

The use of online peer support communities in dermatology

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Commentary: The use of online peer support communities in dermatology

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Over recent years online communities have provided a widely used and readily accessible venue for people seeking health-related information, advice, and support on the management of long-term conditions (LTCs). This includes using online communities to understand disease symptoms and prognosis, find out about available treatment options, and help understand consultations. They have also fostered new opportunities for individuals to obtain social and emotional support from individuals who are managing similar health-related issues.¹ Many people living with a long-term complex skin condition, such as alopecia, experience high levels of psychological and social disability.^{2,3} The visible nature of the condition can lead to feelings of stigmatisation and lowered self-image, resulting in social isolation and feelings of loneliness. In light of these issues, online communities may provide an important and acceptable source of support for individuals with alopecia. Despite this, few studies have explored how individuals living with a skin condition use and benefit from online peer support.

In this issue of the *BJD*, Iliffe and Thompson⁴ report novel insights into how people living with alopecia benefit from the use of an online peer support group provided by the UK charity Alopecia UK. They found that the use of online support could help support psychological adjustment by providing a safe place for individuals to share their experiences and concerns, as well as an opportunity to express their feelings about their condition. This facilitated a sense of acceptance, empowerment, and feeling less alone in their experience of alopecia. Online communities may be a useful means through which people living with a LTC may have access to personally relevant practical advice and support, as well as providing emotional support by connecting with similar individuals within a shared community.⁵

Despite these potential benefits, clinicians may have reservations about recommending online communities due to potential conflicting or misleading health information or incorrect advice on disease management. Patients themselves may feel clinicians have negative perceptions about the usefulness of online communities.⁶ However, online peer support has the potential to make people feel informed and supported, which in turn can help individuals to take a more active role in self-management and influence how they interact with healthcare providers.⁷ Indeed, 82% of individuals using LTC online support groups report discussing the information found online with their clinician.⁸ In order to maximise the potential benefit on shared decision-making, it is important that we make sure individuals views about their condition are actively sought and the issues that matter most to them, which may include information and advice they have received online, are given due consideration and discussion.

Although clinicians may encourage individuals to engage with online peer support groups as a supplementary source of support, it is important that we remind people of their potential disadvantages. More work is now needed to develop guidance to help people get the most from online communities, including working with charities that provide online peer support to develop ways in which we can maximise benefits to its users.

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