

The Benefits of Using Online Health Support Groups for Information Acquisition for People with Type 2 Diabetes in the UK

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Type 2 diabetes (T2D) is a self-managed chronic condition that requires certain skills and knowledge to manage, both by patients and health care professionals. People with T2D take daily decisions regarding their health and are responsible for the consequences. This creates a need to use different resources to obtain the required knowledge and the skills to control and manage the condition. This paper reports on a study investigating the advantages of using online health support groups (OHSGs) for information exchange for people with T2D in the UK. In this paper, we collected data from 814 threads and posts from three diabetes UK-based OHSGs and analysed these using thematic analysis. The thematic analysis revealed three main benefits of using OHSGs for information acquisition: (1) fulfilling information needs, (2) overcoming barriers and (3) supporting control and management of the condition. The results suggest that OHSGs serve as an excellent source for information acquisition for people with T2D.

Keywords

health 2.0, information acquisition, medicine 2.0, online health support groups, type 2 diabetes.

1. Introduction

Diabetes is a serious threat to worldwide public health and a major cause of morbidity and mortality [1]. In 2017, 451 million adults had diabetes in the world and the number is estimated to reach 693 million adults by 2045 [2]. The condition affects a number of organs including heart, kidneys, eyes and blood vessels and can, therefore, cause serious complications such as heart attacks, nerve damage, blindness and kidney failure [3]. The condition caused approximately 5 million deaths in 2017 [2] and accounted for an estimated 11% of healthcare expenditure worldwide [4].

Type 2 diabetes (T2D) is the most common type of diabetes as it accounts for around 90% of all diabetes cases and is a result of not producing enough insulin in the body or the failure to respond to the produced insulin [5]. People with T2D are usually required to modify aspects of their lifestyle such as diet and physical activities [6]. Around 95% of the treatment in T2D is carried out by the patients themselves and healthcare professionals (HCPs) have limited involvement in their care [7]. This requires patients to use different resources, such as peer-to-peer support groups, to acquire the required skills and knowledge to control and manage the condition effectively.

2. Literature Review

Peer-to-peer support groups date back to the 18th century [8] and are based on the idea that people who share the same physical and mental conditions might understand each other more and provide emotional and information support for one another more effectively [9]. More generally, it is believed that life challenges can be faced better when having support from a group of people experiencing

similar situations [10]. Cline [11] indicated that people living with life-threatening and chronic illnesses find mutual aid and self-help in support groups. Benefits from support groups include enhanced decision making, improved life quality and increased lifespan [12]. The literature has shown that peer-to-peer support has a positive impact on patients [8,13-15].

The support can take many different forms and media [16]. For example, face-to-face support groups started forming to connect patients who have similar health conditions [8]. OHSGs are a virtual version of physical support groups in which people with similar health issues can meet on an online platform and exchange information and experiences and support each other. Different forms of OHSGs have been created over time since the 1980s [17]. For instance, email lists and chat rooms were developed to enable people who share the same health interests to contact each other and to gather. More organised communities were established when web-forums were introduced to the Internet. Web-based forums were reported to be the most popular form of communication among patients due to their easy-to-use and friendly design [18]. Patients use OHSGs to break their isolation, get more information about their illness, express their feelings and receive support from others [19]. The use of OHSGs can be influenced by many factors, such as the nature of the condition and contextual factors (e.g., the healthcare system where the discussion is taking place). Information behaviours can also be influenced by various factors which might serve as supportive or preventive, as explained by Wilson's Information Behaviour Model [20]. OHSGs can also help patients change their health behaviour. Patients move through different stages when changing their health behaviour, as explained by the Transtheoretical Model [21]:

- *Pre-contemplation*: no plans have been thought about to perform any activity during the following six months.
- *Contemplation*: a plan is intended to be performed within the following six months.
- *Preparation*: there is an intention to take action within the next month and has taken few behavioural steps.
- *Action*: individual's behaviour has been altered for fewer than six months.
- *Maintenance*: changed overt behaviour for more than 6 months.

To date, there have been no in-depth studies on the benefits of using OHSGs for people with T2D in the UK context. This paper aims to fulfil this gap by investigating how the use of OHSGs benefit people with T2D and how they consequently alter their health behaviour.

3. Methods

An exploratory qualitative methodology was adopted for this study. Three popular, publicly-available UK-based diabetes OHSGs were identified (Diabetes.co.uk [DCUK], Diabetes.org.uk [DOUK], and Diabetes-support.org.uk [DSF]). Following ethical approval from The University of Sheffield, OHSG moderators were approached to obtain their consent to collect and analyse threads and posts from their platforms. To help the researchers to sample the data and limit the number of threads and posts in the sample, a two-month sampling period was chosen (June-July 2017). Data were collected from the general sections/boards of the OHSGs since they contain a wide range of topics and are the most active parts. Only threads and posts posted by members with T2D were included. The sample of threads and posts was purposively selected. Since the study is focused on the UK, users that indicated non-UK locations in their profiles were excluded. The data were then downloaded, anonymised and coded using NVivo 11. Quotes reported in this paper were rephrased to minimise the risk of identifying members and all names have been anonymised. The data were analysed by following Braun and Clark's [22] six-step approach to thematic analysis. The research literature and previous studies were used to interpret the results but not to guide the analysis, which was undertaken inductively. To ensure the quality and validity of the study, regular meetings were conducted through the data collection and analysis between the authors to discuss initial codes and initial and final themes as well as applying Tracy's eight steps in qualitative research quality [23].

4. Results

The sample included 814 threads and posts from 250 unique members across the three platforms. A number of key themes emerged from the analysis. This paper focuses on the benefits of using OHSGs for people with T2D, and the three main sub-themes within this overall theme as illustrated in Figure 1.

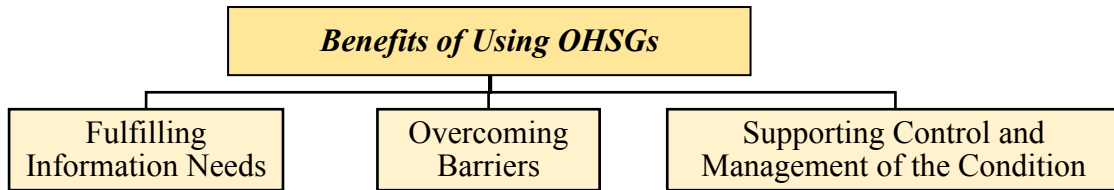


Figure 1 Subthemes of the theme: Benefits of Using OSGs

4.1 Fulfilling Information Needs

The members of the OHSGs fulfilled their information needs about different aspects influencing their understanding of diabetes, which resulted in satisfying a knowledge gap about the condition. Many members stated that the OHSG was their main source of information about T2D. The use of OHSGs as an information source helped many users to overcome the lack of information from health care professionals (HCPs), to know about treatment options and techniques that were not introduced by HCPs, either because they did not agree with these treatment options and techniques or did not have the time to introduce them, and to find information about where to find affordable tools and equipment. For example, members stated how they discovered new information about different issues by using OHSGs. They compared the knowledge they received from the OHSG with other sources of information (e.g., HCPs, educational courses) and that they had before joining the online platform. Some examples of such views are as follows:

“Through the past years, I have learned from this OHSG way more than I learned from my HCPs, my advice is to use this OHSG as your primary information source” (DOUK- Emily)

“I am learning many things about my Type 2 diabetes, all from this OHSG” (DCUK- Alexis)

The information and experiences shared in the OHSGs helped some members to become aware of their unhealthy living habits, which had resulted in their diabetes being poorly managed. The platforms were also helpful to many members, especially for obtaining information about less-known diet options, such as low carbohydrate (LC) programmes. This is mostly because there is considerable debate around such programmes and the National Health Service (NHS) in the UK does not support this approach [24]. Some members, for example, reported their understanding of different LC programmes from other members in the OHSG:

“I was newly diagnosed and learned about the low carbohydrates high fats (LCHF) programme from your helpful posts which helped me to set my LCHF diet plan.” (DCUK- Maria)

“I was horrified when I was diagnosed a few months ago ... friends told me about the LCHF diet and have been reading about it here thereafter ... this is a great OHSG! Thank you all for your posts” (DOUK- Katherine)

These messages about diet programmes were often posted alongside food recipes, which aided members to prepare healthy meals. Consequently, this helped them avoid eating unhealthy food, which might negatively influence the management of their condition:

“I’m reading now and learning about different recipes on this OHSG that I can prepare and eat during lunch breaks and snacks to avoid eating from fast food restaurants” (DCUK- Bryan)

In addition to fulfilling their diet-related information needs, members of the OHSGs also used the platforms to gather information about how and where to find tools and equipment (e.g., self-monitors of blood glucose) and vitamins related to diabetes:

“After reading about the acid here, I have tried it for around three weeks. My blood sugar levels are kind of lower and my feet pain is significantly reduced! ... Thank you Alexis! I ordered the supplement

form the link you provided. It's much cheaper than the website I found. I have also applied the extra discount you told me about! Many thanks" (DCUK- Mary)

Besides fulfilling their information needs about diabetes and diet in general, members also expressed how they obtained information from the OHSGs about different topics and techniques they had not known before, such as hypoglycaemia, food-tracking techniques and how to interpret blood testing results:

"I am still learning about hypoglycaemia. Your post made me understand it more, it now makes more sense for me" (DCUK- Katelyn)

"Now I understand what my testing results mean. I found the page you referred me to very helpful. Many thanks!" (DOUK- Phoebe)

In summary, this sub-theme shows that the OHSGs were used as information sources by their members. Queries might come from people being newly diagnosed and not having experience with diabetes and from people who did not find the information provided by HCPs to be useful or comprehensive. Many members reported that the information they received from the health care system was not as informative as they expected. They obtained more practical information from the OHSGs that helped them to control and manage their condition. For example, a member was informed that he had T2D but was not provided with any information about the condition. He therefore used the OHSG to fulfil his information needs. Another member wanted to know how to evaluate the effect of different types of food on blood sugar levels. She acquired information from the OHSG that testing blood glucose levels before and after eating could help her know what food types affect her negatively (e.g., raise their blood sugar to very high levels) and which helped her control her diabetes. Members also obtained information about different perspectives of controversial topics, such as LCHF.

The knowledge and experiences exchanged in the OHSGs fulfilled some of the members' information needs. Additionally, some members were aware that diabetes is not a static condition and that what works for one person might not work for another. Therefore, members used the OHSGs to navigate through threads and acquire information about different topics to research what could work for them, because the information provided by their HCPs might not have been personalised and might be given to all patients without considering individual differences (e.g. different body reactions to certain medications, food and activities and different lifestyles):

"Diabetes is not the same for all of us! It is different for each person, what works for one does not usually work for all of us. We need to make personal adjustments to reach a balanced point" (DCUK- Lillian)

Accessing additional sources to stay informed and gain the knowledge they need to maintain a high level of participation in health care, which are two main components of health care empowerment [25], show the high level of engagement of OHSG members with their treatment.

The use of the platforms as information sources also shows the trust members have in each other. They believed in other members' experience and knowledge even though they lacked medical expertise. Members often stated that they valued others' experience more than knowledge from HCPs: this is explained in more detail in the following sub-theme (4.2). The use of the OHSGs as informational sources helped many members to successfully self-manage diabetes and overcome different barriers. The following two sub-themes will explain the consequences of using the platforms as information sources to fill a gap in members' knowledge.

4.1 Overcoming Barriers

The informational and emotional support exchanged in the OHSGs helped many members to overcome barriers such as poor communication, limited time with HCPs, unfulfilled informational needs and the use of complex medical language by HCPs. For example, poor communication between health care providers and patients is a challenge in diabetes care that can result in lack of information provided by the health care team [26]. Members posted to clearly express how they found the information they needed in the OHSG and which their HCPs did not provide, as explained below:

"I believe that I was not offered with the information I needed. The leaflet and HCP did not provide the information I needed. I found the information I needed here, after scanning the OHSG" (DCUK- Bryan)
"I received more personal service here in the OHSG more than any HCP I have tried ... I didn't know how little I knew until I joined this OHSG" (DCUK- Justin)

Others experienced a lack of support from their HCPs (e.g., poor communication, limited time in appointments), which led them to use the OHSG instead to learn about the condition:

"All information I received about my condition was via this website only ... I barely see my HCPs ... they love to blame me ... all negative things are my fault ... they disagree with all information on this website" (DCUK- Brian)
"I have a question about my medications ... where I live there is not much help for diabetes ... it has been over a year since I saw my HCP ... I need to pay to see private healthcare services" (DCUK- Danielle)

Seeking information from other peers in the OHSGs was regularly observed to overcome barriers that resulted from a disagreement on certain topics between HCPs and patients. For example, members shared threads and posts about their meetings with an HCP and how they were disappointed with the discussion and that the meetings were of very limited value. They then asked questions and shared their plans to manage the illness with other members to get their feedback:

"I was completely unhappy with the meeting! I even had to pay to see him! I was aiming for an interesting conversation about my diet options and physical activities but he was so narrowed to the system's guidelines. I believe I know better about what works for me, I will carry on with the low-carb diet to control my blood glucose level" (DCUK- Justin)
"My HCP laughed at me when I asked her about the possibility that I (and Type two in general) could get a hypo! Even though she prescribed me [name of drug] whose leaflet clearly states that having hypos is a possible side-effect!" (DCUK- Katelyn)

This is particularly noticeable in controversial topics, such as self-monitoring of blood glucose (SMBG) and low-carb diets. For example, OHSGs members described how they were not offered the help and information they needed when they mentioned to their HCPs that they were on a low-carb diet or SMBG. This debate and different views on controversial topics were confusing for some members who had just been diagnosed with diabetes and lacked trust in their HCPs. They used the OHSGs to acquire the information they needed and to overcome this lack of trust they had towards their HCPs:

"To be honest, I do not have trust in my HCP, as I knew the problem was with my diet and carb intakes, I started reading on this OHSG before seeing him. The first thing he gave me is a pack recommending eating starchy carbs, which in opposition to what members are saying here" (DCUK- Jacqueline)

Other members posted messages to learn about different types of glucose meters and what was the appropriate one for them would be because their HCPs, believing that they did not need to self-monitor, did not provide them with this information:

"Thank you John and Mary! That's exactly what I wanted ... My HCP told me I would not get hypos while taking [name of drug], so a meter was not required ... I told them I am planning to get a meter to see how food influences my blood sugar ... I believe it's all about cutting the cost" (DCUK- Riley)
"My HCP has been prescribing me test strips ... when I went to the pharmacy today I discovered that he stopped them ... where can I find the cheapest place to buy them?" (DCUK- Evan)
"I think people on the OHSG are lucky to learn about self-monitoring because the NHS does not support it ... I feel sorry for the other 3 million people in the UK who have T2D and don't know about it" (DCUK- Ryan)

The OHSGs were also used to overcome intrapersonal factors, such as fear. For example, on different occasions, members posted about their fear of having low blood sugar level or of other issues related

to diabetes (e.g., not being able to have children). Other members provided the emotional support needed to help members who felt panicked. In the case of having low blood sugar level, for instance, other members tried to calm the person down and explained that it might be a false hypoglycaemic attack, also called a 'hypo'. Other members described the symptoms of the false hypoglycaemic attacks, advised them not to drive and supported the member emotionally to help them overcome this negative feeling. This kind of support had a positive impact on members, as shown in the examples below:

"I was home by myself only, so that's why maybe I got worried. Thank you all for your advice. Next time, I will not panic" (DCUK- Abigail)

"Many thanks to all of you. I really value your support. I feel relieved when I read that's quite normal" (DOUK- Phoebe)

"Your posts gave me the courage, self-esteem, hope, support and confidence to overcome my fear" (DSF- Sofia)

Another member expressed their feelings about their addiction to sugar and carbohydrates and how that resulted in managing their diabetes in a negative way. This member expressed their attempts to decrease the amount of sugar intake. However, they were still afraid of the future because of their addiction to sugar. Other members shared techniques to reduce sugar intake and their experience with the member and assured them that this fear could be overcome. After 12 months, the member reported in the same thread, their success in removing sugar from their diet:

"It has been 12 months and I am free from sugar today ... I have lost weight too ... my blood sugar is never high ... my HbA1c is in the normal range" (DCUK- Tracy)

Tracy, in this example, feared having a relapse after cutting sugar from her diet. She and other members compared sugar to alcohol or heroin and described it as an 'addiction'. They shared their previous attempts to reduce their sugar and carbohydrate intake, which lasted for a long period of time. Tracy, for example, had previously tried to cut out sugar but she relapsed after a year. She was therefore afraid to repeat the same scenario again with further (unsuccessful) attempts. The OHSG was therefore perceived as an important source of support for her to reach her goal. She updated the thread occasionally and received support and encouragement from other members. The OHSG, in this instance, served as a source of emotional support that helped members to overcome strong fears.

In summary, OHSGs were found to offer support to members with T2D to overcome barriers and help them control and manage their condition effectively. Members were found to seek information from the online communities when there was a lack of information from HCPs, poor communication, a long waiting time, disagreement and lack of trust. Additionally, they used the platforms to cope with fear and anxiety, which were partly caused by having diabetes. This sub-theme shows how the use of OHSGs can be helpful to overcome different barriers and problems, some of which can be extreme. Other members' knowledge, experience and support assisted members in these OHSGs to cope with various difficulties, making OHSGs a valuable source of support. Being well informed about diabetes and overcoming barriers resulted in good control and management of the condition, as explained in the following sub-theme.

4.3 Supporting Control and Management of the Condition

Members described how the knowledge and support obtained from OHSGs helped them control their illness in general. The word 'control' here refers to the daily blood glucose checking whereas 'management' refers to the long-term overall attempt to maintain a healthy lifestyle. To manage the condition successfully over time, a person needs to adopt a healthy lifestyle and change behaviours in terms of physical activities, eating habits, medications, setting and achieving realistic plans, knowing possible barriers, etc. In this sub-theme, members of the OHSGs expressed how the use of the OHSGs helped them to achieve day-to-day control and overall management of the condition or introduced them to techniques and skills that helped them to do this. For example, members expressed how the information and support they received from OHSGs helped them to manage the overall aspects of their condition:

"I love this OHSG, over the past few years, it helped me to control my diabetes" (DCUK- Sydney)
"We are lucky enough to belong to this community which has useful information and experiences that help us to manage diabetes" (DCUK- Daniel)
"My HbA1c dropped from 11 to 6 in six months. Many thanks to this OHSG. I have been a silent member and learned a lot from all of you. I will try to contribute with my experience" (DCUK- Henry)

More precisely, members learned about specific skills and techniques that helped them to control the condition. For example, members learned from their peers on the OHSGs about the importance of keeping records of test results and food intakes. Keeping a record and being aware of test results and daily food intake are recommended long-term practices for people with diabetes to manage the condition effectively [27]. Members of OHSGs advised others repeatedly to adopt such techniques to control the condition. Members who received this advice reported on their adoption of the techniques, as explained in the examples below:

"I understand that I should have kept a record of my test results. However, I was kind of confused and did not have a clear plan. Thank you for your advice here, I will ask to have printouts after each test and keep them. I did not know that I can do that before! I have also bought a diary to keep tracking my diet" (DCUK- Bryan)
"I have started a food diary after reading your comments ... I now realize it is very important ... I think my meals going to be healthier" (DCUK- Hayley)
"I now understand what caused the spike in my blood sugar level. As you recommended, I went through what I had eaten during the last few months and I think it's all because of the fast food I eat for lunch, due to my work nature. As Sally recommended, I will have a plan to control that and take care of what I am eating" (DCUK- Bryan)

While there is some debate around whether SMBGs are useful for people with T2D or not [28,29], the guidelines from the National Institute for Health and Care Excellence (NICE) in the UK do not, generally, recommend HCPs to advise patients to self-monitor their blood glucose levels except in a few circumstances (e.g., if the patient is taking insulin or is pregnant) [30]. This debate was also largely present in the OHSGs. However, the majority of members believe that their SMBG is essential to manage the condition effectively; therefore, they advised others to self-monitor even though their HCPs did not advise them to do so. For instance, members who were advised to self-monitor reported a positive improvement in the overall management of their condition:

"It has been a month of having the meter. It has been a great improvement in my blood sugar! For those who are new in diabetes: members here ARE RIGHT! You MUST have a meter to adjust your diet and sugar level" (DOUK- Jacob)
"My HCP advised me not to self-test and just do the quarterly HbA1c tests. When I joined the OHSG I was highly advised to test which I did and has been the best advice I received which helped me to control my diet" (DOUK- Isla)

Similarly, members learned about different diet options, which resulted in better management of their condition as explained below:

"A few years ago, I was diagnosed as a pre-diabetic. As I'm taking a medication for another condition, it changed my diet habits and resulted in my blood sugar to be in the diabetic range. So, I decided to alter my eating habits and found very useful information about LCHF in this OHSG which I followed. Now, I'm back to the pre-diabetic range!" (DCUK- Paige)

This shows how the knowledge and support exchanged in OHSGs might contribute to better control and manage diabetes. While some members explicitly reported the pieces of information they learned from OHSGs that helped them to control and manage the condition (e.g., learning about diet options), others referred to the overall knowledge and support obtained from the OHSGs. However, overall, the information and support obtained from OHSGs helped members to learn more about the condition and overcome different barriers which resulted in better control and management of the condition. Members were not previously aware of the information they received on the OHSGs, either because their HCPs did not agree with the advice or had not received such information elsewhere. Therefore,

exchanging experiences among members across the OHSGs allowed some members to learn skills and acquire knowledge that is useful for controlling diabetes.

5. Discussion

The findings revealed that members used the OHSGs at different stages to acquire information and support that would assist them in taking and maintaining their actions/behaviours. As the Transtheoretical Model [21] explains, people move through a set of stages when changing their behaviours. For instance, in the preparation stage, members asked their peers about the number of carbohydrates the low-carb diet involves. They were convinced that the diet would help them and took the first steps to start it. Members reported their progress after a few months of making a health action based on the information they obtained from the OHSGs, which means they can be classified as being in the action stage. For the most part, they posted in the OHSGs to share their positive progress (and, consequently, to receive encouragement), to express appreciation of peers who had helped them, or to seek more information about the action taken. This can also be explained by Wilson's [31] model of Information Behaviour, which suggests successful fulfilment of information needs and use usually creates another need. However, relapse to old unhealthy behaviours usually occurs during the action or maintenance stage of the Model [32]. Members used the OHSGs as a source of support during the maintenance stage to overcome barriers. The findings suggest that members used the OHSGs mainly to obtain information support in the preparation stage, information and emotional support in the action stage, and emotional support in the maintenance stage of their condition.

Users used the OHSGs to fulfil their informational needs that arose from the lack of support received from HCPs, a desire to find new information related to the treatment of the condition and psychological factors with having the condition (such as the need of information assurance and support to control and manage the condition). This was explained in Wilson's model [20], which explained that psychological, demographic, role-related or interpersonal and environmental factors as well as the characteristics of the source, influence information-seeking behaviours. These may support or prevent a person from initiating or completing information-seeking behaviour. In the results, the factors led users to initiate an active and ongoing search to satisfy their informational needs. The supportive and non-judgmental nature of the OHSGs also supported users to engage in the communities. This additionally helped them to enhance their self-efficacy and, as a result, achieve their health goals.

6. Conclusion and future work

This study identified the advantages of using OHSGs for people with T2D in the UK.

Members of the three OHSGs highlighted the importance of using the platforms. They repeatedly explained how the platforms helped them fulfil their informational needs, overcome different barriers and, as a result, control and manage the condition more effectively. It is, however, quite possible that using the platforms might also have affected their members negatively. This, however, was not identified through this stage of the study. The next stage of the study aims to interview current and former members of the platforms to investigate this in a greater detail and develop a more nuanced understanding of how people with T2D use OHSGs.

Abbreviations

DCUK: Diabetes.co.uk

DOUK: Diabetes.org.uk

DSF: Diabetes-support.org.uk

HCPs: Healthcare professionals.

LCHF: Low-carbohydrates high fat.

NHS: The National Health Services.

NICE: The National Institute for Health and Care Excellence.

OHSGs: Online health support groups.

SMBG: Self-monitoring of blood glucose.

T2D: Type 2 diabetes.

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