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P181 -Identifying information needs of patients with IgA nephropathy: an innovative social media approach

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Introduction

Management of chronic diseases is increasingly challenging with ever-increasing numbers of people affected around the World. The Internet and social media enable people to participate in online networks, access information, research and share personal experiences. In this study, we analysed social media data to identify the unmet needs of patients with IgA nephropathy (IgAN).

Methods

We present an analysis, using a novel digital method, of a data set retrieved from a UK IgAN patient Facebook group (1959 posts). It involved:

- Preparation – history data was aggregated and scraped using Facebook and Grytics
- Analysis of data - a deductive (applied matrix, frequency analysis) and inductive (thematic analysis) method to understand information needs
- Organizing and reporting – multi-disciplinary team decision of categories to explore in depth and reporting

Findings

Through frequency of word occurrence and categorisation, the unmet information needs were revealed as diet, symptoms, diagnosis, treatment and co-morbidities. Patients sought particular information on a healthy diet to self-manage the disease and symptoms ('salt and potassium', 'gluten and dairy', 'protein' and 'fish-oil'). Dietary information was discussed in relation to weight and weight loss. Amongst symptoms, patients frequently indicated kidney pain (often developed after a viral infection and associated with a decline in renal function) and fatigue (the relationship of levels of fatigue to the stage of disease, phosphate levels, haemoglobin and iron levels). In terms of diagnosis of IgAN, anxiety before the diagnosis and around the biopsy, or relief about having been given a diagnosis was revealed. The findings regarding medications and treatments were principally divided into 2 groups, specific treatments for IgAN and dealing with the side effects of medications. Furthermore, patients discussed gout and diabetes and their relation to IgAN and CKD.

Key themes that emerged through content analysis were clinician-to-patient communication, peer support, presentation of material and employment. Peer conversations highlighted that much of the traditional advice has been disproven and it is hard to know what is true and what is not. There was a frustration that clinicians dismissed many of the problems patients wanted to discuss. Another key theme that emerged was related to information not being presented in a format that is easy to digest. Patients discussed the implications of illness on employment and that employers are not supportive of their illness, or understanding of it's effects and more should be done to inform them.

Conclusion

The results demonstrate how patients' needs may be understood using an analytical digital approach. This study demonstrates important gaps in information as diet, symptoms, diagnosis, treatment, co-morbidities and highlights the importance of clinician-to-patient communication and peer advice. Finally, it highlights

the importance of presenting information in a simple and easy to understand format and implications on employment.