Published in final edited form as:

Arthritis Care Res (Hoboken). 2021 November ; 73(11): 1568–1576. doi:10.1002/acr.24399.

The Patient Perspective on Using Digital Resources to Address Unmet Needs in Systemic Lupus Erythematosus

Jennifer H. Ra, BA¹, Jerik Leung, BA², Elizabeth A. Baker, PhD, MPH², Alfred H.J. Kim, MD, PhD¹

¹Division of Rheumatology, Department of Medicine, Washington University School of Medicine, St. Louis, MO, USA

²Department of Behavioral Science and Health Education, College for Public Health and Social Justice, Saint Louis University, St. Louis, MO, USA

Abstract

Objective: The clinical variability of systemic lupus erythematosus (SLE) caused by the unpredictability of flares contributes to patients experiencing a diminished sense of social support. Digital health interventions (DHI) have potential to improve patients' social support but have yet to be studied extensively in SLE. Our objective was to assess: 1) general and SLE-specific internet usage and 2) specific suggestions for SLE-related digital resources and tools among SLE patients at the Washington University Lupus Clinic.

Methods: Fifty-six participants were recruited from the Washington University Lupus Clinic. Ten-minute structured interviews consisting of multiple choice and open-ended questions were conducted. A descriptive statistical analysis was conducted with the quantitative data, while the qualitative data was analyzed using an open coding approach.

Results: Nearly all respondents indicated having access to the internet (98.2%). Eighty percent currently use the internet for their SLE. The qualitative data indicate that SLE patients: 1) use the internet for understanding flares and changes in their symptoms and/or lab results; 2) want increased variety of SLE information online; 3) have a desire to exchange personal experiences and knowledge of SLE with others; 4) desire increased diversity in the methods of delivering digital SLE information.

Conclusion: Our findings support the continued use of DHIs for SLE patients. We believe that these findings will aid the future development of DHIs tailored to SLE patients.

Systemic lupus erythematosus (SLE) is a serious, yet often misunderstood autoimmune disease with a paroxysmal and unpredictable disease course (1–2). SLE manifests in various ways that can affect the skin, joints, and kidney, with mild to life-threatening severity (1,3,4). Survival of SLE has improved as treatments have helped better manage physical

Corresponding Authors: Alfred H.J. Kim, Division of Rheumatology, Department of Medicine, Washington University School of Medicine, 660 S. Euclid Ave., Campus Box 8045, Saint Louis, MO 63110, USA; Phone: +1 314 362 4785, akim@wustl.edu; Elizabeth A. Baker, Department of Behavioral Science and Health Education, College for Public Health and Social Justice, Saint Louis University, Salus Center, 3545 Lafayette Ave., St. Louis, MO 63103, US; Phone +1 314-977-3218, elizabeth.baker@slu.edu.

Disclosures: Dr. Kim participated in advisory boards and educational speaker events for Exagen Diagnostics, Inc. and advisory boards and education speaker events for GlaxoSmithKline. No other disclosures relevant to this article were reported.

symptoms (5). However, there are still many aspects of SLE which negatively impact patient experience and health-related quality of life (HRQoL) that are unaddressed in clinical settings (1,2,4–6).

A hallmark of SLE is the clinical variability caused by flares that occur without identifiable triggers (3). This variability contributes to patients experiencing a diminished sense of social support. Particularly, patients report feeling dismissed by healthcare practitioners who do not understand the experience of living with an unpredictable disease. Additionally, patients feel isolated from their peers and family who find it challenging to understand the variable manifestations of SLE (2,6,7). Finally, patients find it difficult to reliably attend in-person social and educational events when symptoms, like fatigue and pain, and fluctuating symptom severity, prevent them from committing to plans.

Previous work has consistently identified social support as an unmet need among SLE patients (2,4,6,8). Social support includes informational (advice and guidance), tangible (material aid), appraisal (sense of belonging or affirmation), and emotional support (expressions of comfort and caring) (9). SLE patients have described experiencing unmet needs of informational and appraisal support (2).

To address these deficiencies in social support, chronic disease interventions have incorporated information, activities, and tools to enhance patients' abilities to maintain or obtain social support (10–14). These interventions have had a positive impact in improving disease self-management behaviors and HRQoL, specifically in SLE (15). Chronic Disease Self-Management Program (CDSMP) helped improve four areas of disease self-management – relaxation, exercise, medication adherence, and diet – in SLE patients, who perceived CDSMP to be valuable in developing and improving fundamental self-management behaviors (15). However, most of these interventions have utilized in-person approaches, failing to reach those who cannot physically or reliably attend these meetings.

Digital health interventions (DHI) – interventions accessible on devices like smartphones, tablets and computers – (16–17) have substantial potential to overcome this barrier and improve healthcare delivery (7,18–20). While in-person interventions are generally deemed more favorable because they allow clearer communication between provider and patients (20–21), DHIs have been found to significantly improve both disease knowledge and behavioral outcomes for diseases such as osteoarthritis, scleroderma, and chronic pain (14,19,23–26). These programs have had the most impact by leveraging a modular format where individuals can tailor the information to their needs by picking topics of most interest, and providing emotional and appraisal support through virtual care (e.g., phone calls or online forums) with others of similar disease profiles or health professionals (7,14,19,27).

Only few studies have focused internet-based resources in SLE (7,18,28–30). Previous work has shown that internet forums have allowed patients to share their SLE experiences, connect with other patients, and obtain information that may be relevant to their situations (4,7). These online forums may provide safe places for patients to be anonymous and vulnerable without worrying about physically going somewhere for a sense of community (28).

Findings also suggest that DHIs can improve SLE knowledge assessed by pre- and post-tests taken by patients who utilized a SLE education website (18) and Computer-based Education Lesson program (31). However, many of these programs provided static written content as opposed to various media and more interactive technologies that can allow material to be tailored to individual needs of patients with different backgrounds and stages in their disease (18). As such, SLE patients have not been able to fully leverage advances in digital technology to obtain better support and improve HRQoL compared to those of other diseases. Moreover, the barriers (digital access, skill) to using DHIs is unknown (32).

This exploratory study aimed to assess: 1) general and SLE-specific internet usage and 2) specific suggestions on SLE-related digital resources and tools among SLE patients at the Washington University Lupus Clinic.

Patients and Methods

Participants and Recruitment

Patients diagnosed with SLE by Washington University Lupus Clinic physicians and further classified with SLE using American College of Rheumatology or Systemic Lupus International Collaborating Clinics criteria were recruited from July 2018 to March 2019. Because SLE affects mostly women (33), only female patients were considered for this study. No other specific characteristics were sought. A convenience sampling method was used to recruit patients during their clinical appointments (34). Once patients were roomed, recruiters introduced the study, consented, and began the interview.

Methods

Ten-minute structured interviews were conducted face-to-face by two recruiters (JHR, JL) who asked multiple-choice and open-ended questions. This was done before the visit with the clinician to ensure that subjects had sufficient time to finish the questions. Multiple-choice questions assessed internet access, types of devices used for internet access, how patients currently use the internet for their SLE, what topics they would be interested to see in the future, and demographics. Open-ended questions assessed what other SLE-related information or support participants would like to use the internet for in the future, and what would make them more likely to use it for their SLE. Approximately five minutes of the interview was allotted for open-ended questions.

Interviewers entered responses into Qualtrics, an online survey platform, as each question was answered. This ensured that all questions were answered by each participant.

Interviewers typed in open-ended responses, using as close to verbatim text as possible, which enabled patients to more completely respond than would have been the case if they had to type into Qualtrics themselves.

Participants who indicated that they do not use the internet for their SLE were directed to different questions that focused on why they do not use the internet, and what would make it more likely for them to use it.

Ethics Approval

This study was approved by the Washington University Institutional Review Board (protocol #201805213, initially approved 25 June 2018, last approved 28 May 2019).

Data Analysis

The quantitative section assessed general trends of current access to and usage of the internet for SLE needs. As the questions measured nominal and ordinal variables, a descriptive statistical approach was applied where the frequency of each answer choice was shown through percentages (34).

Open-ended responses were downloaded from Qualtrics. First, focused-coding procedures were conducted by the initial coder (JHR). To do this, participants' transcribed words were labeled with interview ID numbers to allow the coder to review the original text in context as needed. The text (data chunk) was then copied and pasted into a coding document. The coding document had a predetermined set of codes based on the interview questions, and text was copied under the appropriate code. Afterwards, open coding methods were used where subcodes were generated based on similarity of concepts being conveyed (35). Once the initial coding was complete, the coding documents were shared with the research team (JL, EAB, AHJK), who reviewed the assignment of data chunks to codes and subcodes. The whole team (JHR, JL, EAB, AHJK) discussed differences regarding the coding and developed consensus on the best way to address these differences. This approach enhanced credibility of our data because it challenged the initial coder's biases. The final codes and subcodes were then reviewed for thematic clusters. Summary paragraphs describing key points in the clusters were created with specific quotes under the paragraphs as supporting evidence.

Results

Participant Characteristics

Of the 62 qualified participants invited to participate, 56 were recruited. Approximately half were African American (51.7%, n=30), and 39.7% (n=23) Caucasian. The mean age was 40.6 years. The majority reported an education level of at least Grade 12 or GED (96.4%, n=54). About a third were married (35.7%, n=20), while another third never married (35.7%, n=20). About half (46.4%, n=26) were employed for wages, while about a third (32.1%, n=18) were unable to work. The characteristics of our sample closely represent those of the Washington University Lupus Clinic and general SLE population (36–37). Refer to Table 1 for complete demographical data.

Our data indicates that there were racial differences between those who do use and do not use the internet for their SLE. Nine of 11 participants (75.0%) who do not use the internet were African Americans. However, in looking at this another way, among the African Americans in our sample (n=30), 70.0% (n=21) use the internet, whereas 30.0% (n=9) do not. In contrast, among the Caucasian sample (n=23), 91.3% (n=21) use the internet, whereas 8.7% (n=2) do not.

Quantitative Results

Nearly all respondents (98.2%, n=55) indicated having internet access. The majority reported using either cell phone (92.7%, n=51) or personal computer (78.2%, n=43) for internet access (Table 2). About half reported that other people also provide them with SLE information from the internet (41.8%, n=23).

Twenty-percent of participants (n=11) indicated that they do not use the internet for their SLE. The most frequently cited reason was their preference to obtain SLE information from their physician (45.0%, n=9). Other reasons included not trusting online content, already having looked up everything about SLE, not having many SLE-related questions, or time.

Of the 80.0% (n=44) who indicated that they do use the internet for SLE-related searches, 20.4% (n=9) stated using it multiple times a day, 34.1% (n=15) use it at least once a week, and 22.7% (n=10) use it at least once a month. All participants of this group (n=44) stated that they were still interested in learning more about DHIs.

Participants who utilize the internet for SLE were asked what they use it for. If participants were currently not using the internet for a specific reason, they were then asked if they would be in the future. Participants were interested in most topics presented (Figure 1). A fraction of the participants would not be interested in using the internet to join chat rooms/discussion groups/online support groups (20.4%, n=9), identify financial assistance (22.7%, n=10), or find a physician or healthcare provider (25.0%, n=11).

When these same participants (n=44) were asked how much they trust SLE information online, 13.6% (n=6) indicated that they always trust, 81.8% (n=36) sometimes to usually trust, and 4.5% (n=2) never to rarely trust. In terms of satisfaction with online SLE information, 4.5% (n=2) were never to rarely satisfied, 79.5% (n=35) were sometimes to usually satisfied, and 15.9% (n=7) always satisfied.

Qualitative Results

Open-ended responses revealed multiple topics that are desired and needed to help better manage SLE through DHIs (Tables 3–5). Respondents wanted to better understand flares and changes in symptoms and/or lab results, and to do so, stated the need for increased variety of online SLE information and the desire to exchange personal experiences and knowledge of SLE with others. Additionally, they mentioned the need to diversify the methods of delivering internet-based SLE information.

Understanding flares or changes in symptoms and/or lab results—Participants indicated the difficulty of understanding flare activity, especially when experiencing new/changed symptoms or lab results. They stated that they were likely to seek online information that would help explain and better manage their flares.

Need for increased variety of SLE information online

Need for new and diverse material on SLE: The lack of change in SLE information online over time was voiced as an issue by most participants. They noted the need for websites to better reflect more recent clinical findings, including information on the cause,

diagnosis, and different aspects and types of SLE. Offering this information was seen as an important way to learn the language and concepts to enhance their communication with their physicians and peers.

Need for updated information on SLE treatments and research: Participants desired for more materials on medications, treatments, and progress on cures for SLE, particularly on medication side effects, new/alternative (“natural”) treatments (i.e. acupuncture) and medication options. Some indicated wanting to learn about treatment options that might differ from their physician’s recommendations or from their current plan, particularly regarding options that would take effect more quickly. Others mentioned wanting to use the internet to identify financial resources such as programs that assist patients in paying for medications.

Participants also voiced the need for more information regarding ongoing medical research for SLE, which include studies that focused on medications, treatments, or cures. Others mentioned biological or clinical studies. The internet was also seen as a way to find opportunities to participate in research studies.

Desire for information about healthy lifestyle behaviors for SLE patients: Respondents stated wanting more online information on nutrition – including the potential benefits or lack of benefits of herbal supplements – diet, and exercise related to their SLE, particularly information that will help them feel better and become more motivated to be healthy.

Desire to exchange personal experiences and knowledge about SLE with others

Desire to find assistance in connecting with other people and in locating support groups and chat rooms.: Many respondents would like the ability to interact with people within the SLE community, not only in a virtual sense (i.e. chat rooms or online support groups), but also in finding local support groups to engage with other patients face-to-face. Some desired a facilitator to help connect them to others online.

Desire to connect with SLE-related programs and resources: Respondents mentioned the internet as a way to help them to connect with other programs or resources. Many had a general desire for more information, while others specifically requested notifications as a way to be reminded of SLE-related events or “interesting” materials to read. Overall, participants desired having someone who can recommend or guide them to resources that would be most appropriate for them.

Desire to learn from other SLE patients: The means to connect with other patients online were seen as opportunities to exchange their disease experiences, obtain specific tangible skills in managing SLE, and learn how others emotionally cope with SLE. This was particularly important since most people do not know what it is like to live with SLE. Patients also saw the internet as a place to obtain information that they did not know existed or needed (e.g., filing for disability). These comments highlighted that the internet can help patients know that they are not alone in their experiences.

Desire to use the internet for obtaining information from SLE patients, experts, and physicians: Although experiential advice from SLE patients was generally seen as important, some respondents specified that they are less likely to trust information provided by patients who had not “been in their shoes.” Others voiced that they do not trust information online without the presence of physicians or healthcare experts, as they can “be annoyed when it’s just a bunch of people [...] arguing [...].” Therefore, many participants would be more likely to utilize DHIs if more physicians and “experts” were present on websites and/or in chat rooms to answer questions and provide reliable information.

Need for increased variety in the platforms of delivering digital SLE information—Lastly, respondents suggested the need for varied platforms that provide SLE information, beyond website articles. Some desired the development of a cell phone app that can help manage their disease (i.e. recording flares), educate them about their SLE, and connect with others.

Discussion

Our results indicate that the majority of respondents obtain SLE information online and are interested in further obtaining it digitally. Patients indicated that limitations to digital resources were not related to access (internet or devices), but rather the content and source of internet resources. Our study reveals concrete recommendations for developing new or modifying existing DHIs include 1) customizing interventions so that SLE patients can find pertinent information for their needs like understanding new symptoms or changes in lab results, 2) providing a broad range of SLE-related topics including medications or lifestyle-nutrition, 3) providing structures for patients to exchange personal experiences and knowledge about SLE with others, 4) diversifying how digital SLE information is delivered to better accommodate wider ranges of learning styles.

Other considerations include:

Developing interventions customizable to individual patients

Our study confirms what others have found in terms of the potential benefits of DHIs (38). However, our findings go beyond previous work by highlighting the need for a digital platform that is customizable to individual patients through a modular format where they can pick their informational needs and a virtual function where patients can receive emotional and appraisal support.

It takes approximately five to six years to be diagnosed with SLE from symptom onset (39). During those initial years after disease onset (40–41), SLE symptoms greatly vary and cause patients to have difficulty managing and finding information related specifically to the nature of their disease manifestation.

The diverse nature of SLE, necessitates the development of interventions where the information provided is highly dynamic, recognizing that symptoms are constantly changing, and that are adaptable to each patient’s unique situation. The “new” information our participants are hoping to see is not just recently discovered research material, but

also information that they have not seen nor needed before because they are experiencing variations in symptoms or medication side effects. The movement towards customizable interventions can be seen as organizations like the Lupus Foundation of America and their *SELF program* are also studying the benefits (42). New digital technologies, such as advanced tailoring algorithms and virtual reality, can provide opportunities to overcome the historically static nature of online SLE information so patients can access what they need as their needs change.

Developing interventions that are trustworthy and reliable to patients

Another consideration in developing DHIs is how patients trust different online resources. Studies have shown that trust in websites is highly dependent on the apparent affiliation that source has with well-known healthcare organizations (43). Our study found similar responses by participants who were more likely to trust websites with SLE providers present to validate content and answer questions. Our findings go beyond previous studies in highlighting that information is also considered trustworthy when provided by someone who has “been in their shoes.” This suggests that patients seek medical knowledge from healthcare providers, and experiential knowledge from other SLE patients. In other words, there needs to be a match between the source of the information and the information they want from that source to find the information trustworthy.

Developing interventions to improve consistency of SLE information among DHIs, patients, and healthcare providers

DHIs can also serve as a tool to improve consistency of SLE information and patient experiences among DHIs, patients, and healthcare providers. Because SLE does not present in a clearly defined and consistent manner for every patient, expectations between healthcare providers and patients differ. Therefore, it is very difficult for patients’ experiences and their physicians’ advice to mimic what they obtain online. This discordance could have hindered patients from appraisal-related support for their experiences.

For instance, our participants described that several online resources highlight the proximity of a “cure,” an expectation many rheumatologists would argue as unrealistic based on current research. However, because of the perceived or real messages online, participants felt upset that their physicians were not telling them more about it. As DHIs are more widely used, the need for patients to corroborate online information with their physicians is crucial. However, in communicating with patients, healthcare providers must recognize the potential for new treatments to preserve patient hope for better disease outcomes, while maintaining the professional duty of only recommending clinically proven treatments to ensure that there is no patient harm or misplaced expectations.

The current lack of consistencies between internet-provided and physician-provided information emphasizes the importance of developing DHIs that recognize the differences and provide tools for both physicians and patients to improve their abilities to question these discrepancies and respond to each other’s inquiries.

Study Limitations

Sample characteristics—Having used a convenience sampling method, we recognize the possibility of selection bias. With an all-female sample, we understand that this may not be generalizable to those with other gender identities, and that there may be other demographical differences (i.e. age).

Another possible bias that could arise would be the varying disease activity among patients. Those who were experiencing flares during recruitment may have been less likely to participate, compared to those who were there for routine examinations. Unfortunately, reasons for rejecting the invitation to this study were not recorded.

Data collection methodology—The interview included closed- and open-ended questions. Future research should consider more expansive qualitative interviews to obtain more in-depth responses and further our understanding of how SLE patients use digital resources.

Open-ended questions were asked at the end of interviews and may reveal biases related to collecting responses based on the interviewers' interests. Administering interviews before patients' clinical appointments could have influenced those who were in a rush to see their physician. However, we saw potential benefits of a clinical setting that include interacting with patients who are already in a mindset to focus on their SLE, rather than asking them to make even more of their time available elsewhere.

Geographic location—Our sample was primarily urban and suburban. With uneven distribution of internet access across geographic regions, SLE patients in other locations (i.e. rural) might experience barriers to DHIs.

Disease duration—Some patients who have had SLE for a long time indicated that they no longer needed additional SLE resources. Others stated that their physicians were sufficient enough in helping with their SLE. This suggests that collecting disease duration information would be important in the future to compare how this influences expectations and experiences with DHIs.

Digital Divide—The digital divide, the gap between people who do and do not have access to information and communication technology, has been associated with individual (e.g., age, income, education) (44) and geographic (e.g., urban/rural) characteristics. Physical access to devices and internet connectivity was not an issue for the majority of our participants, regardless of socioeconomic status. As the digital divide shifts to a growing gap of digital skills (ability to command technology) and usage (use of different applications/programs) (31), future studies should focus to further understand the digital divide specifically present in the SLE population.

Participants who do not use the internet for their SLE—Twenty-percent of our participants indicated that they would not use the internet for their SLE for multiple reasons as reported in the quantitative results. Future studies exploring these barriers will enhance our ability to address these limitations and concerns when developing DHIs.

Conclusion

Our findings continue to support the use of DHIs for SLE patients. The majority of our participants currently use the internet for their SLE and were excited to share suggestions for the development of SLE-specific DHIs. As many suggestions were new to the research team, we also recognized the importance of including patients in the development process (18,23,30,31). In future studies, investigating how patients utilize and understand information provided will be significant in ensuring that patients effectively leverage interventions developed for them.

Acknowledgements

We thank all participants for sharing their thoughts and perspectives on DHIs. We acknowledge Lacey Feigl-Lenzen and Nancy Mathis for administrative assistance.

Funding: Ms. Ra was supported by Washington University Summer Undergraduate Research Award and Gina M. Finzi Summer Student Fellowship by Lupus Foundation of America. Mr. Leung was supported by Rheumatology Research Foundation Medical Graduate Student Preceptorship Award and Lawren H. Daltroy Health Professional Preceptorship Award. Mr. Leung, Dr. Baker, and Dr. Kim were supported by NIH/National Center for Advancing Translational Sciences (NCATS) grant UL1 TR002345. Dr. Kim was also supported by NIH/National Institute of Arthritis and Musculoskeletal and Skin (NIAMS) P30 AR073752 and Rheumatology Research Foundation.

References

- Giffords ED, 2003. Understanding and Managing Systemic Lupus Erythematosus (SLE). *Journal of Social Work in Health Care*, 37(4), pp. 57–72. [PubMed: 14620904]
- Leung J, Ra J, Baker EA & Kim AHJ, 2019. "... Not Having the Real Support that We Need": Patients' Experiences with Ambiguity of Systemic Lupus Erythematosus and Erosion of Social Support. *ACR Open Rheumatology*, 1(3), pp. 135–144. [PubMed: 31773100]
- Kuhn A et al. , 2015. The Diagnosis and Treatment of Systemic Lupus Erythematosus. *Dtsch Arztebl Int*, Volume 112, pp. 423–432. [PubMed: 26179016]
- Mazzoni DCE, 2014. Problematic Social Support From Patients' Perspective: The Case of Systemic Lupus Erythematosus. *Social Work in Health Care*, 53(5), pp. 435–445. [PubMed: 24835088]
- Dua AB, Touma Z, Toloza S, & Jolly M (2013). Top 10 Recent Developments in Health-Related Quality of Life in Patients with Systemic Lupus Erythematosus. *Current Rheumatology Reports*, 15(380), 1–11.
- Mazzoni D & Cicognani E, 2011. Social Support and health in patients with systemic lupus erythematosus: a literature review. *Lupus*, Volume 20, pp. 1117–1125. [PubMed: 21828159]
- Mendelson C, 2003. Gentle Hugs: Internet Listservs as Sources of Support for Women with Lupus. *Advances in Nursing Science*, 26(4), pp. 299–306. [PubMed: 14674578]
- Danoff-Burg S, & Friedberg F (2009). Unmet Needs of Patients with Systemic Lupus Erythematosus. *Behavioral Medicine*, 35, 5–13. [PubMed: 19297299]
- Uchino B, 2004. *Social Support and Physical Health*. New Haven and London: Yale University Press.
- Braden CJ, 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), pp. 158–167. [PubMed: 11188603]
- Lorig K, Ritter PL & Plant K, 2005. A Disease-Specific Self-Help Program Compared With a Generalized Chronic Disease Self-Help Program for Arthritis Patients. *Arthritis & Rheumatism (Arthritis Care and Research)*, 53(6), pp. 950–957. [PubMed: 16342084]
- Robbins L, Allegrante JP & Paget SA, 1993. Adapting the Systemic Lupus Erythematosus Self-Help (SLESH) Course for Latino SLE Patients. *Arthritis Care and Research*, 6(2), pp. 97–103. [PubMed: 8399433]

13. Drenkard C, Dunlop-Thomas C, Easley K, Bao G, Brady T, & Lim S (2012). Benefits of a self-management program in low-income African-American women with systemic lupus erythematosus: results of a pilot test. *Lupus*, 21, 1586–1593. [PubMed: 22936126]
14. Lorig KR, Ritter PL, Laurent DD & Plant K, 2008. The Internet-Based Arthritis Self-Management Program: A One-Year Randomized Trial for Patients with Arthritis or Fibromyalgia. *Arthritis & Rheumatism (Arthritis Care & Research)*, pp. 1009–1017. [PubMed: 18576310]
15. Twumasi AA, Shao A, Dunlop-Thomas C, Drenkard C, & Cooper HL 2020. Exploring the Perceived Impact of the Chronic Disease Self-Management Program on Self-Management Behaviors among African American Women with Lupus: A Qualitative Study. *ACR Open Rheumatology*, 2(3), p. 147–157. [PubMed: 32037683]
16. Murray E, Hekler EB, Andersson G, Collins LM, Doherty A, Hollis C, et al. (2016). Evaluating digital health interventions: key questions and approaches. *Am J Prev Med*, 51(5), 843–851. [PubMed: 27745684]
17. World Health Organization, 2019. World Health Organization. [Online] Available at: <https://www.who.int/news-room/detail/17-04-2019-who-releases-first-guideline-on-digital-health-interventions> [Accessed 5 March 2020].
18. Young S, Henderson E, Cheseldine D, Wilson A, Skan J, Heaton S, et al. (2002). Development and assessment of a World Wide Web site for systemic lupus erythematosus patient information. *Lupus*, 11, 478–484. [PubMed: 12220101]
19. Wilson A, Kitas G, Llewellyn P, Carruthers D, Cheseldine D, Harris S, et al. (2001). Provision of Internet-based rheumatology education (<http://rheuma.bham.ac.uk>). *Rheumatology*, 645–651. [PubMed: 11426021]
20. Wantland DJ, Portillo CJ, Holzemer WL, Slaughter R, & McGhee EM (2004). The Effectiveness of Web-Based vs Non-Web-Based Interventions: A Meta-Analysis of Behavioral Change Outcomes. *Journal of Medical Internet Research*, 6(4), 1–20.
21. Harvey-Berino J, Pintauro SJ, & Gold EC (2002). The Feasibility of Using Internet Support for the Maintenance of Weight Loss. *Behavioral Modification*, 26(1), 103–116.
22. Harvey-Berino J, Pintauro S, Buzzell P, Digiulio M, Gold BC, Moldovan C, et al. (2002). Does using the internet facilitate the maintenance of weight loss? *International Journal of Obesity*, 26, 1254–1260. [PubMed: 12187404]
23. Rod K, 2015. Finding Ways to Lift Barriers to Care for Chronic Pain Patients: Outcomes of Using Internet-Based Self-Management Activities to Reduce Pain and Improve Quality of Life. *Pain Research and Management*, Volume 2016, pp. 1–8.
24. Stinson JN, McGrath PJ, Hodnett ED, Feldman BM, Duffy CM, Huber AM, et al. (2010). An Internet-based Self-management Program with Telephone Support for Adolescents with Arthritis: A Pilot Randomized Controlled Trial. *The Journal of Rheumatology*, 37(9), 1944–1952. [PubMed: 20595280]
25. Umapathy H, Bennell K, Dickson C, Dobson F, Fransen M, Jones GJ, et al. (2015). The Web-based Osteoarthritis Management Resource My Joint Pain Improves Quality of Care: A Quasi-Experimental Study. *Journal of Medical Internet Research*, 17(7), 1–13.
26. Poole JL, Mendelson C, Skipper B & Khanna D, 2014. Taking Charge of Systemic Sclerosis: A Pilot Study to Assess the Effectiveness of an Internet Self-Management Program. *Arthritis Care & Research*, 66(5), pp. 778–782. [PubMed: 24115761]
27. Kwakkenbos L, Jewett LR, Baron M, Bertlett SJ, Furst D, Gottesman K, et al. (2013). The Scleroderma Patient-centered Intervention Network (SPIN) Cohort: protocol for a cohort multiple randomised controlled trial (cmRCT) design to support trials of psychosocial and rehabilitation interventions in a rare disease context. *BMJ Open*, 3, 1–11.
28. Miles A, 2009. Of butterflies and wolves: enacting lupus transformations on the Internet. *Anthropology & Medicine*, 16(1), pp. 1–12.
29. Neville C, Da Costa D, Rochon M, Peschken CA, Pineau CA, Bernatsky S, et al. (2016). Development of the Lupus Interactive Navigator as an Empowering Web-Based eHealth Tool to Facilitate Lupus Management: Users Perspectives on Usability and Acceptability. *JMIR Research Protocols*, 5(2).

30. Mazzoni D & Cicognani E, 2014. Sharing experiences and social support requests in an Internet forum for patients with systemic lupus erythematosus. *Journal of Health Psychology*, 19(5), pp. 689–696. [PubMed: 23479300]
31. Wetstone SL, Pfeiffer CA & Rippey RM, 1988. Evaluation of a Computer-based Education Lesson for Patients with Systemic Lupus Erythematosus. *Arthritis Care and Research*, 1(1), pp. 7–11.
32. Van Dijk JA, 2017. Digital Divide: Impact of Access. In: Rössler P Hoffner CA & van Zoonen L, eds. *The International Encyclopedia of Media Effects*. s.l.:John Wiley & Sons, Inc, pp. 1–11.
33. Lupus Foundation of America, 2016. Lupus facts and statistics. [Online] Available at: <https://www.lupus.org/resources/lupus-facts-and-statistics> [Accessed 11 March 2020].
34. Byrne G, 2007. A Statistical Primer: Understanding Descriptive and Inferential Statistics. *Evidence Based Library and Information Practice*, 2(1), pp. 32–47.
35. Strauss A & Corbin J, 1998. *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks (CA): SAGE Publications.
36. Feldman CH, Hiraki LT, Liu J, Fischer MA, Solomon DH, Alarcon GS, et al. (2013). Epidemiology and Sociodemographics of Systemic Lupus Erythematosus and Lupus Nephritis among U.S. Adults with Medicaid Coverage, 2000–2004. *Arthritis Rheum*, 65(3), 753–763. [PubMed: 23203603]
37. Furst DE, Clarke A, Fernandes A, Bancroft T, Greth W, & Iorga S (2013). incidence and prevalence of adult systemic lupus erythematosus in a large US managed-care population. *Lupus*, 22, 99–105. [PubMed: 23042822]
38. Neville C, Da Costa D, Mill C, Cochon M, Avina-Zubieta J, Pineau C, et al. (2014). The needs of persons with lupus and health care providers: a qualitative study aimed toward the development of the Lupus Interactive Navigator TM. *Lupus*, 23, 176–182. [PubMed: 24335012]
39. Sawah SA, Daly RP, Foster S, Naegeli A, Benjamin K, Doll H, et al. (2015). UNDERSTANDING DELAY IN DIAGNOSIS, ACCESS TO CARE AND SATISFACTION WITH CARE IN LUPUS: FINDINGS FROM A CROSS-SECTIONAL ONLINE SURVEY IN THE UNITED STATES. *Scientific Abstracts*, 812.
40. Drenkard C, Villa AR, Garcia-Padilla C, Perez-Vazquez ME, & Alarcon-Segovia D (1996). Remission of Systemic Lupus Erythematosus. *Medicine*, 75, 88–98. [PubMed: 8606630]
41. Swaak A, Nossent JC, Bronsveld W, Van Rooyen A, Nieuwenhuys EJ, Theuns L, et al. (1989). Systemic Lupus Erythematosus. II. Observations on the occurrence of exacerbations in the disease course: Dutch experience with 110 patients studied prospectively. *Annals of Rheumatic Diseases*, 48, 455–460.
42. Gilman S, Levesque D, Cummins C, Wallace D, Werth V, & Davidson P (2019). Design and Development of an Online Intervention for Lupus Self-Management Based on the Transtheoretical Model of Change [abstract]. *Arthritis Rheumatol*, 71.
43. Sillence E, Briggs P, Harris PR & Fishwick L, 2007. How do patients evaluate and make use of online health information?. *Social Science & Medicine*, Volume 64, pp. 1853–1862. [PubMed: 17328998]
44. Van Dijk J, 2006. Digital divide research, achievements and shortcomings. *Poetics*, Volume 34, p. 221–235.

Significance and Innovations:

- Our findings suggest that the majority of SLE patients use the internet to obtain support for their SLE but identified a variety of improvements that are needed in order to fully leverage the potential benefits of digital health interventions.
- Digital health interventions (DHI) - interventions accessible through digital technologies (i.e. apps, internet) on devices such as mobile phones, tablets, and computers - have substantial potential to address the unmet need for social support in SLE.
- The effects of DHIs on SLE patient experiences have not been studied extensively. However, the availability of various platforms and methodologies, present the potential to customize DHIs to meet the needs of individuals with SLE.
- We found that a primary need for SLE patients is a dynamic, interactive intervention that enables the user to access content according to the symptomatology they are experiencing.

Figure 1.
How participants use the internet for their SLE

Table 1.

Characteristics of Sample and Washington University Lupus Clinic

	Sample	Clinic		Sample	Clinic
Gender			Age Groups		
Female	100%	91.5%	<20	1.8%	0.4%
Male	0.0%	8.5%	20-39	42.9%	46.2%
Race			40-59	48.2%	41.3%
White	39.7%	44.2%	60+	7.1%	12.1%
Black or African American	51.7%	49.8%	Marital Status		
Asian	5.2%	2.0%	Married	35.7%	35.8%
Other	3.4%	4.0%	Divorced/Separated	19.6%	9.7%
Employment Status			Widowed	1.8%	1.2%
Full-time	50.0%	47.6%	Single	35.7%	51.2%
Part-time	1.8%	3.4%	Member of an unmarried couple	7.1%	1.8%
Disabled	32.1%	25.4%	Education Level		
Student	5.4%	10.2%	Some high school or less	3.6%	2.0%
Unemployed	5.4%	9.3%	Completed High school or GED	21.4%	18.4%
Retired	5.4%	4.2%	Some college	44.6%	46.9%
			Completed 4-year college or more	30.4%	32.7%

Table 2.

Types of devices used to access the internet

Devices	% of participants
Cell Phone	93%
Personal Computer	78%
Tablet	42%
Work Computer	27%
Library Computer	5%

Table 3.

Illustrative Quotes for Major Themes: Understanding flares or changes in symptoms and/or lab results & Need for increased diversity in the methods of delivering digital SLE information

Themes	Quotations
Understanding flares or changes in symptoms and/or lab results	<p>“[I would like to use the internet to find information on] what happens during flares and instructions to how to deal with the problem and issue.”</p> <p>“If there’s a flare or a new symptom, I might look [online] to see if I can find anything to help explain it to me.”</p> <p>“When I get lab results back and things drastically change.”</p>
Need for increased diversity in the methods of delivering digital SLE information	<p>“[I would like to use] an app where you can input things you need at the time of a flare and help you.”</p> <p>“[I would like] a cell phone app for lupus for general information and connections with people.”</p> <p>“[There is] not enough video information. [I want to see] more virtual talking information deliver, rather than reading.”</p>

Table 4.

Illustrative Quotes for Major Theme: Need for increased variety of SLE information online

Subthemes	Quotations
Need for new and diverse material on SLE	<p>"Information is relatively easy to find. That's not the problem. Nothing has changed much. So, if there is more new information [online, I would be more likely to use the internet]. So [that's why I] haven't been online too much."</p> <p>"[I would] like to see different aspects of lupus... different diagnoses."</p> <p>"[I would like to see online] more information on the cause of lupus."</p> <p>"[I would like to see more information on] the breakdowns of the way you form lupus."</p> <p>"[I would be more likely to use the internet if there was] more variety in information, so that you can be better educated and converse with the doctor better."</p> <p>"A lot of stuff she doesn't see [online]... for lupus, you never see the same symptoms or experience ability to be connected with others with similar situations."</p>
Need for more current information treatments and research on SLE	<p>"I would like to see certain cures [for the] causes [of] the symptoms for lupus."</p> <p>"[I would like to use the internet for] medication side effect information. [There's] not enough info on medications."</p> <p>"If something big were to happen like a new treatment were to come out [, then I would use the internet more]."</p> <p>"Seems like [I have been] on same medication for years. Seems like if you have flares, [they just give you] steroids. [I would be more likely to use the internet] to find other things that can help control the disease."</p> <p>"[I would like to see more information on] how people have been benefited from more natural treatments."</p> <p>"[I would like to see more information on] other options on medications different from those of my physician."</p> <p>"[I would like to see more information on] actually [other] drugs that do not take three to six months for effect to occur."</p> <p>"[I would like to use the internet for] patient assistance programs on medications."</p> <p>"[I would like to use the internet to obtain] updates on what [research] is going on... what are LFA funds being used [for]? How close is WashU to a cure? Is it just treatment, or actively looking for cure?"</p> <p>"[I would like] more [information on] clinical studies."</p> <p>"[I would like to use the internet to see more information on] biological research."</p> <p>"If she can help and get involved with the studies [...]. We don't know about [...] new studies."</p>
Desire for more information related to healthy lifestyle behavior for SLE patients	<p>"[I would like to see online information on] more accurate diet changes for lupus."</p> <p>"Yeah. I use [the internet] all the time. [...] I read an article about [...] somebody who had lupus for a long time [...]. They started eating herbal things, and she says she no longer has lupus by eating different and taking these herbal supplements. She no longer has it. Or it's dormant, one of the two."</p> <p>"[I would like to see online] more information about dietary stuff and exercise for lupus patients that would encourage people to be as fit as they could be."</p>

Table 5.

Illustrative Quotes for Major Theme: Desire to exchange personal experiences and knowledge about SLE with others

Subthemes	Quotations
Desire to find assistance in connecting with other people and in locating support groups, chat rooms, or other SLE-related events.	<p>"[I would like to use the internet to obtain the] ability to connect with more lupus people within community."</p> <p>"[More online] chat room or support group that would make [me] on the internet more... [I currently have] no active support group."</p> <p>"[I would be more likely if I had the resources in] finding more local support groups, closer to home more connection so that [I] can meet face-to-face."</p> <p>"When connecting chat rooms, [I would like to] have a facilitator to help connect people."</p>
Desire to connect with SLE-related programs and resources.	<p>"[I would like to see online] more information [... about] programs, more advertisement for it about lupus and different programs [or events]."</p> <p>"[I would be more likely to use the internet] if there was a specific page that I knew about or referred to."</p> <p>"[I would be more likely to use the internet if there were] notifications about interesting stuff to read."</p> <p>"[I would be more likely to use the internet when] having a facilitator [or] someone to help connect people to online sources."</p>
Desire to learn from other SLE patients.	<p>"Like somebody [...] just by telling their story can help me. It is very hard to talk to people that don't know [what living with SLE is like]. They look at you, [and say,] 'Come on, you'll feel better. You'll snap out of it...'"</p> <p>"[I want to see] how [other lupus patients] cope/live their lives."</p> <p>"Being able to share something [in these chat rooms ... and having the] possibility to talk with others about filing for disability. Maybe a forum like these [would have helped during] the struggles that I went through when applying for disability."</p> <p>"[I would like to use the internet] to learn and know about what other people are going through. Learning from other people about diseases, [and] know that you're not alone."</p>
Desire to use the internet for obtaining information from SLE patients, experts, and physicians	<p>"I tend to trust somebody that has been on my shoes. If I knew that someone on the internet shared my experience, then I would less likely to not pay attention. They know things that the book don't (sic) touch on. They actually been in contact with it through a family member or something when communicating."</p> <p>"[I would be more likely to use the internet if there were] more physician-based websites or chat rooms... [because I] do not trust info [online] that much."</p>
Desire to use the internet for obtaining information from SLE patients, experts, and physicians	<p>"More information out there is better, especially if it's coming from doctors. I can be annoyed when it is just a bunch of people telling their opinions, or if people are arguing over what the best thing to do is."</p> <p>"If there is lupus page where you can actually ask questions to somebody, and experts can help and answer questions, [...] send messages back and forth."</p>