

Living with diabetes

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#### **ABSTRACT**

Research surrounding diabetes implies that there is a definite answer with regards to coping strategies for diabetes that has to be sought after. However, less research explores the individual's unique standpoint and experience of diabetes. The present study qualitatively investigated the lived experience of diabetes of 6 participants. Semi-structured interviews were conducted and analysed using interpretative phenomenological analysis. Analysis revealed five master themes; 'diabetes is an "inconvenience", 'negative aspects of the condition', 'avoiding being "reliant on other people", 'lack of understanding' and 'acceptance of the condition'. It was found that participants used 'positive reappraisal' in order to reframe a seemingly negative situation. By focusing on aspects such as social support and the non debilitating tendencies of diabetes, the participants were able to focus less of their attention on negative aspects of diabetes, such as the inconvenience and lack of control. Implications for the enhancement of previous findings and facilitating diabetic individuals are discussed.

KEY WORDS:	DIABETES	QUALITATIVE	INTERPRETATIVE PHONOMENOLOGICAL ANALYSIS	LIVED EXPERIENCE
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#### Introduction

In 2010 is was suggested that around 3.1 million people in England were living with both type one and type two diabetes, and it is forever increasing, with projections made that by 2030, the rates would rise to 4.6 million (NHS, 2014). Diabetes is a life changing condition therefore, unsurprisingly, "being diagnosed with diabetes and living with diabetes can often feel overwhelming" (Diabetes UK, 2014). The condition not only affects, what could be considered simple, day-to-day activities from everything such as driving, employment and sex, but also life changing experiences, such as travelling and pregnancy (Diabetes UK, 2014).

## **Negative view of Diabetes**

With diabetes being considered a vast, life changing condition, it is understandable that negative connotations are attached. With this in mind, Holt et al. (2014) have found that "diabetes and depression occur together approximately twice as frequently as would be predicted by chance alone" (1). This stresses the importance and necessity to develop and inform diabetic individuals of successful coping strategies that allow them to form a positive relationship with their condition, thus decreasing any debilitating views.

By reviewing the benefits of different coping strategies put in place by diabetic individuals, successful techniques can be determined. This was explored, using a quantitative method, by Jaser and White (2011) who looked at adolescents with Type 1 diabetes. Questionnaires were used in order to look at how coping affected quality of life, competence and metabolic control, with the aim to "identify the most adaptive coping strategies" (335). They found that primary coping strategies, such as problem solving and emotional expression used by individuals, were related to better quality of life, higher competence scores and better metabolic control. In addition, secondary coping strategies, such as acceptance and distraction, were found to be associated with better metabolic rate and quality of life as well as higher social competence. Disengagement coping strategies, such as withdrawal and denial, were unsurprisingly found to be correlated with lower competence levels and poorer metabolic rate. These findings could, therefore, be used to encourage diabetic individuals to adopt primary and secondary coping strategies, as opposed to disengagement, in order to gain greater diabetic control and subsequently reduce negative views.

O'Connell and Hurley (2009), however, suggest that there can be various negative connotations when conducting quantitative studies on topics regarding health issues. It can "give an illusion of certainty" (306) which consequently ignores the complexity of such health issues. Similarly, they suggested that uncertainties and unquantifiable data need to be assessed and represented within the findings of such studies, which is often not the case when using quantitative methods. However, these findings should not be disregarded based on these limitations. They provide a platform, from which qualitative studies stem, in order to enhance our knowledge of the subject.

When interpreting the above study, it is implied that there is a definite answer with regards to coping strategies for diabetes that has to be sought after. Although organisations, such as NHS and Diabetes UK, are able to offer advice on how to cope effectively with diabetes, it's apparent that little or no emphasis is placed on the individual and, instead, general coping strategies are suggested for all to attempt using a trial and error approach. Obviously, the information provided is useful and is a method of support available to the millions of people living with diabetes in the UK. However, it may be considered beneficial to explore an individual's unique standpoint and experience of diabetes. This way coping strategies can be explored through the perspective of an individual rather than through a statistic.

# **Myths and Misconceptions Surrounding Diabetes**

In 2015, The American Diabetes Association created an online resource discussing and eliminating many of the common myths and misconceptions surrounding diabetes. For example, "eating too much sugar causes diabetes" was regarded as a common myth. The association enlightened viewers by providing the following information: genetic and unknown factors are found to trigger the onset of Type 1 diabetes. For Type 2, lifestyle factors can increase the risk, however genetics can also be considered when determining a cause. "People with diabetes should eat special diabetic foods", was also found to be untrue. It was suggested that a healthy meal plan is encouraged, just as it is for any other individual. These misconceptions have arguably caused diabetic individuals, especially those who are newly diagnosed, to have a skewed understanding of the chronic condition they inevitably have to endure (Schneider, 2000). By increasing the education of diabetes, inevitably, these misconceptions will gradually vanish, thus benefiting diabetic individuals.

Furthermore, highlighting which are the incorrect stigmas attached to diabetes may result in increased social support. If participants are able to discuss their condition with others who are informed on the subject, positive effects can occur. This is suggested by Street et al. (2009) who found that communication, via different pathways, including shared understanding and increased social support, can positively influence health outcomes. This supports the notion of raising awareness and increasing the understanding of diabetes. Moreover, social support from family and friends has been found to be extremely valuable to diabetic individuals, suggesting that it allows them to "feel good about their diabetes" (La Greca, et al., 1994: 449). This also supports the importance of increasing understanding; however, more specifically focuses on each diabetic's unique support network, thus implying the benefits of exploring individual accounts of the condition, in order to gain an insight into these distinctive perspectives.

## **Present Study**

Currently, much of the research surrounding diabetes is looking for a definitive coping strategy which will benefit the majority of diabetic individuals. By using these studies as initial thoughts, the present study is able to enhance and expand upon this knowledge. The incentive to carry out this research is focussed largely around the opportunity to gain insight into the lived experience of diabetes. By adopting a qualitative approach, this allows for the complexity of the condition and the essential essence and quality of the individual's account to not be lost within statistical data.

The aims of this study, therefore, are to explore any negative views of diabetes, expressed by those living with the condition. Additionally, this study hopes to enhance the knowledge of successful strategies put in place in order to cope with the strain of these negative associations. Finally, this study will explore the influence outsiders have, both through experiences of or feelings towards misconceptions projected onto the individuals, and through the suggested power of support networks. Whilst incorporating the above aims, this study primarily endeavours to create a greater awareness that diabetes is a lived experience, by exploring and recognising that each individual diabetic has their own unique story to tell.

## Method

## Design

Semi-structured interviews were used to collect the data within this study. This method was considered the most suitable as it allows for an in depth exploration of an individual's social and psychological world (Smith and Osborn, 2008). Additionally, Smith and Osborn (2008) consider the participants to be the experiential experts in relation to the topic they are discussing, and by using semi-structured interviews, the utmost opportunity is granted for them to express their own unique experiences. Although people living with diabetes all have a common characteristic which places them under the same umbrella term 'diabetic', this is not what defines the individual. By using semi-structured interviews, the opportunity arose for diabetic participants to express their individuality in terms of how they cope, experience and most importantly live with the condition on a day-to-day basis.

In addition, the use of semi-structured interviews allowed for interpretative phenomenological analysis (IPA) to be conducted effectively. This form of analysis allows the researcher to take a phenomenological standpoint, whereby they are able to interpret the participant's perceptions of their personal and social world, through the researcher's own experiences (Smith and Osborn, 2008). This is seen as appropriate for the present study, and fitting for the main aim of the research, to explore the lived experience of diabetes. By using this form of analysis, the researcher was able to gain an in depth understanding of the experiences expressed by each participant (Drummond, et al., 2011).

## **Participants**

In keeping with Smith et al (2009)'s recommendation, in order to conduct an effective IPA, six participants were recruited, each of which identified as being diabetic. **Table** 

**1** illustrates the relevant demographic information for each of the participants, including; age, gender, type of diabetes, time since diagnoses and current method of treatment.

 Table 1

 Table showing relevant demographics of participants

Participant (pseudonym)	Age (years)	Gender	Type of Diabetes	Time since diagnoses (years)	Method of treatment
Dorothy	73	Female	Type 2	23	Injections/Tablets
Paul	52	Male	Type 2	9	Injections/Tablets
Jack	22	Male	Type 1	13	Injections
Claire	27	Female	Type 1	14	Injections
John	58	Male	Type 2	7	Injections/Tablets
Betty	75	Female	Type 2	19	Tablets

#### **Materials**

Participants were recruited using a volunteer sampling method, whereby a poster (see **Appendix 1**) was presented on social media websites. The poster informed social media users of relevant information about the researcher and the incentive to carry out the study. Additionally, the poster stated the requirement that all participants be identified as diabetic and that it was necessary for an interview to take place which would last no longer than an hour in length. Participants were invited to contact the email address provided if they wished to gain more information or if they were willing to take part. Due to their restrictive use on social media, Dorothy and Betty were contacted directly by the researcher via telephone.

An interview schedule was produced (see **Appendix 3**) based on the recommendations suggested by Berg (2009.) Berg has identified four types of questions which can help to gain detailed accounts from the participants and will "draw out the most complete story about various subjects or situations under supervision" (113). 'Essential questions' refer to those which concern the central focus of the study and are included in order to elicit "specific desired information" (113). This is demonstrated within questions 3, 5 - 6, 9 - 14, 16, 18 and 20-22 of the interview schedule. 'Extra questions' are those which are related to the essential questions, but are worded differently in order to create consistency within the data the interviewee is providing, as is found within questions 8, 15, 17 and 19. The final type of question suggested by Berg is 'probing questions' which provides the interviewer with the opportunity to draw out more information from the participant by getting them to elaborate on what they have previously stated in answer to another question. An example of this can be found within the extra notes of questions 8 and 19. Additionally, Berg suggests that sequencing is a desired feature when composing an interview

schedule, whereby the order in which the questions are presented can significantly affect the success of the interview. Firstly, a rapport should be established between the interviewer and the participant. This can be done by commencing the interview with seemingly easy questions, such as the demographics of the participant. This is demonstrated within questions 1, 2 and 4 of the interview schedule.

Each interviewee was provided with an information sheet (see **Appendix 5**) fully explaining the procedure and the nature of the questions. Participants were required to sign a consent form (see **Appendix 4**), prior to the interview taking place, confirming they were fully aware and comfortable with continuing with the research. Participants were given a debrief sheet (see **Appendix 6**) post interview, which reiterated the intentions of the study. This also contained contact information for the researcher and additional information on where they can find help and advice if they had been affected by the contents of the study.

## **Procedure**

Prior to the interviews taking place, a pilot interview was conducted. Feedback from this was found to be positive: the schedule was said to flow nicely, where earlier, easier questions were found to ease the participant in and allow them to feel comfortable and more confident when responding. In addition, the schedule allowed for a lengthy interview whereby many of the questions prompted in depth responses, in addition to providing platforms for elaboration and additional relevant questions. Finally, in response to the pilot interview, questions 21 - 23 were added to the schedule, which were found to be of interest to the researcher and the aims of the study.

Each of the interviews were recorded on a recording device and then transferred onto a password protected laptop. This allowed for the interviews to be transcribed within individual documents. Smith and Osborn (2008) emphasise the importance of making sure that the true essence of the interview is captured during the transcription phase, by making note of every pause, laugh and crucially everything that was said, despite it potentially seeming insignificant. Each recording was transcribed following these guidelines (see **Appendix 7**). Additionally, to ensure accuracy, the recordings were replayed while the transcriptions were simultaneously read over in order to detect and correct any errors made within the initial transcription. This process requires accuracy, due to the emphasised importance IPA places on ensuring the final results capture the true essence of what was expressed within the interviews.

IPA was then conducted on each of the transcripts individually, based on the staged process demonstrated by Smith and Osborn (2008). The researcher was required to gain familiarity by reading and rereading the transcript. Next, initial thoughts were noted in the left hand margin. These notes simply reflected any associations, summaries or comments on language which were noticed by the researcher. The initial thoughts were then gathered into clusters based on common features, using concise phrases or summaries to depict the essential quality of detail portrayed in the interview

(see **Appendix 7**). Smith and Osborn (2008) suggest that either the clusters gathered from the first interview transcript can be used as a template for the remaining transcripts, or each transcript can be looked at individually. Within this research, the latter approach was adopted. The clusters from all six of the transcripts were listed and, based on similarities, in terms of meaning, master themes were created (see **Appendix 8**). It is stressed that throughout the analysis process, the quality and detail of the interview is not lost, therefore each stage required the researcher to ensure the clusters and themes were in keeping with the initial interview transcript.

### **Ethical Considerations**

Ethical Approval was obtained prior to the research being undertaken (see **Appendix 2**). Each of the interviews took place in a predetermined setting which was agreed upon by both the researcher and the participant. Deception was not required for this research and participants were reminded of their right to withdraw from the study, up to 4 weeks after the interview had taken place, without having to give a reason. Pseudonyms were used within all documents associated with the research, in order to ensure anonymity of the participants. Participants were made aware of this, in addition to the fact that quotes from the interviews would be used within the final report of the research. Interview recordings and transcripts were stored on a password protected laptop within a password protected file, which only the researcher and, with permission, the dissertation supervisor had access to. These files will be destroyed once the results for the dissertation project are obtained.

# **Analysis**

Integration of the clusters revealed five master themes; 'diabetes is an "inconvenience", 'negative aspects of the condition', 'avoiding being "reliant on other people", 'lack of understanding' and 'acceptance of the condition'.

### Diabetes is an "inconvenience"

A common theme which arose from each of the participant's interviews was the expression of diabetes as an inconvenience to their everyday lifestyle. This was the exact term Dorothy, Paul and Claire used to answer the question 'what does diabetes mean to you?'

"Err [p] an inconvenience" (Dorothy: 24)

"to me it's a bit more of an inconvenience" (Paul: 6)

"I see it as more of an inconvenience" (Claire: 12)

From the above responses, it is apparent that diabetes, above all else, is an inconvenience, as it is incorporated within the meaning the participants attribute to the condition. This theme is further supported when the participants discussed the restrictions diabetes has on their day-to-day life and activities. Both John and Claire

express this in terms of the medication they are required to take and their methods of treatment.

"the biggest problem is the freedom, because you've got to take your drugs and you've got to inject... the medication I'm on at the moment, I feel as though it is" (John: 158-161)

"it was a pain in the arse really, if anything, like I was on syringes and, erm, it was really strict and a lot of it was you have to eat this, this and this, you can't have this, this and this" (Claire: 87-89)

"you couldn't really have a lie in because you had to be up at a certain time for your morning injection, you had to eat so much because you were on this much insulin" (Claire: 101 - 102)

John depicts, from the above extracts, that in order to gain the required control through taking the necessary medication, his body has to be manipulated in such a way that is having negative effects on the perception of his own freedom. Claire, however, expressed examples of how she had to alter her regular routine, including sleeping patterns and diet, based around her medication. Expanding from this, nearly all of the participants expressed how diabetes can be or has been restrictive on specific aspects of their life. For Dorothy, John and Paul this was in terms of their career.

"I was still at work, I was a personal tax manager and a magistrate, I was doing everything. Didn't have time for this." (Dorothy: 205-206)

"they want to put me on a particular drug which is gonna be difficult... and that I'm concerned about, especially working where I do at the airport." (John: 100-101)

"in relation to the type of job that you do, if your job, you know, becomes a little bit sociable you know, you make new contacts with people by being in a bar and things like that, and I am held back sometimes" (Paul: 123-125)

The restrictions on seemingly everyday activities, such as hobbies or even simply getting out of the house were expressed by Claire, Paul and Jack.

"if you go hypo mid workout or something you're doing, you're kind of done really, you can't, you shouldn't really sort of carry on because you need to get your blood back up and if you carry on there just going to come down again" (Claire: 228-231)

"I've got to always be checking myself before I do something, to want to do it... like the running... I can't just head off and go and do it" (Paul: 99-101)

"if I'm like running late and I'm going to a friend's house or going to the train station, I go into a hypo before I leave and it sets me back" (Jack: 91-93)

The above examples offer an insight into the many aspects of life that diabetes restrictively impacts for the participants. Furthermore, the need to become organised was a common lifestyle change participants expressed that they had to endure.

"it's just slightly planning things differently" (John: 162)

"it's a whole organisational thing " (Dorothy: 73)

"you've got to plan ahead" (Paul: 102)

Throughout all of the interviews, it was extremely apparent that diabetes was considered an inconvenience. This was expressed through limitations and restrictions within many aspects of the participants' lives as a result of the condition, in addition to the lifestyle modifications the participants were required to make. This negative association was founded within the participants understanding and meaning they attributed to the condition. Thus implying, however inconvenient, that this is an inevitable aspect of diabetes.

## Negative aspects of the illness

All of the participants expressed examples of the negative aspects associated with diabetes. It was apparent that these negative associations often stemmed from the unwanted and unexpected onset of the condition.

"Disappointed me because now I was a diabetic, which is, I've been trying to avoid" (John: 35-36)

"it was a little bit upsetting because, you know, you don't want any kind of a long term chronic illness" (Paul: 21-22)

"I got it and I had no family history of it" (Claire: 189)

Additionally, participants expressed negative feelings towards diabetes based on their desire for, and yet lack of, control that the condition implements.

"so long as you feel as though you can keep, get back in control, then you feel better about yourself... it's when you start to lose control a little bit, I think that's when you get a bit more frustration and concern" (Paul: 80-82)

"I'm not saying I'm a controlling person but I like to be in control of what I do and that makes me not in control of what I do" (Dorothy: 26-27)

Unsurprisingly, this lack of control often led to further negative aspects of diabetes, including a feeling of frustration. Furthermore, this feeling covered a number of aspects associated with the condition. John expressed his frustration towards the lack of control, whereas Claire expressed her frustration towards the restrictive tendencies of diabetes. John also conveyed the frustration he feels towards the unrealistic and inconsistent requirements being placed on him by specialists, whereas Paul found

himself to be frustrated with individuals who have the chance to avoid diabetes and yet demonstrate ignorance.

"My sugar levels have gone up and I'm frustrated again as to why they've gone up" (John: 60-61)

"that can be frustrating at times, and you just think, you just wanna crack on" (Claire: 237-238)

"I think the frustrating thing I find is that the goal posts keep moving" (John: 18-19)

"I get frustrated that there's so many people that are on the edge of diabetes and that can cure themselves" (Paul: 202-203)

The above extracts suggest that the feeling of frustration covers both personal problems which have been encountered by the participants, and frustrations aimed towards external people. Resulting from the undesired, initial surprise, the lack of control and the frustration associated with diabetes, it is understandable that a number of the participants experienced feelings of hatred and denial towards the condition.

"I have... my phases where I literally hate it" (Claire: 13)

"realised what it was all about and what I had to do for the rest of my life... it was daunting and I hated it" (Jack: 104-105)

"just trying to cope with it, erm, that's because up here [points to head], there's nothing to cope with" (Dorothy: 112-113)

"it took a little while to sink in" (John: 47)

Above all, the negative aspect which was found to be most common was the desire to be 'normal'.

"it'd be nice to be able to do what normal people do" (Claire: 221-222)

"I try and live my life as normal as anybody else" (John: 135-136)

"if they're warned... you can have a normal life. It is in so many instances an avoidable illness" (Paul:206, 208)

From the interviews, by referring to a desire to be considered 'normal', it can be assumed that participants deemed themselves and their condition as an abnormality.

In summary, the interviewees expressed a vast array of negative aspects associated with diabetes which could be viewed as a gradual process. Initially, negative aspects are associated with the unwanted surprise of diabetes, in addition to the lack of control diabetes afflicted on the participants. This can therefore lead to frustration and

subsequently hatred and denial. Throughout the whole process, the desire to be considered 'normal' occurs.

# Avoiding being "reliant on other people"

"I don't want to be reliant on other people to, to have to look after me" (Paul: 116-117)

As expressed by Paul, the above extract demonstrates the desire to avoid having to rely on other people to look after him. Arguably, this could be the explanation for why many of the participants expressed the wish to mask their condition from others. The extracts below provide examples of this being done. Although Betty is referring to being on crutches, which was not stemming from her diabetes, she suggests that because of the type of person she is, this would be the case with any 'abnormality'.

"once you're on, er crutches, it, it, it's alright having to go out, with crutches but people look at you, you know, so I never did" (Betty: 164-164)

"you try and mask it with people that you don't know, whether it be alcohol consumption or jabbing at certain points... it's embarrassing sometimes" (Paul: 126-125, 129)

Although it was found to be a common feature across the interviews, it was apparent that many of the participants were in fact reliant on others. This, however, was not in terms of physical aid, but mental support. Paul often discussed the support of his wife throughout his diabetic journey, from detecting symptoms, through diagnosis, to the present day. In some instances he referred to his diabetes in a manner that suggested it was shared between him and his wife.

[referring to what he did when he was diagnosed] I think I just probably called Kim and just [p] we had a good idea as to what it was" (Paul: 31-32)

"that's worrying as well from my wife's point of view" (Paul: 148)

Similarly, concern was expressed from family members for Betty and Dorothy.

"my sister in actual fact... she said "go and see the doctor" (Betty: 52-54)

[referring to when she was diagnosed] "my daughter, she started crying" (Betty: 15-16)

Within Dorothy's interview, her husband entered part way through in order to provide Dorothy with and remind her to take her diabetic medication.

For Claire and Jack, the type of support they discussed was provided by their parents and more specifically, their mothers.

"I had my parents around me... I had a good support system around me" (Claire: 71-72)

[referring to a diabetic support group] "I went with my mum" (Claire:84)

"my mum would say "don't put sugar on your weetabix"" (Jack: 83)

John expressed that his family showed concern prior to his diagnosis, however he found support by talking to friends who he knew were diabetic in order to gain reassurance.

"the family were like, giving me grief to go and get myself checked out" (John: 22-23)

"I spoke to Pip about you, because obviously then I know you were a diabetic" (John: 48-49)

The above examples emphasise the vast amount of mental support that was obtained in order for the participants to successfully deal with their illness. However, as it was expressed within the interviews, being reliant on others was not a position the participants wanted to find themselves in. It was, therefore, almost unnoticed how much they currently relied on others in order to create a stable support network which would help them from the onset and throughout their condition.

## Lack of understanding

Within each of the interviews, it was discussed that there was an apparent lack of understanding from people who you would not consider to be within the diabetic community. This was expressed, firstly, through each of the participant's admission that they had a very limited understanding of diabetes prior to their diagnoses. Below are the responses to the question 'did you know much about diabetes before you were diagnosed?':

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"Nothing at all" (Dorothy: 48)
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"Not at all, no, I knew nothing about it, no" (Jack: 40)

"Not really... no, I didn't, no not really" (John: 42)

Additionally, the participants expressed that they often found themselves subject to misconceptions and assumptions associated with diabetes.

"all you hear about is if you're overweight or obese you will get type 2... or they don't even say type 2, they'll just say, you'll get diabetes" (Claire: 185-187)

"There's a stigma that if you have diabetes, you are overweight or you're unhealthy, and it's not the case" (Claire: 188-189)

"they look at your size and they say "well are you surprised... that you've got it?" and I'm saying "well [p]... I think I was born with the gene" (Dorothy: 134-136)

"people say type 2 is the obesity, erm, diabetes but I mean, you look at Sir Steve Redgrave" (John: 122-123)

Throughout the interviews, the participants seemingly agreed that in order to prevent these misconceptions, an accurate education should be provided. Additionally, Paul suggests that this education may also encourage people to avoid diabetes where possible.

"I think more could be done to educate people" (Claire: 197)

"I think education provides, you it need to be put out there, erm, because it's frightening the cost it's going to be to, to the NHS" (Paul: 215-216)

"I think if you're gonna talk about something you've gotta know what you're talking about" (Claire: 194-195)

It is apparent that most of the participants believed that an education about diabetes would be beneficial in order to eliminate certain misconceptions around the subject, in addition to potentially reducing the rising number of sufferers. However, Jack expressed that this may not be an obtainable goal.

"you [don't] truly know what it's like until you have it" (Jack: 73-74)

This is further supported by participants who expressed that they 'knew their own body'.

"there's sort of like signals, like signs that I pick up on, and that I can tell, even without doing a blood sugar... just know" (Jack: 62-63)

"I know my body now, I know, I can tell when I'm low, I can feel when I'm high" (Paul: 91-92)

"it is a case of just knowing your own body" (Claire: 118)

The above examples emphasise that diabetes is specific to the individual, and that despite a desire to educate others about the condition, it may be impossible to make them fully aware of how it is to be diabetic, due to the huge amount of knowledge gained from the experience of actually having diabetes. Moreover, this emphasises the importance of raising the awareness that every diabetic is different. Dorothy expresses a frustrated opinion on this matter in relation to the medical support she receives.

"every insulin patient is an insulin patient, there's no individuals" (Dorothy: 212-213)

## Acceptance of the condition

Throughout all of the interviews, a positive attitude was expressed in terms how the participants had accepted diabetes. Firstly, comparisons were made.

"if I'd have had diabetes [p] you know if my parents had had it, or grandparents, you know they probably would have died from it" (Paul: 43-44)

"there's a lot worse things out there" (Paul: 8-9)

"it could be so much worse" (Claire:11)

"it's much better than erm [p] in the 1900s... they weren't aware of it and they didn't know what it does to you" (Betty: 138-139)

This could be considered an expression of how the participants feel lucky. By using examples of how medicine and knowledge has improved over the years, they were able to draw upon the fact that that they could be in a much worse position. This is further supported through the participants' expression of how they don't find diabetes to be debilitating.

"it's not stopped me doing anything" (Betty: 151-152)

"I live exactly how I would, even if I didn't have it" (Jack: 88)

"I don't find it that debilitating" (Dorothy: 184)

"I struggle ever to see it as a disability" (Claire: 253)

The participants expressed how diabetes was simply an unfortunate event which you have no choice over. With this in mind, in addition to diabetes' non debilitating tendencies, a unanimous agreement echoed across all of the transcripts: life goes on.

"I've just basically, just got on with it" (John: 50-51)

"life goes on with it" (Paul: 9)

"your life's not over!" (Claire: 267)

### Conclusion

The themes discussed above provide an insight into the life of the participants who are living with diabetes. The inconveniences and negative aspects that diabetes implements on everyday life were expressed. Additionally, the relationship between external individuals (referring to individuals who do not have the condition) and diabetes was articulated. This is in relation to how they can create a sturdy support network which facilitates the diabetic individual, whilst simultaneously being able to cast misconceptions about the condition. Finally, an expression of acceptance was demonstrated by each of the participants. It could arguably be suggested that once acceptance is obtained, all the negative associations of diabetes are lessened.

#### **Discussion**

The aim of this study was to create awareness that diabetes is a lived experience, by exploring and recognising that each individual diabetic has their own unique story to

tell. IPA generate 5 master themes from the interview transcripts: 'diabetes is an "inconvenience", 'negative aspects of the condition', 'avoiding being "reliant on other people", 'lack of understanding' and 'acceptance of the condition'.

## **Comparisons with Existing Literature**

It was apparent that the participants from the current study were not afflicted with the extremity of depression as a result of the "psychological burden of diabetes" suggested by Holt et al. (2014: 1). However, it became apparent that negative emotions were associated and incorporated into the very understanding of diabetes the participants expressed. This was demonstrated within the themes 'diabetes as an inconvenience' and 'negative aspects of the condition'. Some comments offered were indicative of the symptoms of depression as stated by the NHS (2014). The current findings could, therefore, be seen as supporting evidence for the positive, correlational relationship between diabetes and depression.

Similar to the participants within Street et al.'s (2009) study, the current participants highlighted the positive affiliations associated with being able to communicate about their health conditions. This was expressed within the theme 'lack of understanding'. Participants expressed their displeasure towards misconceptions surrounding diabetes by encouraging the need for education, which would subsequently lead to the increased ability to widely discuss diabetes. This, therefore, is reflective of findings from the existing study.

Furthermore, within the theme 'avoiding being "reliant on other people", findings mirrored those of Le Greca, et al. (1994). The existence of social support was apparent for all of the participants. More specifically, and in keeping with the previous literature presented, these support systems were found to influence the participants positively in terms of their relationships with and expressed views of their personal experience of diabetes.

The final theme, 'acceptance of the condition' appeared to belittle the many negative aspects of diabetes. With the participants maintaining positive attitudes towards the situation they have unfortunately found themselves within, they were able to show acceptance towards their condition. This process has been summarised by Folkman (1997) as 'positive reappraisal', whereby cognitive strategies are used in order to reframe a seemingly negative "situation to see it in a positive light" (1212). This is arguably the most important and influential finding of the study. Not only does positive reappraisal incorporate all of the other themes, it also organises them into a hierarchical manner, providing a structure. By focusing on aspects such as social support and the non debilitating tendencies of diabetes, the participants are able to focus less of their attention on negative aspects such as the inconvenience and lack of control the condition brings.

## **Implications of Findings**

The finding of this study offer practical implications which can be put in place regarding diabetes. Firstly, importance is placed on the need to raise awareness and increase the education of diabetes, as misconceptions have been found to be somewhat damaging and distressful to diabetic individuals. Secondly, findings can be incorporated within, but not exclusive to, medical support provided for diabetics. This research highlights the essential need to explore and treat each person as a unique individual, as this allows for maximum understanding and subsequently the best suited treatment plan can be created.

Positive reappraisal towards diabetes, as found within this study, can be used to enhance and elaborate on previous findings of existing literature. It offers a potential solution for the worrying statistic provided by Holt, et al. (2014): "diabetes and depression occur together approximately twice as frequently as would be predicted by chance alone" (1). Additionally, elaborating from Jaser and White's (2011) findings which incorporated successful coping strategies, this research has suggested that positive reappraisal and subsequent acceptance of the condition are extremely powerful coping strategies. It may, therefore, be beneficial to advise and educate individuals suffering with diabetes about this finding, in order for them to adopt such a technique.

## **Strengths and Limitations**

A clear strength of this study is the qualitative approach which was adopted as it allowed for an in depth exploration of diabetes as an individually lived condition. By using a sample that was diverse in terms of age, gender, type of diabetes, length of diagnosis and method of treatment, differences in experiences can be not only acknowledged, but celebrated, rather than suppressed into an unsentimental statistic.

The relationships between the participants and the researcher could be seen as a limitation, due to the fact that they were established prior to the research. This could be construed as a limitation, as participants may not feel comfortable disclosing personal information to someone they have previous connections to and which continue outside of the research. In addition, the researcher indentified as a type 1 diabetic herself, which may provide the illusion of a bias standpoint. However, IPA emphasises the importance of gaining an in depth understanding of the experiences expressed by each participant. Thus, the researcher may have been able to gain greater phenomenological understanding of the experiences expressed within the interviews.

## **Future Research**

The overriding finding of this study regarding positive reappraisal leading to acceptance of the condition warrants further investigation. Within this study, its existence is established; however future studies could question how it is achieved. Findings from this study could then be used in order to improve the medical supports suggestion for coping with diabetes. More importantly, by raising awareness of how to

achieve positive reappraisal within diabetes, the diabetic community will undoubtedly benefit.

#### Conclusions

Diabetic individuals are in a unique position in that they are gifted with the knowledge which results from experience. Awareness has been made about the negative aspects of diabetes, in addition to the influence of 'outsiders'. Most importantly, the positive attitude which is allowing participants to accept their condition and subsequently live by the motto 'life goes on', is inspirational. By allowing participants to talk in detail about their experiences, it has allowed us to explore diabetes as a lived experience in depth. It is hoped that these findings have raised awareness of diabetes and will inspire people to gain a greater understanding of the ever growing condition.

### References

American Diabetes Association (2015) Diabetes Myths. [Online] [Accessed on 20<sup>th</sup> April 2015] <a href="http://www.diabetes.org/diabetes-basics/myths/">http://www.diabetes.org/diabetes-basics/myths/</a>

Berg, B.L. (2009) Qualitative Research Methods: For the Social Sciences. 7<sup>th</sup> ed., Boston: Pearson.

Cameron, F.J., Amin, R. de Beaufort, C. Codnor, E. and Acerini, C.L. (2014) 'Diabetes in adolescence.' Pediatric Diabetes, 15(20) pp. 245 - 256.

Diabetes UK (2013) Living with Diabetes. [Online] [Accessed on 26<sup>th</sup> November 2014] <a href="http://www.diabetes.org.uk/Guide-to-diabetes/Living">http://www.diabetes.org.uk/Guide-to-diabetes/Living</a> with diabetes/

Drummond, J., Hendry, C., McLafferty and Pringle, J. (2011) 'Interpretative phenomenological analysis: a discussion and critique.' Nurse Researcher, 18(3) p. 20.

Folkman, S. (1997) 'Positive Psychological States and Coping With Severe Stress.' Social Science and Medicine, 45(8) pp. 1207 - 1221.

Gale, E.A.M. and Gillespie, K.M. (2001) 'Diabetes and Gender.' Diabetologia, 44(1) pp. 3 - 15.

Holt, R.I.G., de Groot, M. and Golden, S.H. (2014) 'Diabetes and Depression.' Current Diabetes Reports, 14(6) pp. 1 - 9.

Jaser, S.S. and White, L.E. (2011) 'Coping and resilience in adolescents with type 1 diabetes'. Child: Care Health and Development, 37(3) pp. 335 - 342.

La Greca, A.M., Auslander, W.F., Greco, P., Spetter, D., Fisher, E.B. and Santiago, J.V. (1994) 'I get by with a little help from my family and friends: adolescents' support for diabetes care.' Journal of Pediatric Psychology, 20(4) pp. 449 - 476.

Neu, A. Willasch, A., Ehehalt, S., Kehrer, M. Hub, R. and Ranke, M.B. (2001) 'Diabetes incidence in children of difference nationalities: an epidemiological approach to the pathogenesis of diabetes.' Diabetologia, 44(3) pp. 21 - 26.

NHS (2014) Clinical Depression - Symptoms [Online] [Accessed on 20<sup>th</sup> April 2015] http://www.nhs.uk/Conditions/Depression/Pages/Symptoms.aspx

O'Connell, E. and Hurley, F. (2009) 'A review of strengths and weaknesses of quantitative methods used in health impact assessment.' Public Health, 123(4) pp. 306 - 310.

Schneider, J.M. (2000) Diabetes A to Z: What you need to know about diabetes-simply put. USA: The American Diabetes Association.

Smith, J.A. and Osborn, M. (2008) 'Interpretative Phenomenological Analysis.' In Smith, J.A. (ed.) Qualitative Psychology: A practical Guide to Research Methods. 2<sup>nd</sup> ed., London: Sage Publications, pp. 53 - 80.

Smith, J.A., Flowers, P. and Larkin, M. (2009). Interpretative phenomenological analysis: theory, method and research. London: Sage.

Street, R.L., Makour, G., Arora, N.K. and Epstein, R.M. (2009) 'How does communication heal? Pathways lining clinician-patient communication to health outcomes.' Patient education and counselling, 74(3) pp. 295 - 301.

Whiting, L. S. (2008) 'Semi-structured interviews: guidance for novice researcher.' Nursing Standard, 22(23) p. 35.