Is social media the answer to the support desired by people with Rheumatoid Arthritis? A qualitative exploration

S Naidoo,¹ I Haq,² S Otter¹

¹ University of Brighton, ² Brighton & Sussex Medical School

Statement of Purpose

The aim was to identify the use of social media by people with RA and to determine if these current methods of technology could aid the development of a more patient-centred model of care.

Literature Review

Social media and the use of smartphone and tablet 'apps' are part of daily life for many, with diverse roles ranging from entertainment to education with increasing potential for sharing health information and providing support. Users can create and link into networks of people with shared interests or experiences in real-time, which may have an important role to play in health care. In contrast, outcomes in rheumatoid arthritis (RA) have too often been associated with loss of mobility and reduced quality of life, leading to loss of independence, anger, frustration and depression. Although recent advances in pharmacological management have improved outcomes for many, it often adds to the overall complexity of disease management for the individual.

Methodology

Semi-structured interviews were carried out with 14 people with RA to explore the lived experience of their disease, identify the current use of social media and 'apps' and specifically how they would like to see this technology used in their future care. Interviews were recorded and transcribed verbatim by an independent transcriber, data were analysed using N Vivo.

Results

Six key themes were identified from the analysis with an overriding theme of ownership of their disease: whereby social media could be used to provide support. Interestingly, at the point of diagnosis, respondents reported being overwhelmed by existing online resources. The desire for more **patient-centred** social media and a tool such as an 'app' tailored to the individual was noted. Such technology could be used to allow the sharing of similar experiences by people who are geographically distant, together in a meaningful way, e.g. through blogs. The respondents felt they needed a source of reference for disease management and/or a resource when attending appointments e.g. tracking symptoms. Moreover, because of the hand pain and deformities experienced by respondents (Figure 1) the use of touch-screen technology (e.g. smart phones and tablets) were reported to be a much easier way of navigating health resources. Finally, the immediacy of support and information that can be provided by social media and 'app' use is something respondents desired.

Figure 1: A respondent's hand deformity from her RA. Age 26.

Conclusions

The range of social media technology that people with RA would find most useful does not yet appear to exist. The data has been used to aid the creation a multi-platform 'app', patient-centred 'app' that can be used to aid patients' ownership of their disease and health.

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