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Online Support Groups as a Source of Empowerment for People with Type 2 Diabetes

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Abstract

People with Type 2 Diabetes (T2D) control much of their illness by making daily decisions regarding their health behaviours. They require certain skills, information, and support, which might not be obtainable from healthcare providers, and they may seek support through other media, such as online support groups (OSGs). This study seeks to understand the role of OSGs in empowering people with T2D by thematically analysing threads and posts from two UK OSGs.

Keywords:

Patient Empowerment; Self-Help Groups; Diabetes Mellitus, Type 2.

Introduction

Diabetes is a serious chronic condition that has serious comorbidities, such as increased risk of stroke, vision loss, and kidney failure. It is a growing global threat with approximately 425 million adults diagnosed worldwide in 2017, a figure that is estimated to reach 629 million by 2045 [1]. In 2017, approximately 850 billion United States Dollars (USD) were spent on the treatment of diabetes and its complications worldwide, which is around 10% of global healthcare expenditures [1]. In the UK, approximately 4.5 million people have diabetes according to estimates, including 1 million undiagnosed cases [2].

Type 2 diabetes (T2D) accounts for 90% of all diabetes cases, and people are usually diagnosed with T2D in late adulthood [1], which makes them struggle with managing the illness. Because of its ongoing nature, people with T2D manage 95% of their condition and healthcare professionals (HCPs) only have limited control [3]. Therefore, it is especially important to empower people with T2D, since the proposed behavioural changes relate strongly to their lifestyle [4]. However, with the limited information provided during and after diagnosis, they often seek other sources of information, e.g., the Web and online support groups (OSGs), which have been shown to be effective media to provide information and emotional support for patients [5]. This is particularly important when these types of support are not readily available from HCPs.

Empowered patients are knowledgeable, skilled, and responsive to set and attain their own health goals [6]. Patient empowerment (PE) can lead to more effective communications between patients and HCPs [7], increased quality of decision making [8], improved control and management of the illness [8], and lower costs for healthcare providers [9]. Healthcare organisations around the world, including the UK [10], the EU [11] and the US [12], have set PE as a main component and have developed many initiatives to achieve this.

The Health Care Empowerment model (HCEM) identifies empowered patients as those who are engaged in the treatment of their illness, committed to it, collaborative with HCPs, informed

about treatment options as well as their rights, and are able to cope with uncertainty, which can occur during any phase of the treatment [13]. The model proposes that a dynamic interplay of contextual factors, personal resources, and intrapersonal processes can influence PE for a patient who undertakes ongoing treatment. The aim of this study was to investigate how these elements, as well as empowerment elements identified by the model (i.e., patient engagement, being informed, collaborative, committed, and able to cope with uncertainty), are influenced by the use of OSGs for people with T2D. In particular, it seeks to answer the following research questions: 1) what are the information needs and behaviours of people with T2D using OSGs? 2) how do various contextual and intrapersonal factors and personal resources influence PE for people with T2D? 3) how do patients with T2D utilise the information they receive on OSGs, and how does this influence their health behaviours?

Methods

To answer the research questions, an inductive approach, utilising qualitative methods was adopted for this study. Two UK OSGs, *Diabetes.co.uk* (DCU) and *Diabetes-support.org.uk* (DSOU), were selected, and threads from June 1st to July 31st 2017 in the general discussion sections in the groups were purposively sampled and analysed. In order to investigate the importance of OSGs in the context of empowering patients in the UK's National Health Service (NHS), members who indicated a non-UK location in their profiles were excluded from the analyses. A total sample containing 57 threads, which included 555 posts, were purposively selected (with an inclusion rate of 25% for *Diabetes.co.uk* and 17% for *Diabetes-support.org.uk* of the total sample). These threads clearly showed how the use of the OSGs helped people with T2D to manage their illness and overcome social, environmental, and intrapersonal barriers. In a number of threads, members reported how using the OSGs helped them to overcome the barriers. Members with T2D themselves posted the sampled threads and posts, not family members or friends. The first author analysed the collected threads thematically [14]. Tracy's eight criteria were followed to enhance the quality of the study [15]. Further research (i.e., interviews with OSG users) will be used to check the validity of the findings.

Prior to the data collection, the managers of the OSGs within the above organisations provided consent for undertaking the study. The study received ethics approval in accordance with the University of Sheffield Research Ethics Policy.

Results

The sample included posts from a total of 189 unique members with a mean number of 2.9 posts each. Preliminary analyses uncovered several themes, as shown in Figure 1 below.

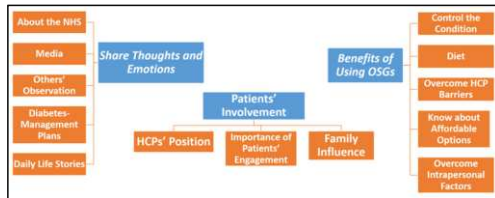


Figure 1– Map of the Themes and Sub-Themes

Members mainly benefited from the use of the OSGs to control and manage the illness, learn about dietary options, overcome barriers with healthcare professionals (HCPs), seek information about affordable options for tools to manage diabetes, and cope with intrapersonal factors (e.g., fear, anxiety, etc.). Information obtained from other members in the OSGs helped them to understand test results and set realistic plans to achieve better outcomes. Diet plans, recipes, and eating tips were widely discussed, and this clearly informed many members about eating options and how to make healthier choices. As a result, a number of members reported that the information and support they received from OSGs contributed to different elements of empowerment elements mentioned by the HCEM.

Emotions and thoughts about how members felt about the UK National Health Service (NHS), how the media was criticising the amount of spending on diabetes, and how they have been observed by others (especially employers and insurance companies) were expressed. They also discussed thoughts and plans about the management of the illness. Members also used the OSGs to share daily stories that were not necessarily related to diabetes. This was observed more in the Diabetes-support.org.uk OSG, since it is smaller in size and the members appeared to be closer to and confide more in each other.

Members had debates about whether HCPs expect them to be involved in the management of the illness, and if they are knowledgeable and capable enough to get involved in health decisions. On different occasions, they assured the importance of patients' engagement in diabetes management, especially when not receiving an effective healthcare service.

Conclusions

This study has provided a preliminary overview of ongoing research that seeks to understand the role of OSGs in empowering people with T2D in the UK. The results indicate that OSG members use the platforms to control various aspects of diabetes management. While the results answered some of the research questions, others remain unanswered; therefore, in the future, threads from the same period will be collected and analysed from a further OSG, to investigate whether these findings are present across other communities. Additionally, semi-structured interviews with current or former OSG users will be undertaken to understand in greater depth how the use of OSGs has changed their level of empowerment and to check the validity of these findings. The results of this study might help OSG moderators, HCPs, healthcare organisations, such as the NHS, friends and family members of people with T2D to understand their needs and challenges in managing the illness.

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