WORKING THROUGH THE PAIN... AND GETTING ON WITH IT—SOME PATIENTS’ EXPERIENCES OF LIVING WITH LUPUS-RELATED FOOT PROBLEMS

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Background: Along with its skin manifestations, SLE can present with a variety of musculoskeletal signs and symptoms and vascular problems that can affect the feet. Furthermore, there is the potential for reduced tissue viability, leading to thinning of the skin and/or callus formation. Further, systemic resistance to viral, bacterial and fungal infections may be reduced and, together with poor tissue viability, create the opportunity for these infections to proliferate in the feet. A recent survey by the same authors (unpublished) has shown a high prevalence of these infections, with many experiencing the impact of vascular and musculoskeletal problems. To date there is no research that has explored the impact of foot problems on people’s lives.

Methods: Following ethical approval, 12 participants who fulfilled the inclusion criteria were recruited: diagnosed with SLE (ACR diagnosis), current and/or past experience of foot/lower limb problems and age ≥18 years. Consent was obtained and then conversational-style interviews were carried out with an interpretivist phenomenological approach. The interviews were digitally recorded and complemented by field notes. An opening question was used for all participants: ‘Tell me about your experiences of having foot problems?’ If necessary, further trigger questions were used in order to maintain the conversation and the focus on foot problems. Data were transcribed verbatim and analysed using a thematic framework approach. The transcripts were verified by the participants and were analysed by a second researcher in order to add to the credibility of the analyses.

Results: The data was organized into seven themes: Foot problems and symptoms—what they are and the feeling associated with them; Experiences of foot problems being diagnosed; Impact of foot problems on activities; Treatment of foot symptoms/problems; Perceived obstacles to professional foot care; Unanswered questions about feet and foot care; and Recognition of the need for professional foot care and foot care advice. These people experienced a wide variety of foot problems that impact significantly on activities. Some reported working through the pain in order to achieve visible normality while experiencing the negative emotions of anger, frustration and anxiety. Although some had experienced professional foot care, there were obstacles to the foot problems being diagnosed, resulting in many unanswered questions and some inappropriate self-management.

Conclusion: Despite reporting foot pain, negative emotions and activity restrictions related to their foot symptoms, people with SLE tend to get on with it and self-treat rather than seeking professional foot care. The lack of focus on the feet in the medical consultation is caused by the participants’ belief that it is not the consultant’s role. There is a clear need for foot assessments to be included in the medical consultation and for professional foot care to be provided.

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