A qualitative pilot study into the impact of type 1 diabetes on everyday anxiety levels

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Previous research has suggested that psychological factors, such as anxiety, may have a role to play in the control of type 1 diabetes. Specifically, one study has shown that raised levels of anxiety in people with type 1 diabetes may lead to complications, while people with diabetes who demonstrated more adaptive coping strategies have been shown to have better overall blood glucose control. The current study aims to expand on previous research by looking at the impact of type 1 diabetes and metabolic control on feelings of anxiety and lifestyle. Interviews and questionnaires were used to collect data from a small sample of people with type 1 diabetes and the responses were analysed for recurrent themes.

Factors known to affect the control of type 1 diabetes (T1D) include exercise, insulin, diet and lifestyle, although recently it has been suggested that psychological factors, such as anxiety, may have a role to play. This association was first suggested by Metsch et al (1995) and more recently by Sultan et al (2008). These studies considered how coping impacts on the control of T1D and this current study expands on this theory by looking at the impact of T1D treatment on coping and anxiety in daily living.

Both of the previous studies have looked specifically at trait and state anxiety. Trait anxiety refers to a general underlying disposition, while state anxiety is subjective and situation specific (Hardy et al, 1996).

It has been reported by Sultan et al (2008) that raised levels of anxiety, specifically trait anxiety, in people with T1D may lead to complications, while those who demonstrated more adaptive coping strategies have been shown to have better overall blood glucose control (HbA_{1c}) and fewer complications. However, follow up of the study was limited. The present study develops the concepts identified by Metsch et al (1995) and Sultan et al (2008) by exploring the various psychological themes and blood glucose control, in addition to the role of factors such as medication, symptoms and choices in determining the behaviour of people with T1D. The study looked at changes in behaviour reported by people with T1D that may affect their health.

Method

Participants

The participants involved in this small study were three females and four males with T1D. They were aged 18–80 years, providing a broad range of time since diagnosis with T1D, and they were recruited through social networking sites and a diabetes support workshop. Descriptive data of the sample can be found in *Table 1*. Participants reported being free of acute or chronic medical conditions other than T1D. Ethical approval for the study was obtained from Cardiff University Ethics Committee.

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Article points

1. The impact of anxiety on type 1 diabetes control and behaviour remains to be explored in depth. The present study looked at how daily blood glucose control can have an effect on anxiety and behaviour in people with type 1 diabetes.
2. An increase in "state anxiety" was reported when glucose levels were unstable or abnormal. Participants who were able to adapt their routine displayed better glucose control over time.
3. Female participants reported feelings of embarrassment and this resulted in medication administration being delayed or taken in private.

Key words

- Anxiety
- Glucose control
- Lifestyle
- Type 1 diabetes

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1. The study was made up of two parts: a questionnaire and an interview. The questionnaire included items from the State-Trait Anxiety Inventory (STAI) and the Multidimensional Health Locus of Control (MHLC) scale.
2. The interview aimed to discuss: general life experiences since diagnosis; the affective experience of their condition generally and the control that the individual felt they had over their condition.
3. The interviews were transcribed and themes were identified and subsequently organised under the relevant category heading within a participant matrix. This approach is known as "thematic composition" This enabled identification of re-occurring themes.

Procedure

The study was made up of two parts; the first was a self-administered questionnaire, which asked about participant characteristics and length of diagnosis, as well as questions derived from the State-Trait Anxiety Inventory (STAI; Spielberger et al, 1983) and the Multidimensional Health Locus of Control (MHLC) scale (Wallston et al, 1994). The second element was a semi-structured interview. Prior to data collection, both elements were pilot tested on an individual with T1D, with a follow-up interview exploring clarity, integrity and content. The questionnaire and interview were found to be valid and structurally logical.

Anxiety measures

The STAI (Spielberger et al, 1983) measures both trait and state anxiety. Each item is rated 1 to 4 (1 being "not at all" or "almost never" and 4 being "extremely" or "almost always").

The MHLC scale (Wallston et al, 1994) assesses a person's beliefs about whether his or her health status is determined by their actions and, if so, whether the "locus of control" (LOC) is internal or external. The MHLC assesses four subscales within 18 items: internal, chance, doctor or other people. All the subscales are independent to one another.

The interviews were conducted immediately after completion of the questionnaire. Participants were interviewed separately using a semi-structured interview guide. The interview guide was divided into three themes:

- Their general life experiences since diagnosis, for example, any behavioural changes the individual has had to make and any recurring thoughts about their condition.
- The affective experience of their condition generally, specifically with reference to episodes of high and low blood glucose and comparison of these events by the individual.
- The treatment and control that the individual felt they had over their condition by first reviewing their treatment regimen and then moving on to the effect of changes in the routine, both predictable and unpredictable. This theme also considered the impact of others on their treatment and control.

Additional probing questions were used to obtain detailed information and allow the participant to explore their T1D. All interviews were recorded and the interviews were then transcribed and stored with the participant's questionnaires.

Themes were identified from the interviews and subsequently organised under the relevant category heading within a participant matrix. This particular approach, known as "thematic composition" was developed by Watts et al (2010). This enabled identification of recurring themes emanating from the participants' responses. Transcriptions were independently checked for accuracy. From these, the emerging themes were identified. The interview matrices were reviewed by another researcher for independent identification of emerging themes and these findings were cross-referenced with those identified by the primary researchers. In addition, each matrix was compared to the results of the individual's pre-interview questionnaires to identify any patterns.

Results and discussion

Table 1 shows details of the seven individuals' characteristics including findings from the STAI and the MHLC scale, in addition to group summary data. Thematic analysis of the interviews confirmed some congruence with factors previously alluded to in other studies but clear identification was made of new themes that previously have not been observed in people with T1D. These themes will now be explored.

The importance of routine in blood glucose control

Having a good routine has previously been linked to glucose control (Watts et al, 2010) and this was also apparent in this sample. However, while having a routine was identified as important, this theme was further developed in the interviews with an identification of the importance of being able to adapt that routine and be flexible to deal with unexpected situations. Participants who reported a good routine but also talked about being able to adapt and be flexible had a more desirable HbA_{1c} status. A typical example of the strategy to achieve this was the presence of a glucose testing kit and antidiabetes medication at all times, which helped them stay in control of their glucose levels,

irrespective of dietary and exercise routine changes. This finding is supported by the work of Herzer and Korey (2010). A routine may be beneficial to people with diabetes but it is also important to have the means to deal with unexpected situations.

The present data did not support the view that too much routine testing would be counter-productive to the condition. From previous research, it can be noted that the participants who reported having good control over their condition, reported the fewer health issues (Metsch et al, 1995), although it is important to note that there may be discrepancies in individuals' ability to recall all health events. In this data, there was a trend between more frequent glucose testing and lower HbA_{1c} values. Statements from the interviews supported the belief that lack of blood glucose testing throughout the day may result in poor HbA_{1c} levels, especially where circumstances or the person's behaviour prevented the typical level of testing. A common barrier to regular blood glucose monitoring in the group was being in full-time employment or education, as many would report being too busy or forgetting. This was not seen in those individuals who were not in employment.

Table 1. Participant diabetes details with anxiety and locust of control scores.

ID	Gender	Age	Age at diagnosis	Testing frequency (per day)	HbA_{1c}	Frequency of appointments Consultants (per year)	Frequency of appointments GP (per month)	Trait anxiety score	State anxiety score	LOC internal	LOC chance	LOC doctors	LOC other people
1	F	19	1	2	184 mmol/mol (19%)	4	0	48	23	28	18	13	10
2	M	24	17	2	56 mmol/mol (7.3%)	2	0	52	21	29	21	12	9
3	M	21	10	0	72 mmol/mol (8.7%)	3	0	46	20	32	11	10	5
4	F	20	12	2	54 mmol/mol (7.1%)	4	2	43	21	25	8	14	7
5	M	20	14	2	62 mmol/mol (7.8%)	1	0	48	25	31	23	12	12
6	F	80	62	3	58 mmol/mol (7.5%)	2	3	43	18	23	18	13	12
7	M	80	77	2	62 mmol/mol (7.8%)	0	0	40	21	36	14	12	8
							Mean	45.71	21.28	29.14	16.14	12.28	9.00
							SD	3.48	1.91	4.05	4.99	1.16	2.58

LOC=Locust of control; SD=Standard deviation.

Page points

1. Feelings associated with neuroticism play a role in maintaining a healthy diet for those living with type 1 diabetes.
2. The majority of participants in the study mentioned feeling elevated levels of anxiety under certain conditions, although these differed depending on whether they were experiencing antecedents, such as hypoglycaemia, hyperglycaemia or unexpected change, preventing them from sticking to their routine.
3. The results of this study do not suggest a trend between trait anxiety and blood glucose control.
4. The current study also identified embarrassment as a factor and this has not been identified in previous research. Some participants explained embarrassment in terms of specific events or situations. Others related embarrassment to generally having type 1 diabetes.

Neuroticism

There is evidence to support the view that neuroticism is associated with long-term diseases, for example, these tendencies are more prominent in people with cardiovascular disease (Booth-Kewley and Friedman, 1987). The strong link between neuroticism and anxiety and the impact on some long-term diseases meant that it was important to assess how prominent it was in the sample. Five of the participants made comments linked to neuroticism regarding the consumption of certain foods and drinks high in sugar. Concerns over both the availability and content of food to avoid adverse health events appeared to affect their feelings towards their diet. This is a complex and dynamic relationship, which requires further study. Generally, having T1D was viewed negatively, in terms of its impact on their health and lifestyle. However, two participants considered that their situation could be worse, had the recent advances in treatment of T1D not occurred.

State anxiety

The majority of participants in the study mentioned feeling elevated levels of anxiety under certain conditions, although these differed depending on whether they were experiencing antecedents, such as hypoglycaemia or hyperglycaemia, or unexpected change, preventing them from sticking to their routine. A number of interviewees linked elevated levels of state anxiety with induced feelings of low blood glucose levels. State anxiety scores (see *Table 1*) higher than the mean by one standard deviation have been regarded as clinically relevant (Laux et al, 1981). Only two participants had clinical state anxiety scores, although many anxiety themes emerged across all of the interviews conducted. Further research to understand this relationship would be useful to consider the interaction between state anxiety, environmental factors and blood glucose levels.

Trait anxiety

Results from the trait anxiety questions suggest that only one participant displayed high trait anxiety. Previously it was found there is no clear relation between trait anxiety and metabolic control (Metsch et al, 1995) and the present study also did not identify a link between trait anxiety and blood glucose control.

Embarrassment

The current study also identified embarrassment as a factor and this has not been identified in previous research. Some participants explained embarrassment in terms of specific events or situations. Others related embarrassment to generally having T1D, suggesting an internalisation of the condition. However, the relationship between T1D and feelings of embarrassment is not straightforward. The data suggest that age and gender both play a role in the understanding of how T1D and embarrassment interact. Throughout the interviews with the younger people, the topic of embarrassment emerged strongly, while neither of the older participants reported feeling embarrassment.

The impact of gender is also evident from the comments of the two female participants who expressed the strongest feelings of embarrassment. From the interviews it can be seen that this embarrassment may have a large impact on their condition. Participant 1 stated: "If I am in a public place I will not administer my medication". It is recognised that Participant 1's interview data reflected elevated feelings of anxiety and embarrassment above those of the other participants. Interestingly, their high HbA_{1c} value did not appear to be motivating them to contact their GP any more frequently than the other participants, although their consultant visits were in the top of the range. At the end of the interview, the participant was directed to seek medical advice. It is important to note that there were only two females in the sample who reported this factor strongly and both of these were young adults.

Males also reported embarrassment linked to the demonstration of symptoms of hyper- or hypoglycaemia in the presence of others. This finding supported the evidence of Birkeland et al (2011). The reasons for this difference may be due to experience dealing with these issues and therefore knowing how to manage them or being less self-consciousness. Indeed, the older participants reported looking at their condition in a positive light, suggesting they could

be in a worse situation, though it was unclear whether they were referring to their T1D or their general health. Embarrassment, anxiety and symptoms appear to interact with gender and age to produce a complex response process in a person with T1D. In turn, embarrassment and anxiety may have reciprocal relationships with the person's glucose testing regimen and environmental control, although further research would be needed to understand this more clearly.

Anger

Anger was another theme to emerge from the interviews. Participants reported elevated feelings of depression, anxiety and anger and this is something that has been shown in previous research (Suls and Bunde, 2005). It is thought that the chronic nature of diabetes may be a cause of these problems. The majority of the participants talked about anger or feelings associated with anger, which were typically directed internally. For example, in some cases anger emerged as self-anger due to neglectful control or frustration when glucose levels were low or high without apparent reason. The reason for anger in some cases may also be manifestations of the fact that participants worry about the long-term effects of the illness if they cannot control their glucose levels, or if their glucose levels are unstable and they are unsure what is causing this instability.

The MHLC scale (Wallston et al, 1994) identified that there was a relationship with how participants attribute their control of their T1D, with higher scores linked to how they attribute their control to that theme. In *Table 1* some links can be seen between MHLC and STAI total, for example, Participant 7 had high internal MHLC scores and a low STAI score, as well as having the strictest and most adaptable routine. In contrast, Participant 6 did not have a high internal control score, which could be linked to quotes from the interview when they talked about having very high/low blood glucose results but without any indication as to why this is happening. Most participants attribute their control internally. These participants attributed more control to doctors than other people, while it can also be seen in *Table 1* that other people had a relatively low mean value (9.00) compared to the other factors and thus did not have a significant effect on the participants' diabetes control. These results contradict the observations made by participants in the interviews, who reported that other people had a more significant role with their condition.

Conclusion

This in-depth pilot study looking at the lifestyle experiences of individuals with T1D has revealed new dimensions linked to living with the daily concerns, medication regimen and symptoms of the condition. The factors of embarrassment, anxiety, anger and a direction of attribution towards themselves for their diabetes control are important factors that require further investigation in a larger population. The experience of embarrassment seems complex and multifactorial.

Notwithstanding the sample size, the findings support the findings of Metsch et al (1995), that people with T1D do not have high levels of trait anxiety. However, in contrast to Sultan et al (2008), the evidence here shows state anxiety increases related to medication and symptoms related to this condition. Further research should explore the factors identified here because there appears to be implications to the health and well-being of individuals with T1D. ■

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