Exploring young people's perceptions of living with type 1 diabetes

Jane Samson

The objectives of this study were to explore and describe the perceptions of living with type 1 diabetes of people aged 18–25 years. The interviewees described living with type 1 diabetes as a journey; some participants moved quickly to accept and integrate diabetes into their lives, while others moved more slowly, depending on the support, knowledge, barriers and coping skills of each young adult. Throughout the narratives it was clearly seen that there was a wide range of abilities to integrate diabetes into their lives and cope with the condition.

Adolescents and young adults with type 1 diabetes are a unique group with distinct physical and emotional needs that differ from the needs of younger children and older adults (Peyrot and Rubin, 1994). Young adults living with diabetes face the same developmental tasks and demands as their peers in addition to learning to manage and live with their diabetes.

The purpose of this study was to explore and describe the perceptions of living with type 1 diabetes of young adults aged 18–25 years. The objectives of the study were:
- to explore and interpret the experiences of young adults with type 1 diabetes
- to identify barriers for young adults with type 1 diabetes
- to identify coping strategies that young adults with type 1 diabetes use.

The methodology employed was a qualitative, phenomenological approach, using semi-structured, topic-driven interviews that were tape-recorded and transcribed.

Why a qualitative, phenomenological approach?

Qualitative research is essentially a way of describing and analysing the culture and behaviour of people from the point of view of those being studied (Bryman, 1988). It is a broad term to denote a family of interviews with varying degrees of flexibility for the purpose of studying phenomena, uncovering the aspects of 'what', 'why' and 'how' from the perspective of the participant, i.e. the 'insider's perspective'.

Knowledge of these processes, in this case the experiences of young adults with type 1 diabetes, increases understanding and provides a basis for interventions that may enhance quality of life (Munhall and Oiler, 1992).

Article points

1. In addition to learning to manage and live with their condition, young adults with diabetes face the same developmental tasks and demands as other young adults.

2. Part of coming to terms with diabetes is learning about personal 'limits' and 'balance'.

3. The participants of this study were able to overcome practical barriers in their lifestyle through the combination of knowledge and acceptance.

Key words

- Young adult
- Perceptions
- Type 1 diabetes
- Coping strategies

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Page points

1. The goal of phenomenological research is to fully describe the lived experience and the perceptions to which it gives rise.

2. The thematic analysis demonstrated the major themes as: context, support, barriers and coping mechanisms.

3. In order to formulate the interview schedule a literature review was conducted into areas of relevance and importance to young adults with diabetes.

Phenomenology proposes that individuals interpret their world to make it meaningful and that interpretations are the participants' social reality. Researchers and healthcare professionals therefore need to try and understand individuals' interpretive processes in order to understand the participants' experiences (Bryman, 1988). Thus, the individuals' perceptions and accounts of their experience are important (Smith, 1996).

The goal of phenomenological research is to fully describe the lived experience and the perceptions to which it gives rise.

Each interview transcript was interpreted using an interpretive phenomenological analysis framework. The thematic analysis demonstrated the major themes as:
- context
- support
- knowledge
- barriers
- coping mechanisms.

Literature review

In order to formulate the interview schedule a literature review was conducted into areas of relevance and importance to young adults with diabetes.

Lloyd et al (1993) compared the social relationships of young adults with type 1 diabetes with those of healthy controls. The data were collected from interviews using the Self-evaluation and Social Support Questionnaire (O'Connor and Brown, 1984). Lloyd et al's study was rigorous in design and methodology and provided a valuable insight into this specific area. The results identified that young adults with type 1 diabetes are just as committed to the social arena, but they are more likely to experience social isolation and an inability to form close relationships. Additionally, they consider these relationships as lower quality than those of the healthy control group.

Strachan et al (2000) identified increased initial isolation for those who move away and attend college. For those at college Strachan et al (2000) and Ramchandani et al (2000) identified that the ready access of alcohol and recreational drugs acted as barriers. Ramchandani et al (2000) also identified 'peer pressure' as a barrier.

This evidence demonstrated the importance of including topic areas such as support and college experiences in the interview schedule.

Ramchandani et al (2000), Fox (1995) and Dunning (1995) all identified fear of hypoglycaemia as a barrier; although Dunning identified other aspects of fear and hypoglycaemia in respect to relationships, work and driving or if the person experienced a hypoglycaemic reaction in the street.

The above research revealed the importance of including work and social aspects into the current study's interview schedule.

Dunning (1995) found evidence of uncertainty about the future of living with diabetes. Lloyd et al (1993) explored this in their questionnaire, which also revealed issues regarding the future. They reported that those living with diabetes would be less likely to have children and that many were concerned about the impact of diabetes on their future, such as marriage and parenthood. These studies emphasised the importance of the future as a topic in the interview schedule.

Schur et al's (1999) study of young adults with type 1 diabetes (aged 16–22 years) found that participants expressed a pervasive fear of stigma, a fear of being discovered as 'different' and of being judged by others as less acceptable than the norm (either on account of diabetes or the associations others might make with diabetes), despite little or no experience of enacted stigma. However, the sample size was small (n=8), all of the participants were in higher education and were Caucasian in origin.

The current study included the topic areas of stigma and disclosure and used young adults' experience to elaborate on this aspect. To further develop and elaborate on Schur et al's (1999) work, this study included other ethnic groups and young adults who were from a variety of socio-economic status groups.

One health psychology model that is increasingly being used to understand and predict an individual's emotional and behavioural response, and therefore coping with and subsequent self-care of diabetes, is the self-regulation model (Leventhal et al, 1984; Leventhal and Nerenz, 1985), more commonly

known as personal model beliefs.

The significant advantage of personal models is that they are participant-generated as opposed to researcher-generated. This means that such models identify those variables that participants believe to be central to their experience of illness and its management, thus providing greater data about the participants' 'insider's perspective'.

Hampson et al (1990) found that including participants' emotional responses to the condition contributed to both the 'how long it will last' and 'treatment efficacy' constructs, confirming the important role and inclusion of emotions in personal models.

The above research justified the inclusion of questions during the interview about participants' feelings, what diabetes meant to them and exploring the consequences of the illness socially, in the family, at work or college and for the future.

Study sample

For the purpose of this study the researcher chose to use the framework from her own clinical area, which has a 'young adult' clinic, as a guide. People between the ages of 18 and 25 years attend this clinic.

The DSN who manages the caseload of all young adults was able to identify those participants who were representative of the entire population. Factors that needed to be considered were the inclusion of young adults from diverse ethnic groups and diverse social circumstances and young adults who opined that they had problems with their diabetes as well as those who did not.

Theoretical sampling was chosen as it offered the researcher a degree of control. Twelve participants were approached initially and eight finally agreed to take part. (See *Table 1* for some details of the eight participants.)

The analytical process

The researcher followed a structured process for the analysis.
- Data collection from the interviews.
- Transcribing.
- Analysis of transcriptions.
- Mapping; the objective of which is to create groups of categories from all the themes identified. By considering each cluster of themes that had an overriding common element, the master themes are identified.
- Structure and master theme list construction; Smith (1999) advises that researchers need to decide which themes to focus upon. Those that are selected are not simply chosen on their prevalence within the transcripts, but by the richness of data available and how the data demonstrated other aspects of themes that are taken into account as justification for choosing the major themes.

Page points

1. For the purpose of this study the researcher chose to use the framework from her own clinical area, which has a 'young adult' clinic, as a guide. Patients between the ages of 18–25 years attend this clinic.

2. Twelve participants were approached initially and eight finally agreed to take part. All participant and place names were changed to preserve participant confidentiality and anonymity.

Table 1. Profiles of the eight participants.						
Identifier	**Sex**	**Age (years)**	**Age at diagnosis (years)**	**Duration of diabetes (years)**	**Social circumstances**	**Ethnicity**
S	F	21	13	8	Living with parents; works two jobs to make 37.5 hours/week	White British
Ka	M	19	8	11	Lives with parents; college F/T	Turkish
Ki	F	24	21	3	Lives with sisters; works F/T	Black Caribbean
C	F	23	0.5	22.5	Lives with stepsister; works shifts F/T	White British
B	F	25	15	10	Lives with parents; works F/T	White British
J	M	18	1.5	16.5	Lives with parents; works F/T	White British
T	M	18	3.5	14.5	Lives with mother; works F/T	White British
R	F	18	15	3	Lives with parents; college F/T	Pakistani

F, female; M, male; F/T, full time.

Analysis of master themes

The master themes provide the key elements that describe the participants' lived experiences of type 1 diabetes as a young adult (the 'insider's perspective'). The interviews described living with type 1 diabetes as a journey for all the participants; some moved quickly to accept and integrate diabetes into their lives, while others moved more slowly depending on the support, knowledge, barriers and coping skills of each participant.

'Context' identified where the individual was in this journey.

Context
The interviewees could be categorised into three groups.

Group one
Participants moved from shock, biographical disruption and feeling 'different' to integration of diabetes into their lives and feeling 'normal'.

R describes how she felt at diagnosis:

> R: 'I realised I had the same as what this woman was talking about, so I went to the doctors and I got diagnosed.'
> Jane Samson [JS]: 'Right.'
> R: '... by the blood test, […] it just really shocked me.'

For those at the beginning of the journey of integration and acceptance of the condition, accounts were provided that demonstrated the individuals recognising themselves at odds with the wider perception of diabetes.

R was the only one who had not yet managed to integrate diabetes into her life. Skinner and Snoek (2000) outlined the stages of change behaviour: in the pre-contemplative stage denial is apparent. R was found to still be in the 'shock' phase and by being in this stage she was still in denial, this means that although she was not wanting to initiate change in her life to begin to integrate diabetes she was 'surviving' by doing the basics, that is, taking enough insulin.

> R: '... and erm, its just, I just feel that I can't fully cope with the diabetes.'
> JS: 'Right.'

> R: 'Because everybody says that it doesn't change your life and everything.'
> JS: 'Right.'
> R: 'That you should fit your life around the diabetes. No, that you should fit your diabetes around your life, rather than your life around the diabetes.'
> JS: 'Yes.'
> R: 'But I find it hard to do that.'

Group two
The second group, which included B, described accepting diabetes as taking a longer time, but eventually they had managed to integrate diabetes into their lives and had overcome the shock.

> B: '... and so it's only just recently, about a year, that I've started [integrating diabetes into my life].'

Group three
Group three included those who had accepted diabetes and had integrated diabetes positively into their lives. Accounts were provided that demonstrated the individual had come to terms with the condition and felt aligned with the public perception of the illness, as Ka described:

> 'It's probably […] 'cos I got it from such an early age, you just get used to it.'

Support
Support provided a constructive framework to enable participants to incorporate diabetes into their life more effectively. Family was central to the support framework, but it is important to recognise the need of young adults to move from an inter-dependent relationship to one where they can become more independent from their peers and family members.

Knowledge
Knowledge added to the cognitions of illness representation. Participants learned to live with diabetes by acquiring knowledge through healthcare professionals, through reading books and through other sources of media. The vast majority of learning to live with

diabetes was found to be achieved through personal experience.

Acquiring knowledge took place initially by participants understanding the basics to survive diabetes.

> Ki: *'But then it was a case of I probably didn't learn about, learn a lot about, it just because I didn't want to. I knew that it was about sugar, so I cut sugar out completely.'*
> JS: *Right, OK.'*
> Ki: *'And erm, you know, besides the regular visits here, I just kind of knew I had to take my insulin when I ate and that was basically it. I didn't really find out about what diabetes was all about, you know.'*

Participants acquired knowledge gradually through personal experience, as Ki described.

> Ki: *'I sort of learn more and more about it just through everyday life, it's not like I've gone and got a whole load of books or anything.'*
> JS: *'No, no.'*
> Ki: *'But just what I experience through everyday life is what I learn about it now.'*

Part of coming to terms with diabetes was about learning about personal 'limits' and 'balance'. Participants used their own lifestyles and activities to learn how to get diabetes to fit into their lives, as Ki describes.

> *'Erm, oh, the drinking thing is a bit strange still, but I've found my balance; I've found a way to kind of drink, but not drink excessively, to get drunk again. Like I can still get drunk and not have a large amount, if you know what I mean.'*

Participants chose to not use knowledge if they had negative cognitions of illness representation, as R described earlier. R's lack of positive support away from the diabetes clinic in addition to her negative cognitions of illness representation potentially resulted in her remaining in the shock stage of diabetes much longer than the others.

However, it was also found that participants who held negative cognitions and lacked positive support, but had developed problem-solving skills, logical analysis and information skills, i.e. knowledge, were found to be able to use task-orientated coping strategies to 'survive' diabetes. These types of strategies are demonstrated by those moving from, for example, two to four injections a day, which reduces the pressures of having to eat all the time, and this increases life flexibility. As Ka identifies:

> *'It's just a lot easier and then if your blood, if you can feel your blood being high and then you're just about to eat, you can just do more [insulin] and it's just a lot easier.'*

In order for knowledge to be effective, young adults need to learn through trial and error so that they can find the solutions that are personal to them.

Barriers

Lack of sufficient support was a considerable barrier to self-care. Support provided ways in which the feelings of isolation were mediated. Reducing feelings of isolation was a significant factor that facilitated the integration of diabetes into participants' lives. The following three categories of barriers were identified:

- *Practical*. These included aspects such as food choices and medication taking.
- *Personal*. The importance of non-diabetic events throughout a young adult's life must not be underestimated as they have a distracting effect, in that participants were absorbed by these non-diabetic events and consequently their diabetes self-care suffered. These were as varied as being raped, trusting the wrong friends and battles with weight loss.
- *Psychological*. Depression and anxiety continue to act as barriers for young adults in self-care. Psychological barriers were found to be more difficult to overcome than personal barriers.

Coping mechanisms

Three types of coping strategies were found:
- task-orientated
- intrapersonal
- interpersonal.

Page points

1. In order for knowledge to be effective, young adults need to learn through trial and error so that they can find the solutions that are personal to them.

2. Lack of sufficient support was a considerable barrier to self-care. Support provided ways in which the feelings of isolation were mediated.

3. Coping was found to be the way in which participants overcame and dealt with barriers in their lives.

Task-orientated strategies

Task-orientated strategies were found to be the most constructive for participants as they facilitated positive adaptation to diabetes. Such strategies are those that require action, such as drinking a sugary drink if feeling hypoglycaemic.

The participants were able to overcome practical barriers in their lifestyle through the combination of knowledge and acceptance.

Intrapersonal strategies

Intrapersonal strategies were found to enable participants to protect their sense of self, to give them greater control in the present and the future and, when denial was evident, to provide them with space and time to come to terms with diabetes. These were considered to be the fundamental base for which other coping mechanisms were used.

Participants used denial to avoid events and distressing emotions, as B describes:

JS: 'Alright, OK, and then you said that you were very very bad, I mean, what happened there?'
B: 'I didn't want to deal with it [type 1 diabetes].'
JS: 'No.'
B: 'I didn't want to know, it's not happening to me.'

Participants, like S, used downward comparisons to make themselves feel more comfortable with living with diabetes.

S: 'Yeah, there's people out there that are a lot worse, [aren't] they, I've only got two things [type 1 diabetes and epilepsy].'

B used self-protective strategies by externalising the problems and rationalising them.

B: 'If [my boyfriend] can be like that then everyone else can, and if they're not, well then, that's their problem.'
JS: 'Yeah, OK.'
B: 'Nothing to do with me.'
JS: 'No.'

B: 'So its up to them, they've got the problem.'
By externalising these problems, participants focused the experience on the other person.

When participants were asked about how they felt about the future, the responses were similar. They centred on fears about the following.

● *Complications.* Fear of complications was a motivator to control diabetes more successfully.

J: 'Er, they just did a urine sample and it come up it was [anomalous], but it's kind of like, its still a threat, even though it was negative, if you know what I mean, its still a threat, I mean. I mean the most thing I'm worried about is going blind.'

● *Early death.* R described this well when she said:

'If it comes up in conversation, I will say, I think that I'm going to die young 'cos of diabetes.'

● *Having children.*

T: 'The only thing I'm scared of, cos, erm, me and Mum was discussing before, and I said, if I have a baby.'
JS: Yeah.
T: 'I don't want him to go through, or he or she, to go through what I've been through.'
JS: 'No.'
T: 'I can't picture myself giving my baby a needle.'
JS: 'R'ight OK'
T: 'I don't want to have to, everyone says, ah, it's not hereditary.'

The way in which participants mediated these fears was by using adaptive denial (i.e. people who are found to be controlling diabetes well currently are comforted by this in light of the future):

Ka: 'I think if you control it well, the doctors always said if you control it well when you are younger ...'
JS: 'Right.'
Ka: '...you shouldn't have too many complications, that's why its good to do sports and that it's good for your heart and ...'

JS: 'Yeah.'
Ka: '... yeah, your arteries, and things like that, and eat quite, don't eat all fatty foods and high sugar things.'
JS: 'Right, so you think that you look after yourself quite well in those respects?'
Ka: 'Yeah.'

Participants highlighted a final intrapersonal self-protective strategy as maintaining a positive morale, as C describes.

C: '... and I'm more of a positive and confident person now than I was, say, a year ago or two years ago.'
JS: 'Yes.'
C: 'And it's like, how can I put it? I mean, I'm, to me, I'm just making the best of it, basically.'
JS: 'Right, OK.'
C: 'As much as I can.'
JS: 'Yeah.'
C: 'And I'm not going to sit there and worry, oh, what could happen tomorrow?'
JS: 'Yeah.'
C: 'You know, I'm not like that.'
JS: 'No.'
C: 'I was, but I'm not now. I'm more or less like, oh, if it happens it happens, you get over it.'

When intrapersonal strategies were not present then positive cognitions could be deconstructed, stopping participants from using task-orientated strategies.

Interpersonal strategies

When coping with stressful events involving others, the participants used several types of coping mechanisms that have been categorised as interpersonal strategies. For some they expressed anger but used dismissal to avoid these feelings, and for others they used denial.

Other strategies included maintaining options and tolerating or relieving affective distress. Affective distress is a term which describes people who perceive situations that are out of their control. When individuals use exasperated comments it demonstrates an acceptance of tolerance of the situation; however, people employ dismissive reactions to relieve the affective distress, as J highlights when talking about his ability to control diabetes.

J: 'And that's all self-inflicted and then something outside of your control is doing the same to you.'
JS 'Right, ok. So do you feel as though you are out of control? Or do you feel this thing is?'
J: 'Well I don't know really, because I mean, you know, 'cos to everyone else my diabetes is out of control, but to me it's nothing out of the usual.'
JS: 'No.'
J: 'So it is in control, in my eyes, if you know what I mean.'

B vividly used dismissal to process angry emotions when talking about doctors:

B: 'I throw it [the advice] out the window.'
JS: 'Do you?'
B: 'Because I know they are professionals, but sometimes they just haven't got a clue about what they are talking about.'
JS: 'Right.'
B: 'And I think, well, it's my life.'
JS: 'Yeah.'
B: 'I know what I'm doing.'

Maintaining options was identified as another type of interpersonal coping which was used by participants when a situation could not be changed or if a change had a negative consequence as C describes.

C: 'I have actually thought about moving up and thinking about, should I go for another job, experience new places?'
JS: 'Right.'
C: 'And there's always the crunchline […] where you think to yourself, well, give it a week if you move into a new job.'
JS: 'Yeah.'
C: 'You didn't know the people there, but you moved into the new job.'
JS: 'Yeah.'
C: 'Erm, how would they look at you?'
JS: 'Right.'
C: 'And you know, and that's the only thing that would be worrying me, they might take you on for a week or month.'
JS 'Right.'
C: 'And then say, no, you're not up to scratch.'
JS: 'Right.'
C: 'And that's the only downfall that I've always had worries about.'

Page points

1. When intrapersonal strategies were not present then positive cognitions could be deconstructed, stopping participants from using task-orientated strategies.

2. When coping with stressful events involving others, the participants used several types of coping mechanisms that have been categorised as interpersonal strategies.

3. For some they expressed anger but used dismissal to avoid these feelings, and for others they used denial.

JS 'Right, OK.'
C: 'And that's why I'm sticking in this job for now.'

Throughout the narratives it was clear that there was a wide range in participants' ability to cope with and integrate diabetes into their lives. When participants had positive cognitions their ability to use task-orientated coping was improved dramatically. When participants had strong intrapersonal strategies, this further reinforced their ability to use task-orientated strategies. When participants were unable to cope with certain barriers in living with diabetes then interpersonal strategies were used, which had a stagnating effect on their ability to integrate diabetes.

Important considerations for healthcare professionals

The author has found that it is essential for healthcare professionals to use a collaborative equitable empowerment strategy, to promote positive cognitions, accurate knowledge and support. When this approach was used it facilitated the ability of the participants to adapt and integrate diabetes into their lives positively and ensured that they engaged in the self-care process. Personal barriers need to be considered as an integral part of an individual's care. The importance of framing medication changes from his or her perspective was found to be an effective strategy: when knowledge is delivered and received from the patient's perspective it is more likely to be recognised and accepted.

Considering patients as experts and utilising a patient empowerment strategy are important, if not essential, approaches for healthcare professionals and researchers to ensure that they are able to remain positively engaged with patients.

The opportunity for people with type 1 diabetes to talk to others with type 1 diabetes was considered an important support mechanism to reduce the anxiety of isolation for some and should be considered as an important addition to the service offered. A support network may also be beneficial for parents of young adults with diabetes, especially if it goes towards strengthening their ability to provide more effective support. ∎

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