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The Lived Experience of Diabetes: conceptualisation using a metaphor

Bel Youngson, Helen Wilby, Fiona Cole and Diane Cox

Abstract

Introduction: It is important for healthcare professionals to understand the personal issues and reality of living with diabetes in order to better engage and enable people to self manage. The purpose of this research was thus a preliminary exploration of the lived experience of diabetes to inform future practice.

Method: This was a qualitative study involving seven people with a diagnosis of type I, type II or pre-diabetes. Data was collected via semi-structured interviews and analysed using a phenomenological approach which included the use of metaphor. Findings were shared with participants using a felt metaphor of charting a course of health and wellbeing through a choppy sea.

Findings: Themes were explored within the elements of the metaphor in terms of the boat (self identity, control, balance, compliance and empowerment, emotions), the sea (physical and social environment, lifestyle, life events), the course (information gathering, change, self action) and the boatyard (relationships with healthcare providers).

Conclusion: For those with type I, type II and pre-diabetes the elements of charting a course of health and wellbeing through a choppy sea are very much focussed on the person in their own context, impacted by their environment, life stage, occupations and attitudes to diabetes self management, all of which fall within the remit of occupational therapy.

Introduction

There are 2.9 million people diagnosed with diabetes in the UK and an estimated further 850,000 who may not be aware that they have this condition (Diabetes UK 2012). Additionally an estimated 7 million have pre-diabetes, a condition in which glucose levels are higher than normal, and which can lead to the development of type 2 diabetes (Diabetes UK 2009). In the current climate of increased healthcare costs generally with competing claims on scarce resources, the impact of diabetes on health and social care costs is significant, with considerable personal impact for the person with diabetes and their family.

The current thinking on the long term treatment of diabetes is on education, lifestyle change and self management to improve outcomes and ultimately reduce health costs. Education is around individual health beliefs, dietary advice, facilitating behaviour change, improving quality of life, optimising metabolic control (in terms of managing blood sugar levels (HbA_{1c}), blood pressure and cholesterol), addressing cardiovascular risk factors and reducing depression (NCCC 2008). However evidence suggests that despite educational programmes many people with diabetes fail to adhere to advice on self management and there are many barriers to successfully incorporating this into individual lifestyles (Mulvaney 2009, Nagelkirk et al 2006). A misunderstanding has been identified between empowering people to take control of diabetes daily care and expecting compliance with metabolic control (Anderson and Funnell 2010, Paterson 2001). Overall diabetes management requires a complex interaction between medication administration, self monitoring, diet, exercise, and consultation with healthcare professionals (Moser et al 2008).

This research article describes the initial stage of a PhD study exploring the lived experience of type 1, type 2 and pre-diabetes.

Literature review

Diabetes and Pre-diabetes

Diabetes is a condition in which blood glucose levels are too high because the body cannot use it properly. Type 1 develops where the body cannot produce insulin, required to help glucose enter the cells where it is used as fuel, due to the destruction of insulin-producing cells in the pancreas. (Diabetes UK 2012). Type 2 develops when the body does not make enough insulin or the insulin does not work properly (Diabetes UK 2012). Treatment in type 1 involves insulin therapy and in type 2 may require medication to lower blood glucose levels. Both type 1 and type 2 require monitoring of blood glucose levels (HbA_{1c}), blood pressure and cholesterol, collectively known as metabolic control, in order to prevent complications of cardiovascular, kidney and eye disease, and to reduce the risk of amputation and neuropathy (Diabetes UK 2012). In addition gaining control over weight, diet and exercise are seen as essential to improve health (International Diabetes Federation 2007). Pre-diabetes is a borderline condition, characterised by higher than normal blood glucose levels, but not yet high enough to be diagnosed as diabetes (American Diabetes Association 2011).

Occupational therapy in diabetes care

Occupational therapy literature in diabetes care is sparse, particularly in relation to managing diabetes in the context of everyday life (Pyatak 2011a). There appears to be evidence regarding the effectiveness of occupational therapy in general with chronic diseases in improving occupational outcomes however, in their systematic review, Hand et al (2011) found no studies related specifically to diabetes. Previous occupational therapy papers (from the 1970s and 1980s) are based solely on practical occupational therapy solutions to complications of diabetes to enable people to manage independence in occupational roles (Andrew 1987, Budurowich and Lofton 1979). More recently Hwang et al (2009) identified that blood sugar and cholesterol control, foot care, and pain and fatigue management were the main areas of concern to older adults with diabetes. They concluded that the role of occupational therapy is not clearly defined to enable the incorporation of diabetes

self care into daily routines. Other occupational therapy approaches have looked at specific areas of diabetes intervention such as early identification of hand dysfunction (Poole et al 2010; Ratzon et al 2010), treating vision loss (Cate et al 1995), foot care (Jansen and Casteleijn 2009) or improved medication adherence (Sanders and Oss 2013). Pyatak (2011b) examined how engagement in occupation influenced young adults' ability to manage their type 1 diabetes and how self-management strategies shaped occupational participation.

The Lived Experience of Diabetes

Overall, there is a paucity of information on the lived experience of pre-diabetes. Andersson et al (2008) studied the meaning of living with pre-diabetes and concluded that this was conceptualised as a turning point where participants were caught between possibilities (of changing lifestyle to prevent development of type II diabetes) and obstacles (developing the condition). A search was made of the nursing literature to find evidence for the lived experience of diabetes. It is acknowledged that people need to gain ownership or control over this complex condition in order to successfully self manage (Handley et al 2010; Edwall et al 2008). A number of factors, including personal belief, support from friends and family or by interaction with healthcare professionals, achieves control. Although it appears that the participants in these studies adapted to and maintained control over their diabetes, the authors all acknowledge the difficulties of managing diabetes on a daily basis. Edwall et al (2008) focussed on the importance of a trusting healthcare relationship while Handley et al (2010) concluded that the primary focus of intervention should be on the person and their story, their needs and support system.

The literature suggests that it is imperative for healthcare professionals to understand the personal issues and reality of living with diabetes in order to better engage and enable people to self manage (Handley et al 2010). The objective of this first stage of the research was therefore to explore the lived experience of diabetes, from an occupational perspective.

Method

Ethical approval for this study was given by the Ethics Committee of the University of Cumbria. A qualitative methodology and phenomenological research design were chosen in order to capture the lived experience (Finlay 2011). These offered the philosophical and practical tools to explore the personal insights and understanding of the participants in the day to day issues of living with diabetes (Finlay 2011). A purposive, convenience sample of people was sought. A purposive sample ensures that the participants have particular characteristics to enable exploration of the themes (in this case living with diabetes) but also some diversity of experience so that these characteristics can be explored (Ritchie et al 2003). The convenience sample was chosen for ease of access. Although there can be concern about potential bias (Ritchie et al 2003), this was mitigated by selecting a range of ages, types of diabetes and time with the condition. Participation was entirely voluntary and the proposed participants were adults over the age of 18 with any duration of diabetes who were 'information rich' i.e. able to articulate their feelings and experiences of diabetes and who did not have dominant coexisting health conditions which might detract from the focus of the study. Participants who volunteered to take part were provided with an information sheet and, written consent was sought prior to participation in the study. Data was collected using digitally recorded individual, semi-structured interviews of 60-90 minutes duration by the first author. Interviews began by asking participants to describe what it was like to live with diabetes and subsequent questions allowed further exploration or explanation (Legard et al 2003). Interviews were transcribed in full and sent to participants for checking, although none requested changes to the transcriptions.

Thematic analysis of the data began with an initial immersion of reading and re-reading the transcripts. A line by line active coding followed from which broad categories were developed (Finlay 2011). Although there are no prescribed methods, strategies suggested in phenomenological analysis (Smith et al 2009) were employed to identify patterns and themes to structure the data.

This was not a linear route and many returns were made to the data to check that the lived experience of each participant was being authentically represented.

In order to ensure rigour the first author in the manner of a 'bricoleur' (Denzin and Lincoln 2005, p4) employed a number of different analytical and reflexive strategies, to ensure representation of the voices and perspectives of the participants. These strategies included reflection using a fieldwork diary and, contemplating and describing each stage of the analysis using mixed media art work. Although uncommon in occupational therapy research, many artists, potters and textile makers describe how creating visual art allows for thinking time and problem solving (see Allen 1995; Dickie 2003; Lydon 1997). Transforming ideas into visual art organises those ideas to create new insights and learning (Marshall 2007). The analytical process thus combined a traditional narrative account of key themes plus a more 'whole' metaphoric account of the findings depicted in a felted metaphor. The felted metaphor was congruent with the first author's preferred learning style of thinking visually and, through reflection on both the metaphor and narrative data, gave her a means to represent the findings as a complete piece while also displaying the relationships between the different themes (Potter 2001). Dadds and Hart (2001) comment that the juxtaposition of these different types of methods helps to find new perspectives. A photograph of the felted piece and an explanation of the findings were sent to participants for their review and comments (Figure 1). Participants who responded confirmed that the results made sense and encapsulated their experience; some additionally supplied further detailed information about their experiences in response to the felted metaphor.

Findings

Seven people with a diagnosis of type 1, type 2 or pre-diabetes were recruited to the study. Table 1 shows the demographic details of the participants. All had strong family support, either from partners or parents and, with the exception of Alan and Anna, all were employed. Two of the

participants (Terry and Albert) were recently diagnosed and were able to give a perspective on what it was like to be at the beginning of this journey. The others were able to draw on their experiences from 4 to 19 years, sharing their changing attitudes, attempts to self manage and their thoughts on living with diabetes.

Table 1. Demographics of Participants

Participants' Pseudonym	Age	Type of diabetes	Time since diagnosis
Simon	23	Type 1 diabetes	14 years
Rosemary	50	Type 1 diabetes	19 years
Alan	64	Type 2 diabetes	4 years
Terry	41	Type 2 diabetes	1-2 months
Anna	64	Type 2 diabetes	12 years
Rachel	54	Pre-diabetes	5 years
Albert	51	Pre-diabetes	Recently diagnosed

The reflexive and creative approach used during data analysis generated rich data about the extent of shared lived experiences of type 1, type 2 and pre-diabetes. The research findings are presented, both as a traditional narrative account of key themes (Table 2) and as a visual metaphor represented as a felted artwork (Figure 1). The two are combined in Figure 2 to show how the felted metaphor relates to the themes and how these themes interact to impact on participants' ability to manage their diabetes.

Table 2. Key themes

Major theme	Sub themes	Representation in metaphor
Impact of Environment	Physical environment Social environment Lifestyle Life Events	The Sea
Self Identity	Control Balance Compliance Empowerment Emotions	The Boat

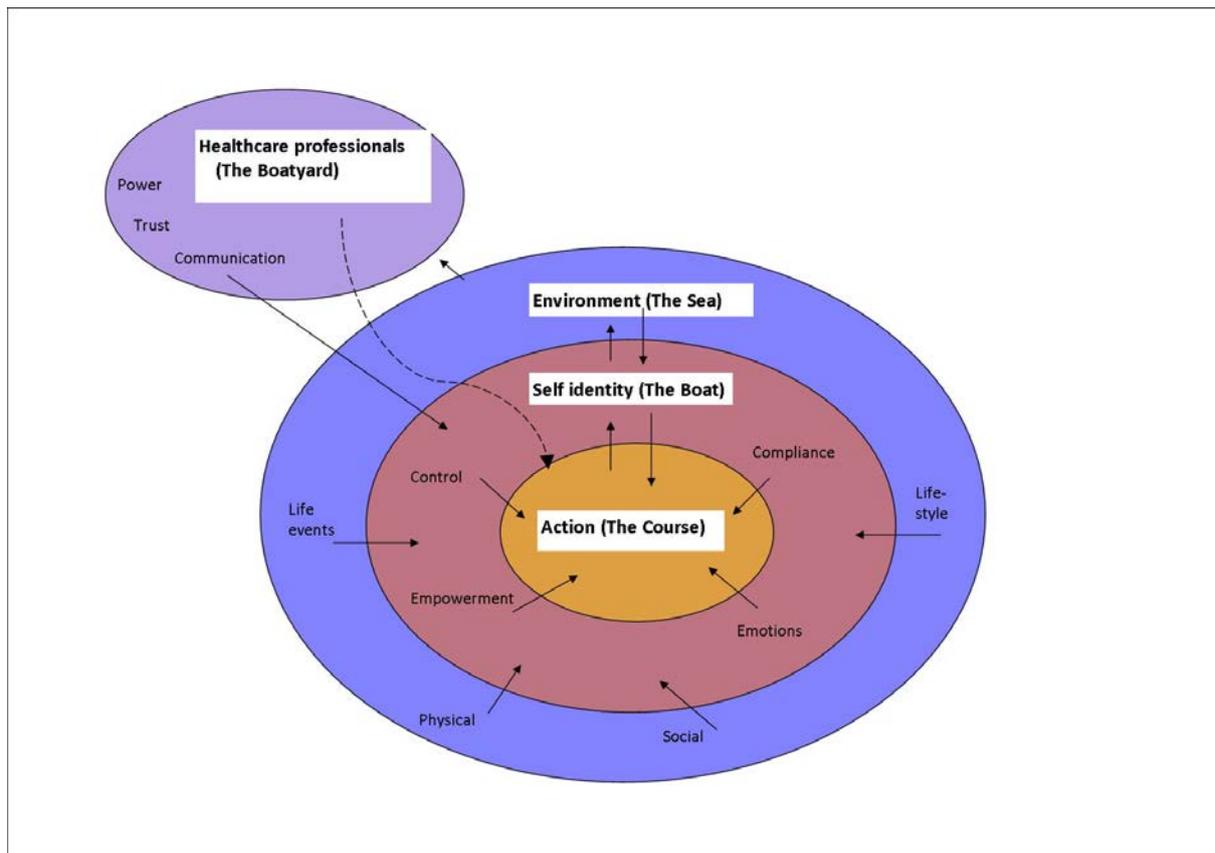
Individual Action	Information gathering Change Self management	The Course
Relationships with healthcare providers	Power Trust Communication	The Boatyard (outside the picture boundary)

Figure 1. Felting metaphor: charting a course of health and wellbeing through a choppy sea



Due to the shared nature of the participant experiences the term ‘diabetes’ is used regardless of the type of diabetes of the participant. Quotes are included to give voice to the participants and to evidence the researcher’s representation of the findings. The findings are discussed in terms of Figure 2 to show the interaction of the themes.

Figure 2. The interface between the findings and the metaphor



Environment

Many aspects of the environment, symbolised by the sea in the felt metaphor, had the impact of 'blowing people off course' or making it difficult to find a way forward to managing their diabetes. The environment is seen in its widest sense of both the social, which includes lifestyle and life events, and the physical environment. Participants struggled to balance many aspects of life leading to erratic meals, stress, sedentary or chaotic work life which then affected medication and testing:

I think I'm so busy that for a lot of the time I do forget to have injections, meal times are completely erratic during the day, I very seldom have anything to eat during the day, I go off to work and that's that (Rosemary)

Similarly major life events (family in general and family ill health, redundancy, difficult personal events) took precedence over diabetes:

It was a horrible time, it was a really, there was lots and lots of things happening that were really horrible and I think I just, I didn't bother about myself at all, you know..... I came so far down the list that I just wasn't bothering. (Anna)

Socially, friends and family were either a help or sometimes a hindrance to management, especially in terms of temptation. Terry, newly diagnosed, explained:

It's quite hard really, I find it quite difficult. Especially when everybody in work are eating sweets and cake and biscuits and putting them in front of your face going "Mmmmmm, look at this cream cake" and they know I'd be the first one in cream cake box or sweet box or whatever. (Terry)

Other aspects, such as exercise routines were affected by people's physical environment eg steep hills, proximity to gyms/pools, and the work place.

Self Identity

The issues that participants had to deal with, which impacted on and were influenced by their sense of self (symbolised by the boat in the metaphor), included a sense of control, how to achieve a balance between diabetes and the rest of life, how to comply with advice and the emotional aspects of living with this condition. Most participants did not want to be defined by diabetes; it was separate from their sense of self, although it also challenged their view of themselves. For example Rosemary was determined that she was not going to let diabetes characterise her:

When I first was diagnosed we had a friend who was so into her diabetes I remember thinking 'I do not want to get like that' because she just, she talked about it all the time and was very openly sort of testing herself all the time and then talking about it. And it was just such a big part of her life I thought 'No, I'm not going to have that, I'm just going to get on with it' but took it to the other extreme I think. (Rosemary)

Alan and Anna found a way to feel comfortable with control over their diabetes mostly through making deliberate choices about their diet, but for the rest control was a struggle. This involved finding it difficult to commit to a particular course of action, needing to find the right route, or feeling there were too many steps to perfect control:

I guess I kind of see the goal of perfect control and I see it like so far away that I kind of almost, I try and do the next thing, the next step to get there but I guess there just feels like there are so many steps that it feels like it's never quite going to happen. (Simon)

Rosemary found that not complying with her diabetic regime was actually easier to manage:

And then I began to realise actually by not having as tight a control, it's more convenient for me and then it just slips (Rosemary)

Most participants struggled to comply with advice and sometimes felt worse when they achieved what was expected of them:

And I thought right, well I did try the diet sheets for about 3 months and then I didn't feel any better and I did feel lousy and I was beginning to think perhaps I have got diabetes"..... "I weren't feeling brilliant and I've been back and they said "oh you've got it down to 7, well done". And I was thinking 'this is a lot of effort to get it down' (Albert)

Issues with compliance led to feelings of guilt, feeling blamed, and resentment. Diabetes also resulted in frustration, confusion, fear, anxiety and feelings of incompetence.

I guess it's quite frustrating sometimes it becomes quite a battle all the time to sort of keep everything the way it should be I guess why isn't it just really easy, why doesn't it just workmaybe I resent it a little bit (Simon)

Only one participant, Alan, recognising that his experience could be different from others, had come to terms with his diabetes:

I think the main message is that separate from quite a lot of other people my diabetes is not a burden, it's something I live with and I'm quite happy with the kind of inevitable restrictions that making right choices brings. Yep. (Alan)

Individual Action

Action in terms of self management is symbolised by the course through the sea in the metaphor. In order to make changes most participants collected and considered a lot of information before trying out a particular course of action. This mostly came from sources other than the health service. For Rachel and Anna in particular making decisions based on the best evidence was difficult:

I read books about why it's a great idea and then I do it. And then I read another book that says 'no it's not a good idea, actually it's really bad for you'..... So it's lack of knowing what the best thing to do is I think that stops that being a permanent commitment. (Rachel)

Even when I'd been inspired and looked at things, it took me a while to decide what path I ought to take. And even when I started down a path I realised it wasn't going to be right for me. (Anna)

Participants successfully changed routines on their own terms by getting into the right 'head space' (of *wanting* to change), making healthy eating and lifestyle choices:

Now my head is saying I need to do something about it but also something inside me is wanting to do something about it which I think is the big difference to previously. (Rosemary)

For others change was a struggle with lack of will power. Simon and Albert in particular felt a lack of commitment and a feeling of having to give up too much:

I think I want to think differently but I just sort of don't and that's down to me, isn't it. (Simon)

So when, I mean I cut down on my potatoes and done this and that and I was trying to follow the diet sheet, you know reasonably accurately, I felt lousy and it hadn't cured me of me cravings. So I'd nick a biscuit you know, I'll just have a biscuit, it won't do any harm. (Albert)

All participants felt that they had to find their own route and tried out a number of actions – different diets, changing attitudes to food – which also involved changing lifetime habits, often culturally determined:

But I have found a level of intake that suits me and I know I now will put half a plate of food aside if I've had enough. We weren't allowed to do that growing up (laughs). You ate what was in front of you and that was that. And that's actually remarkably difficult to stop doing. (Alan)

It was clear that the environment, self identity and individual action were all interlinked. Life events impacted on sense of self; participants' values and beliefs filtered knowledge and advice that then

influenced action. Successful or unsuccessful attempts to manage affected participant's sense of control which in turn impacted on lifestyle.

Relationships with Healthcare providers

In addition to the interaction of environment, self and action, the metaphor included the boatyard (off picture) to represent relationships with healthcare professionals, which were characterised by trust, power and communication. Participants reported that they did not always trust the medical profession and that they received conflicting information or had support denied. As Simon explained,

I think I started quite a while ago taking what I get told with a bit of a pinch of salt because one minute [medication name] is the amazing new thing that no diabetic should live without and then I get told by someone else that actually that's rubbish and I should be on this other one. (Simon)

Often communication was seen to be negative and unhelpful with a lack of understanding of each individual's needs. Rachel tried to pre-empt development of diabetes by asking for blood sugar monitors but was refused. She saw this as a disincentive:

I felt blamed for making an effort rather than encouraged. (Rachel)

Rosemary compared going to see the consultant with being summoned to the headmaster. She found the experience antagonistic and unhelpful:

Because I know if I go into the doctor's and just feel as though I've just been slapped over the wrist, the first thing I want to do when I come out is go and get a chocolate bar because I feel really quite sort of told off and it's not helpful. I find it quite stressful. (Rosemary)

Albert was concerned about what he described as "tick the boxes" medicine and being treated as a statistic rather than a person.

Well I didn't think I had diabetes when they told me I had diabetes. I felt as though they just labelled me with another illness. (Albert)

There were, however, examples of participants feeling supported, in particular, by Diabetes Specialist Nurses.

She's brilliant, she's so patient (laughs). She's very, very supportive. (Rosemary)

What was clear, as shown in figure 2, is that most interactions with healthcare professionals did not take into account the impact of the participants' environment and sense of self on their actions. It appeared that instead advice was directed at actions that the professionals thought were important, regardless of whether this suited the individual.

Following the dissemination of results to the participants, two followed up the report with further thoughts resulting from their reflection on the metaphor. These are included in the discussion as they form part of their overall consideration of the lived experience in relation to the previous literature and the findings of the study.

Discussion and implications

The narrative findings in relation to the literature and, the use and value of the metaphor as a representation of the lived experience are discussed.

The findings suggest that living with diabetes or pre-diabetes is a complex balancing act and that participants recognised the impact of life events on managing their condition. All participants were faced with possibilities and obstacles (Anderson et al 2008). In relation to compliance with test results (blood glucose, blood pressure and cholesterol), while seen as important, getting on with life seemed to take priority. Participants reported that they wanted to manage but often found that they did not get the support they felt they needed. Unlike the experiences of the participants in the studies reviewed earlier, it was clear that participants had not always managed to achieve and stay in control. Handley et al (2010) discussed the fact that mastery over diabetes was complex and that to be in control was to integrate or accept diabetes. Only one of the participants considered this, which he put in his feedback following the interim report:

As long as the condition of diabetes is 'out there' as something 'other' or 'foreign' it will be a threat, something with which to fight, with which to be in constant conflict. The condition and the individual are not two but integrated and the degree to which they are integrated is the degree to which the individual is healthy. (Alan)

Edwall et al (2008) also discussed the need to incorporate diabetes into everyday life by internalising mastery. They concluded that access to diabetes nurse specialists “in trust-filled conditions” (p779) was key to this to become confident and independent. Clearly the participants in this study did not feel this same sense of trust and this is also commented on by Alan:

There has to be a balance between imparting factual and technical information and a nurturing caring encouraging relationship, patient centred with those conditions of empathy, positive regard and non-judgment.

(Alan)

Alan had obviously given this much thought and indicated that current attitudes from healthcare staff resulted in disempowerment for the patient. Rachel continued this theme in her feedback:

The holistic approach makes it clear that blame is inappropriate and that labelling someone as coping poorly is a mistake - changes are occurring all the time. We have some influence on health, but not total control. If health professionals took the whole of life into account and listened to the experience and journey of people with diabetes, they would have more chance of promoting positive health behaviours. (Rachel)

Anderson and Funnell (2010) also addressed this issue. They stated that the traditional acute care approach of expecting patients to comply with diabetes care recommendations often leads to non-compliance. Instead they advocated a requirement for better understanding of all aspects of a person’s life that influences their self-management and a need to empower people to think critically to make informed decisions. Being belittled by healthcare staff had a major impact on compliance for the participants, notably Rosemary who admitted to rewarding herself with chocolate to make herself feel better after a particularly negative experience with her GP. Stuckey and Tisdell (2009) also noted that a concentration on numbers (test results) caused a focus on the negative side of diabetes, which was not helpful for those living with the condition. For these participants it was clear that encounters with healthcare professionals were focussed primarily on test results, with little interest in, or understanding of, people’s life circumstances.

Use and value of the metaphor as a representation of the lived experience

The felt metaphor not only allowed the first author to conceptualise the data as a whole but it also resonated with those participants who responded. It is not the focus of this paper to go into depth about the use of metaphor but in this instance to show its value as a reporting method to participants. Anna responded that she had found the report interesting and identified with the metaphor describing “having been tossed about a sea with my diabetes for a long time”. She went on to say that “it does make a difference when you have hit calm seas” which represented where she felt she was at the time.

Alan commented “Firstly I think the metaphor works very well - certainly far more interesting and approachable than the usual dry presentations of such surveys and reports.” He went on to comment on the art work itself and the skeleton leaf used to depict the boat:

My first view of The Boat [self identity] was that it was too frail and fragile and could not possibly survive the gales and turbulence of the wild ocean with all its elements. I would like to see The Boat having the capacity to grow into robustness as the creative elements are encountered and embodied by the patient.

Here he was using the metaphor to further describe not only his own journey but to explain the need in general for people to be able to grow strong to manage their diabetes.

Rachel stated that she felt that the metaphor was useful as a visual representation of

how environmental demands and challenges can influence health behaviours, health related choices and the ever changing nature of the coping skills needed. It also implies that diabetes is just one aspect of life and sometimes has to take second place to other issues as they crop up.

Stuckey and Tisdell (2009) discuss the benefit of creativity in establishing meaning (comparing it to the type of emotional work that is done in cancer) and make a plea for more of this in supporting and understanding people with diabetes.

It is acknowledged that four of the participants did not respond to the report. Despite the fact that this metaphor was ‘imposed’ by the first author, it is clear from the response that the other three

participants felt that it encapsulated their experiences and it gave them the opportunity to make further comments on this.

Critical evaluation of Research Trustworthiness

This was a small scale study of a self-selecting group of people who chose to talk about their diabetes. It was intended to garner in-depth understanding of participants and not to be representative of the larger population. The use of mixed media art work and the metaphor added an extra dimension to the design and enabled participants to comment both on the original findings and then contribute to the discussion. Further research into the value of metaphor in research design is recommended. This will form part of the second stage of the first author's research.

Conclusion and implications for practice:

Analysing the lived experience of diabetes and pre-diabetes has shown a complex balance between

- the person (their self identity, sense of control, ability to comply with medical advice, gather information and make changes)
- their environment (physical ,social and cultural, lifestyle and life events) and
- relationships with healthcare providers

Living with diabetes is not just about achieving optimum test results but integrating diabetes into the whole life experience in a way that leads to health. Rather than blaming people for not getting test results 'right', an holistic approach which enabled 'robustness' alongside a better understanding of each individual, would seem to be fundamentally more important and effective.

KEY FINDINGS

- Participants identified a range of factors that supported or hindered living well lives with diabetes

- Medically focussed managed of blood sugar levels by itself was insufficient to achieve 'control' of diabetes
- The use of a metaphor to describe the experiences appeared relevant and useful

WHAT THE STUDY HAS ADDED

This research provides a deeper understanding of the lived experience of diabetes. To promote health and wellbeing occupational therapists must consider all aspects of this experience.

Acknowledgements

This study formed the first stage of the first author's doctoral research undertaken at the University of Cumbria, supervised by Diane Cox, Helen Wilby and Fiona Cole. The first author wishes to thank her supervisors for their support and comments and all of the participants who gave their time and valuable feedback to the research.

Conflict of interest: none declared

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