Information Experiences of People Affected by Lupus

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I pledge on my honor that I have not given or received any unauthorized assistance on this paper.

Introduction

Comprising but a fraction of the 23.5 million people in the United States affected by autoimmune diseases, people with lupus not only have to navigate the often unpredictable and serious manifestations of their diagnoses, but often the ignorance of the general public and medical establishment of their experiences (Office on Women's Health, 2019). As someone with lupus, among other autoimmune diseases, I have first-hand knowledge of the struggles and successes of information seeking regarding my condition, as well as the psychological toll when those needs are not appropriately met. As such, I have selected people with lupus as a population to focus on.

Though the inequities and barriers I have faced may be different from others, I am keenly aware of the negative outcomes that may result. It is for that reason that I have chosen to use my own experiences with autoimmune diseases, in addition to the undermentioned article, to inform on potential ideas for future research regarding the information behavior and information related inequities experienced by people with this condition.

Article Summary

Waldron et al. (2011) set out to determine the information needs of patients that were newly diagnosed with systemic lupus erythematosus (lupus) to inform the design of a future education package. They identified three principal research questions to guide them in the interview protocol:

1. What information is needed for patients with newly diagnosed lupus?
2. How much information is needed?
3. When should this information be given?

The authors of this study recruited forty-three participants from seven rheumatology centers in England and Wales. These participants were referred by a consulting clinician at their visit to the clinic. Purposive selection methods were used in order to ensure the views of both newly diagnosed patients (who would reflect on their recent experiences) and those that had a lupus diagnosis for some time were included. The participants that had a lupus diagnosis for some time were admitted in order to share their reflections on whether more or different information would have impacted the future management of their disease.

Eight semi-structured focus groups were held, with four to seven participants (ages 20-70 with a range of disease severity) per group. A study coordinator and a specialist rheumatology nurse were in attendance for each session as well. Each focus group lasted about one hour, with fifteen minutes before the start time allotted to allow for the participants to meet each other. Following each focus group, amendments were made to the interview protocol in response to emerging data. The study authors transcribed the focus group meetings verbatim, then used thematic inductive analysis to extract themes from the transcripts.

Three key themes emerged from the focus groups: impact of early information, information received vs. information sought, and early education needs. They found that many participants had little prior knowledge of lupus prior to their diagnosis and that information was hard to absorb or difficult to find, which led to feelings of fear and confusion. Few participants said that they felt that they received clear and consistent information around the time of their diagnosis. Many felt that the information they received was insufficient, leading them to seek information elsewhere and experienced increased distress if they were still unable to find the answers to their questions. The general consensus from the participants was that they would rather be informed about lupus than stay naïve. They mentioned that receiving a comprehensive

information pack in addition to verbal information from their doctor would have been most useful at the time of their diagnosis. Prompt access to knowledgeable professionals if/when they had questions was also desired.

The authors concluded that the current information and support that is provided for people with lupus at the time of their diagnosis is inadequate for their needs. They also expressed that these individuals should be supported by knowledgeable professionals that are ideally available when patients have questions or need to discuss their health. However, Waldron et al. acknowledged the difficulty of healthcare providers to meet their patients' needs in the most beneficial and cost effective way.

Critical Assessment

Overall, I believe that this study was well designed and resulted in findings that are replicable and sound. The authors appeared to fill an important gap in the literature at the time of publication, particularly with regard to information behaviors and experiences at the time of diagnosis. I have no major reservations regarding the recruitment methods utilized by Waldron et al., and the sample size seemed sufficient to ensure data saturation and did not appear to be overtly biased.

One critique relates to the data analysis methods employed in the study. While qualitative approaches allow for a more nuanced and in-depth exploration of participants' experiences, they are inherently subjective, which can limit the generalizability of the findings beyond the study population. This subjectivity introduces the possibility that researcher interpretation – such as variation reflected in intercoder reliability – may influence the results, even when rigorous analytic procedures are followed (O'Connor & Joffe, 2020).

Another critique concerns the data collection method. There are several challenges associated with this approach, but the two most concerning in this context are the dominance effect and issues of confidentiality. The dominance effect may allow for one or more individuals to disproportionately shape the discussion, and while it is the responsibility of the researchers to prevent this, it may not be possible (Nyumba et al., 2018). This could potentially impact the data and findings as not everyone in attendance would have the opportunity to express their opinions and experiences. As the participants are being asked to talk about their experiences and other highly personal topics, confidentiality and anonymity becomes a concern. It is of utmost importance that researchers ensure that participants are fully informed about the risks and benefits of their disclosure (Sim & Waterfield, 2019). Participants may also be reluctant to share their true feelings and experiences even with the promise of anonymity, which could also impact the findings.

Applications

The findings of Waldron et al.'s study could be used by multiple populations in order to aid in fulfilling the information needs of people with newly diagnosed lupus. This research could be helpful for healthcare providers to gain a better understanding of what their patients' information needs are so that they can tailor their counseling during those crucial first appointments. These findings could also be used by other researchers to understand the possible gaps in literature and the areas that research needs to be conducted. Although the exact format was not mentioned in the article, the developers of the ideal information resource (whether that be web developer or some other type of author) could find this information beneficial in that it allows them to create a product that will be usable and useful to this population.

Ideas for Future Research

Waldron et al. indicated that there was a need for a lupus-specific educational resource with content that goes beyond what is currently available in order to address the anxiety that can arise not just from a lack of information, but from a lack of awareness that information is even needed. This state of incognizance, as described by St. Jean (2013), also involves a diminished ability to recognize the relevance and usefulness of available information, which can lead to negative health outcomes. A more comprehensive resource should include details on the pathological process of lupus, available treatments, possible complications, and both practical and emotional coping strategies. Although the aforementioned study detailed what exactly should be contained in this resource, they mentioned that there is still a need to determine the best ways to provide this information in a way that is accurate and relevant, but is not distressing or frightening to the patients.

I suggest that future research should be conducted to determine if there are information grounds (as first described by Pettigrew, 1999) created at lupus or other rheumatology clinics, and if so, how they affect long term health outcomes for the patients. I would also suggest focusing research on whether providing the aforementioned kind of information at the point of diagnosis actually makes a difference in long term health outcomes and what effect it has on self-efficacy (and/or information avoidance) and the desire to seek further information.

Conclusion

This article by Waldron et al. (2012) details a study they conducted on the information needs of people that have recently been diagnosed with lupus in order to inform on the design of a future education package. This study fills a gap in the literature as (at the time of this article's publication) there had been few studies on the information needs of people that have been recently diagnosed with lupus. Although not entirely surprising, their finding that the current

information and support provided to patients after diagnosis is inadequate promotes a challenge for healthcare providers and other developers to meet this need in the most cost effective and beneficial way that also takes into account the individuality of patients and their differences in health literacy. Although there has been follow-up research by these authors, it is unclear whether or not the education package was ever created. This, and the aforementioned recommendations, creates a justification for additional research in order to provide information for people with lupus that is actionable, useful, comprehensible, and minimally distressing.

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