

Development and implementation of a virtual Lupus Patient Education Event during the COVID-19 pandemic

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During routine patient visits, we are frequently met with time and resource constraints making it difficult to provide optimal counselling, consultation with other care team members, and answers to patient questions and concerns. This is particularly true when seeing patients with SLE. With its heterogeneity of symptoms, multi-organ involvement and complex medication regimens, SLE is a difficult disease for patients to navigate and engage in effective self-management. Given the limitations of counselling and patient education in a typical clinic visit, in conjunction with patients who expressed a desire to learn more about their disease, we developed the first annual Lupus Patient Education Event in 2011.

Patient education interventions decrease hospitalisations, reduce visits to emergency departments and improve patient quality of life.^{1–3} Patient education is an important component of health literacy, defined as the degree to which individuals have “the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”.⁴ The Paasche-Orlow and Wolf Model includes patient knowledge and health education in the causal pathways between health literacy and health outcomes.⁵ Because low health literacy is associated with worse clinical outcomes in other chronic diseases, improving delivery of patient education in lupus may help increase disease understanding and self-management, resulting in better health outcomes.

The Lupus Patient Education Event serves as an opportunity for patients with lupus to learn about aspects of managing lupus, ask questions and share personal experiences collectively. Topics to cover are suggested by patients and members of the planning committee, including lupus nephritis, cardiovascular health in SLE, contraception and pregnancy, diet and nutrition, and managing medications. We created an interdisciplinary half-day event that has included adult and paediatric rheumatologists,

ophthalmologists, dermatologists, certified health coaches, patient advocates, dieticians and nurse navigators, among others. There are breakout sessions following the main talks to enable participant engagement and interaction in more intimate, smaller groups with lunch provided. Some of the topics covered in the small group sessions include prescription assistance, applying for disability, skin care, meditation, fatigue management, paediatric lupus and a group for men with lupus.

Our Lupus Patient Education Event has been held annually since 2011 at the Medical University of South Carolina (MUSC). With the onset of the COVID-19 pandemic in Spring 2020, the in-person Lupus Patient Education Event was cancelled. This provided an opportunity for collaboration between the MUSC and Duke Rheumatology divisions to host an inter-institutional virtual event during the COVID-19 pandemic, held in September 2020. In addition to the traditional topics, we included a session on COVID-19 and SLE which reviewed what was known at the time regarding risk factors, COVID-19 outcomes related to SLE, and research on hydroxychloroquine and immunosuppressive medications in the setting of COVID-19. Other topics, similar to prior events, included medication adherence advice, cutaneous manifestations in SLE, depression and fibromyalgia. Several patients spoke about their personal experiences fighting lupus. To conclude the event, we hosted a lupus advocacy talk and a meditation relaxation session.

There were 208 participants registered; 109 participants (noted by attendance on the Zoom platform for at least 60 min) attended our virtual event. Prior to the event, participants completed a registration form and selected the top three breakout sessions they were interested in attending. The most frequently selected topics of interest are shown in [figure 1](#): (1) “dealing with fatigue, fibromyalgia and depression” (n=128),

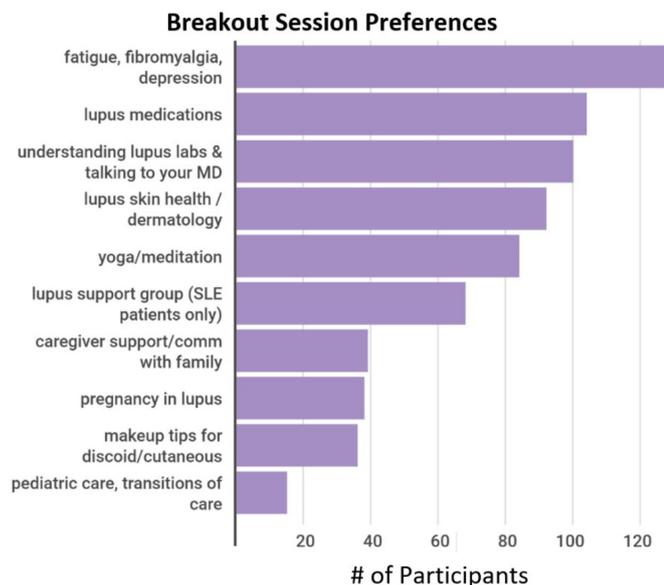


Figure 1 Number of participants requesting each breakout session.

(2) lupus medications (n=104), and (3) understanding lupus labs and talking to your doctor (n=100). Thus, we propose that future patient education seminars and materials should focus on these topics of substantial interest to patients with SLE, including addressing concomitant fibromyalgia or depression as well as understanding of common lupus medications and lab monitoring.

Our post-survey had 34 respondents; 91% said they would definitely (n=27) or most likely (n=4) recommend the event to others. Also, 100% of respondents said they felt we achieved our goal of providing information and education about lupus, increasing awareness of issues impacting the health of those living with lupus, and answering patient questions about lupus. Ninety-four per cent rated ease of joining the virtual platform as “excellent” or “good”. The chat was active throughout the 5-hour programme, with questions for the speakers to address as well as helpful comments and feedback. Two Zoom moderators helped introduce the speakers and read questions from the chat, which helped facilitate engagement with attendees.

We were initially uncertain what the feedback and participation would be, especially given transition of the event from in-person to virtual. We provided technical support for several patients unfamiliar with Zoom prior to the event, so that they could attend via smart phone or computer. Ultimately, 109 people attended our virtual event, which is similar to typical in-person attendance numbers (100–125 people). Several participants expressed an interest in maintaining a virtual

option for the event, even after the COVID-19 pandemic, in addition to an in-person event. One participant in the post-event survey expressed, “I learned more about lupus through this event than I have in more than ten years of clinic visits.” We look forward to future inter-institutional collaborations and fostering other avenues to discuss topics related to lupus and to engage patients in order to meet their needs in managing SLE.

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