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The Illness-Disease Dynamic: Psychological Wellbeing in Type 2 Diabetes: An Interpretative Phenomenological Analysis

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Abstract

Distress and depression often go unrecognized in people with diabetes. In this article, I present an Interpretative Phenomenological Analysis (IPA) of the lived experience of people with Type 2 diabetes, based on individual in-depth interviews with 10 patients. The purpose of this research was to gain a deeper understanding of these psychological symptoms through a detailed examination of how patients interpret and respond to their experience of the condition. I propose a revised model for the connection between the disease of diabetes and patients' lived experiences of illness, as one of embodied coexistence rather than relation. Through my analysis, I identify the psychological processes that might need to be addressed in an effective preventative support system.

Keywords

Depression, Diabetes, Distress, Illness Experience, Interpretative Phenomenological Analysis, Psychological Wellbeing

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The Illness-Disease Dynamic: Psychological Wellbeing in Type 2 Diabetes: An Interpretative Phenomenological Analysis

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Distress and depression often go unrecognised in people with diabetes. In this article, I present an Interpretative Phenomenological Analysis (IPA) of the lived experience of people with Type 2 diabetes, based on individual in-depth interviews with 10 patients. The purpose of this research was to gain a deeper understanding of these psychological symptoms through a detailed examination of how patients interpret and respond to their experience of the condition. I propose a revised model for the connection between the disease of diabetes and patients' lived experiences of illness, as one of embodied coexistence rather than relation. Through my analysis, I identify the psychological processes that might need to be addressed in an effective preventative support system. Keywords: Depression, Diabetes, Distress, Illness Experience, Interpretative Phenomenological Analysis, Psychological Wellbeing

Type 2 diabetes is a common and increasing health problem. The prevalence of diabetes in England is anticipated to reach 5.9% by 2020 (Yorkshire & Humber Public Health Observatory, 2008). People with diabetes are up to twice as likely to develop depression as those without the condition (Ali, Stone, Peters, Davies, & Khunti, 2006; Anderson, Freedland, Clouse, & Lustman, 2001). Approximately 10% meet the criteria for comorbid major depression (Ali et al., 2006; Anderson et al., 2001) yet only half of people with diabetes and major depression are recognised as depressed (Katon et al., 2004). Cross-sectional studies have found a prevalence of 5-15% for subthreshold depression (elevated depressive symptoms that do not meet DSM-5 criteria for major depression) in the general population (primary care) (Kessler, Zhao, Blazer, & Swartz, 1997; Rucci, Gherardi, & Tansella, 2003). In people with diabetes the prevalence of subthreshold depression is estimated at 17-20% (Ali et al., 2006; Anderson et al., 2001). In a Dutch study of patients with diabetes and moderate to severe anxiety or depression, only 20-30% of them were recorded as having any emotional problems by their diabetes nurses (Pouwer, Beekamn, & Snoek, 2006).

Many factors contribute to under-recognition of depressive symptoms, with detection further complicated in patients with comorbid physical health problems (Prince, Patel, Saxena, Maj, Maselko, Phillips, & Rahman, 2007). Social and self-stigma are prevalent (Sherwood, Salkovskis, & Rimes, 2007) and are associated with reluctance to seek professional help (Barney, Griffiths, Jorm, & Christensen, 2006; Corrigan & Watson, 2002). Lustman and Clouse (2004) suggest that depression can also be regarded as an inevitable consequence of chronic illness by both patient and practitioner, and this might become a basis for not requesting or providing treatment (Lustman & Clouse, 2004).

Addressing this under-recognition, and promoting help-seeking behaviour before depressive illness develops, requires a multifaceted approach. Two approaches identified as potentially beneficial are (a) mass media campaigns that stress that it is possible to prevent the onset of depressive disorders and (b) utilising the Internet as a stigma-reducing platform for depression, enabling targeting of tailored interventions for subgroups such as those with

specific medical conditions (Cuijpers, van Straten, Warmerdam, & van Rooy, 2010). Online psychological support can be cost-effective and time-efficient (Christensen, Griffiths, & Jorm, 2004; Spek, Cuijpers, Nyklyaycek, Riper, Keyzer, & Pop, 2010). Helping patients with subthreshold depression to better understand depression and recognise its early signs might also assist in long-term reduction in unmet need for treatment (Wells, Sherbourne, & Duan, 2005).

The purpose of the present study, which was conducted as part of my PhD research, was to develop an Internet platform for people with Type 2 diabetes to promote psychological wellbeing. To facilitate the design of a platform that would engage patients and promote emotional literacy, I undertook a qualitative interview study to tap into their lived experience (Husserl, 1970). The aim of this qualitative study was to investigate the psychological symptoms experienced by adults with Type 2 diabetes, with special attention to the relationships patients made between physiological changes and psychological distress and the vocabulary used by patients to describe their distress.

Methods

Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) is an experiential qualitative approach with a strong idiographic focus. Its theoretical roots lie in European phenomenological philosophy and hermeneutics. Its ontological foundation directs attention to the world as it is lived, represented by the phenomenological phrase "*Lifeworld*." The analytical principles of IPA as a distinct research methodology were first developed by Jonathan Smith (Smith, 1996a).

IPA has "a theoretical commitment to the participant as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people's speech and their thinking and emotional state" (Smith, & Osborn, 2007, p. 54). This connection is a complicated one; struggles with self-expression and reasons not to self-disclose might dominate. Integral to IPA is the notion that one cannot completely access the participant's *Lifeworld*; the researcher's own conceptions are needed to decipher it through the interpretative process. Researcher self-reflexivity is paramount to this process and might be achieved via activities such as multiple close readings of the transcripts, line by line analysis and keeping a research journal.

In IPA, a thorough description can be given from a first person perspective on the meaning and impact of the illness experience (Charmaz, 1983) via inductive, open-ended questioning and detailed, often lengthy discourse. The terms "disease" and "illness" are often used interchangeably in the literature and their definitions are widely debated (Eisenberg, 1977; Lupton, 2012). The term "disease" in this article refers to a diagnosable medical condition, whereas "illness" captures a patient's experience of their disease and feelings associated with living with it. The "illness-disease dynamic" refers to the interaction between these two phenomena. IPA embraces the unique qualities of an individual's lived experience, recognises the importance of how meaning is created and structured (von Eckartsberg, 1998) and uses the researcher's self-reflexivity as active data to attempt to get as close to the other's experience as possible. These components distinguish it from other qualitative approaches and made it a particularly appropriate method for addressing my research questions.

Following Finlay's aphorism of "reporting research in whatever mode is going to have the most relevance and impact" (Finlay, 2009, p. 14), a conscious choice has been made to adopt a first-person, more personal tone in this paper in order to emphasise the self-reflexivity which is intrinsic to my IPA approach. Although it was I who led data collection and analysis, this paper represents a collaborative effort with my PhD supervisors, whose critical input and

ongoing dialogue contributed to the development of the findings from descriptive data to conceptual themes.

Selection of Interviewees

Purposive homogeneous sampling is used in IPA research because of the small sample sizes involved. This type of sampling involves selecting participants based on a specific similar characteristic or set of characteristics. This allows for a “more closely defined group for whom the research questions will have personal significance” (Fife-Schaw, Smith, Hammond, & Breakwell, 2006, p. 329).

I approached a sample of 40 general practices for help in identifying suitable participants. Potential participants were identified by practices’ diabetic nurses during routine diabetes appointments. I then contacted them with further information about the study and obtained informed consent prior to their participation.

Patients with Type 2 diabetes aged 18 or older were eligible unless they had a diagnosis of major depression, a psychotic illness, alcohol dependency, substance abuse or dementing illness, or could not understand English. Subthreshold psychological symptoms were this study’s focus, hence the exclusion of those with major depression (see Discussion for additional explanation.) The Patient Health Questionnaire-9 (Howie, Heaney, Maxwell, & Walker, 1998) was used to screen for major depression and a “current diagnosis” was defined as being within 12 months of the recruitment date.

Ethical approval for the study was gained from the appropriate Research Ethics Committee in the United Kingdom.

Data Collection

I conducted interviews between November 2008 and February 2009. I offered to interview participants in their homes to encourage a relaxed atmosphere; however, other venues could also be requested. My semi-structured topic guide included open-ended questions to encourage participants to expand their responses. I made the decision to disclose my own insulin condition where it felt natural to do so during an interview. I felt that knowing I had some experience of life with diabetes might encourage honest disclosure and more natural discourse. With consent, I audio recorded all interviews and had them transcribed verbatim.

Participants were made anonymous in all study documentation and pseudonyms are used for participants throughout this article. All other people mentioned in quotes and their identifying details are also anonymised. Where necessary, I identify myself by the term “author.”

Data Analysis

My analysis drew on the IPA techniques suggested by Smith and Osborn (2003): I initially read the interview transcripts multiple times to imbibe the data—the words. This surrounded me with the people that were speaking. Each time I tried to adopt an open, receptive presence.

I undertook broad coding for recurrent themes within each transcript and slowly worked across them, ensuring I followed an idiographic approach (Smith, 1996b). This provided me with an initial thematic framework for further investigation, which I recorded using Atlas.ti software to facilitate data management. I found, however, that the individual voices became fragmented during this process and it was necessary to refocus my attention to the participant’s

Lifeworld and put aside my own developing interpretations for a time. I attempted to do this in three ways:

- (1) I recoded the transcripts from what I felt might be the participants' perspective.
- (2) I organised the variations and contradictions across and within the participants' transcripts.
- (3) I referred to the notes I had written shortly after each interview that recorded thoughts about the participant, surroundings, the interview or my own judgements.

These three processes provided me with rich additional levels of interpretation, both challenging and refining the themes I had already perceived as well as shaping new insights.

Results

Ten general practices consented to take part in my research; from those, 10 participants (five men, five women) consented to being interviewed. They were aged between 46 and 78 years with a recorded diagnosis of Type 2 diabetes. The interviews lasted between 16 and 49 minutes, the former being uncharacteristically short for an IPA approach. This participant (Afra) was tired from nightshifts and did not wish to be re-interviewed at a later date; nevertheless, I felt her contribution still offered unique qualities due to her profoundly religious outlook and insulin use.

Eight main conceptual themes emerged during the course of my iterative analysis (Table 1). The descriptive themes reflect the major topics that were raised during interviews. The conceptual themes were arrived at based on my IPA analysis of underlying issues that related to participants' psychological wellbeing.

Table 1.
Overview of thematic framework

Analytic (Initial themes)	Interpretative (Expanded themes)
Attitudes to diabetes	Contradiction
Co-morbidity	Process of adaption (denial/loss/anger/acceptance)
Lifestyle changes	Incongruence of self
Diabetic control	(Lack of) information
Experience of diagnosis	Power(lessness)
Family situation & emotional support	Responsibility
Information provision & understanding	Coping strategies
Effects on family	Relationship between physical and lived self
Relationship with/role for health practitioner	
Emotional responses	

Prior knowledge about diabetes	
Successful coping initiatives	
Severity of diabetic complications	

It is not possible within the confines of this article to exhaustively illustrate each conceptual theme. Therefore, the three themes that emerged as most central to the illness-disease dynamic will be discussed in detail to give an insight into my interpretations. These are: process of adaption, power(lessness) and connection between physical and lived self.

Process of Adaptation

Denial. Participants sometimes adopted denial as a form of coping and dealing with loss and future fears associated with diabetes.

Bernard is an erudite, 63-year-old man who is wheelchair bound due to double leg amputation. These operations took place consecutively within the last three years, the result of knee impact from powerboat racing and infection from diabetic neuropathy in his feet. His wife is now his main carer. In the following quote, he uses denial to shield himself from the worry about further diabetes complications, which I found all the more poignant in the face of his already severe consequence from diabetes:

Author: So, in terms of, specifically the diabetes, do you have any particular worries about it? Or worries about your future?

Bernard: Well, you push them to the back of your mind really. You know, where next? Sort of thing. I mean as a condition it's not going to get any better.

Author: So the worries that you maybe push to the back of your mind, are they more to do with, "what could happen to me in future?"

Bernard: Yes...one of them has already happened (amputation of both legs).

Afra is a 52-year-old black African woman who uses insulin to control her diabetes. She lives with her husband and older children and is a devout Christian. She has fairly frequent mild hypoglycaemic attacks when her carbohydrate intake is too low. She talks here about her difficulty believing that the symptoms she experienced prior to diagnosis could have indicated diabetes:

Afra: I was having symptoms and I was denying it. I always thought, "No, it can't be" ...even though I felt that the symptoms were to do with diabetes, I still didn't believe that...I still didn't believe that I was going to get that reply (diagnosis).

Sharon is a 60-year-old woman who lives with her husband. She exhibits a pragmatic attitude toward the dietary control of her diabetes and takes Metformin. Many members of her family have Type 2 diabetes. The following quote is not a clear indication of denial as much as an illustration of how denial can work insidiously as part of a larger dynamic often involving control and shame. She described how she had begun to hide what she ate from colleagues who were aware of her diabetes:

Sharon: ...I used to always work in the Co-op shop that used to be up here, and I worked in there for 22 years. And, at the same time as I was diagnosed with it, three other members of staff had been diagnosed, all around my age. So it was like we had our own little gang.

Author: Yes! Your own little community of people...

Sharon: ...And if you see one eating a big cream cake, you say, "You ain't supposed to eat that" And it got eventually that you don't want to eat in front of anybody.

It was fairly common among participants to utilise denial as a form of coping both at the time of diagnosis and with aspects of diabetes management.

Loss. For many of the participants, an emotional undercurrent appeared to be a sense of loss. This loss was attributed to many aspects of the life changes and complications associated with diabetes, often in conjunction with other comorbidities.

Barbara is a 60-year-old woman who was diagnosed with diabetes five years ago. She has multimorbidity: asthma, psoriasis and arthritis. She experiences fairly frequent episodes of hyperglycaemia, which she indicated make her very tired. She conveyed that since menopause, her health seems to have deteriorated noticeably. She lives with her husband who suffers with an asbestos-related lung disease, which keeps them housebound at times.

The following quote illustrates how Barbara misses the playful interactions she used to have with her grandchildren:

Barbara: I mean I thought when I got old I would be out with my grandchildren doing this, that, and the other, and I just can't do it...The youngest ones sort of think, "Well, why can't you do this with me?" My youngest...she says, "Ooh, run with me, nan!" Oh, yea, no way! You know and she used to ask me to pick her up and I did it once and I was in so much pain, I said to her, "I can't pick you up anymore, my love." And that's what I miss. Because when I had the eldest, when she was 16, I was doing everything with her. And then slowly it just sort of ceased, well, it ceases. I just don't do it.

George is a 61-year-old white British gentleman who lives with his wife and welcomes her taking control of the dietary aspects of his diabetes. He is treated with Metformin and antihypertensive medication. He generally appears to exhibit a nonchalant attitude toward his diabetes and did not use emotional language a lot during our interview; yet in the following quote he seems to indicate a subtle sense of loss regarding his previous good health now that he has developed bad eyesight from diabetic retinopathy:

George: And, you see, I've been lucky. I have had very good health through all my life...I think I only took a weeks' sick leave in about 40 years. You know, I got the flu badly one Christmas, but I think that was the only time. So, you know, I don't like not feeling very well.

Leena is a 46-year-old black African woman who is a single parent to a young adult daughter whom lives with her. She had been diagnosed with diabetes for six weeks but felt she had had symptoms for a long time prior, notably memory disturbance, which she associated with her uncontrolled blood sugar. She talks in the following quotes about how her relationship with her daughter has changed because of her symptoms. Her sadness was palpable in her tone of voice and facial expressions:

Leena: I was ironing yesterday and Fatima (daughter) was getting her things ready...and the next minute she was saying goodbye to me and I thought, "What? Where are you going? You're going already?" I didn't even give her a hug...she must think I'm so horrible; I didn't make a conversation with her...I think she is understanding a little bit that I'm not meaning to be like that. It's just I haven't got any control. I think, "Oh, what's the matter with you? Why didn't you sit down with her?"...Hope she didn't notice.

Many participants experienced multiple losses throughout the progression of diabetes, often in conjunction with other health concerns and life circumstances.

Anger. Participants commonly expressed anger in various forms; resentment about lost health or needed lifestyle changes and irritation about loss of autonomy when it was felt that family members interfered.

Barbara conveyed her resentment about her expected quiet retirement being interrupted by ill health:

Author: And when you first found out about having diabetes - obviously you found out through your eyes - so was that quite a shock?

Barbara: Oh yes. Because I thought I was going blind to be honest because everything was bleary...and it frightened me a bit...it was the diabetes...I mean before I've had nothing wrong with me, but since I've gone on the change [menopause] and got a lot older everything seems to be thrown at me. I thought I would have a nice quiet retirement and it's just gone the opposite way.

She talks here about feeling somewhat alienated when needing to disclose her diabetes in company and her choice of words "I don't know why this was put on me" indicates a sense of injustice about her circumstances:

Barbara: I doze off to sleep and it's not because I'm bored, it's just that you can't stop yourself...I'm always worried that I'm going to be in company that aren't going to understand...With strangers I'm a bit like I don't want people to know. And I'm not sure how they would react because some people don't realise what diabetes is...they sort of go like that, you know, "It's not catching is it?"

Author: Sure.

Barbara: ...I'm diabetic, I'm asthmatic, I got arthritis, I got psoriasis...but not one person in the family has ever had it (diabetes)...So I don't know why it was put on me... It really pulls me down sometimes.

Afra conveys here how her family is much more aware of what she eats since her diabetes diagnosis and her irritation that they do not fully comprehend how difficult it is to stick to a restricted diet.

Author: ...have your relationships with your family changed at all?

Afra: I think my girls are quite concerned. My husband as well, but he is more sort of keep it to himself. But I know that he is concerned because he always watches what I eat as well. He always reminds me that I can't have this or that...

Author: And do you feel like if somebody is watching what you're eating, or being careful, does that annoy you or are you ok with it?

Afra: It does sometimes because I feel that they don't seem to understand that it's not that easy, you know, for one to stick to a diet all the time...I once said

to them that if they were so concerned then they would not eat the sort of things they were eating in my presence...

Fred, my eldest participant at 78-years-old, speaks in the following quote about how his health has changed what he is able to do physically and that he feels some resentment that his sons do not offer more help. He has breathing difficulties from Chronic Obstructive Pulmonary Disease (COPD) and pain in his legs from diabetic neuropathy. He lives with his frequently ill wife.

Author: ...Have you noticed, in terms of family and friends, have there been any changes in those relationships since you were diagnosed, or?

Fred: I've got two sons that come here occasionally, like I said, not very regular, but they only come for a cup of tea and a biscuit, never a bit of help, and they're gone...I find at times with my breathing now that some jobs out in the garden, like cutting the grass, and certain jobs, it would be nice to have a bit of help with it...

Anger and resentment were experienced in connection with adjustment to life with diabetes and toward those who it was felt involved themselves too much or too little in the participants' diabetes management.

Acceptance. Participants' acceptance of living with diabetes was often fragmented or only partial and aspects of this acceptance were achieved in a variety of ways and at differing stages after diagnosis.

Barbara spoke of how a process of trial and error with her food and blood glucose led to a more balanced dietary approach that was acceptable to her:

Author: Have there been any times when your diabetes has been more difficult to control?

Barbara: ...Yes. Because I had it in the beginning and then, as I said, nobody told me what was going to happen, I panicked: "Oh, my sugar's up, what am I going to do now? I'll just sit quiet and calm myself down" you know, thinking it was going to go away. And then the other way, I was eating things and I thought, "No, you've got to stop this and just relax. You got it and you can't do anything about it, it's there for good, so you might as well just get on with it." And then it sort of balanced itself out.

George showed a consciousness about his staged process of accepting the lifestyle changes necessary to manage his comorbidities:

Author: Sure, so you were able to talk about it (diabetes diagnosis)?

George: Yes. And my doctor, he knows that I found it difficult to begin with. Part of the problem was, is, because I had been healthy all my life—I never used to take pills, not even an Aspirin—and of course I've ended up taking ten pills a day. So he said to me, "I'm afraid you're going to have to take another pill you know?"...And I said, "I'm passed that stage now. You don't have to worry about me complaining about that..."

Sharon felt that her experience of diabetes within her extended family prior to her own diagnosis helped prepare her, thus aiding her acceptance.

Sharon: ...I knew what to look for (with diabetes) and then when we went to Chester, my sister-in-law tested my blood, because she's got all the equipment. She said you want to get to your doctor straight away...I just said to him (doctor), "I think I've got diabetes."

Author: Yes. So, do you think that helped in terms of your acceptance of it because it was such a short period of time as well?

Sharon: Yes.

Participants' acceptance of having diabetes tended to be a process that occurred in recognisable stages, although this was not always experienced in the same sequence.

Power(lessness)

Feelings of accomplishment, agency and autonomy were detectable when participants felt in control of their bodies, treatment and relationships. Feelings of empowerment were increased for some participants when they were diagnosed – satisfying unanswered questions. Self-motivated research into diabetes by participants, such as looking up medical terms on the Internet, also tended to increase feelings of empowerment.

The deep faith Afra has is a great source of comfort and power for her to help combat difficult emotions associated with her diabetes:

Author: Has the way that you felt changed since you were diagnosed? So, for instance, have you felt low about having diabetes? Or anything like that?

Afra: Perhaps I would be but the simple reason is that...I am a Christian, and I do believe in God, you know, I deeply believe in him and I put my trust in him. And I believe that he would bring me through it, and I think that's what helped me to cope through it.

Her faith helped her to cope with the diabetes diagnosis; however, she experiences powerlessness at times with the day-to-day management of the condition, such as when she was kept ill-informed about a complication that came about with her diabetes treatment. To gain her sense of control in the situation, she stopped taking the tablets that were making her unwell without consulting her practitioners. Loss of agency returned when she was told she had to be treated with insulin.

Author: But it (diabetes medication) was actually causing a condition?

Afra: Yes. And they were checking up on me in the hospital and the doctors never would say anything...never just talked to me about changing the tablets or anything. And I'm the one who decided to come off and stop taking it. And then about a year after that particular time they gave me, put me, on the insulin. You know, I didn't want to go on the insulin but I felt that that was the only option I had.

The following quote brings to attention the anger that was stirred as a result of Bernard's diabetic nurse confronting his excessive drinking habits, affecting his sense of autonomy and agency:

Author: ...sometimes people with diabetes find that once people know they've got it people start to question what they are eating, and things like that. But you've not really found that?

Bernard: ...No, nobody has sort of smashed into me, except the diabetic nurse when we had a little argument about my drinking habits. But then I said to her that I don't drink to get drunk, I drink because I like the taste of it.

When it was felt others (family members, medical practitioners) had gained control in an area of participants' life that they had not had prediagnosis or when the participant felt ill-informed, feelings of powerlessness were experienced.

Connection between Physical and Lived Self

A complex dynamic emerged between participants' relationship with their objective biological body (having diabetes, treatment, practical elements) and their body as they subjectively experienced it (emotional, lived experience of diabetes). To support the explanation of this concept, indications of the two states have been used within quotes to differentiate between them.

The following quote illustrates how Bernard could relate anger to the restrictions his double leg amputation placed on him and he could talk freely about practical changes to his diet yet avoided, or perhaps did not have access to, any direct emotional connection between his diabetes (the partial cause of his amputations) [biological/practical] and his lived [emotional] experience of its disabling consequence.

Author: So do you think it's changed, the way that you felt about yourself at all (since diagnosis)?

Bernard: I'm not too sure what you're trying to get at, "changed how I feel about myself?" I feel annoyed about it [lived experience]...I'm very snarly about things at times, and usually they're little things, little irritants that just build up. I'll feel like punching something.

Author: And do you think that's to do with any of the restrictions that diabetes places on you?

Bernard: Well, in this condition it's not just diabetes [biological], it's other things as well. I mean the things that you don't – having diabetes obviously you don't have sugars, or food with a lot of sugars in it...

Author: So, it's maybe the mixture of the varying things that you live with that causes that kind of frustration?

Bernard: I don't miss them, you know? I don't miss chocolate for instance; I never ate that much anyway. But the only thing that does annoy me is you pick up a bar of diabetic chocolate and look at the constituents and it's got more sugar in it...

Barbara demonstrated here the difficulty she had navigating her relationship between the symptoms of her diabetes [biological/practical] and her lived experience of them such as feelings of anxiety about whether she was experiencing hypoglycaemia or not:

Author:..I would imagine it's quite difficult to differentiate sometimes between what is affecting your life in terms of diabetes and what's maybe the arthritis?

Barbara: Yes. Because sometimes I think, "Oh, I don't feel very well, but is it the diabetes? Or is it just because I'm tired, physically not with the diabetes?" One time they stopped me having my needles...I said that I only used them

when I know I don't feel well...I said, "If I don't feel well and I take some more sugar I'm going to be in trouble..."

Author: Or if you thought it was just tiredness, but actually your sugar was low

Barbara: I should be in a lot of trouble. So they gave me back the needles.

Henry is a 73-year-old man who was diagnosed with diabetes 25 years ago and is treated with Metformin. He has COPD & diabetic retinopathy and relies on his wife to manage his diet. Both Henry and Sharon expressed pragmatic attitudes [lived experience] toward their diabetes during our discourse yet differed in the motivations behind their diabetes management [biological/practical]. Sharon appeared to acquire her pragmatic/matter of fact attitude through evaluating the condition's possible physical effects on her lived experience (based on observations of diabetic family members) and as a result adopted a proactive approach to her diabetes management.

Author: And then you went and got officially tested with the Doctor, and so how did you feel when that happened?

Sharon: It honestly didn't bother me. Because I had known my sister was already diabetic, my son's already diabetic, and obviously my dad...Because when "Jayne" (diabetic nurse) asked me if I'd do it (home blood testing), I said, "Well to be honest, 'Jayne', it don't bother me." I do as I gotta do and I've coped with it and I've kept it all under control.

In contrast, despite more severe diabetes complications (retinopathy) Henry's pragmatic attitude [lived experience] appeared to have formed because he found treatment by tablet relatively unobtrusive, a seemingly more passive stance to take toward his diabetes management [biological/practical].

Author: Ok. And how have you found the changes that you have had to make because of the diabetes...?

Henry: It doesn't worry me at all...I just got on with it. Well, I suppose I would have taken more notice if I was (Type 1) where you've got to have insulin and things like that. I suppose I would have taken more notice then. But when they were controlling it by tablets, I don't suppose you take all that much notice, really.

Alice is a 63-year-old woman who lives alone since her son left to marry. She struggles to control her blood sugar with Metformin but has never experienced a hypoglycaemic attack. She is a member of Diabetes UK, reads their magazine and has friends and relatives who have diabetes. She conveyed a contrast in her interview:

She exhibited anxiety about the possibility of having a hypoglycaemic attack in the night and of future insulin use [lived experience]:

(a) *Alice:* ...well it's usually Type 1 people that end up in comas and kids save them. You read that in the newspaper. So I was reassured I had my son with me, thinking something would happen in the night. But I haven't been ill to have either a low or a high. So I just plod on thinking it won't happen to me. Or I've got a phone in my bedroom so I would phone somebody.

(b) *Alice:* But I just pray I don't go on to (insulin) injections, that would really do me in.

Yet she indicated during her interview a few times that she was not particularly disciplined with her blood sugar control [biological/practical]:

Alice:...well, at the moment I had a blood test done on Friday and I've just phoned at two o'clock today and they want me to see my doctor...

Author: Sure. So are you suspecting that it's (high blood sugar)

Alice: Mmm, well. I'm glad you've come really. Because I was beginning to think "oh heck, what have I done!"...I'm probably going to get a rollicking when I get the doctor phoning, and he's threatened me with it, with insulin, before now.

The often discordant dynamic described between a participant's biological body and the practical management of diabetes and their emotional, lived experience of the condition was particularly pervasive and was potentially at the core of many fears, coping mechanisms and psychological disturbances. (Figure 1: Conceptualisation of the dynamic between interpretative themes).

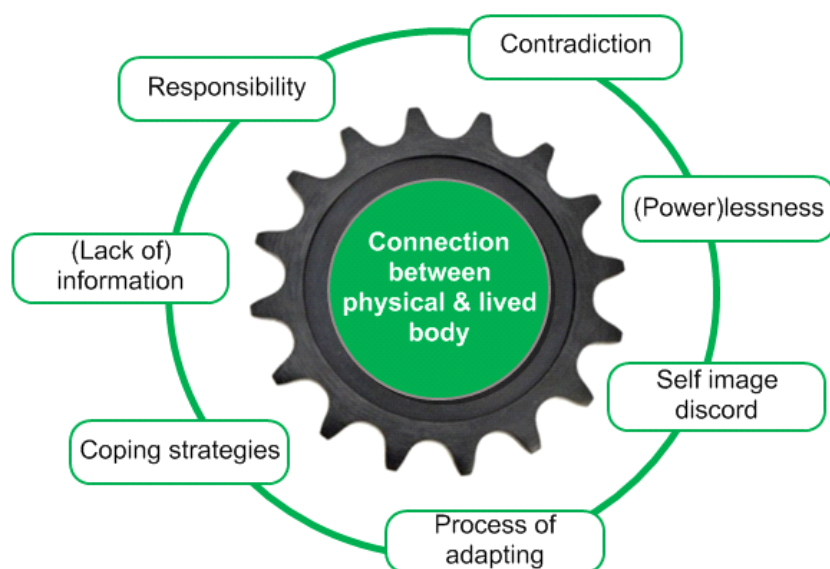


Figure 1: Conceptualisation of the dynamic between interpretative themes.

Discussion

Beyond Expression

Participants' dominant expressed attitudes toward diabetes can be categorised as untroubled (George, Fred), angry (Bernard, Barbara), practical (Sharon, Henry) or anxious (Leena, Alice). There was often a discrepancy between the attitude that was verbalised and my interpretation of the meaning behind its expression, hence the importance of the thorough self-reflexivity in the IPA process. Seemingly untroubled attitudes could result from an acceptance of the condition or be a consequence of denial. Attitudes of anger were conveyed through blaming, resentment and self-pity about having the condition or about others who did not. Participants who conveyed a practical "just get on with it" approach often stated that they felt neutral about having the condition; however, on closer analysis this attitude seemed to mask anxieties and fears, particularly about future diabetic complications and was perhaps more of an emotional resignation than an accepting embrace.

Interplay of Comorbidity

The psychological effects of participants' comorbidities were often indistinguishable from one another. It was apparent that the cumulative effect of multiple health conditions was a major component of stress. The burden of this relationship was heightened by lack of information about the possible side-effects of polypharmacy, and often resulted in fear of the unknown.

Practical and Emotional Responsibility

The two aspects of practical lifestyle change that participants described as having the greatest impact on them were the constant requirement for diabetes medication and dietary self-control. The women participants seemed to find greater impact of diet alteration on their social and family relationships than the men. Resentment, guilt and shame were the associated emotions expressed. The men often passed responsibility for dietary management to their wives, which in turn unconsciously shifted emotional responsibility for their condition as well - their wives were often more concerned than they were. This finding is supported by the results of a meta-analysis of gender differences in caregiving. It concluded that "caregiving increases gender differences in depression and physical health, primarily because women experience more caregiving stressors" (Pinquart & Sörensen, 2006). The analysis found that, compared with male caregivers, female caregivers experienced greater caregiving burden and depression and provided a larger amount of care. These gender differences were both statistically and practically significant.

Emotional Literacy and Entitlement to Feelings

Participants said that the emotional impact of diabetes was rarely broached by either themselves or their practitioners; despite participants believing it was an essential component of overall treatment. The few participants who said they had discussed how they felt described doing this in an indirect way with friends who also had the condition, focusing on practicalities rather than emotions. Similarly, participants did not regularly employ emotional vocabulary to describe their feelings during interviews but rather used "stories" about their condition to convey how they feel, a finding consistent with other chronic illness studies (Hooper & Ong, 2005; Riessman, 1990).

The Process of Grief in Diabetes

The experiences of denial, anger, depression (powerlessness/loss) and acceptance that were identified in this study are consistent with four of the five stages of grief in the much cited Kübler-Ross model (Kübler-Ross, 1997). The element that was not directly represented was "bargaining," which involves trying to negotiate one's way out of the hurt (loss). This may be due to many variables, for instance, different experiences of diagnosis, previous knowledge of the condition or different depths of engagement with the loss. Not all participants in this study experienced grief to the same extent, at the same time points or for the same duration. Despite the Kübler-Ross model being widely understood as a linear, prescriptive process, it was originally intended as a flexible individual framework that acknowledges this variability in depth of engagement with the grieving process (Friedman & James, 2011). The experience of grief being congruous with a chronic disease diagnosis is corroborated by data from numerous other studies (Orto & Pouwer, 2007; Stewart & Shields, 1985). In diabetes, sources of grief were identified in the analysis as loss of health, mobility, agency and autonomy, among others. Losses are often multiple and increase in number and severity as the condition progresses. The process of grieving mirrors that in depression (Friedman, 2012) and evidence shows that major

depression can affect people's ability to self-manage their diabetes (Lin, Katon, & Korff, 2004), creating a circular persistent dynamic.

Connection between Physical and Lived Experience

Carel's phenomenological work on chronic illness (Carel, 2007) discusses the complex relationship that was highlighted in the analysis between participants physical (biological) body and their lived (feeling) experience. She defines disease as one's physical experience and illness as one's lived experience of that disease. She argues that illness distances us from the physical body; where it was once healthy and predictable, it becomes erratic and the source of pain and disability. In the healthy, this distance is not normally available; illness brings this once unnoticed, unobtrusive relationship into focus. Carel considers that having lost this habitual relationship between the two, the ill person must form a new one, requiring and inducing adaptability and creativity. These two responses are the basis for her conclusion that one can be ill *and* happy.

Gadamer (1993) defines health as:

...not a condition that one introspectively feels in oneself. Rather it is a condition of being there (Da-Sein), of being in the world...of being taken in by an active and rewarding engagement with the things that matter in life...It is the rhythm of life, a permanent process in which equilibrium re-establishes. (pp. 144-145)

Illness, in this view can be considered therefore as a condition of being far from one's sense of being. Svanaeus goes on to investigate this relationship further and refers to one's sense of being as "homelike" (Svanaeus, 2000) – familiar, comfortable and secure and postulates that the essence of illness is a sense of being estranged from one's "home." He argues that through devoting attention to the patient's sense of being, paths back to "homelikeness" might open up.

Though both Carel and Svanaeus' theories shed light on the illness experience, neither address the phenomenon highlighted both in the literature and in the current study that people with diabetes often do not make a relationship between their diabetes and how they feel, even in cases where there is severe disability. One of the keys to providing an effective psychological support system for diabetes might lie in understanding the dynamic of this phenomenon. Carel's question "Can you be ill and happy?" leads one to a perhaps more pertinent line of questioning, "What makes a person with diabetes believe they are ill?"

Coexistence of the Physical and Lived Experience

I propose a revised model for the connection between illness and disease in diabetes as one of embodied coexistence rather than relation. I found that participants were not always aware of the stances evidenced in their discourse about their disease or lived experiences. Emotional responses such as stigma, denial, avoidance and incongruences of self-clouded their vision.

Participants such as Bernard and Henry reported good psychological wellbeing in relation to their diabetes yet neither paid the required attention to their physical selves – they separated their lived and physical selves (Figure 1. Henry). On the contrary, Barbara was acutely aware of the deteriorations of her physical self and this greatly impacted her view of her lived self – she allowed the two to leak into each other (Figure 1. Barbara). For equilibrium to occur, both phenomena must be embodied by the patient and the dynamic between them must be managed. This management can be likened to a membrane – selectively permeable.

The membrane provides a means of managing the two elements separately and allows them to necessarily influence each other without one becoming overly dominant (Figure 2. Proposed model of embodiment).

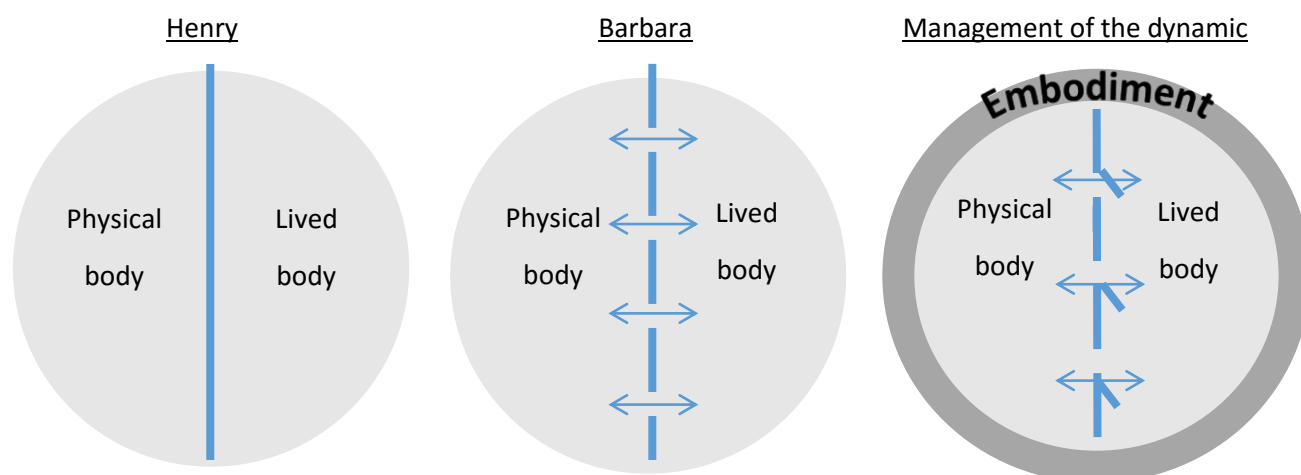


Figure 2. Proposed model of embodiment

The proposed model acted as the foundation from which I designed the subsequent intervention and as a guide for developing patient engagement with the support system. Aspects of findings from the focus groups and design workshop that followed also contributed to this process and will be described in subsequent articles.

Limitations of the Study

Aspects of my approach might have influenced the interviews and analysis, such as preempting participants’ expression of their feelings in the way I phrased questions. Also, by disclosing my own insulin condition, I might have influenced participants’ answers to reflect those they felt I might approve of. However, my ability to truly relate with participants’ experiences also potentially aided their honest disclosure. There is scant research specific to self-disclosure in the researcher-participant dynamic. The implications of therapist self-disclosure have been more widely studied, particularly in the feminist literature (Fisher & Shueman, 1990). A recent qualitative review of the role of therapist self-disclosure concluded that its use was potentially helpful (Henretty & Levitt, 2010). For instance, in building rapport, promoting client disclosure and normalising and promoting feelings of universality. The importance of context, “who, what, when, why,” when deciding to self-disclose was emphasised in the review.

One must consider that the intensive interpretative nature of IPA might in fact bias the researcher’s interpretation of the meanings participants give their experiences. Perhaps when participants state they are happy, they are indeed simply that.

A possible additional limitation of this study was that patients with diagnosed major depression were not eligible. Their inclusion was strongly debated during the design of the study. At present within diabetes literature about psychological wellbeing, there is little clarity among terms used to describe degrees of depression; for example, subthreshold, minor, mild, moderate are used interchangeably. The generic term “depression” is also often used to describe multiple conditions and assessment tools and thresholds vary greatly and are not comparable (Gonzalez, Fisher, & Polonsky, 2011). It was felt that had patients with major

depression been included in the study, potentially, a biased impression of psychological needs of the target population might have resulted.

Future Research

There is wide research available in the related fields of illness perception, self-regulation theory and coping that can also inform the issues discussed in this article. These are areas for further research, together with robust testing of the proposed model with larger, more culturally diverse samples. It is possible that the proposed model applies only to patients who are not suffering from major depression or that major depression alters its structure.

Concluding Words

The IPA approach chosen for this study allowed for a detailed exploration of the psychological impact of Type 2 diabetes for 10 people whom have been diagnosed with the condition for varying degrees of time. Though no broad generalisation can be claimed from this study, it is hoped that my idiographic contribution to the literature will increase professional knowledge of subclinical psychological distress in people with Type 2 diabetes, an often overlooked and difficult to access aspect of living with the condition. Shedding light on the barriers these patients face in disclosing how they feel and their perceptions of their medical practitioners might contribute toward more open and informed communication between parties. The findings from the study informed phase two of the PhD project, which was the design of an online support system (POSD) for adults with Type 2 diabetes to promote psychological wellbeing.

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