The Role of Online Support Groups in Empowering People with Type 2 Diabetes

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Abstract. Online health support groups and forums provide the opportunity for patients to share information, knowledge and experiences, through which they become more empowered. Empowering patients has been a desirable goal for multiple health organisations around the world: it enables patients to gain greater control over their health and, as a result, to achieve better health outcomes. When patients are more aware of their health status and daily activities, they are more realistic in setting health goals and determining the best ways to achieve them. This is especially important in chronic illnesses, such as diabetes, where patients make decisions that affect their illness on a daily basis. To be empowered, patients need to understand their role and to be knowledgeable about their illness and its consequences. Online support groups can provide different types of support for patients, helping them to better understand their illness, compare their health situation and progress to those of their peers and break their isolation by enabling communication with other patients who have the same illness. The study primarily seeks to answer questions regarding the role that online support groups play in empowering people with Type 2 diabetes and in shifting the focus of healthcare from doctor-centred to patient-centred care.

Keywords: Online Support Groups, Patient Empowerment, Patient-Centred Care, Shared Decision Making, Health 2.0, Medicine 2.0, Diabetes.

1 Introduction

Type 2 diabetes occurs when the body fails to produce enough insulin or when the cells in the body do not react effectively with the produced insulin [1]. The illness can cause serious long-term consequences, such as vision loss, kidney failure and stroke. In 2015, there were approximately 415 million people diagnosed with diabetes around the world and the figure is estimated to increase to 642 million by 2040 [2].

Type 2 diabetes is a self-managed chronic disease in which patients control more than 95% of their care and health providers have little control over the management of the illness [3]. Patients with diabetes make daily decisions related to the management of their illness within the context of their personal goals, priorities, family and work demands and health issues. They have the right to set their health goals and decide the best ways to achieve them, as well as to carry out those decisions and take responsibility for the consequences. Therefore, it is especially important for diabetes care to change the focus from doctor-directed care to patient-directed care. Online support groups (OSGs) have the potential to provide patients with the required information and support that would make them active during the care process.

In order to successfully achieve a patient-directed approach, patients need to be empowered to make informed decisions and to manage their diabetes effectively. The
social environment plays a significant role in facilitating empowerment for individuals [4,5]. OSGs are reported to serve as a new supportive environment that can meet patients’ needs to be empowered [6]. OSGs are found to provide emotional, informational and relational support for their participants that results in the improvement of their sense of control, self-confidence, feeling of independence and social interaction skills [7].

This research focuses on patients with Type 2 diabetes since they form approximately 90% of the diabetes population [1] and, unlike people with Type 1 diabetes, they are usually diagnosed with the illness in older age, which makes them struggle in the transition phase and seek different types of support. It is therefore important to understand the role of OSGs in empowering patients with Type 2 diabetes.

2 Literature review

Patients are empowered when they have the required skills, knowledge and self-awareness to set and attain their own health goals [8]. When patients are empowered, there is more effective communication between healthcare providers and patients [9], an increased quality of decision making [10], improved control and self-management of the illness [10], increased patient satisfaction [11] and lower costs for health providers [12]. There have been many attempts to foster empowerment in healthcare systems around the world, including the UK [13], the US [11,14] and the EU [15]. Empowerment is seen both as a process, in which the goal of an educational intervention is to increase individuals’ ability to think critically and to act independently, and as an outcome, when an enhanced self-efficacy results from the process [16]. Empowerment for people with Type 2 diabetes aims to help them choose personal, meaningful, realistic goals that are related to weight loss, nutrition and physical activity [16]. Its intention is to improve patients’ quality of life by enabling them to take responsibility for their own health via recognition and promotion of individual strengths, personal goals and informed choices [17], which can contribute to health improvements [18].

Connecting to other patients who have similar health conditions has also been associated with positive outcomes in the literature [19,20,21], and OSGs provide a means for patients to connect with each other via the Internet. OSGs are created to gather people with similar health conditions in one virtual space. They are reported to provide information and emotional support [22,23], which are reported to be significant predictors of patient empowerment [10]. While previous studies have outlined positive processes that take place in OSGs as empowering and negative processes as disempowering [22,23], few studies have investigated whether the positive processes result in positive outcomes. To evaluate the role of OSGs in empowering people with Type 2 diabetes, and to analyse the connection between positive/negative processes in OSGs and positive/negative outcomes for these patients, this study will use the Health Care Empowerment model [24] and the Diabetes Empowerment Scale [25]. The aim of the study described here is to develop a better understanding of the role of OSGs in empowering people with Type 2 diabetes.
3 Methods

The study will consist of two phases. Posts from selected diabetes OSGs will be collected and analysed thematically [26]. Themes related to patients’ health decisions will be captured, including but not limited to: patient-doctor relationship, treatment decisions and lifestyle and diet-related decisions.

Based on the results of the thematic analysis, the second phase will involve a direct study of people with Type 2 diabetes who are users of OSGs. The study will explore how OSG users fulfil their information needs and seek health information. Information behaviour theories and models will be explored to understand how OSG users interact with the information they receive through the support groups. The analysis of the collected data will follow Marshall and Rossman’s six-phase guideline: (1) organise the data; (2) generate categories or themes; (3) code the data; (4) test emergent understandings of the data; (5) search for alternative explanations of the data; and (6) write up the data analysis [27].

The study will purposefully select OSGs that are publicly available and in which the terms and conditions make it clear that the posts may be used for research purposes. The study will follow the Ethics Guidelines for Internet-mediated Research of the British Psychological Society [28] and the University of Sheffield [29]. The administrators/moderators of the groups will be contacted to request permission to analyse the posts. Members of the groups will be anonymized and will not be identified explicitly or by implication in the research. Furthermore, any quotes from the collected posts in the research will be paraphrased to ensure that members of OSGs cannot be traced via search engines.

4 Findings

A pilot study encompassing thematic analysis of posts from Type 2 diabetes OSGs and semi-structured interviews with current or former OSG users will be undertaken to investigate the role that OSGs play in forming and changing patients’ decisions and empowering them. Since the purpose of the study is to develop a better understanding of what makes patients empowered through the use of OSGs, the findings will be of value both to health organisations and to organisations hosting OSGs.

References

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