what my meds were. *My Doctors* is filled out as well. I think the *My Doctors* and *My Meds* sections are the most vital part of the app itself. I really use the app a lot at home. If you call me and you need something, I just go to the app and look it up. It made me feel good that we have the app. No other chapter has anything like it."

Eva is a proponent of the *LupusOhio* app especially for new lupus patients who do not know where to turn for information. She continued:

> "I would like to see a journaling page. I suggested this to my support groups when I have newly diagnosed patients. Patients in general can track what's going on with their disease between the times they see their doctors, so they don't forget because they're not going to remember. When the doctor comes in and asks how you've been, rather than just saying fine, they can say, 'You know this is what happened, and this is what's happening. You can just open that up…"

She wants to increase awareness and prevent young lupus patients from going through what she had to experience due to a lack of understanding of the disease.

Fran. Fran is a 51-year-old Caucasian who attended graduate school. She is single mom with one daughter and lives in an urban region. Fran facilitates a lupus support group through the LFAGOC.
She was diagnosed with lupus at age 46. However, Fran experienced lupus symptoms for at least four years prior to that.

Diagnosis narrative. As stated above, Fran experienced symptoms for at least four years prior to her diagnosis of lupus. She reported a very complex course of her symptoms and her disease. She described her experience as follows:

> "My symptoms were very palindromic. They would come and go. The one constant was always my hands. I had stiffness here and there. One day, I was fine and the next day, my knee is swollen and hard to bend. Two days later, I'm fine again. I probably had many flares when I was travelling on two different occasions, where it was so bad that I couldn't bend my arms. I was so stiff, and my neck was uncomfortable. Even just to raise my arms when I was trying to wash my hair was very painful. There was one time when I took my daughter to [vacation], my feet were bothering me so bad, I couldn't walk. I was crawling around the hotel room to pack us because I was so miserable. I was losing a lot of hair. Then I got Bell's Palsy. They put me on prednisone, and… 'Oh my gosh, I felt great!' I felt better than I had in years."

Fran reported other symptoms such as the positive antiphospholipid antibody which is often found in patients with autoimmune diseases and the butterfly rash also common in lupus. Fran then proceeded to describe her complex experience the year she was diagnosed:

> "In July, I caught a cold. I started feeling feverish and fatigued. It just got worse from there. I complained to Dr. G that I'd lost weight. I had already been to urgent care because I thought I had mono or strep throat. They told me, 'No, but you need to see your [primary care] and get blood tests done.'"

This doctor would not tell Fran what they suspected. When she went for her follow-up, Fran's physician examined her thyroid and scheduled another test. Then Fran went for her routine ophthalmology appointment and was found to have inflammation in the back of both of my eyes. Fran stated:

> "He got very alarmed, which knowing him as well as I did, kind of alarmed me. He told me I want you to see a retinal specialist today, but he couldn't get me in for about 10 days. The retinal specialist was like, 'Oh, you are a thorough mystery! Many people have it [lupus] and have lived well with it. We'll work through this.' He was very reassuring."

Despite getting closer to a diagnosis, Fran was getting worse. Her brother, an ER physician, became very concerned with her current symptoms and asked, 'What test did Dr. G. order for your blood work?" He wrote a prescription and advised her to follow-up and ask the doctor to run a specific blood test. Following these tests, Dr. G. said, “I’m thinking you have lupus.”

Fran’s diagnosis was masked by her pregnancy:

> “When I was pregnant with my daughter, it was eight years before they found the antiphospholipid antibody. My perinatologist called me and told me, ‘You know one of your tests came back positive for [unrelated disease], but don’t be worried, you don’t have it. We did the confirming test…You have a funky antibody in your blood. It’s no big deal, but you should know, it’s related to lupus.’”

Disease experience. Once Fran’s diagnosis was finally confirmed, progression really began.

> “Then it was everything at once. It was my eyes, my hair, and my skin was dry. I was losing weight. By the time I got to the specialist, I had the mask and daily fevers. I was extremely fatigued. I went to see my family doctor and he wanted to see me back in two weeks. In that two-week period, I lost even more weight despite all my efforts. He did more blood work and set me up with a gastroenterologist and a rheumatologist. This is now mid-September. The rheumatologist’s office called me but couldn’t get me in until November. So, I’m suffering for two months.”

Disease progression happened so quickly that Fran’s primary care physician called her and told her, “I don’t want to scare you, but I am this close to putting you in the hospital. I think this is lupus, but since your blood work came back, I have to check for leukemia.”

Fran’s family doctor helped to secure an immediate appointment with a rheumatologist, who after repeating the blood tests confirmed that she was in a flare. Fran remarked:

> “I think I had at least 16 different blood draws between all my doctors.”

Response to lupus diagnosis and disease. Fran is very aware of all her medical diagnoses and follows up with all her specialists regularly. Despite seeing all these specialists, Fran claimed that the only information that she received regarding her lupus was instructions from her family doctor to stay out of the sun. She is very knowledgeable about her lab tests and the meaning of the results. Fran stated:

> "I kept expecting somebody to give me a pamphlet or something. I had that when I had to get a procedure. They give you a piece of paper with an explanation of the procedure, but there was nothing. My family doctor told me to stay out of the sun and make sure that I wear sunscreen and big hats. When he came back, he talked to me about anti-inflammatory foods that I could be eating. He asked me lots of questions but gave me nothing. So, that's when I went looking."

After receiving her diagnosis, Fran found the LFAGOC. Fran stated:

> "I went looking in the beginning of January because I got diagnosed officially in October when everyone agreed and when the rheumatologist confirmed it. I found the Lupus Foundation."

She contacted the LFAGOC office to inquire about information. She was sent a packet of lupus information and informed of the new patient education class.

> "I took the new patient class. The man that taught the class started off with the books available. I zeroed in on *The Lupus Book* by Dr. Daniel Wallace. I started reading it cover to cover. I really like having the book and knowing what I'm really at risk for. Every now and then when something happens, I go to the book to see if this is lupus related. I tend to go to the material I can trust. I prefer to get my information from the Lupus Foundation and from that book. There are lupus groups on Facebook, but I won't join them because it's often a lot of people crabbing and passing out bad information."

Fran studied the many chapters in *The Lupus Book* to help her understand her lupus symptoms and her lab results. One chapter discusses the various diagnostic tests that PLWL need to have monitored, along with simple explanations of what the tests were and what the results meant. Fran found this book immensely helpful in understanding the various tests being done, why they were being done, and how the results pertained to her.

Fran made dietary changes long before she was diagnosed with lupus after watching a PBS special where a dietician was discussing the effects of gluten and inflammation. Fran attempted the gluten-free diet to help reduce her inflammation. She consumes lots of fruits and vegetables and cut out red meat. Prior to her diagnosis, Fran participated in half-marathons, instructed a spin class, and weightlifting. Though she is no longer able to do these activities, Fran wears a Fitbit to monitor her activity and sleep. She monitors her steps and is very self-aware of her activity and the need to move more. She consumes at least 64 ounces of water per day which she feels is very important in maintaining her resting heart rate. Fran stated:

> "I'm trying to do everything right. I eat nuts and dark chocolate. I really try to avoid a lot of sugar."

When Fran experiences a flare, she has symptoms of extreme fatigue, joint pain, muscle pain, headaches, and nausea. She describes knowing her lupus is managed as:

> "I can tell by the way I feel. I don't have any joint pain or muscle pain. That's not to say every now and then, I don't suffer from fatigue. If I try to do too much, then I go down to where I just don't feel well. The doctor will ask, 'What does it mean you don't feel well?' It's kind of like when your computer acts up and you must shut it down and reboot it. That's me. I get nauseous, have a headache and lightheaded, and I'm exhausted. I just must go to bed as soon as I can. When it's bad, I start to pass out."

LupusOhio application use. Fran has been using the *LupusOhio* app monthly for "a couple years". Fran discussed the things that she liked about the app (*My Meds* and *My Doctors*) which were the same things that frustrated her. She discussed her frustrations:

> "I put my information into the app one time and the app just stopped working for me. I had to uninstall it and reinstall it. Another time, it was one of my phone updates and it seemed to be because of that. I went back into the app and everything was gone. Another area of my frustration was when I put my meds in. It lists all my doctors on the same screen. When I go to *My Doctors*,

> its lists all my medicine. It doesn't keep them separate. I still like the *My Meds* and *My Doctors*. I just wish the pages were separate. Another frustration is with the *Ask the Experts* page. I can register, but it does not give any information about the previous ones."

Fran also uses the app to keep up with lupus news such as new research on lupus and various lupus events. Fran shares this information with the support group she facilitates. She frequently connects to the LFA website through the app to look for information to share with her group. Fran links to the lupus store through the app where she can purchase items to wear to increase lupus awareness. Increasing awareness of lupus is very important to Fran. Fran remarked:

> "I am a big advocate, but I'm not the only one."

Fran ended the interview by saying, "Thank you for doing this research because I definitely wanted to be a part of that."

Grace. Grace is a 29-year-old Caucasian who is married and lives in an urban area. She attended graduate school and currently works. She was 26 years old when she was diagnosed with "early lupus", that is, undifferentiated connective tissue disease.

Diagnosis narrative. Grace first knew something was wrong when she displayed multiple symptoms such as joint pain, swelling, rashes due to sun sensitivity, severe fatigue, hair loss, proteinuria, dry mouth, dry eyes, and dry nose. She had symptoms for six months before the actual diagnosis of lupus was confirmed by a rheumatologist. Besides lupus, Grace also has fibromyalgia, hypothyroidism, asthma, and Sjorgrens's syndrome which is another type of autoimmune disease. Grace describes her pathway to her diagnosis:

> "I was referred to [a rheumatologist] to be tested for lupus because I had a lot of the symptoms. I got the positive ANA result and I had the symptoms, but I didn't have the positive double stranded DNA. I was told they thought I had lupus. I have early lupus, so I don't have significant organ damage at this point. They told me, 'It's either lupus or early lupus. Either way, we treat it the same.'"

Grace was advised to return in one month to be retested. Her rheumatologist thought Grace might also have sleep apnea and fibromyalgia. When Grace returned the next month for her testing, she had a rash on her face. The doctor told her, “We really need to test you for lupus.” Grace displayed frustration as she talked about this visit:

> “I said, ‘That’s what I’m here for!’ This went on for six months. Then I went and got a second opinion. She [new rheumatologist] looked at my old lab work and said, ‘You’ve got lupus, so we have work to do.’”

When Grace was diagnosed at age 26, she was given minimal information on lupus.

> “I think they did give me some information about lupus, but I did most of my own research. I don’t think they gave me a lot. It’s so complex. It’s not black and white. I mostly went on online and to WebMD. I just googled it and clicked on things that seemed relevant.”

Disease experience. Grace moved back to her hometown to be near her parents when her disease began progressing rapidly. She discussed the difficulty she experienced in trying to find a new rheumatologist here.

> “It was really hard to get into a rheumatologist here. I never had that experience in [previous location]. It took me several months to get in.”

When Grace finally got into her new rheumatologist, she was made to feel like she was “crazy” and was told that she did not have lupus.

> “I had been being treated for lupus for two years. They told me they would not treat that here. I go in every three months to have my lab work done and every time, my kidney function gets worse. I’m afraid I’m going to have chronic kidney disease in the next three to six months if it continues. I’ll have multiple body systems fail. It makes me feel like I’m going crazy. They have in their heads what they think lupus is, and if you don’t fit that, then you don’t have it. Lupus is much more complicated.”

Grace like the other PLWL, experiences extreme fatigue. She describes the symptoms she experiences during her flares:

> "I have severe fatigue. I'm always tired and just achy. It almost feels like a hangover. My eyes get dry and I have dry mouth and dry nose. That goes more with the Sjorgrens's overlapping stuff."

Grace describes how she knows her lupus is managed:

> "When I wake up and don't have instant fatigue, and I don't hurt, then I'm feeling okay. It's crazy because I've been dealing with it a long time and it's taking me longer to figure it out."

Response to lupus diagnosis. Grace was a former worker for Social Security Disability and had access to a variety of different health conditions. She recalled that lupus was one of the conditions that they covered, so she felt she had a little knowledge of the disease. She uses the Internet to find a lot of practical information about how to live with lupus, how lupus might affect her, and different strategies for managing lupus. Grace talked about different strategies that she uses to manage her lupus such as medications, rest, exercise, and diet.

> "I take a lot of supplements in addition to just my normal lupus meds like turmeric and biotin with coconut oil. I also take iron and vitamin D. My lupus doctor advised me to do the vitamins because I was still having symptoms even after taking the [lupus medication]. I get a lot of rest. I have to start getting ready for bed at 9:00 for me to be functional the next day."

Grace tries to do low impact exercise such as yoga and rock climbing to "get a little workout." She has cut processed food from her diet and follows the Johns Hopkins diet which restricts garlic. Grace went on to say:

> "Garlic is an anti-inflammatory, so you'd think it would be okay, but there's something in it that doesn't agree with lupus. Another thing I do is avoid the sun. I wear sunblock. I have hats like the UV hats. If I'm in the sun, that's not going to be good for me."

Grace sees her rheumatologist and family doctor on a regular basis and gets her lab work drawn as needed. She feels that her family doctor and her rheumatologist communicate well with each other such as when ordering lab work or sharing results. During flares, Grace notifies her rheumatologist rather than her family doctor of her concerns.

Grace identified her family as her support system. She talked about how well they understand what she is going through because her mother was recently diagnosed with lupus and deals with blood clots and severe degenerative changes. Her father and grandmother both have other autoimmune diseases.

Grace mentioned a support group that she in which she participated through Facebook. She said it made her feel worse about her condition and described it as "depressing." So, she stopped participating. Grace verbalized a desire to participate in the lupus walks but has been unable due to her symptoms:

> "I saw there was a walk in Dayton, but I didn't want to be in the car for that long. I've been getting progressively better to where I feel like I could participate, where last year, I couldn't."

Other strategies Grace uses to help her manage are the informational summits. It was a lupus summit where she first learned about the *LupusOhio* app.

LupusOhio application use. Since the lupus summit, Grace uses *LupusOhio* app about every other month to maintain her medication list, look up events, listen to the *Ask the Experts*, and look up information. Grace stores her medication list in the app so that her husband has access to her information. Grace described the importance of keeping her med list updated for her husband:

> "He [her husband] doesn't always know exactly what I'm on. I have a ton of meds sitting next to my bed stand. He told me, 'If you ever went to the hospital, I think I would grab all of them and hope I had what you needed.' I also like the events tab and *Ask the Experts*."

Grace went on to discuss other pages of the app that she uses such as questions about lupus, the resource guide, and the support groups link.

Grace feels that the *LupusOhio* app has made living with lupus a little easier for her with the information it provides her. However, she was frustrated with many of the links not working and the inability to listen to past teleconferences. She did not like how the app linked her directly to the LFA website “instead of just giving you the information.” She suggested updating the *LupusOhio* app with a symptom tracker especially for new patients to keep track of what is going on with their body. Another suggestion was:

> “I wish there was a podcast. I like to listen when I’m driving to work. I missed the teleconferences because of work, so I would like to go back and listen to them. If they could do a podcast every other month just having a whole new topic coming out every month, that would be great!”

Grace ended the interview saying, “Every day is a little bit different. You just got to go with it. Who knows what tomorrow will bring? If it’s not a good day tomorrow, then I’ll do what I have to do to get through it.”

Domains. Three primary domains were identified from the data obtained from the interviews: 1) Diagnostic Uncertainty; 2) Disease Self-management; and 3) Perceptions of the *LupusOhio* Mobile Application. Within each domain, several themes were gleaned which follow.

Diagnostic Uncertainty. When interviewing these women, several similarities were found. Themes identified include: Lack of patient education upon diagnosis and Self-education (See Table 9).

Table 9

Disease Uncertainty and Themes of Lack of Patient Education on Diagnosis and Self- Education for LupusOhio App Users (*n*=7)

Themes	Example Quotes
Lack of Patient Education on Diagnosis	“[Rheumatologist] ‘You have lupus. I prescribed you medication. Go pick up your medication. Don’t look it up’ and hung up the phone. I had no idea what lupus was, no idea what the medication was.”
Self- Education	“[Once diagnosed] From there, I did most of my own research. I don’t think they gave me a lot. It’s so complex. It’s not black and white. I mostly went on online and to WebMD. I just googled it and clicked on things that seemed relevant.”

Lack of patient education. Only two of the seven participants interviewed reported receiving any information at diagnosis. Comments from the women included:

> Alicia: “I don’t think I was very educated by my doctor, considering I had never heard of it. I definitely think the doctors need to start doing a better job educating; however, how is that possible when they’re only supposed to spend 15 minutes with you?”
>
> Bonnie: “[Rheumatologist] ‘You have lupus. I prescribed you medication. Go pick up your medication. Don’t look it up’ and hung up the phone. I had no idea what lupus was, no idea what the medication was.”
>
> Connie: “My cancer doctor didn’t really have information and at least he was honest.”
>
> Eva: “When I was diagnosed, I didn’t receive any information. I was told you have lupus and that was it. My OB didn’t have anything [information] to give me and my primary didn’t have anything to give me either. He [rheumatologist] didn’t have anything to give me for a resource or even mention the Lupus Foundation.”
>
> Fran: “I kept expecting somebody to give me a pamphlet or something. He asked me lots of questions but gave me nothing.”

Self-education. All reported doing their own research on the Internet through Google, WebMD, or blogs to learn about the disease, symptoms, and treatments. Other sources included the LFAGOC website (5/7), lupus support groups (4/7), and new patient information class (3/7). Searched information topics included symptom management (4/7), symptoms (3/7), local support groups (3/7), types of lupus (2/7), treatments / cure (2/7), and aggravating factors/ complications (1/7). The women discussed informational sources used to find answers to their questions about lupus:

> Alicia: “Basically, it was me doing the research which is not always a good thing.” Bonnie: “I googled which that was very scary. That is obviously not a good option…I did find the Lupus Foundation and I went to the class…the information class. That was a big help.”
>
> Connie: “I looked them [recent diagnoses of lupus and myasthenia gravis] all up.”

Debbie: “Sometimes, I google symptoms. Sometimes, I’ll google medications that my doctor wants to prescribe me before I actually agree to take them.”

Eva: “What I would read online, [one site] said one thing and I’d read something else on another website, and it just didn’t jive. Then my mom found Lupus Foundation of America and talked to [Patient Liaison] for a long time. She got me to a support group.”

Fran: “When the rheumatologist confirmed it [diagnosis of lupus], I found the Lupus Foundation. I contacted the [local] office. They sent me a packet of information and I took the new patient class. I zeroed in on *The Lupus Book* by Dr. Daniel Wallace.”

Grace: “[Once diagnosed] From there, I did most of my own research. I don’t think they gave me a lot. It’s so complex. It’s not black and white. I mostly went on online and to WebMD. I just googled it and clicked on things that seemed relevant.”

Disease Self-Management. Themes identified within disease self-management include: Mind with a sub theme of support and altruism; Body including subthemes of medications, diet, and exercise; and Spirit including subthemes of prayer or meditation, and self-determination (See Table 10).

Table 10

Disease Self-Management Domain and Themes of Mind, Body, and Spirit for LupusOhio App Users (*n*=7)

Themes	Example Quotes
Mind	
Support	“I went [to the support group]. I met ladies there who had been living with lupus for a long time and I saw that with lupus, I can do this. I can work! I can manage! ...So, I quit. [Support group facilitator] called, ‘We have other people that you might benefit from talking with or they might benefit from talking to you.”
Altruism	“I love the lupus walk every year. I try to get as many people on my team as possible. Last year, my mom was my co-captain. We had our biggest team yet. My employer actually paid for the fees for any co-worker of mine that wanted to walk. I’m going to keep asking every year. We raised over $3,000 and it was the largest team that I’ve had. We need more awareness because I know there’s people out there living with lupus and they don’t know they have lupus.”
Body	
Medication	“We fought for 11 months for me to get on [infusion] and that’s the one I’m on right now. I’ve done three rounds of infusions of that and that helps amazingly!”
Diet	“I learned that you could change your diet to help. It won’t cure it, but it’ll help manage it.”
Exercise	“I do low impact…yoga and rock climbing, so I get a little workout.”
Fatigue management	“I get a lot of rest. I have to start getting ready for bed at 9:00 for me to be functional the next day.”
Spirit	
Meditation / Prayer	“I thank God every day that I wake up and I have another day.”
Self-determination	“I fight because I want to see my kids grow up. I have a small goal to see them graduate high school.”

Mind. When asked what sorts of things helped them to manage their lupus, four of the women stressed the importance of emotional support to help with coping with lupus. This support is found through support groups, family support, positive attitude, changing circle of friends, and mental health counseling.

Bonnie: “I actually have not needed to go to a support group because I have a very supportive family.”

Connie: “The kids are pretty good about it. When I need to rest, they know. If they want to do something, they can call grandma and she’ll take them.”

Debbie: “You have to beat it. Don’t let it win. You take charge!”

Eva: “I went [to the support group]. I met ladies there who had been living with lupus for a long time and I saw that with lupus, I can do this. I can work! I can manage! ...So, I quit. [Support group facilitator] called, ‘We have other people that you might benefit from talking with or they might benefit from talking to you.”

Altruism is another important factor in creating a supportive environment for self-management. This is done in the form of volunteering as a support group facilitator, becoming a patient liaison, volunteering for lupus events along with family members, encouraging others to participate in fundraisers for lupus research, and increasing awareness by wearing lupus attire.

Bonnie: “I told my boss that next year, we should have a fundraiser…We should do a fundraiser and do the walk together.”

Debbie: “I love the lupus walk every year. I try to get as many people on my team as possible. Last year, my mom was my co-captain. We had our biggest team yet. My employer actually paid for the fees for any co-worker of mine that wanted to walk. I’m going to keep asking every year. We raised over $3,000 and it was the largest team that I’ve had. We need more awareness because I know there’s people out there living with lupus and they don’t know they have lupus.”

Fran: “I am a big advocate, but I’m not the only one. When people are getting involved and come to the support groups, they might wear purple or their walk shirts.”

Body. Taking medications is another form of management shared by all the participants. Many of the participants discussed difficulty in finding the right combination of medications that worked. They also talked about the adverse effects of the medications. Follow up visits with their rheumatologists and routine blood work was another key factor in lupus management reported by all participants.

Bonnie: “We fought for 11 months for me to get on [infusion] and that’s the one I’m on right now. I’ve done three rounds of infusions of that and that helps amazingly!”

Connie: “I take at least 10 medications. I’m on a chemo now for the myasthenia gravis, but it also helps with the lupus. I still have flares for both, but it is not anywhere near as bad. It helps for both. The medications I am on, I consider a band aid.”

Eva: “I take five pills a day. I used to take 22. I take [infusion drug] every month. It’s my friend. It does wonders for me.”

Grace: “I take a lot of supplements in addition to just my normal lupus meds like turmeric and biotin with coconut oil because I was still having symptoms.”

Six of the seven women made dietary changes to help relieve inflammation such as avoiding sugars, avoiding red meats, eliminating gluten, and eliminating garlic.

Connie: “I learned that you could change your diet to help. It won’t cure it, but it’ll help manage it.”

Debbie: “I think the most important thing is eating healthy. So, trying to change my eating habits…”

Eva: “I haven’t been able to let sugar go totally. It’s my friend.”

Fran: “I’m trying to do everything right. I eat nuts and dark chocolate. I really try to avoid a lot of sugar.”

Grace: “Diet wise, I try to cut out processed food. I use the Johns Hopkins diet…no garlic. [Garlic] doesn’t agree with lupus.”

Exercise was another technique used by four of the participants to assist in alleviating joint pain and stiffness. Exercises included activities such as stretching, yoga, low impact exercises like rock climbing. One of the women wears a Fitbit to monitor her activity and sleep.

Grace: “I do low impact…yoga and rock climbing, so I get a little workout.”

All seven participants discussed managing fatigue and the importance of resting when the fatigue occurred. Many participants gave the following responses regarding how fatigue was managed:

Alicia: “I take lots of naps.”

Connie: “I just rest when I can. I try to fight through it.”

Debbie: “I just sleep all the time. It feels like I can’t wake up.”

Eva: “I just need to rest. I don’t want to get out of bed.”

Fran: “If I’ve got a headache or lightheaded, I have to go to bed as soon as I can.”

Grace: “I get a lot of rest. I have to start getting ready for bed at 9:00 for me to be functional the next day.”

Spirit. Meditation or prayer and self-determination were identified as subthemes.

Connie: “I fight because I want to see my kids grow up. I have a small goal to see them graduate high school. I thank God every day that I wake up and I have another day.”

Debbie: “You have to beat it. Don’t let it win. You take charge!”

Perceptions of the LupusOhio Mobile Application. As stated previously, these women were selected for interviews based on their use of the *LupusOhio* mobile application. The length of time the app was used ranges from “a few” months to four years. The frequency of usage of the *LupusOhio* app ranges from weekly to once every other month. All the women agreed that the *LupusOhio* mobile application is a good resource for lupus patients and their families to help manage lupus symptoms. Six participants used the app to find support groups to attend and to look up information on symptoms and treatments. Five of the women used *LupusOhio* to manage their medications and physicians. Three women used the app to look up events in which to participate. Two women visited the Lupus Spot which is a tab with daily encouragements.

The themes identified from the interviews are availability with subthemes of access and dated information, app functionality, shareability, and recommended improvements (See Table 11).

Table 11

Perceptions of LupusOhio Mobile Application of Users for Availability, App Functionality, Shareability, and Recommended Changes (*n*=7)

Themes	Example Quotes
Availability	
Access	"I use it to refer new patients about what is going on and details of the events like how to sign up. I use it as a tool to introduce younger people to the LFAGOC. I put my meds in there… It is a good resource."
Dated Material	"I think it could be updated a little more, like the events."
App Functionality	"I tried using the *Ask the Experts*, but it doesn't work. It says, 'We encountered an error.' It didn't go where I wanted it to go. It doesn't feel like a true app. So, I don't feel it has the same functionality of a normal app. Many of the links don't work."
Shareability	"I think that the medication list is a good tool for people who are newly trying to manage…I think that I have been dealing with this for so long that I know what to look for but for somebody that's new, I think it would be beneficial."
Recommended improvements	"I would like to see monthly podcasts…would be helpful to have some kind of symptom tracker."

The first theme identified is availability. Participants talked about the accessibility of the app and materials in the app not being updated. Statements included:

Alicia: "It makes me more educated…it's kind of an easy reference. I think it could be updated a little more, like the events."

Bonnie: "I like that that the support groups are on there. If I'm having a bad time, I can just look and see what's on there. …easy to navigate, clearly defined, and readily available."

Connie: "I can see what's going on with the LFA and see events coming up. I can put my notes in [Notes for the doctors]. It's easier for me when I go to the doctor."

Debbie: "It's easy to use and I can go there and find what events are going on. I can get more information on the events and I was able to sign up for the events."

> Eva: “I use it to refer new patients about what is going on and details of the events like how to sign up. I use it as a tool to introduce younger people to the LFAGOC. I put my meds in there… It is a good resource.”
>
> Grace: “I think it [*LupusOhio* app] makes living with lupus a little easier…with the information I found on it.”

App functionality. Most of the women believed that the app functioned well, but two women had issues with pages not loading properly, links not working, and information being lost with updates. Comments regarding functionality included:

> Fran: “I put my information into the app one time and the app just stopped working for me. I had to uninstall it and reinstall it. Another time, it was one of my phone updates…I went back into the app and everything was gone. …when I put my meds in [*My Meds*] …all my doctors [appeared] on the same screen [as the medications]. When I go to *My Doctors*, its lists all my medicine. It doesn’t keep them separate. When I lose it, I must re-enter all that information. I still like the *My Meds* and *My Doctors*. Another frustration is with the *Ask the Experts* page…it does not give any information about the previous ones.”
>
> Grace: “I tried using the *Ask the Experts*, but it doesn’t work. It says, ‘We encountered an error.’ It didn’t go where I wanted it to go. It doesn’t feel like a true app. It always links to the website. So, I don’t feel it has the same functionality of a normal app. Many of the links don’t work.”

Shareability. The next theme identified is shareability. Participants identified several areas of the app that they felt would be beneficial to others such as information on the new patient classes, support groups, *My Meds* and *My Doctors*, encouragements through the *My Lupus Spot*, lupus information on *Lupus Answers* and *Ask the Experts,* and connecting on *Social Media*.

> Alicia: “I think that the medication list is a good tool for people who are newly trying to manage…I think that I have been dealing with this for so long that I know what to look for but for somebody that’s new, I think it would be beneficial.”

Debbie: “Support…for caregivers, so they can find a support group…and especially the events.”

Recommended improvements. The last theme identified is recommended improvements to the app. Some of the recommendations for improvement included the medications tab to include an alarm reminder, a way to connect directly with physicians, fixing the nonfunctioning links, monthly podcasts, making *My Meds* and *My Doctors* separate links rather than combined, adding a journaling page to keep notes regarding health changes between physician visits, and changing the background color for readability. Participants commented:

Bonnie: “I think it would be helpful to connect to your doctor.”

Debbie: “Making the tabs at the bottom a different color…and make it easier to read what’s on the buttons.”

Eva: “A journaling page to keep track of what’s going on…between times you see your doctor.”

Fran: “Fix the meds and doctors so they are separate lists. Make the old *Ask the Experts* available through the app instead of having to go to the website.”

Grace: “Fix the links and make sure they work. I don’t like that it links you to the website instead of just giving you the information. I would like to see monthly podcasts…would be helpful to have some kind of symptom tracker.”

Chapter V

Discussion

Overview

The purpose of this concurrent mixed methods study was to determine if the *LupusOhio* mobile application is an appropriate tool to educate PLWL about their disease and to assist them in managing their symptoms. Lupus patients are often given minimal to no patient education upon diagnosis and left with the responsibility to complete their own research which can lead to inaccurate or false information. Providing a mobile application, like the *LupusOhio* mobile application will give PLWL a place to obtain accurate information about lupus by directing them to a reputable site. This study investigated the perceptions of both new users, PLWL who had never used the *LupusOhio* mobile application, and previous users, PLWL that have used the *LupusOhio* mobile application prior to the study. Results showed there was not a significant difference in lupus knowledge or self-management after using the *LupusOhio* mobile application. However, it was discovered that the majority of PLWL were either not educated or minimally educated at the time of diagnosis which may impact self-management. These results provide valuable insight into the needs of PLWL and how the *LupusOhio* mobile application may be used or adapted to meet those needs. This chapter includes a discussion of the major findings of the new users of the *LupusOhio* app, perceptions of the apps value and usability of previous users, implications of the results, limitations of the study, and recommendations for future research.

Results Summary

***LupusOhio* Mobile Application Use.** Pages of the app most commonly opened by new users were those that provided information regarding lupus diagnosis, treatment, symptoms, and coping mechanisms, as well as current lupus research. These results are consistent with pages used most commonly by previous users for obtaining lupus knowledge. For example, *Lupus Answers* links the user to the National Resource Center for Lupus and *News* links the user to current research being conducted and opportunities to participate in research.

Other pages of the app viewed frequently by new users were those that provided opportunities for social support and networking, such as *Events* which is a calendar of lupus-related events and *Support Groups,* which provided PLWL a list of the various support groups with times of meetings and directions to the group site. Previous users identified using similar pages frequently to stay connected with PLWL who understood their disease. These results may be due to a feeling of connectivity with other PLWL or a need for psychosocial support which helps them to cope with their symptoms. The importance of psychosocial support from health care providers, families, and peers in assisting patients in coping and managing their diseases has shown a positive impact on health-related quality of life (Bandura, 1986; Zhang, 2017; Beckerman, Auerbach, & Blanco, 2011; Waldron et al., 2011; Delis, 2019). For example, in Beckerman, Auerbach, and Blanco (2011) lupus patients reported less anxiety and depression when they had a higher sense of control over lupus and were able to maintain relationships with friends. This was consistent with the results of this study in that participants discussed the importance of family and peer support in helping them to cope with lupus. Participants also discussed the importance of managing their lupus through having a positive attitude and being motivated to move forward despite their disease which is self-efficacy

Overall app usage decreased over the requested 30-day period. One potential reason for this result may be due to app functionality. The *LupusOhio* app had several non-functioning links at the time of the study which was discovered after the study began. One study by Zuniga et al. found that app functionality and performance had an impact on mobile app use retention (2019). Another potential reason for the decline in usage of the app may be a lack of engaging activities within the app. There is evidence that apps that do not engage users, show no long-term rewards, and lower retention rates result in abandonment of the app (Lin et al., 2015; Clement et al., 2018; Zuniga et al., 2019).Other studies also reveal that app use retention steadily declines after first use, and especially after 14 days due to lack of interest, functionality, technical issues, and costs to name a few (Lin et al., 2015; Tong & Laranjo, 2018; Zhao, Freeman, & Li, 2016; Pfammatter et al., 2017; Zuniga et al., 2019). Pulman et al. (2013) found that several features identified by patients with diabetes to enhance app engagement included symptom or medication tracking, alarm reminders, dietary counseling, and various other means of managing the disease. The *LupusOhio* app provides a page to list medications and a page to list physicians, as well as a list of support groups, but does not provide any type of tracking or other engaging activities.

Outcome Assessment

A concurrent mixed methods study was used to answer the overarching research question: Does using the *LupusOhio* mobile application benefit PLWL? This method was appropriate for this study because the qualitative strand results (previous users) were able to elaborate on the results obtained in the quantitative strand (new users). The quantitative strand alone would provide minimal information on the function of the app with no explanation of the benefits or flaws of the app. Using only the qualitative strand would provide only information on the perceptions of PLWL who used the *LupusOhio* mobile application which could be biased. Due to the low response rate of the online survey, there was not a large enough sample to complete a randomized controlled trial. By using the concurrent mixed methods study, the quantitative results identify whether using the *LupusOhio* application is a significant predictor of knowledge and self-management. The qualitative interviews of previous users help to explain why the *LupusOhio* application is not a significant predictor of knowledge and self-management. This data also reveals the needs of PLWL before and after diagnosis, their experience with living with lupus, and their experience with using app which helps to explain the data retrieved from the new users.

Does using the *LupusOhio* mobile application increase disease knowledge among PLWL in Ohio?

The quantitative study strand focused on new users of the *LupusOhio* mobile application. New users completed the screening survey (i.e., pretest) and posttest survey after using the *LupusOhio* mobile application for 30 days. The results revealed no significant difference in the mean SLE knowledge scores after using the *LupusOhio* application for 30 days.

Does using the *LupusOhio* mobile application improve self-management among PLWL in Ohio?

Pretest screening survey means for self-management were compared with the posttest survey means using a one-tailed *t*-test. These results were not statistically significant.

Factors considered when analyzing self-management results included length and severity of illness, educational levels of PLWL, number of other chronic diseases, and amount and quality of education received at diagnosis (Beckerman, Auerbach, & Blanco, 2011; Waldron et al., 2011). Support groups provide a resource for individual coping, as well as a support system for dealing with the uncertainty and unpredictability of lupus. Although no studies of apps specific to lupus management were identified, studies of mobile applications for a variety of other chronic diseases, such as diabetes, mental illness, chronic respiratory disease, and heart disease have shown improvements in patient knowledge, self-management, and health outcomes (Abogunrin & Martin, 2013). For example, Timmers, Janssen, Kool, and Kremer (2020) found that early education of patients using smartphones or other electronic devices has a positive effect on knowledge, treatment adherence, patient satisfaction, and clinical outcomes.

Interview Findings

Previous users were interviewed with the following research question in mind: Do people diagnosed with lupus perceive the *LupusOhio* application as a usable and valuable tool for living with the disease? General domains included: 1) diagnostic uncertainty, 2) disease self-management, and 3) perceptions of the *LupusOhio* mobile application.

Diagnostic Uncertainty. Two themes identified within this domain are a) lack of patient education on diagnosis and b) the need for self-education. Previous users reported a lack of patient education upon diagnosis which led them to search the Internet for answers. App users reported feeling uncertain about their symptomatology, treatment, future, and ability to manage or cope with their disease. These feelings of uncertainty align well with the conceptual framework of the uncertainty of illness theory (Zhang, 2017). Uncertainty of expectations and lack of disease knowledge places an added layer of stress on PLWL (Miljetig & Graue, 2009; Waldron et al., 2011; Cleanthous et al., 2013). Because of the unpredictable nature of lupus, providing patient specific education can be difficult. Healthcare professionals have limited time with lupus patients in which to provide adequate patient education. Timely education is a positive predictor of improved knowledge, medication adherence, patient satisfaction, and clinical outcomes (Timmers et al., 2020). Many lupus studies have shown an increase in anxiety due to insufficient patient education which can interfere with one’s ability to cope, decrease self-management, and produce poor patient outcomes (Zhang et al., 2019; Farhat et al., 2019; Waldron et al., 2011; Braden, 1991; Cleanthous et al., 2013).

Another layer of uncertainty verbalized by respondents concerned the accuracy and reliability of information found on the Internet. Multiple studies provide a better understanding of how people search for health-related information (Griffith & Ford, 2017; Zhang, Song, & Bai, 2013; Young et al., 2002; Wang, et al., 2014; Peek et al., 2014). People typically start with a basic search engine (e.g., Google) which can lead people to inaccurate or irrelevant information (Griffith & Ford, 2017; Zhang, Song, & Bai, 2013; Young et al., 2002; Wang, et al., 2014; Peek et al., 2014). In this study, some respondents verbalized that the *LupusOhio* mobile application provided direct links to resources from the LFA website, considered a reputable site for lupus information. In this way, the app effectively mitigated uncertainty associated with information credibility. However, a few of the previous users verbalized not being aware of the availability of these resources on the app.

Disease Self-Management. This domain reflected strategies used to support self-management and cope with the uncertainty of lupus. Themes reflected Mind (subthemes: support and altruism), Body (subthemes: medication, diet, exercise, and fatigue management), and Spirit (subthemes: meditation/prayer and self-determination).

Evidence of Social Cognitive Theory

This study is rooted in constructs of SCT, including self-motivation, self-efficacy, self-monitoring, and observational learning. Bandura's Social Cognitive Theory (1986) discusses the importance of influential interaction between cognitive ability, behavior, and environmental factors. Social support is one of many environmental factors that have been found to influence health status and health behaviors (Gonzalez, Goeppinger, & Lorig, 1990; Lorig & Holman, 2003). Each of these factors plays a vital role in the ability to self-manage chronic disease (Angwenyi et al., 2018; Bandura, 1986). Self-management of lupus develops cognitively over time through living the experience or by learning from other PLWL and healthcare professionals. Adoptive behavior changes, such as using the *LupusOhio* mobile application, may occur through perceived benefits of downloading the app while among peers at the lupus support group (Bandura, 1986). An environmental factor such as social support has been found to influence health status and health behaviors (Gonzalez, Goeppinger, & Lorig, 1990; Lorig & Holman, 2003). Social support meets one's basic need for a sense of belonging to a group of people with like issues (PLWL) (Glanz et al., 2008).

App user participants verbalized development of self-management skills such as decision-making and problem-solving through self-education regarding lupus information, networking with other PLWL about ways to manage symptoms, and following up with healthcare providers. These skills are considered important for self-management (Lorig & Holman, 2003; Bradway, Arsand, & Grettland, 2015; Blake, 2008; Lin et al., 2015). As self-management becomes more of the focus of chronic disease management, patient engagement is vital to this process (Bradway, Arsand, & Grettland, 2015; Blake, 2008a; Lin et al., 2015). Bradway et al. (2015) found that by empowering patients with the task of monitoring their health, the costs of self-management decreased; patient disease knowledge increased; self-control over their disease increased; and patient-healthcare provider communication increased. Improved self-management can decrease the use or abuse of healthcare services, result in early detection of complications, delay disease progression, and ultimately improve quality of life (National Center for Chronic Disease Prevention & Health Promotion, 2015). Other studies that looked at app interventions for self-management of chronic illnesses such diabetes, mental health, heart failure, and weight management used many of these constructs as well (Lin et al., 2015; Payne, Lister, West, & Bernhardt, 2015). The *LupusOhio* mobile app did not provide any means of engagement between the user and the app to assist with self-management, such as tracking symptoms, medication reminders, or connecting with healthcare providers to relay symptoms

SCT also highlights support as a way to instill self-efficacy, identify expectations, and use observational learning as a means of obtaining behavioral change (Bandura, 1986). Support groups provide an interconnectedness between PLWL as a means of offering emotional support and exchanging disease-related information App users verbalized the importance of support from healthcare professionals, family, friends, and other PLWL throughout their disease journey. Many studies have assessed the benefits of support in helping patients cope with and manage chronic illness. These studies discussed support groups, social media, volunteering, and having a good patient-health professional relationship (Delisle et al., 2016; Parmanto et al., 2013; Lorig & Holman, 2003). For example, Delisle et al, (2016) found that people with chronic medical conditions join support groups to gain information and to help cope with the challenges of the disease. The *LupusOhio* app provides the *Social Media* tab with a variety of social media venues. PLWL can connect with other PLWL through social media sites such as the LFAGOC Facebook page. However, users stated that they did not access social media on the app, but through the main pages online.

App users also accessed the *LupusOhio* mobile application to find events and activities in which to participate and interact with other PLWL such as support groups, fundraising events, and lupus walks. The *Events* tab on the app informs users when and where events take place, as well as how to register for events; however, users reported frustration with the *Events* tab not being up to date and as a result, primarily used the LFAGOC website.

Many of the participants displayed altruism through volunteering such as support group facilitators, new patient liaison, assisting with lupus events, and raising money for awareness such as creating teams for the walks Altruism s based on the construct of observational learning and reciprocal determinism from the SCT (Bandura, 1986; Glanz et al., 2008). Volunteering is an important part of self-management for many PLWL, as well as people living with other chronic diseases. Studies revealed volunteering can be beneficial to not only those being served, but the volunteers as well by improving self-efficacy, mental health outlook, social support, better life satisfaction, and a level of understanding from someone who is experiencing many of the same symptoms (Dolovich et al., 2019; Arnstein et al., 2002). Users reported the importance of volunteering for the LFAGOC to help increase awareness in the community. Users verbalized using the *LupusOhio* app as a tool to assist with activity registration, to inform new patients of education classes and support groups available, and to direct new users to the LFA web site to obtain information.

The overall theme of "Body" reflected subthemes that included several quotes about medications adjustments, finding the right diet, and exercise/fatigue management. Medications are a primary component of lupus management. PLWL are often prescribed numerous medications which can be overwhelming especially during flares. Many medications have severe adverse effects and may not work for all PLWL. Users may put their medication lists in the *My Meds* tab along with dosages to ensure that family has access to the information. However, the app does not provide any type of tracking for adverse effects or alerts to take the numerous meds they may have, nor does it provide a symptoms tracker which would be beneficial for communication with the healthcare providers. Diet and exercise are also important factors in managing joint pain and fatigue. This includes strategies such as avoiding foods that cause inflammation and performing stretching and aerobic exercises. Eating properly and remaining active can improve one's overall outlook and decrease fatigue in PLWL (Wu, Yu, & Tsai, 2017; Williams, et al., 2016; O'Riordan, Doran, & Connolly, 2017). O'Riordan et al. (2017) found that self-efficacy in managing lupus may be increased through providing self-management skills and knowledge of how to manage pain and fatigue. The *LupusOhio* mobile app provides links to the National Resource Center for Lupus for PLWL. By clicking on this link, it takes the user to multiple other links such as *Understanding Lupus*, *Living with Lupus* which directs PLWL to *The Expert Series*, *National Network of Support*, *Information Resources*, and *Participating in Research.* While some of the previous users obtained information from these resources connected to the National LFA, other users denied knowing the links existed.

Prayer and meditation, along with self-determination were identified as subthemes within the spirit theme. Some participants verbalized the importance of prayer and maintaining a positive attitude to keep fighting for a better life despite the effects of lupus. Others verbalized a determination to continue fighting to be able to see their children grow. Studies have shown a relationship between coping and the constructs of self-determination such as autonomy, competence, relatedness, and quality of life which was seen in participants (Altena, Boersma, Beijersbergen, & Wolf, 2018). The *LupusOhio* app provides users with multiple inspirational tips in the *My Lupus Spot* link for maintaining a positive attitude while living with lupus; however, many of the users reported not being aware of this link.

Perceptions of the LupusOhio Mobile Application. The last domain focused on user perceptions of *LupusOhio* mobile application. During the interviews, participants were asked various questions about app usage. Four themes identified within this domain include availability (subthemes: access and dated material), app functionality, shareability, and recommended improvements. Availability reflected two subthemes in which participants discussed information that they accessed through the app and material that they felt needed updated. Although some participants identified the app as functional, there were many negative issues identified that impaired the use and value of the app. Within the subtheme shareability, participants identified areas of the app that they felt could be beneficial to others, such as new patient education classes, links to the LFA National Resource Center for information, and links to encouragements to manage their disease. The last theme identified was recommended improvements to the *LupusOhio* app to make the app better suited to the needs of PLWL. Although the previous users continued to use the app, they felt that there was much room for improvement.

Merged results of *LupusOhio* Study

Quantitative findings from the new app users appeared to be similar to the qualitative perceptions of previous app users. Data from the screening questionnaire revealed no significant differences between user groups. The majority of the participants were Caucasian women of childbearing years. Participants were primarily from urban areas in which there is a higher number of lupus patients. All participants in this study are highly educated with at least a high school education or higher. In this way, the sample is not reflective of the general population of people living with lupus (Williams et al., 2016; LFA, 2020b).

Implications and Recommendations

The *LupusOhio* mobile application has the potential to be a valuable tool for PLWL to teach them about the disease, how to treat the disease, and how to manage the disease. Although, the results of the *LupusOhio* mobile application study were not statistically significant, these results provide the researcher with valuable information to disseminate to the LFAGOC. Since the app has never been evaluated in any way, these results will show the LFAGOC areas of the *LupusOhio* app that are working well for PLWL and areas that need improvement. Participants recommended multiple features that would be beneficial to PLWL that are not currently supported by *LupusOhio* app. This study will add to the literature for others that may be developing health apps as a guide of areas that need to be addressed to meet the needs of constituents.

Positive features of the *LupusOhio* app include links to a variety of patient education resources, links to support groups and networking, and links for managing lupus. An important feature of the app is the direct link to the LFA which is the leading national organization for PLWL. This site provides patient information, current research, support, and advocacy. People living with lupus can have confidence in the material obtained from this site. Pages for listing medications and physicians were among the tools supported by the *LupusOhio* app for managing lupus. Although these areas were identified as helpful, they were also areas of frustration for the users.

Participants identified several negative features of the *LupusOhio* app such as nonfunctioning links and background colors impeding readability. Participants identified outdated information as another negative characteristic of the app. Another negative feature reported was the inability to revisit previous educational recordings listed on the app. When attempting to open these recordings, participants reached an error message. These negative features may have affected study results due to poor functionality. Although the *LupusOhio* mobile application provided a place to list medications, it was primarily a blank screen in which one could only type the names of medications and dosages. This created frustration for users when their phones updated due to the loss of all the information which had to be re-entered. Another area of frustration was the physician page (also a blank screen). This page merged with the medication page rather than keeping the pages separate and was lost with updates. Participants also revealed that the *LupusOhio* mobile app needed to be more engaging. Using the uses and gratification theoretical framework in addition to SCT might be more appropriate for development of health-related apps that address specific needs of users (Rui & Stefanone, 2016). Experiencing so many technological difficulties with the app will affect the expectations and gratification resulting in a lack of motivation to use the app (Rui & Stefanone, 2016).

Participants offered several suggestions for improving the *LupusOhio* app to assist PLWL in self-management. Some suggestions include providing a list of rheumatologists in Ohio by county, including a journal page to record disease activity to report to physicians, and linking the app directly physicians' offices for requesting medication refills or reporting symptoms. Other self-management features suggested were adding a medication reminder with an alarm, adding a symptom tracker which could provide physicians with valuable information on disease progress and management, adding more information about support groups, and making the app more interactive between other PLWL.

Other potential recommendations for the app might include incorporating a weekly blog vetted by lupus experts, providing weekly podcasts with new updated information, and offering research opportunities for participation in research studies or clinical trials for new treatments.

Multiple studies have identified various features that are important for maintaining mobile application usage for various chronic diseases. Important general features considered in app development include an easy to use interface, monitoring and tracking, data security and patient privacy, user motivation and psychological support, learning behaviors, and communication (Tsalatsanis et al., 2011). More specific features include a symptom recorder, alarm system for medication reminders, a medication tracker, health care appointment tracker, a system to support self-care tasks, a social network, continuous adherence to regimens, adherence monitoring, a link to a 24 hour online helpdesk, and secure two-way communication between patients and clinicians (Pulman, Taylor, Galvin, & Masding, 2013; Parmanto et al., 2013; Herschman et al., 2014; Bailey et al., 2014; Chomutare et al., 2013).

Limitations of the ***LupusOhio*** Study

There are many limitations to this study. One limitation is the small sample size. There may be a variety of reasons for this recruitment challenge such as the unpredictable course of the disease, lupus fog resulting in forgetfulness to complete the survey, data collection occurring in the late fall around the holidays, a lack of confidence in participating in research, inability to read the instructions online, or not allowing enough time for data collection to occur. One possible strategy to increase recruitment is for the researcher to visit the various support groups in person to describe the study, read the instructions to the participants, and have participants fill out the prescreening survey in person (focus groups) where they would have the opportunity to ask questions and receive clarification (Acocella, 2012; Blanch et al., 2008). Focus groups are used as a method for explaining unexpected information in social phenomenon (Acocella, 2012). This method is also useful for interaction between the moderator and the participants and between participants. Focus groups are a good source for obtaining information from people in similar situations (Acocella, 2012). Another potential strategy to increase participation would be to gain more confidence and trust of the participants by including families of PLWL in the consent process, providing verbal explanation of the study, and including lupus professionals as part of the investigating team (Ferland & Fortin, 1999).

A second limitation to the study is that the prescreening survey and posttest survey were Web-based surveys in which a low participation rate is to be expected (So et al., 2018). Although this is method reaches a more specific population and is a much less expensive method of recruitment, it does have disadvantages. One disadvantage to web-based surveys is that recipients may delete the invitation survey without ever reading the subject line (So et al., 2018; Lucic, Brkljacic, & Lipovcan, 2018). Another disadvantage is internet literacy. This may cause participants to have difficulty reading and following detailed directions when answering certain questions (So et al., 2018; Lucic, Brkljacic, & Lipovcan, 2018). Yet another disadvantage is that many participants may have been overlooked due to lack of Internet availability. With face-to-face questionnaires, the researcher has more control over the participants and applying questionnaires to specific groups (Lucic, Brkljacic, & Lipovcan, 2018). To rectify this limitation, the researcher might have mailed the prescreening and post surveys to participants with a self-addressed stamped envelope for returning the survey and provided better incentives to increase responses (Lucic, Brkljacic, & Lipovcan, 2018). Though this approach requires additional costs, it might have presented better response rates.

A third limitation is generalizability. The study relied on a purposive sample in which the majority respondents are female. The results are not generalizable to the male population who display different symptoms and may be missing new information and treatment options. Another factor affecting generalizability is that most of the sample are White / non-Hispanic women, so the results are not representative of the Black / Non-Hispanic population or other people of color living with lupus. An attempt was made to recruit more men without success. A potential solution to this limitation would be work closely with the local Office of Minority Health to explain the study to people of color.

Another limitation is that several of the links of the app were not functioning properly. As stated previously, this may have affected the study results due to users becoming frustrated with being unable to access information. Although the LFAGOC updated the *LupusOhio* app monthly, it might be better to have a designated person to update the app more frequently to ensure information is timely and links are functioning properly. The last limitation is the degree of illness displayed by the participants. Those that participated in the study reported their health status as good to very good. This could bias the study outcomes because people with worse health status may have been too ill to participate. Offering the study over a longer period with varying recruitment dates may have achieved more PLWL participating during times of remission.

Importance to Public Health

Lupus is a disease that is found globally with no cure, so management is the key to reduce inflammation, identify and control flares, and recognize symptoms of complications to prevent organ damage. The *LupusOhio* mobile application could provide PLWL a tool to assist them with the management of the disease through education, social support, communication with healthcare provider, and tracking of symptoms and medications. Not having to rely on memory for reporting symptoms could improve self-management and ultimately improve quality of life by receiving treatment in a timelier fashion. Information retrieved from the tracking of symptoms could provide healthcare researchers with information that could lead to improved treatments.

Future research

Future research for the *LupusOhio* mobile application should begin with a comprehensive needs' assessment from PLWL. Understanding specific needs of PLWL through epidemiologic data, qualitative information, health disparities, and how PLWL utilize health resources is needed to truly improve the *LupusOhio* app. Improving app features to meet the needs of PLWL will make the app a better tool for supporting knowledge and self-management (Brownson et al., 2011; Morgan et al., 2018).

As part of a comprehensive needs' assessment for the app, the *LFA* should support additional qualitative research. Because of the initial information deficit at diagnosis, PLWL are accustomed and dedicated to supporting each other. For example, this study showed that resources, such as a list of rheumatologists, or other credible sources, was needed by people with new diagnoses. Focus groups conducted with area LFA chapters would be an ideal way to leverage the broad capacity of group discussion to brainstorm these important resources. Another important focus should be with people who have tried, but do not use the app. This inquiry may shed light on additional barriers to use or improvements of existing functions. Of course, given the difficulty recruiting this population, the full commitment of the LFA, and/or a clinical research team would be needed to recruit and follow this population.

Finally, future research and efforts toward lupus support should consider incorporating the recommendations obtained from this study. These points are listed in a bullet point list in the appendix section of this document (See Appendix J).

Conclusion

People living with lupus that did use the *LupusOhio* mobile application reported that the app was a good tool for accessing basic lupus information and resources to assist with self-management. However, there are many areas of the app that need addressed. Findings from this study offer meaningful information for improving the *LupusOhio* mobile application. Data presented here make it clear that people newly diagnosed with lupus a) need comprehensive, credible information to be better equipped for managing this unpredictable disease and b) they do not receive this from treating clinicians. Though better self-management is thought to lead to better health outcomes, PLWL require the education and support this disease demands.

References

Abogunrin, S., & Martin, A. (2013). Can the use of social media and mobile apps improve patient knowledge of disease and health outcomes? A systematic review. *Value in Health, 16*, A326. doi: 10.1016/j.jval.2013.08.020

Acocella, I. (2012). The focus groups in social research: Advantages and disadvantages. *Quality & Quantity, 46*(4), 1125-1136. doi: 10.1007/s11135-011-9600-4

Altena, A. M., Boersma, S. N., Beijersbergen, M. D., & Wolf, J. R. (2018). Cognitive coping in relation to self-determination and quality of life in homeless young adults. *Children and Youth Services Review, 94*, 650-658. doi: 10.1016/j.childyouth.2018.09.007

Angwenyi, V., Aantjes, C., Bunders-Aelen, J., Lazarus, J. V., & Criel, B. (2019). Patient-provider perspectives on self-management support and patient empowerment in chronic care: A mixed methods study in a rural sub-Saharan setting. *Journal of Advanced Nursing, 75*, 2980-2994. doi: 10.1111/jan.14116

Archer, N., Keshavjee, K., Demers, C., & Lee, R. (2014). Online self-management interventions for chronically ill patients: Cognitive impairment and technology issues. *International Journal of Medical Informatics, 83*, 264-272. doi: http://dx.doi.org/10.1016/j.ijmedinf.2014.01.005

Bailey, S. C., Belter, L. T., Pandit, A. U., Carpenter, D. M., Carlos, E., & Wolf, M. S. (2014). The availability, functionality, and quality of mobile applications supporting medication self-management. *Journal of American Medical Informatics Association, 21*, 542-546. doi:10.1136/amiajnl-2013-002232

Baysari, M. T., & Westbrook, J. I. (2015). Mobile applications for patient-centered care coordination: A review of human factors methods applied to their design, development, and evaluation. *IMIA Yearbook of Medical Informatics, 10*, 47-54. doi: http://dx.doi.org/10.15265/IY-2015-011

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory.* Albert Englewood Cliffs, NJ: Prentice Hall.

Beckerman, N. L., Auerbach, C., & Blanco, I. (2011). Psychosocial dimensions of SLE: Implications for the health care team. *Journal of Multidisciplinary Healthcare, 4,* 63-72. doi:10.2147/JMDH.S19303

Belisario, J. S., Huckvale, K., Greenfield, G., Car, J., & Gunn, L. H. (2013). Smartphone and tablet self-management apps for asthma (review). *The Cochrane Database of Systematic Reviews, 11*. doi: 10.1002/14651858.CD010013.pub2

Bengoa, R. (2003). New WHO internet-based resource centre. *International Journal of STD & AIDS, 14*(4), 291. Doi: 10.1258/095646203321264980

Bertoli, A. M., Alarcon, G. S., Calvo-Alen, J., Fernandez, M., Vila, L. M., & Reveille, J. D. (2006). Systemic lupus erythematosus in a multiethnic US cohort. *Arthritis & Rheumatism, 54*(5), 1580-1587. doi:10.1002/art.21765

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation. *Qualitative Health Research*, *26*(13), 1802-1811. doi:10.1177/1049732316654870

Blake, H. (2008a). Innovation in practice: Mobile phone technology in patient care. *British Journal of Community Nursing, 13*(4), 160-165.

Blake, H. (2008b). Mobile phone technology in chronic disease management. *Nursing Standard, 23*(12), 43-46.

Blanch, D. C., Rudd, R. E., Wright, E., Gall, V., & Katz, J. N. (2008). Predictors of refusal during a multi-step recruitment process for a randomized controlled trial of arthritis education. *Patient Education and Counseling, 73*, 280-285. doi: 10.1016/j.pec.2008.06.017

Boulos, M. N., Brewer, A. C., Karimkhani, C., Buller, D. B., & Dellavalle, R. P. (2014). Mobile medical and health apps: State of the art, concerns, regulatory control, and certification. *Online Journal of Public Health Informatics, 5*(3), e229. doi:10.5210/ojphi. V5i3.4814

Braden, C. J. (1991). Patterns of change over time in learned response to chronic illness among participants in a systemic lupus erythematosus self-help course. *Arthritis Care and Research, 4*(4), 158-167.

Brady, T. J., Kruger, J., Helmick, C. G., Callahan, L. F., & Boutaugh, M. L. (2003). Intervention programs for arthritis and other rheumatic diseases. *Health Education & Behavior, 30*(1), 44-63. doi:10.1177/1090198102239258

Bradway, M., Arsand, E., & Grottland, A. (2015). Mobile health: Empowering patients and driving change. T*rends in Endocrinology and Metabolism, 26*(3), 114-117. doi: 10.1016/j.tem.2015.01.001

Breland, H. L., & Kamen, D. L. (2012). Lupus patient education: An examination of approaches. *International Journal of Clinical Rheumatology, 7*(5), 505-513.

Brooke, J. (1986). SUS-A quick and dirty usability scale. Retrieved from https://hell.meiert.org/core/pdf/sus.pdf

Brooke, J. (2013). SUS: A retrospective. *Journal of Usability Studies, 8*(2), 29-40.

Brown, J., Hanson, J. E., Schmotzer, B., & Webel, A. R. (2014). Spirituality and optimism: A holistic approach to component-based, self-management treatment for HIV. *Journal of Religious Health, 53*, 1317-1328. doi: 10.1007/s10943-013-9722-1

Brown, S. J., Somerset, M. E., McCabe, C. S., & McHugh, N. J. (2004). The impact of group education on participants' management of their disease in lupus and scleroderma. *Musculoskeletal Care, 2*(4), 207-217. doi:10.1002/msc.72

Brownson, R. C., Baker, E. A., Leet, T. L., Gillespie, K. N., True, W. R. (2011). *Evidence- Based Public Health* (2nd ed.). New York: Oxford Press.

Caburnay, C. A., Graff, K., Harris, J. K., McQueen, A., Smith, M., Fairchild, M., & Kreuter, M. W. (2015). Evaluating diabetes mobile applications for health literate designs and functionality, 2014. *Preventing Chronic Disease, 12*(5)*,* e61. doi: http://doi.org/10.5888/pcd12.140433

Cano-Martin, J. A., Martinez-Perez, B., de la Torre-Diaz, I., & Lopez-Coronado, M. (2014). Economic impact assessment from the use of a mobile app for the self-management of heart diseases by patients with heart failure in a Spanish region. *Journal of Medical Systems, 38*(9), 96. doi:10.1007/s10916-014-0096-z

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum, 41*(5), 545-547.

Centers for Disease Control and Prevention. (2015). *Arthritis: National statistics.* Retrieved from http://www.cdc.gov/chronicdisease/stats/index.htm

Centers for Disease Control and Prevention. (2015). *Arthritis: Systemic lupus erythematosus (SLE).* Retrieved from http://www.cdc.gov/arthritis/basics/lupus.htm

Centers for Disease Control and Prevention. (2015). *Chronic diseases: The leading causes of death and disability in the United States.* Retrieved from http://www.cdc.gov/chronicdisease/overview/index.htm

Centers for Disease Control and Prevention. (2016). *Lupus basic fact sheet.* Retrieved from http://www.cdc.gov/lupus/basics/index.html

Chen, L., Chuang, L., Chang, C., Wang, C., Wang, I., Chung, Y., … Lai, F. (2013). Evaluating self-management behaviors of diabetic patients in a telehealth care program: Longitudinal study over 18 months. *Journal of Medical Internet Research, 15*(12), e266. doi:10.2196/jmir.2699

Chomutare, T., Tatara, N., Arsand, E., & Hartvigsen, G. (2013). Designing a diabetes mobile application with social network support. *Studies in Health Technology & Informatics, 188,* 58-64. doi:10.3233/978-1-61499-266-0-58

Cleanthous, S., Newman, S. P., Shipley, M., Isenberg, D. A., & Cano, S. J. (2013). What constitutes uncertainty in systemic lupus erythematosus and rheumatoid arthritis? *Psychology & Health, 28*(2), 171-188. doi: http://dx.doi.org/10.1080/08870446.2012.701628

Clement, I., Lorenz, A., Ulm, B., Plidschun, A., & Huber, S. (2018). Implementing systematically collected user feedback to increase user retention in a mobile app for self-management of low back pain: Retrospective cohort study. *Journal of Medical Internet Research Mhealth Uhealth, 6*(6), e10422. doi: 10.2196/10422

Coberly, E., Boren, S., Davis, J. W., McConnell, A. L., Chitima-Matsiga, R., Ge, B., …Hodge, R. H. (2010). Linking clinic patients to internet-based, condition-specific information prescriptions. *Journal of Medical Library Association, 98*(2), 160-164. doi:10.3163/1536-5050.98.2.009

Coleman, M. T., & Newton, K. S. (2005). Supporting self-management in patients with chronic illness. *American Family Physician, 72*(8), 1503-1510.

Creswell, J. W., & Clark, V. L. (2011). *Designing and conducting mixed methods research*. Los Angeles: Sage.

Crocco, A. G., Villasis-Keever, M., & Jadad, A. R. (2002). Analysis of cases of harm associated with use of health information on the internet. *JAMA, 287*(21), 2869.

Cruz, J., Brooks, D., & Marques, A. (2014). Home telemonitoring in COPD: A systematic review of methodologies and patient adherence. *International Journal of Medical Informatics, 83*, 249-263. doi: http://dx.doi.org/10.1016/j.ijmedinf.2014.01.008

De Jongh, T., Gurol-Urganci, I., Vodopivec-Jamsek, V., Car, J., & Atun, R. (2012). Mobile phone messaging for facilitating self-management of long-term illnesses. *Cochrane Database of Systematic Reviews, 12,* 1-50. doi: 10.1002/14651858.CD007459.pub2

Delis, P. C. (2019). Uncertainty and quality of life in systemic lupus erythematosus: A cross-sectional study. *Rehabilitation Nursing, 44*(1), 2-10. doi: 10.1097/rnj.0000000000000118

Delisle, V. C., Gumuchian, S. T., Kloda, L. A., Boruff, J., El-Baalbaki, G., Korner, A., … Scleroderma Support Group Advisory Team. (2018). Effect of support group peer facilitator training programmes on peer facilitator and support group member outcomes: A systematic review. *BMJ Open, 5,* e013325. doi:10.1136/bmjopen-2016- 013325

Donker, T., Petrie, K., Proudfoot, J., Clarke, J., Birch, M. R., & Christensen, H. (2013). Smartphones for smarter delivery of mental health programs: A systematic review. J*ournal of Medical Internet Research, 15*(11), 29. doi:10.2196/jmir.2791

Drenkard, C., Bao, G., Dennis, G., Kan, H. J., Jhingran, P. M., Molta, C. T., & Lim, S. S. (2014). Burden of systemic lupus erythematosus on employment and work productivity: Data from a large cohort in the southeastern United States. *Arthritis Care & Research, 66*(6), 878-887. doi:10.1002/acr.22245

Drenkard, C., Dunlop-Thomas, C., Easley, K. Bao, G., Brady, T., & Lim, S. S. (2012). Benefits of a self-management program in low-income African American women with systemic lupus erythematosus: Results of a pilot study. *Lupus, 21,* 1586-1593.

Driscoll, D. L., Appiah-Yeboa, A., Salib, P., & Rupert, D. J. (2007). Merging qualitative and quantitative data in mixed methods research: How to and why not. *Ecological and Environmental Anthropology*, *3*(1), 19-28. Retrieved from: http://digitalcommons.unl.edu/cgi/viewcontent.cgi?article=1012&context=icwdmeea

El-Shafey, A. M., Abd-El-Geleel, S. M., & Soliman, E. S. (2012). Cognitive impairment in non-neuropsychiatric systemic lupus erythematosus. *The Egyptian Rheumatologist, 34*, 67-73. doi: 10.1016/j.ejr.2012.02.002

Epping-Jordan, J. (2001). The challenge of chronic conditions: WHO responds. *British Medical Journal, 323,* 947-948.

Epping-Jordan, J. E., Pruitt, S. D., Bengoa, R., & Wagner, E. H. (2004). Improving the quality of health care for chronic conditions. *Quality Safe Health Care, 13,* 299-305. doi:10.1136/qshc.2004.0107

Essays, U. K. (2018). Pros and cons of mixed methods research. Retrieved from https://www.ukessays.com/essays/psychology/a-study-on-using-mixed-methods-in-research-psychology-essay.php?vref=1

Evans, B. C., Coon, D. W., & Ume, E. (2011). Use of the theoretical frameworks as a pragmatic guide for mixed methods studies: A methodological necessity. *Journal of Mixed Methods Research, 5*(4), 276-292. doi: 10.1177/1558689811412972

Ferland, D., & Fortin, P. R. (1999). Recruitment strategies in superiority trials in SLE: Lessons from the study of methotrexate in lupus erythematosus (SMILE). *Lupus, 8,* 606-611.

Frei, A., Svarin, A., Steurer-Stey, C., Puhan, M. A. (2009). Self-efficacy instruments for patients with chronic diseases suffer from methodological limitations – a systematic review. *Health and Quality of Life Outcomes, 7,* 1-10. Doi: 10.1186/1477-7525-7-86

Gallagher, J., O’Donoghue, J., & Car, J. (2015). Managing immune diseases in the smartphone era: How have apps impacted disease management and their future? *Expert Review Clinical Immunology, 11*(4), 431-433. doi:10.1586/1744666X.2015.1010518

Garris, C., Oglesby, A., Sulcs, E., & Lee, M. (2013). Impact of systemic lupus erythematosus on burden of illness and work productivity in the United States. *Lupus, 22*, 1077-1086. doi:10.1177/0961203313498795

Gill, M. (2015). The chronic abyss and electronic bridge. *International Journal of Care Coordination, 18*(1), 27-30. doi:10.1177/1742395315573822

Ghannadi, S., Amouzegar, A., Amiri, P., Karbalaeifar, R., Tahmasebinejad, Z., & Kazempour-Ardebili, S. (2016). Evaluating the effect of knowledge, attitude, and practice on self-management in type 2 diabetic patients on dialysis. *Journal of Diabetes Research, 2016*, 1-7. doi: 10.1155/2016/3730875

Glanz, K., Rimer, B. K., & Viswanath, K. (Eds.). (2008). *Health behavior and health education: Theory, research, and practice* (4th ed.). San Francisco, CA: Jossey-Bass.

Glynn, L. G., Hayes, P. S., Casey, M., Glynn, F., Alvarez-Iglesias, A., Newell, J. … Murphy, A. W. (2013). SMART MOVE – a smartphone-based intervention to promote physical activity in primary care: Study protocol for a randomized controlled trial. *Trials, 14*, 157. doi:10.1186/1745-6215-14-157

Grindrod, K. A., Li, M., & Gates, A. (2014). Evaluating user perceptions of mobile medication management applications with older adults: A usability study. *Journal of Medical Internet Research, 2*(1), e11. doi:10.2196/mhealth.3048

Guetterman, T. C. (2015). Descriptions of sampling practices within five approaches to qualitative research in education and the health sciences. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 16*(2), Art. 25. doi: http://nbn-resolving.de/urn:nbn:de:0114-fqs1502256.

Harrison, R., Flood, D., & Duce, D. (2013). Usability of mobile applications: Literature review and rationale for a new usability model. *Journal of Interaction Science, 1*(1). doi:10.1186/2194-0827-1-1

Hayward, K. L., Horsfall, L. U., Ruffin, B. J., Cottrell, W. N., Chachay, V. S., Irvine, K. M., … Valery, P. C. (2017). Optimising care of patients with chronic disease: Patient-oriented education may improve knowledge and self-management. Internal Medicine Journal, 47, 952-955. doi: 10.1111/imj.13505

Herschman, J., Kasenberg, T., Levy, D., Ruth, N., Taberner, C., Kaufman, M., & Regina, A. (2014). Development of a smartphone app for adolescents with lupus: A collaborative meeting-based methodology inclusive of a wide range of stakeholders. *Rev PANAM sALUDpUBLICA, 35*(5/6), 471-476.

Hirsh, J. M., & Gardner, E. M. (2009). A pilot study to determine whether patients are likely to understand the educational information available on-line about arthritic disorders. *Journal of Clinical Rheumatology, 15*(7), 367-368. doi:10.1097/RHU.0b013e3181be2439

Hughes, A. S. (2016). *Mixed methods research.* Retrieved from https://www.psychologicalscience.org/observer/mixed-methods-research

Jacobsen, K. H. (2012). Qualitative studies. In K. H. Jacobsen, *Introduction to health research methods: A practical guide*. Sudbury, MA: Jones and Bartlett Learning.

Jin, B., Kim, J., & Baumgartner, L. M. (2019). Informal learning of older adults in using mobile devices: A review of the literature. *Adult Education Quarterly, 69*(2), 120-141. doi: 10.1177/0741713619834726

Justiz-Vaillant, A., Akpaka, P. E., & Poonking, P. (2015). Systemic lupus erythematosus: Some epidemiological and clinical aspects. *American Journal of Public Health Research, 3*(2), 46-50. doi:10.12691/ajphr-3-2-2

Karasouli, E., & Adams, A. (2013). Assessing the evidence for e-resources for mental health self-management: A systematic literature review. *Journal of Medical Internet Research, 1*(1), e3. doi:10.2196/mental.3708

Kueh, Y. C., Morris, T., Ismail, A. A. (2017). The effect of diabetes knowledge and attitudes on self-management and quality of life among people with type 2 diabetes. *Psychological Health Medicine, 22*(2), 138-144. doi: 10.1080/13548506.2016.1147055

Lau, A. Y. S., Siek, K. A., Fernandez-Luque, L., Tange, H., Chanabhai, P., Li, S. Y. W., … Eysenbach, G. (2011). The role of social media for patients and consumers. *Yearbook Medical Informatics, 6*(1), 131-138.

Leeman-Castillo S., Beaty, B., Raghunath, S., Steiner, J., & Bull, S. (2010). LUCHAR: Using computer technology to battle, heart disease among Latinos. *American Journal of Public Health, 100*(2), 272-275. doi:10.2105/AJPH.2009.162115

Lin, P., Intille, S., Bennett, G., Bosworth, H. B., Corsino, L., Voils, C., … Svetkey, L. P. (2015). Adaptive intervention design in mobile health: Intervention design and development in the Cell Phone Intervention for You Trial. *Clinical Trial,12*(6), 634-645. doi: 10.1177/1740774515597222

Long, E., Ponder, M., & Bernard, S. (2017). Knowledge, attitudes, and beliefs related to hypertension and hyperlipidemia self-management among African American men living in the southeastern United States. *Patient Education Counseling, 100*(5), 1000-1006. doi: 10.1016/j.pec.2016.12.011

Lorig, K. R., & Holman, H. R. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B.W., Ritter, P. L., González, V. M., … Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care*, *37*(1), 5-14.

Lorig, K. R., Ritter, P. L., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A…. Holman, H. R. (2001a). Chronic disease self-management program: 2-Year health status and health care utilization outcomes. *Medical Care*, *39*(11), 1217-1223.

Lorig, K.R., Sobel, D.S., Ritter, P.L., Laurent, D., & Hobbs, M. (2001b). Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice*, *4*(6), 256-262.

Loucas, C. E., Fairburn, C. G., Whittington, C., Pennant, M. E., Stockton, S., & Kendall, T. (2014). E-therapy in the treatment and prevention of eating disorders: A systematic review and meta-analysis. *Journal of Behavioral Research and Therapy, 63*, 122e131. doi: http://dx.doi.org/10.1016/j.brat.2014.09.011

Lupus Foundation of America (LFA). (2015). *What is lupus?* Retrieved from http://www.lupus.org/answers/entry/what-is-lupus

Lupus Foundation of America (LFA). (2020a). *Common diseases that overlap with lupus.* Retrieved from https://www.lupus.org/resources/common-diseases-that-overlap-with-lupus

Lupus Foundation of America (LFA). (2020b). *Statistics on lupus: Cases of lupus.* Retrieved from http://www.lupus.org/about/statistics-on-lupus

Macejova, Z., Zarikova, M., & Oetterova, M. (2013). Systemic lupus erythematosus – Disease impact on patients. *Central European Journal of Public Health, 21*(3), 171-173.

Mack, N., Woodsong, C., MacQueen, K. M., Guest, G., & Namey, E. (2011). *Qualitative research methods: A data collector's field guide.* Research Triangle Park, NC: Family Health International.

Mackay, M. (2015). Lupus brain fog: A biologic perspective on cognitive impairment, depression, and fatigue in systemic lupus erythematosus. *Immunological Research, 63*, 26-37. doi: 10.1007/sl2026-015-8715-3

Mahmood, K. (n.d.). Overview of mixed methods. Retrieved from https://cirt.gcu.edu/research/developmentresources/research_ready/mixed_methods/overview

Mattila, E., Korhonen, I., Salminen, J. H., Ahtinen, A., Koskinen, E., Sarela, A. … Lappalainen, R. (2009). Empowering citizens for well-being and chronic disease management with well diary. *IEEE Transactions on Information Technology in Biomedicine, 14*(2), 456-463. doi:10.1109/TITB.2009.2037751

Mattila, E., Orsama, A. L., Ahtinen, A., Hopsu, L., Leino, T., & Korhonen, I. (2013). Personal health technologies in employee health promotion: Usage, activity, usefulness, and health-related outcomes in a 1-year randomized controlled trial. *JMIR Mhealth and Uhealth, 1*(2), e16. doi: 10.2196/mhealth.2557

McAlister, A. L., Perry, C. L., & Parcel, G. S. (2008). How individuals, environments, and health interact: Social cognitive theory. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.) *Health behavior and health education: Theory, research, and practice* (pp. 169-188). San Francisco CA: Jossey-Bass.

McDaniel, A. M., & Stratton, R. M. (2006). Internet-based smoking cessation initiatives: Availability, variates, and likely effects on outcomes. *Disease Management & Health Outcomes, 14*(5), 275-285.

Meacock, R., Dale, N., & Harrison, M. J. (2013). The humanistic and economic burden of systemic lupus erythematosus: A systematic review. *Pharmacoeconomics, 31*(1), 49-61. doi:10.1007/s40273-012-0007-4

Mendelson, C. (2006). Managing a medically and socially complex life: Women living with lupus. *Qualitative Health Research, 16*(7), 982-997. doi:10.1177/1049732306290132

Miller, D. M., Moore, S. M., Fox, R. J., Atreia, A., Fu, A. Z., Lee, J. C., … Rudick, R. A. (2011). Web-based self-management for patients with multiple sclerosis: A practical, randomized trial. *Telemedicine Journal and E-Health, 17*(1), 5-13. doi:10.1089/tmj.2010.0133

Morse, J. (1999). Qualitative generalizability. *Qualitative Health Research, 9*(1), 5-6.

Morgan, C., Bland, A. R., Maker, C., Dunnage, J., & Bruce, I. N. (2018). Individuals living with lupus: Findings from the LUPUS UK Members Survey 2014. *Lupus, 27*, 681-687. doi: 10.1177/0961203317749746

Mosa, A. S. M., Yoo, I., & Sheets, L. (2012). A systematic review of healthcare applications for smartphones. *BMC Medical Informatics and Decision Making, 12*(67), 1-31. doi: 10.1186/1472-6947-12-67

National Center for Chronic Disease Prevention and Health Promotion (U.S.). Office of the Director. (2015). *The four domains of chronic disease prevention working toward healthy people in healthy communities.* Retrieved from http://www.cdc.gov/chronicdisease/pdf/four-domains-factsheet-2015.pdf

Nundy, S., Razi, R. R., Dick, J. J., Smith, B., Mayo, A., O'Connor, A., & Meltzer, D. O. (2013). A test messaging intervention to improve heart failure self-management after hospital discharge in a largely African American population: Before-after study. *Journal of Medical Internet Research, 15*(3), e53. doi:10.2196/jmir.2317

Oglesby, A. K., Durden, E., Narayanan, S., Juneau, P., & Wilson, K. (2013). Economic burden of systemic lupus erythematosus (SLE) in a commercially insured population in the United States. *Value in Health, 16*(3), A1-A298. doi: 10.1016/j.jval.2013.03.607

Ohio Development Services Agency. (2015). *Ohio African Americans*. Retrieved from https://development.ohio.gov/files/research/P7003.pdf

Or, C. K. L., & Tao, D. (2014). Does the use of consumer health information technology improve outcomes in the patient self-management of diabetes? A meta-analysis and narrative review of randomized controlled trials. *International Journal of Medical Informatics, 83,* 320-329. doi: 10.1016/j.ijmedinf.2014.01.009

O'Riordan, R., Doran, M., & Connolly, D. (2017). Fatigue and activity management education for individuals with systemic lupus erythematosus. *Occupational Therapy International, 2017*, 1-11. doi: 10.1155/2017/4530104

Parmanto, B., Pramana, G., Yu, D. X., Fairman, A. D., Dicianno, B. E., & McCue, M. P. (2013). iMHere: A novel mHealth system for supporting self-care in management of complex and chronic diseases. *Journal of Medical Internet Research mHealth and uHealth, 1*(2), e10. doi:10.2196/mhealth.2391E

Payne, H. E., Lister, C., West, J. H., & Bernhardt, J. M. (2015). Behavioral functionality of mobile apps in health interventions: A systematic review of the literature. *JMIR mHealth and uHealth, 3*(1), e20. doi: 10.2196/mhealth.3335

Peek, S., Wouters, E., van Hoof, J., Luijkx, K. G., Boeije, H. R., & Vrijhoef, H. (2014). Factors influencing acceptance of technology for aging in place: A systematic review. *International Journal of Medical Informatics, 83*, 235-248. doi: 10.1016/j.ijmedinf.2014.01.004

Peeples, M. M., Iyer, A. K., & Cohen, J. L. (2013). Integration of a mobile-integrated therapy with electronic health records: Lessons learned. *Journal of Diabetes Science and Technology, 7*(3), 602-610. doi: https://doi.org/10.1177/193229681300700304

Porta, M., Gasull, M., Puigdomenech, E., Rodriguez-Sanz, M., Pumarega, J., Rebato, C., & Borrell, C. (2009). Sociodemographic factors influencing participation in the Barcelona Health Survey study on serum concentrations of persistent organic pollutants. *Journal of Chemosphere, 76*, 216-225. doi: 10.1016/j.chemosphere.2009.03.030

Puchalski, C. M. (2001). The role of spirituality in health care. *Baylor University Medical Center Proceedings, 14*(4), 3523-357. doi: 10.1080/08998280.2001.11927788

Pulman, A., Taylor, J., Galvin, K., & Masding, M. (2013). Ideas and enhancements related to mobile applications to support type 1 diabetes. *JMIR Mhealth Uhealth, 1*(2), e12. doi:10.2196/mhealth.2567

Ristau, R. A., Yang, J., & White, J. R. (2013). Evaluation and evolution of diabetes mobile applications: Key factors for health care professionals seeking to guide patients. *Diabetes Spectrum, 26*(4), 211-215. doi:10.2337/diaspect.26.4.211

Rovensky, J., & Tuchynova, A. (2008). Systemic lupus erythematosus in the elderly. *Autoimmunity Reviews, 7,* 235-239. doi: 10.1016/j.autrev.2007.11.014

Rui, J. R., & Stefanone, M. A. (2016). The desire for fame: An extension of uses and gratifications theory. *Communications Studies, 00*(00), 1-20. doi: 10.1080/10510974.2016.1156006

Sahebalzamani, M., Farahani, H., Jamarani, M. T., Faezi, S. T., Moradi, K., & Paragomi, P. (2016). Effects of a continuous care model on patients' knowledge and health-related quality of life in systemic lupus erythematosus. *Rehabilitation Nursing, 0*, 1-11. doi: 10.1002/rnj.283

Sama, P. R., Eapen, Z. J., Weinfurt, K. P., Shah, B. R., & Schulman, K. A. (2014). An evaluation of mobile health application tools. *JMIR mHealth and uHealth, 2*(2), e19. doi:10.2196/mhealth.3088

Sauro, J. (2011). Measuring usability with the System Usability Scale (SUS). Retrieved from http://www.measuringu.com/sus.php

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle3, R., … Whitmore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship, 44*(2), 136-144. doi:10.1111/j.1547-5069.2012.01444. x.

Segerstahl, K., & Oinas-Kukkonen, H. (2011). Designing personal exercise monitoring employing multiple modes of delivery: Implications from a qualitative study on heart rate monitoring. *International Journal of Medical Informatics, 80*, e203-e213. doi: 10.1016/j.ijmedinf.2011.08.011

Shiel, W. C., Diamond, B., Isherwood, D., & Witter, J. (2011). Systemic lupus erythematosus quiz: Test your SLE IQ. Retrieved from: http://www.medicinenet.com/systemic_lupus_erythematosus_quiz/quiz.htm

Sohng, K. Y. (2003). Effects of self-management course for patients with systemic lupus erythematosus. *Journal of Advanced Nursing, 42*(5), 479-486. doi:10.1046/j.1365-2648.2003.02647.x

Soule, M. C., Beale, E. E., Suarez, L., Beach, S. R., Mastromauro, C. A., Celano, C. M., … Huffman, J. C. (2017). Understanding motivations to participate in an observational research study: Why do patients enroll? *Social Work Health Care, 55*(3), 231-246. doi: 10.1080/00981389.2015.1114064

Stanford Patient Education Research Center. (2007). Chronic disease self-management program questionnaire code book. Retrieved from http://patienteducation.stanford.edu/research/cdCodeBook.pdf

Sutano, B., Singh-Grewal, D., McNeil, H. P., O'Neill, S., Craig, J. C., Jones, J., & Tong, A. (2013). Experiences and perspectives of adults living with systemic lupus erythematosus: Thematic synthesis if qualitative studies. *Arthritis Care & Research, 65*(11), 1752-1765. doi:10.1002/acr.22032

Timmers, T., Janssen, L., Kool, R. B., & Kremer, J. A. (2020). Educating patients by providing timely information using smartphone and tablet apps: Systematic review. *Journal of Medical Internet Research, 22*(4), e17342. doi: 10.2196/17342

Torbjornsen, A., Jenum, A. K., Smastuen, M. C., Arsand, E., Holmen, H., Wahl, A. K., & Ribu, L. (2014). A low-intensity mobile health intervention with and without health counseling for persons with type 2 diabetes, part 1: Baseline and short-term results from a randomized controlled trial in Norwegian part of RENEWING HEALTH. *Journal of Medical Internet Research, 2*(4), e52. doi:10.2196/mhealth.3535

Trivedi, D. (2015). Cochrane review summary: Smartphone and tablet self-management apps for asthma. *Cochrane Nursing Care Field, 16*, 111-113. doi:10.1017/S1463423615000018

Trudel, M., Cafazzo, J. A., Hamill, M., Igharas, W., Tavelli, K., Picton, P., … Logan, A. (2007). A mobile phone based remote patient monitoring system for chronic disease management. *MEDINFO,* 167-171.

Tsalatsanis, A., Gil-Herrera, E., Yalcin, A., Djulbegovic, B., & Barnes, L. (2011). Designing patient-centric applications for chronic disease management. *Engineering in Medicine and Biology Society,* 3146-3149. doi:10.1109/IEMBS.2011.6090858

Turner-McGrievy, G., & Tate, D. (2011). Tweets, apps, and pods: Results of the 6-month mobile pounds off digitally (mobile POD) randomized weight loss intervention among adults. *Journal of Medical Internet Research, 13*(4), 39. doi:10.2196/jmir.1841

United States Census Bureau. (2013). 2010 Demographic profile: Ohio. Retrieved from http://www.census.gov/popfinder/

Waldron, N., Brown, S., Hewlett, S., Elliott, B., McHugh, N., & McCabe, C. (2011). "It's more scary not to know": A qualitative study exploring the information needs of patients with systemic lupus erythematosus at the time of diagnosis. *Musculoskeletal Care, 9*(4), 228-238. doi: 10.1002/msc.221

Wang, J., Wang, Y., Wei, C., Yao, N., Yuan, A., Shan, Y, & Yuan, C. (2014). Smartphone interventions for long-term health management of chronic diseases. *Telemedicine & e-Health, 20*(6), 570-583. doi:10.1089/tmj.2013.0243

Watts, S., Mackenzie, A., Thomas, C., Griskatis, A., Mewton, L., Williams, A., & Andrews, G. (2013). CBT for depression: A pilot RCT comparing mobile phone vs. computer. *BMC Psychiatry, 13*, 49. doi:10.1186/1471-244X-13-49

Widmer, R. J., Collins, N. M., Collins, C. S., West, C. P., Lerman, L. O., & Lerman, A. (2014). Digital health interventions for the prevention of cardiovascular disease: A systematic review and meta-analysis. *Mayo Clinic Proceedings, 90*(4), 469-480. doi: 10.1016/j.mayoocp.2014.12.026

Williams, E. M., Bruner, L., Adkins, A., Vrana, C., Logan, A., Kamen, D., & Oates, J. C. (2016). I too, am America: A review of research on systemic lupus erythematosus in African Americans. *Lupus Science & Medicine, 3*, e000144. doi: 10.1136/lupus-2015-000144

Williams, E. Lorig, K., Glover, S., Kamen, D., Back, S., Merchant, A. … Oates, J. C. (2016). Intervention to improve quality of life for African American lupus patients (IQAN): Study protocol for a randomized controlled trial of a unique a la carte intervention approach to self-management of lupus in African Americans. *BioMed Central Health Services Research, 16,* 339. doi:10.1186/s12913-016-1580-6

Wiginton, K. L. (1999). Illness representations: Mapping the experience of lupus. *Health Education & Behavior, 26*(4), 443-453. doi:10.1177/109019819902600403

Womenshealth.gov. (2010). *Lupus.* Retrieved from https://www.womenshealth.gov/minority-health/african-americans/lupus.html

Womenshealth.gov. (2019). *Lupus and women.* Retrieved from https://www.womenshealth.gov/lupus/lupus-and-women/#8

World Health Organization. (1997). WHOQOL: Measuring quality of life. Retrieved from http://www.who.int/mental_health/media/68.pdf

Wu, M., Yu, K., & Tsai, J. (2017). The effectiveness of exercise in adults with systemic lupus erythematosus: A systematic review and meta-analysis to guide evidence-based practice. *Worldviews on Evidence-Based Nursing, 14*(4), 306-315. doi: 10.1111/wvn.12221

Yazdany, J. (2011). Health-related quality of life measurement in systemic lupus erythematosus: The LupusQol, SLEQoL, and L-QoL. *Arthritis Care Research, 63*(11), S413-S419. doi:10.1002/acr.20636

Young, S.P., Henderson, E. Cheseldine, D. L., Wilson, A. S., Skan, J., Heaton, S., … Gordon, C. (2002). Development and assessment of a world wide web site for systemic lupus erythematosus patient information. *Lupus, 11*, 478-484. doi:10.1191/0961203302lu225oa

Zaldonis, J., Alrawashdeh, M., Atman, K. S., Fatigati, A., DeCito Dabbs, A., & Bermudez, C. A. (2015). Predictors and influence of goal orientation on self-management and health-related quality of life after lung transplant. *Progress in Transplantation, 25*(3), 230-236. doi: 10.7182/pit2015189

Zhang, J., Song, Y., & Bai, C. (2013). MIOTIC study: A prospective, multicenter, randomized study to evaluate the long-term efficacy of mobile phone-based internet of things in the management of patients with stable COPD. *International Journal of COPD, 8*, 433-438. doi: 10.2147/COPD.S50205

Zhang, L., Luan, W., Geng, S., Ye, S., Wang, X., Qian, L., …Jiang, A. (2019). Lack of patient education is a risk factor of disease flare in patients with systemic lupus erythematosus in China. *BMC Health Services Research, 19:378.* doi: 10.1186/s12913-019-4206-y

Zhang, Y. (2017). Uncertainty in illness: Theory, review, application, and extension. *Oncology Nursing Forum, 44*(6), 645-649. doi. 10.1188/17.ONF.645-649

Zuniga, A., Flores, H., Lagerspetz, E., Tarkoma S., Manner, J., Hui, P., & Nurmi, P. (2019). Tortoise or hare? Quantifying the effects of performance on mobile app retention. *Proceedings of the 2019 World Wide Web Conference*. doi:10.1145/3308558.3313428

Appendix A

Participant Letter

CELEBRATE CENTENNIAL
KENT STATE
UNIVERSITY
1910·2010

Dear Members of *Lupus Foundation of America, Greater Ohio Chapter (LFAGOC)*,

It is my pleasure to support Diana L. Fleming, MSN, RN in her proposed study: *Using the LupusOhio Mobile Device Application as a Strategy to Increase Knowledge and Improve Self-Management in Lupus Patients: A Mixed Methods Study.* Mrs. Fleming's work is highly significant because knowledge of lupus is necessary for self-management of the disease and to identify and prevent complications. Mrs. Fleming's knowledge and compassion for educating people living with lupus with mobile technology will prove beneficial for improving self-management for people living with lupus.

As Vice President of Operations / Patient Navigator of the *LFAGOC*, I am pleased that Mrs. Fleming has chosen people living with lupus for this study to increase awareness and improve health outcomes.

At *Lupus Foundation of America, Greater Ohio Chapter,* we see patients and families who have had little to no education on this disease. The *LFAGOC* has adopted *LupusOhio* application as the official app of the Chapter to assist people living with lupus in managing their disease. Identifying users' perceptions of areas of the *LupusOhio* application that are well used and areas of needed improvement will facilitate in improving the application thus improving use and patient knowledge.

Again, I am pleased to support Mrs. Fleming's research with *Lupus Foundation of America, Greater Ohio Chapter* and have agreed to distribute an email invitation to current members of *LFAGOC* for study participation. You can look for a link to participate in the study in an upcoming email from the *LFAGOC*. I hope that we will be able to apply the knowledge we gain from this study to improve education for people living with lupus to increase knowledge and improve self-management of the disease. Please know that no other contact information will be released. Your participation is completely voluntary.

Sincerely,

Leslie Tierney

Vice President of Operations/Patient Navigator

Appendix B

Invitation Letter

Invitation to People Living with Lupus for the *LupusOhio* Application Study

330-206-4710

Using the *LupusOhio* Mobile Device Application as a Strategy to Improve Knowledge and Self-Management in Lupus Patients: A Mixed Methods Study

Diana L. Fleming, MSN, RN
Kent State University
College of Public Health
P.O. Box 5190
Kent, OH 44242

Dear Participants, May 11, 2018

Using the *LupusOhio* Mobile Device Application as a Strategy to Improve Knowledge and Self-Management in Lupus Patients: A Mixed Methods Study

I am a doctoral student at Kent State University College of Public Health in Kent, Ohio. I am interested in educating people living with lupus to self-manage their condition and be able to recognize signs and symptoms of flares using the *LupusOhio* application for mobile devices. I am inviting you to take part in a research study called: Using the *LupusOhio* Mobile Device Application as a Strategy to Improve Knowledge and Self-Management in Lupus Patients: A Mixed Methods Study.

The study has two areas for participation. If you have used the *LupusOhio* application previously or are using the application currently, I would like to interview you to get your perceptions of the *LupusOhio* application as a valuable tool to assist people living with lupus in managing their disease. If you have not used the *LupusOhio* application, I would like to introduce the *LupusOhio* application to you and have you use the application for one month to see if you gained knowledge about the disease and tools for self-management. I hope to use this information from this research to find ways to improve the lives of people living with lupus and improve the application to better meet the needs of people living with lupus.

You are very important to the lupus community. I am inviting all people from the Lupus Foundation of America, Greater Ohio Chapter to take part in this study. All potential participants are asked to complete a brief questionnaire. Upon completion, if you have used or are currently using the *LupusOhio* application, you will be asked to participate in an interview lasting approximately 45 minutes by contacting me. If you have not used the application, you will be asked to use the *LupusOhio* application for 30 days and then complete another brief questionnaire.

All information obtained is confidential and will not be shared with any other parties. Participation is strictly voluntary, and participants may withdraw at any time.

You will receive an email from the Lupus Foundation of America, Greater Ohio Chapter with a link to the study questionnaire.

Thank you for your consideration.

Sincerely,

Diana L. Fleming, MSN, RN

Kent State University

College of Public Health

Doctoral Student

Appendix C

Email Script for Participation

KENT STATE
UNIVERSITY

Using the *LupusOhio* Mobile Device Application as a Strategy to Improve Knowledge and Self-Management in Lupus Patients: A Mixed Methods Study

You are being invited to participate in the *LupusOhio* Mobile Application research study. This is an online survey.

By completing the survey, you will be eligible to be entered a drawing for a chance to win a $50 gift card to Target.

If you are under 18, do not respond to the survey.

You have been selected to complete the survey regarding your knowledge of lupus and self-management of your lupus symptoms and complications. It is hoped that you will take a moment (~ 20 minutes) to answer all the questions as doing so provides us with a better understanding of your needs as a lupus patient.

Follow this link to complete the survey:

Complete the LupusOhio App Survey

OR

(survey URL: https://kent.qualtrics.com/jfe/form/SV_6S7a7o123CXYfDn)

There is no penalty for not participating in this study and you can stop at any time.

Upon completion of the survey you will have the opportunity to enter a drawing for a $50 gift card to Target. If you choose to enter the drawing, you will be taken to a separate website and asked to provide your contact information for the prize drawing--your contact information WILL NOT BE LINKED TO YOUR SURVEY RESPONSES. The drawing is a separate website from the survey and only participants who complete the survey will be eligible for the prize drawing.

Questions regarding this survey can be directed to Dr. Mary Step at mstep@kent.edu or Diana Fleming at dflemin4@kent.edu. Questions about the rules for research should be directed to the Kent State University IRB at 330/6722704.

Appendix D

Consent Form

Study Title: Using the *LupusOhio* Mobile Device Application as a Strategy to Improve Knowledge and Self-Management in Lupus Patients: A Mixed Methods Study

Principal Investigators: Mary Step, PhD (PI); Eric Jefferis, PhD (PI); Diana L. Fleming, Co-Investigator

Welcome to "The *LupusOhio* Mobile Application Study". This is an online survey to learn more about people's perceptions of the *LupusOhio* mobile application. We wish to see if *LupusOhio* is an effective strategy for educating lupus patients about disease symptoms and self-management.

Before taking part in this study, please read the consent form below. If you understand the statements, and freely consent to participate in the study, click on the "I Agree" button at the bottom of the page.

Consent Form

Purpose

The purpose of this study is twofold. First, we want to understand existing users' perceptions of the *LupusOhio* mobile application in terms of usability and value. Secondly, we want to assess new users' lupus knowledge and lupus self-management before and after using the *LupusOhio* mobile application.

Procedures

This study has two potential areas for participation – 1) those who have used the *LupusOhio* mobile application, or 2) those who have not used the *LupusOhio* mobile application. The study lasts approximately two months (two periods of one month each).

An email letter will be sent by the Patient Navigator of Lupus Foundation of America Greater Ohio Chapter (LFAGOC) via the LFAGOC website to all members of the LFAGOC with a link to complete the online survey consisting of two short surveys to measure knowledge and self-management. Upon completion of the surveys, those participants that have used the *LupusOhio* mobile application will then be asked to participate in a face-to-face interview to gain an understanding of your perceptions of the *LupusOhio* application usability and value.

Study participants that have not used the *LupusOhio* application will be randomly assigned to one of two groups: 1) an intervention group – this group will receive directions on how to download the *LupusOhio* application to a mobile device of their choosing and be asked to use the application for 30 days and log their activity, or 2) a control group – this group will not receive the link for the application for the first 30 days. At the end of the 30-day period, the groups will switch. The intervention group will now become the control group and the control group will become the intervention group which will receive the link for downloading the *LupusOhio* application and be asked to log application activity. Study participants will be asked to complete two short surveys online at the end of each 30-day period regarding lupus knowledge and self-management.

When the participant receives the link for the download of the *LupusOhio* mobile application, the participant will also receive instructions on how to use the application and how to log the activity. Control group study participants will be asked to go about their normal activities. The researcher's contact information will be provided for those with questions. Participation is voluntary.

Audio and Video Recording and Photography

The interviews will be recorded using audio. Upon completion of the study, the recordings will be erased. The recordings will be used to assure that the information being documented is accurate.

Benefits

Participants in this study will benefit from the use of this free application to enhance their understanding of lupus and how to better manage their disease using educational tools, self-management tools, and support information designed specifically for lupus patients.

Risks and Discomforts

There is no anticipated physical, psychological, social, or economic risks associated with this research study. The only potential risk is the patient's information that the participants input into the application, if they do not use password protection as recommended. To potentially prevent this, I will be asking participants to choose a username and password to protect their information.

Privacy and Confidentiality

All responses are treated as confidential. Participants will be assigned a number and all names will be removed from the data. All data will be pooled and published in aggregate form only. Participants should be aware, however, that the experiment is not being run from a "secure" https server of the kind typically used to handle credit card transactions, so there is a small possibility that responses could be viewed by unauthorized third parties (e.g., computer hackers).

Compensation

Use of the *Lupus Ohio* application is free of charge to all lupus patients. All participants will be placed in a lottery for a drawing for a $50 gift card.

Voluntary Participation

Taking part in this research study is entirely up to you. You may choose not to participate, or you may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. You will be informed of any new, relevant information that may affect your health, welfare, or willingness to continue your study participation.

Contact Information

If participants have further questions about this study or their rights, or if they wish to lodge a complaint or concern, they may contact the principal investigator, Professor Mary Step at 330-672-2630 or mstep@kent.edu or Diana L. Fleming at dflemin4@kent.edu. Questions about your rights as a research participant or complaints about the research project may be directed to the Kent State University Institutional Review Board, at (330) 672-2704.

Appendix E

AUDIOTAPE/VIDEO CONSENT FORM

KENT STATE
UNIVERSITY

Using the *LupusOhio* Mobile Device Application as a Strategy to Increase Knowledge and Improve Self-Management in Lupus Patients: A Mixed Methods Study

Diana Fleming Dissertation

I agree to participate in an audio-taped/video taped interview about [INSERT DESCRIPTION]as part of this project and for the purposes of data analysis. I agree that [NAME] may audiotape/video tape this interview. The date, time and place of the interview will be mutually agreed upon.

____

Signature   Date

I have been told that I have the right to listen to the recording of the interview before it is used. I have decided that I:

____want to listen to the recording   ____do not want to listen to the recording

Sign now below if you do not want to listen to the recording. If you want to listen to the recording, you will be asked to sign after listening to them.

Diana Fleming: <u>may</u> / <u>may not</u> (circle one) use the audiotapes/video tapes made of me. The original tapes or copies may be used for:

X_this research project _____publication _____presentation at professional meetings

____

Signature   Date

****Note highlighted Section is for Level II/III only****

Appendix F

Stanford Education Research Center

Stanford University School of Medicine

Chronic Disease Self-Management Questionnaire

Name: ____ Today's date: _________________

Address: ____

City, state, zip: ____

Telephone: home (___) ______-____________ Date of birth: ___________________________

work (___) ______-_____________ Sex *(circle)*: Female Male

Background

1. Ethnic origin *(check only one):*

☐White not Hispanic
☐Black not Hispanic
☐Hispanic
☐Asian or Pacific Islander
☐ Filipino
☐ American Indian/Alaskan Native
☐ Other: ________________________

2. Please circle the ***highest*** year of school completed:

1 2 3 4 5 6 *(primary)*
7 8 9 10 11 12 *(high school)*
13 14 15 16 *(college/university)*
17 18 19 20 21 22 23+ *(graduate school)*

3. Are you currently *(check only one):*

☐ Married
☐ Single
☐ Separated
☐ Divorced
☐ Widowed

4. Please indicate below which chronic condition(s) you have:

☐ Diabetes ☐ Asthma ☐ Emphysema or COPD
☐ Other lung disease *Type of lung disease:* ____
☐ Heart disease *Type of heart disease:* ____
☐ Arthritis or other rheumatic disease *Specify type:* ___________________________________
☐ Cancer *Type of cancer:* ____
☐ Other chronic condition *Specify:* ____

General Health

1. In general, would you say your health is:

(Circle one)

Excellent 1
Very good..............................2
Good......................................3
Fair 4
Poor 5

Symptoms

How much time during the **past 2 weeks ...?**

1. Were you discouraged by your health problems?

None of the time	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All the time**
0	**1**	**2**	**3**	**4**	**5**

2. Were you fearful about your future health?

None of the time	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All the time**
0	**1**	**2**	**3**	**4**	**5**

3. Was your health a worry in your life?

None of the time	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All the time**
0	**1**	**2**	**3**	**4**	**5**

4. Were you frustrated by your health problems?

None of the time	**A little of the time**	**Some of the time**	**A good bit of the time**	**Most of the time**	**All the time**
0	**1**	**2**	**3**	**4**	**5**

1. We are interested in learning whether you are affected by fatigue. Please *circle the number* below that describes your **<u>fatigue</u>** in the **<u>past 2 weeks</u>**:

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No fatigue										**Severe fatigue**

2. We are interested in learning whether you are affected by shortness of breath. Please *circle the number* below that describes your **shortness of breath** in the **past 2 weeks**:

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No shortness of breath										**Severe shortness of breath**

3. We are interested in learning whether you are affected by pain. Please *circle the number* below that describes your **pain** in the **past 2 weeks**.

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No pain										**Severe pain**

Physical Activities

During the past week, even if it was not a typical week for you, how much **total** time *(for the **entire** week)* did you spend on each of the following?
*(Please circle **one** number for each question.)*

1. Stretching or strengthening exercises (range of motion, using weights, etc.) …

None	**Less than 30 min/wk**	**30-60 min/wk**	**1-3hrs/wk**	**More than 3 hrs/wk**
0	**1**	**2**	**3**	**4**

2. Walk for exercise…

None	**Less than 30 min/wk**	**30-60 min/wk**	**1-3hrs/wk**	**More than 3 hrs/wk**
0	**1**	**2**	**3**	**4**

3. Swimming or aquatic exercise …

None	**Less than 30 min/wk**	**30-60 min/wk**	**1-3hrs/wk**	**More than 3 hrs/wk**
0	**1**	**2**	**3**	**4**

4. Bicycling (including stationary exercise bikes) …

None	**Less than 30 min/wk**	**30-60 min/wk**	**1-3hrs/wk**	**More than 3 hrs/wk**
0	**1**	**2**	**3**	**4**

5. Other aerobic exercise equipment (Stairmaster, rowing, skiing machine, etc.) …

None	**Less than 30 min/wk**	**30-60 min/wk**	**1-3hrs/wk**	**More than 3 hrs/wk**
0	**1**	**2**	**3**	**4**

6. Other aerobic exercise Specify_________________________ …

None	**Less than 30 min/wk**	**30-60 min/wk**	**1-3hrs/wk**	**More than 3 hrs/wk**
0	**1**	**2**	**3**	**4**

Confidence about Doing Things

For each of the following questions, please *circle the number* that corresponds with your **confidence** that you can do the tasks regularly at the present time.

How confident are you that you can...?

1. Keep the fatigue caused by your disease from interfering with the things you want to do?

Not at all Confident	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Totally Confident**

2. Keep the physical discomfort or pain of your disease from interfering with the things you want to do?

Not at all Confident	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Totally Confident**

3. Keep the emotional distress caused by your disease from interfering with the things you want to do?

Not at all Confident	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Totally Confident**

4. Keep any other symptoms or health problems you have from interfering with the things you want to do?

Not at all Confident	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Totally Confident**

5. Do the different tasks and activities needed to manage your health condition to reduce your need to see a doctor?

Not at all Confident	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Totally Confident**

6. Do things other than just taking medication to reduce how much your illness affects your everyday life?

Not at all Confident Daily Activities	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Totally Confident**

During the **past 2 weeks**, how much... (Circle one)

1. Has your health interfered with your normal social activities with family, friends, neighbors or groups?

Not at all	**Slightly**	**Moderately**	**Quite a bit**	**Almost totally**
0	**1**	**2**	**3**	**4**

2. Has your health interfered with your hobbies or recreational activities?

Not at all	**Slightly**	**Moderately**	**Quite a bit**	**Almost totally**
0	**1**	**2**	**3**	**4**

3. Has your health interfered with your household chores?

Not at all	**Slightly**	**Moderately**	**Quite a bit**	**Almost totally**
0	**1**	**2**	**3**	**4**

4. Has your health interfered with your errands and shopping?

Not at all	**Slightly**	**Moderately**	**Quite a bit**	**Almost totally**
0	**1**	**2**	**3**	**4**

Medical Care

1. When you visit your doctor, how often do you do the following *(please circle **one** number for each question):*

a. Prepare a list of questions for your doctor…

Never	**Almost never**	**Some-times**	**Fairly often**	**Very often**	**Always**
0	**1**	**2**	**3**	**4**	**5**

b. Ask questions about the things you want to know and things you don't understand about your treatment…

Never	**Almost never**	**Some-times**	**Fairly often**	**Very often**	**Always**
0	**1**	**2**	**3**	**4**	**5**

c. Discuss any personal problems that may be related to your illness…

Never	**Almost never**	**Some-times**	**Fairly often**	**Very often**	**Always**
0	**1**	**2**	**3**	**4**	**5**

2. **In the past 6 months**, how many TIMES did you visit a physician?
*Do **not** include visits while in the hospital or the hospital emergency department ...*______ visits

3. **In the past 6 months**, how many TIMES did you go to a **hospital** emergency department?
_______ times

4. **In the past 6 months**, how many TIMES where you hospitalized for one night or longer?
________ times

a. How many total NIGHTS did you spend in the hospital **in the past 6 month**s?
__________ nights

b. Were any of these hospitalizations at a skilled nursing facility, convalescent hospital, or other minimum care facility? *(circle)* **YES** **NO**

Thank you for your help!

Appendix G

LupusOhio Interview Guide

I would like to thank you for agreeing to help me learn about the *LupusOhio* application. I am going to ask you a few questions about living with lupus. After, I would then like to ask you questions about the application. I assure you that all information will be kept confidential and will not be shared with your doctors, nurses, or family. I will be asking basically the same questions of everyone in the study, regardless of how long they have had lupus or how well they are. If you are not comfortable answering any question I may ask, please let me know and I can skip it. You can also stop the interview at any time.

First, I would like to take some time to better understand your experiences with lupus.

1. How long have you had lupus?

2. How old were you when you were diagnosed?

3. Did you receive information on lupus at the time of diagnosis?

4. What kinds of things did you do to learn about your diagnosis?

5. What kinds of things helped you in managing your lupus?

6. How do you know when your lupus is under control?

OK, I would now like to change over to discussing the application.

7. How long have you used the *LupusOhio* application?

8. What do you like about the *LupusOhio* application?

9. Is there anything you dislike about the *LupusOhio* application?

10. How often do/did you use *LupusOhio* application?

11. Can you give me an example of information that you found to be helpful?

12. In what ways did using the app influence how you were taking care of yourself or how you thought about living with lupus?

13. If you were revising the *LupusOhio* application, what would you change?

14. If you shared the *LupusOhio* application with others, what would you point out to them?

Appendix H

Log Sheet for *LupusOhio* Usage

Please describe your *LupusOhio* application activities. Use one page for each usage.

Your I.D.: ________________________ **Age:** _____ **Sex:** M or F (circle one)

1. Date of usage: ________ mo. ________ day
2. Time of usage: ________ hour AM or PM (circle one)
3. Length of usage: ________ hour ________ min
4. Which pages (tabs) did you use when you opened the app?

1	2	3	4
Call us	Directions	Share	Events
5	6	7	8
About	Rita Dennis	Walk 2017	More

5. Did you find the information that you were looking for?

1	2
Yes	No

If no, what information were you looking for? ___________________________________

6. Did you find the information helpful?

1	2	3	4	5
Not at all helpful	A little helpful	Neither helpful nor not helpful	Helpful	Very helpful

7. Did you find the information valuable?

1	2	3	4	5
Not at all valuable	A little valuable	Neither valuable nor not valuable	Valuable	Very valuable

8. Describe areas of the application that you liked.
9. Describe areas that you feel need improvement.
10. What additional items would you like to see on the app?

Appendix I

Systemic Lupus Erythematosus Quiz

1. Lupus is an infection. True False

2. Men are more affected by lupus than women are. True False

3. The rash on lupus patients is in the shape of a spider. True False

4. Some medications can cause lupus-like symptoms. True False

5. Lupus can only affect the kidneys. True False

6. Lupus can be diagnosed based on blood tests. True False

7. Commonly used drugs to suppress the autoimmunity of SLE include corticosteroids (e.g. prednisone) True False

8. Antimalarial drugs like chloroquine and hydrochloroquine are sometimes used in SLE patients. True False

9. Unlike arthritis, there is only one form of lupus. True False

10. Patients with SLE may suffer from flares of the disease. True False

Appendix J

Study Recommendations

- Numerous non-functioning links
- Changing background colors for better readability
- Outdated information especially *Events*
- Inability to revisit past *Ask the Experts* sessions
- Received error messages when attempting to open Ask the Experts recordings
- More detailed page to add medications
- My Meds and My Doctors pages merged into one page
- Information was lost and had to be re-entered when devices updated
- No engaging activities such medication tracker or symptoms tracker
- Provide a list of rheumatologists in Ohio by county
- Include a journal page to record disease activity to report to the physician
- Linking the app directly to the physician's office for requesting medication refills / reporting symptoms
- Medication reminder alarms
- More information on support groups
- Making the app more interactive between PLWL
- Including a weekly blog vetted by lupus experts
- Providing weekly podcasts with new updated information
- Informing PLWL of opportunities in which to participate in research