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Version 1

Original Research Paper

Patient generated ‘Frequently Asked Questions’: Identifying informational needs in a RCT of peer support in type 2 diabetes

Running head: Patient generated questions in peer support in T2DM

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Abstract

Aims: The purpose of this study is to discuss the use of a system of patient generated "frequently asked questions" (FAQs) in order to gain insight into the information needs of participants.

Methods: FAQs generated during group meetings taking place in a randomized controlled trial of peer support in type 2 diabetes are described in terms of their frequencies and topic areas. Data from focus groups and semi structured interviews concerning the FAQs was subjected to content analysis.

Results: 59/182 (33%) of the FAQs were directly related to the topic area of the scheduled peer support meeting with foot care, eyes & kidneys generating the most specific questions. The FAQs addressed mainly knowledge and concerns. The FAQs appeared to enhance peer support and also enabled participants to ask questions to experts that they may not have asked in a clinic situation.

Conclusions: The use of FAQs to support peer supporters proved beneficial in a randomized controlled trial and may be usefully added to the tools used within a peer support framework. The use of FAQs provided valuable insight into the informal information needs of people with diabetes. Means of providing a similar structure in routine clinical care should be explored.

Keywords: type 2 diabetes; peer support; health information; frequently asked questions

Introduction

Peer support is a strategy that has been widely promoted as having the potential to improve physical, emotional and psychological health, and to support behaviour change and self-care across diverse conditions and population groups[1-3]. The main objective of peer support interventions is to provide support based on the sharing of information and experience, mutual counselling and exchange among 'peers'[4]. However, peer support is generally ill-defined and can vary in terms of structure and formality. One formal definition of peer support is “the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person”[4]. According to this definition, peer supporters generally offer three types of support: emotional, appraisal and informational. All three types of support are based on experiential knowledge, rather than arising from formalized sources. However, there is often a need expressed for professional input in the context of peer support[5].

This may not be surprising as information giving and self management training in the clinical setting for patients with diabetes has been shown to be poor[6], in spite of evidence that supports its effectiveness in the short term in improving outcomes[7]. The reasons for knowledge deficits in patients are diverse but include inconsistency in information provision, lack of motivation and lack of awareness that knowledge was poor or incomplete[8, 9]. Peer support may provide an opportunity to address some of these areas. Participants in a pilot study within the exploratory phase of a randomized controlled trial of peer support in type 2 diabetes[10] requested a system to address questions that arose from the peer group for which a professional response was deemed helpful[11]. This was discussed among the trialists and as a result an opportunity was

provided for the groups to identify questions in each session that they could not answer but would like answered with professional input. We set out to explore this process through an analysis of the content of the “frequently asked questions” and through interviews with both peer supporters and participants within the trial in order to gain insight into the additional information needs of participants with Type 2 diabetes that may not be addressed through formal routes.

Deleted: Within this paper, the authors discuss the use of this process of “frequently asked questions” in order to gain insight into the additional information needs of participants with Type 2 diabetes that may not be addressed through formal routes. The authors also describe the feedback received during the qualitative process evaluation of the trial from peer supporters and participants concerning the “frequently asked questions”.

Methods

In a cluster randomised controlled trial twenty general practices were assigned to control and intervention groups, respectively[12]. Each practice compiled a diabetes register and randomly selected 21 patients to participate in the trial. All practices implemented a standardised diabetes care system. In the intervention group all practices recruited two or three peer supporters each of whom ran a group for approximately seven patients. 29 peer support groups were formed in the ten intervention practices. The primary outcomes of the trial (HbA1c, blood pressure, total cholesterol, and the Diabetes Well-being score) are reported elsewhere[10]. The peer supporters were trained to conduct nine group meetings in their general practice over a period of two years. The full details of the intervention components and the training received by peer supporters is reported elsewhere[10] and summarized in Box 1.

Deleted: were

The exploratory phase of the trial revealed that both peer supporters and participants agreed that each peer support meeting should have a focus and a short structured component, e.g. a ten to fifteen minute discussion on a particular aspect of diabetes management which was incorporated into each meeting in the main trial. The themes of the meetings are outlined in Box 2. Peer supporters also received additional information including a list of potential questions to put to the group on each topic. A system was developed to address questions that arose from the peer group

that they were unable to answer themselves or for which a professional response was appropriate. It was agreed that at the end of each meeting there would be a general discussion and the group would identify and record any questions (“Frequently Asked Questions” or FAQs) regarding the session topic. The questions from all the groups would be distributed to appropriate members of the multi disciplinary research team, who would develop answers from the existing evidence base and their clinical experience. The answers were discussed and commented on by the whole team and checked to ensure their readability and presentation in lay language by the lay member of the research team. The questions and answers from all groups were combined into one document and sent back to the peer supporters who presented and discussed them at the start of the next meeting.

The “frequently asked questions” (FAQs) were then compiled from eight group meetings (the final meeting did not contain FAQs). Each question was categorized into a topic area, based on the topics of the peer support meetings. They were also categorized according to the emphasis of the question – related to whether the question was seeking knowledge or addressing a concern of either an individual or the group. Frequencies were computed and comparisons made with the meetings from which the FAQs arose.

As part of the process evaluation of the main study, focus groups and semi-structured interviews were carried out at the conclusion of the trial with both peer supporters and participants to explore the experience of peer support. The transcripts were subjected to content analysis. Content from the transcripts that related to the FAQs is included in this paper.

Results

29 peer support groups were formed in the ten intervention practices. 182 FAQs were fed back from the peer support groups over the eight peer support meetings (Mean 22.7, Median 24) with between 12 and 29 emerging from each round of meetings. Table 1 indicates the topic areas that were raised from the peer support meetings.

59 (32%) of the FAQs were directly related to the topic area of the scheduled meeting with foot care, eyes & kidneys generating the most specific questions. Analysis of the FAQs suggested that they were addressing two main areas: informational knowledge and concerns.

Informational Knowledge

84/182 (46%) of the FAQs appeared to be requesting informational knowledge. These questions covered most areas from general diabetes to specific complications:

Is there only type 1 and type 2 diabetes?

Heart disease may be stopped if diabetes was diagnosed early, why so late?

What is HbA1c and what is the reason for it and what does it show?

Can damage caused by neuropathy ever be reversed by medication and if so do you have to stay on medication for the rest of your life?

Why do consultants [diabetes physicians] have to be reminded to check patients' eyes and feet?

Deleted: *What place do 'ACE inhibitors' have in the treatment of diabetes?¶
What are enzymes?¶*

Other questions appeared to be seeking knowledge but perhaps based on some individual concern:

Does stress increase blood sugar levels?

Can diabetes cause problems with your teeth?

Is it ok to wear socks with a hot water bottle in bed?

Concerns

The remaining 98/182 (54%) of FAQs addressed concerns that were held by the peer support group or individuals. These fell into several categories. The largest group of concerns (56 FAQs) was requesting information on symptoms or problems that may have been experienced by one or more members of the group:

Tingling in the right jaw in the afternoon after exercise – any cause for concern?

What causes thirst at night times?

Is there any advice for someone who, when out walking, tends to weave from side to side?

Does diabetes medication affect male libido?

Deleted: Do some medications make your blood sugar go up? Particularly interested in warfarin.¶

The other large area of concern (21 FAQs) was related to diabetes management:

Why does your blood sugar take so long in coming down after taking insulin?

Why are there such difficulties arranging chiropody appointments?

Is it alright for people with type 2 diabetes to take glucosamine for arthritis?

Two further areas of concern related to the future treatment of diabetes and to financial support:

As people get older do they have to have insulin?

Fish is becoming so expensive in recent times. Any alternatives?

Is there an allowance for people with diabetes in terms of food and footwear?

Qualitative data

Data from the semi-structured interviews with peer supporters and participants focus groups revealed that the FAQs were highly valued, with superlatives such as *'brilliant'*, *'wonderful'* and *'fantastic'* being used to describe them. This was related to several perceived benefits:

Continuity between meetings

'the first thing I would always do at these meetings was to go through the answers to the questions from the previous meeting so there was that continuity' (PS3)

The FAQs were considered integral to each meeting:

'I discussed that at every meeting. I took it out ... we discussed that at length and there was a lot of interesting things to come up on that' (PS2)

'if you couldn't answer them in the group and PS couldn't answer it straight off he'd say he'd get them and he'd have them back for us the next time on paper, all the answers to the questions' (FG5, R3)

Provoking peer discussion

One participant identified that they never referred a question back to the 'expert' group but answered them all within the meetings either between themselves or from questions from other groups

'I don't think we ever left a question to be answered, we always got it sorted out ourselves didn't we? If somebody asked it, somebody would come in and say 'oh well I asked that before and I got this answer' (FG1, R1)

One participant outlined the two levels involved in the FAQs – benefitting both from the peer discussion of questions and the 'expert' answers:

Deleted: *'it was nice to talk about your – talking about where it's affecting each other and we could ask each other questions and if there was any questions that we didn't finalise that we could notify you and we got it at the next meeting'* (FG1, R6)

'what you were really doing was finding out how the other half gets on and I think that we got far more information from the likes of us than we did from anyone else. We were told things that we were entitled to that we knew nothing about, you know, people never explain to you 'you can get this or you can get that or you can get the other' and no-one has ever went around and told us – to explain what diabetes is, no-one ever said an awful lot with it' (FG2, R2)

Comfort with asking questions

Participants felt comfortable to raise the questions. This was contrasted with experiences with the formal health services.

'the questions and answers which I thought were absolutely magnificent, they were brilliant and they were all questions that were asked by participants in other groups and they came back and people said 'Jesus, I didn't think of that' (PS2)

'there was nothing you couldn't ask questions about or tell them about' (FG4, R7)

The answers

Many of the concerns in the questions focus on basic day-to-day issues and most participants considered the responses may be best used in a forum of shared experiences. The manner in which the questions were answered was valued by participants:

'clarity is much more important than trying to make an impression' (PSfg2, R2)

It was suggested that the questions and answers be reproduced and distributed to people with diabetes as a lasting legacy/resource from the study. The questions and answers were treated as a resource by some of the participants

' they kept them all, believe it or not, all the questions, the group members particularly wanted them ... and they said they used to take them out and read them over' (PS3)

Deleted: *'actually I have all the leaflets at home now in a folder and I can look back on them .. like if I forget anything, you know, look up was that answered in such a meeting'* (FG1, R4)¶

Discussion

The use of FAQs to support peer supporters proved beneficial in a trial situation and may be usefully added to the tools used within a peer support framework. Within the trial carried out on peer support in type 2 diabetes, we used a series of mechanisms to train and inform peer supporters including training, structured meetings, access to the project manager and FAQs. It is difficult to assess the effectiveness of each of these within a complex intervention. However, the FAQs were widely used and appeared to provide informational support to the peer support mechanism. It appears that the FAQs may have facilitated the peer support by encouraging the asking of questions and subsequent discussion within the group. The motivation for the initial request for a system of FAQs during the pilot study arose out of a possible insecurity amongst the peer supporters in seeking not to misinform the group. The FAQs may have acted as a safety net for the peer supporters by providing indirect professional support and thereby increasing their confidence.

The definition of peer support used within this trial falls within the social support model, which is defined as the process through which social relationships might promote health and well-being[13]. Within the social support model, the direct effect model would postulate that peer support could reduce feelings of isolation and loneliness, provide information about access to health services or the benefits of behaviors that positively improve health and wellbeing and encourage more positive health practices[4]. The authors would postulate that the FAQs were facilitatory to this model both through encouraging discussion within the group, thereby reducing feelings of isolation, and through the confidence generated that information about health services and the disease processes were being adequately addressed.

Deleted: The peer support mechanism appears to have enabled the identification of informational needs that the participants may not have asked in a more formal clinical setting.

Patients access health information in a variety of ways. Physicians remain the most trusted source of health information to patients, although patients are more likely to access health information online than through their physician[14]. However, online resources are still not accessible to everyone, with older and less educated patients being the least likely to have access[15]. In addition, much health information is produced with a reading age that excludes over 20% of the population[16, 17]. The use of FAQs in a peer support setting enabled participants to identify informational needs and initially access the experiential knowledge of their peers to address these. The peer discussion of both generated questions in the peer support group and the questions answered by the professional team was a means of enabling health information to become accessible to all participants – regardless of age, educational level or literacy.

The question arises as to how this process could be introduced into standard clinical practice.

Whilst a moderated internet community may be the easiest option, many peer to peer groups on the internet are un-moderated and there is no robust evidence surrounding the effectiveness of online consumer led peer to peer communities[18]. The alternatives are to integrate moderated FAQs into existing peer support structures or to establish a mechanism for FAQs in diabetes clinics, with published answers given to patients during their attendance.

The topic areas raised in the FAQs broadly followed the topics proposed for the structured peer support sessions with notable exceptions. Topic areas of great concern for physicians, such as the risk of cardiovascular disease or the prevention of microvascular disease in terms of nephropathy, neuropathy and retinopathy, did not rate highly with participants. There were also few questions on physical activity. This could be explained if the structured sessions adequately addressed the questions of the patients within the sessions, or if these 'FAQs' were answered

entirely within the peer group. However, it may be a reflection of the lack of knowledge or concepts of the seriousness of diabetes accounting for these problems[19]. In addition, many of the questions addressed concerns or information that would normally not be addressed by structured diabetes education. The benefit of the FAQs in addressing these concerns was clearly seen through the comments of individuals who have collected and stored the answers and the suggestion that they should be made more widely available. The FAQs suggest that there is a large unmet patient centred information need amongst those with type 2 diabetes. The degree of this unmet need is further emphasized by the enthusiasm of patients for a system of FAQs when the responses (received at a subsequent peer support meeting) were often considerably delayed from the initial question. However, this may alternatively suggest that the value of the FAQs rested more in the generation and discussion of the questions in the peer support group as in the expert responses.

A strength of this study is that data was collected in a structured peer support system with a cross section of patients with type 2 diabetes from diverse backgrounds. The collection of such information in a 'natural' setting has the benefit of capturing concerns and questions that may not normally be directed to health care workers. However, the authors were unable to capture the process through which these questions were generated. The authors were also unable to capture the emotional and informational needs that were addressed during the structured component of the meeting or through the peers, as it was thought that such data collection would interfere with the peer support process. The study's generalisability is limited due to its reliance on questions generated by one peer support study. It would be of interest to expand this study using other peer support programmes and clinical environments in order to provide insight into the range and diversity of FAQs that would be generated.

Version 1

The use of FAQs within a peer support programme was well received by participants and provided valuable insight into the informal information needs of people with diabetes. It enhances both the peer interaction and social support and the appraisal and informational support integral to the process. Further use of this tool within peer support programmes and in clinical practice is to be encouraged.

Conflict of interest statement

The authors declare that they have no conflicts of interest.

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