Being diagnosed with type 1 diabetes during adolescence. How do young people develop a healthy understanding of diabetes?

Abstract
The aim of this study was to gain greater insight into the experience of being diagnosed with type 1 diabetes during adolescence, and the factors that influence how a young person makes sense of the condition over time.

Interpretative phenomenological analysis (IPA) was employed in an attempt to convey an understanding of what it feels like to be diagnosed with diabetes during adolescence and to highlight implications for health care professionals. The perspectives of eight adults, aged 28–36 years who were diagnosed with diabetes during adolescence, were gathered using an unstructured interview and were analysed using IPA.

The results showed that chronic illness impacts on the sense of self and can be especially devastating for an adolescent trying to cope with the conflicting nature of adolescence and the demanding, restrictive nature of diabetes. In some young people this can lead to risky self-care behaviours. However, through active encouragement and support from significant others, young people are able to develop an integrated sense of self, which is more suited to living with a chronic condition. These findings suggest that the relationships between illness beliefs and psychological adjustment lie in the family and social context.

It was concluded that health care professionals need to support the young person by having a better understanding of the impact of diabetes on adolescent development and by tailoring their approach to these young people. Psychology teams can be approached to provide consultation and training for diabetes teams to assist in the setting up of developmentally appropriate transition services for young people. A list of training and educational resources for health care professionals and young people is provided. Copyright © 2015 John Wiley & Sons.

Key words
type 1 diabetes; adolescent development; psychological adjustment; sense of self; illness beliefs and social context; implications for health care professionals

Introduction
Managing the multiple demands of diabetes while negotiating the developmental tasks of adolescence and young adulthood is a process that is neither well described nor understood.1 For example, it remains unclear why some young people with diabetes adjust well to the condition2,3 and others experience significant emotional and psychological vulnerabilities, which persist into adult life.4–6 Recent qualitative research studies have been concerned with gaining a greater understanding of the influence of diabetes upon psycho-social development in order to help answer this question and to aid service development and planning.1,7,9 Other studies have explored how different attitudes to diabetes may influence self-management8 and how self-management is embedded in relationships with significant others and the social environment.10

A popular health belief model used to understand and predict individuals’ coping and self-care following the diagnosis of a chronic illness is the Self Regulatory Model.11 This model proposes that it is the individual’s illness representation or personal model of illness that is the proximal determinant of coping behaviour. For example there is consistent evidence that illness representations are predictive of diabetes self-care behaviours,12 metabolic control,13 and psychological well-being.14 The model has also been linked to the social and family context.15 This present paper aims to establish a sense of what it feels like to be diagnosed with diabetes as an adolescent and to gain further insight into the factors that mediate
the relationship between illness beliefs and psychological adjustment to diabetes.

**Methodology**

Ethical approval was granted by City University, London. Participants aged 26–36 years, diagnosed between 11–17 years of age, were recruited from flyers posted on diabetes internet forums. A narrow age band of 10 years was chosen to increase homogeneity. The final sample reflected the voices of three male and five female participants, from different parts of the country, with at least 10 years’ experience of living with diabetes. Seven of the participants were white British and one was white European (French). The duration of the condition ranged from 11–24 years, with a mean duration of 17 years. The participants were educated to varying levels; three were single and the remainder were either married or living with a partner.

**Data collection and analysis**

A semi-structured interview schedule was constructed with consideration of the literature and through feedback obtained from pilot studies. Participants were asked to fill in a demographic questionnaire before participating in a face-to-face interview of approximately 1 hour. Broad open questions were employed inviting the participants to reflect upon what they remembered about their experience of living with diabetes. Seven of the participants described a complex array of emotions, similar to the grief reaction, including feelings of confusion, disbelief, fear, sadness and feeling too young to cope with what was happening to them, consistent with previous studies.18,19

At first you’re in between being confused, not understanding, not realising … the one thing that’s clear in my memory is crying … and being scared,’ (Nadia).

Fear was reflected in the participants’ accounts as they began to recognise that their diagnosis meant changes to many aspects of their adolescent lifestyle. They also described a sense that something had ended or died, and they spoke of being forced to confront their long-term future and what this meant for their identity.

At first I thought that my world had caved in. I was thinking why me, it is really unfair … I did kind of feel like my life was over,’ (Laura).

The emergence of existential meanings about death is not surprising. It has been suggested that taking on board the long-term demands of diabetes care forces the young person to engage with thoughts of their long-term future and mortality.7

The main psychological impact this whole thing has had on me is I have a distinct fear of the future, and it completely relates to that day in 1983 when I was told about the horrible way I was going to die,’ (Laura).

Laura’s fear does not relate to her illness and the complications but to the moment she was told, threatening her future identity in such a profound way that she cannot bear to look into the future. Her response resembles a typical response to a traumatic experience where the current fear is based on a perception of threat,20 resulting in a ‘sense of foreshortened future’.21

The experience of diagnosis as a crisis was not shared by all of the participants. Craig reacted according to the relevance of the news to his situation and the context of his life at the time.

I don’t remember there being a sudden change in the way I was personally … they knew that I was diabetic and my parents knew what that meant, and so there was limited change … I wasn’t panicking or feeling like my life had ended,’ (Craig).

His sister’s diagnosis several years earlier appears to protect him from the overwhelming feelings described by the other participants. This seems to provide him with an explanatory framework as to why he developed the condition.

**Analysis and discussion**

**Impact upon self**

Initial reactions and trying to make sense. The participants’ accounts described a complex array of emotions, similar to the grief reaction, including feelings of confusion, disbelief, fear, sadness and feeling too young to cope with what was happening to them, consistent with previous studies.18,19

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**Loss of freedom/missing out.** The participants spoke of a sense of loss in terms of their freedom and flexibility, and of feeling they were missing out on things. The language used by the participants implied loss of choice and imposition of fixed rules of living.

I felt I lost my freedom and my ability to do things at the drop of a hat, because I was always a very active child; I’d go out in the morning and walk about the fields and play armies and not come back until I was hungry,’ (Tony).

Tony’s account captures the sense of abundant freedom and independence that was taken from his childhood leisurely world. This theme emerged most frequently in the narratives of the participants who were diagnosed in later adolescence. It has been proposed that the boundaries of the self-concept are rooted in habits constructed over time, which once ingrained become harder to change.22 Other participants spoke of their life temporarily evaporating:

‘There was probably some girls from college that I should have been going out with but I didn’t, it just went, disappeared, wasn’t there,’ (Stuart).

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Stuart appears to suffer a crisis of self, where time and acceleration of symptoms move too quickly for the individual, with their self-concept remaining in the past. Similarly, Tony claimed he was held back from participating in age-appropriate activities until later in life, Molly talked of missing out on going out with friends, and Nadia spoke of delaying her first sexual experience until she had the support and confidence she required. Interestingly, however, the participants described a time-limited sense of missing out on things at around the time of diagnosis, with normal functioning and social activities resuming as they became more comfortable with living with diabetes.

**Feelings of difference.** Mirroring other qualitative findings, a strong sense of being different from their peers emerged from the participants’ accounts of their adolescence. They expressed a pervasive fear of stigma, and being discovered as different or less acceptable than their peers.

'I didn’t want to see myself as being any different than anyone else,' (Tony).

This would be typical of the period of adolescence where there is a strive towards normalcy and not wanting to be different. This need for social acceptance had serious consequences for some of the participants in terms of disclosure, resulting in them omitting injections and seeking to maintain their identity as a well person. Karen told how she got into the habit of not wanting to be different and subsequently paid less and less attention to her diabetes, resulting in a cycle of deliberate mismanagement and several hospital admissions with diabetic ketoacidosis. Laura had her own way of coping with being different.

'I felt like it was something that set me apart from everybody else in a bad way, and the way I dealt with it was talking to people at school about how I didn’t plan to live past 40. I just felt like I had made this decision in order to cope with having a future at all,' (Laura).

Feeling ‘set apart’ from her peers forces Laura to adopt the fatalistic stance that she will die prematurely, telling people that she would have a short life appeared to be the only way she could cope with her feelings of vulnerability.

**Feelings of isolation.** Most of the participants talked about feeling alone with their diabetes, particularly during the initial stages. This was partly as a result of not knowing other people with diabetes:

'Every stage when I was younger I always remember thinking, “God I am the youngest diabetic in the universe…” I would sit in this waiting room and not a single young person around me,' (Jannine).

Jannine’s vivid description conjures up a powerful sense of being alone in a world of diabetes and having no-one around to identify with. This was echoed further by Laura:

'I was quite depressed from the age of 12 ... the reason I started writing diaries was because I had no-one else to talk to … I had no medical support and my parents had no idea how many hypos I was having ... I was completely isolated with it. I felt like it was my burden,’ (Laura).

Although Laura’s depressive symptomatology was distinct from the other participants, type 1 diabetes is a known risk factor for depression, and is perhaps a reflection of the insufficient support she received from her family. In addition, parental involvement has been implicated as the single most important predictor of positive adolescent outcomes, with less parental involvement and greater responsibility taken by the adolescent resulting in worse control. The participants favoured the setting up of groups for young people with diabetes to share their experiences and reduce their sense of isolation.

**Mediating factors**

**Support from friends and family.** The reactions of other people to the young person’s diagnosis played a reciprocal role in how they interpreted and responded to the news.

'I was more bothered that it bothered my mum,’ (Stuart).

This illustrates the way diabetes is shared by the whole family system, and highlights the need for health care professionals to help the parents as well as the young person to manage their emotions. Parental actions that are motivating or accepting have been identified as important in supporting engagement in health care systems. This was demonstrated within both Laura’s and Molly’s struggles to attend to their self-care.

‘My parents were terrified and in denial,’ (Laura).

Leventhal and colleagues’ self-regulation model proposes that family members can differ in the way that they represent the illness in terms of chronicity, consequences and control, suggesting that these differences hold important implications for adjustment. The participants also spoke of how the reactions of their friends played an important role in how they interpreted and made sense of their diagnosis.

**The power of health care professionals.** The participants described being profoundly affected by what health care professionals said and did, particularly at the time of diagnosis. They relayed important messages concerning the impact of these experiences over their management and psychological well-being.

'I hadn’t had anything explained to me before the consultant gave me this list of the delights of blindness, kidney disease, gangrene … it was horrifying, like I was being given a death sentence … I used to tell my friends that, if I wasn’t dead by 40 I would kill myself, because I didn’t want to go through all those diseases,’ (Laura).

Laura’s meaning-making process is clearly illustrated in the above example as she internalises the consultant’s words and begins to develop her own conceptualisation of what diabetes means. She refers to this as ‘the shock treatment approach’ leaving her and her mother feeling ‘terrified’ and ‘traumatised’.

Similarly, Jannine spoke of being shown pictures of gangrene feet, and she recounted how she was placed on a ward with older people suffering from diabetic complications which left her feeling so frightened and helpless that she avoided testing her blood sugars.

‘If you don’t think the end of your life has already happened, that
will just seal the deal for you. I have never quite forgiven them for that,’ (Jannine).

These accounts bring to the forefront the damaging impact of inaccurate illness representations facilitated by health care professionals. It highlights the depth of responsibility held by health care professionals and the need to sensitively manage the delivery of a diagnosis of a chronic condition, allowing time for emotional processing while also managing the young person’s expectations in terms of the consequences of the condition. Behaviour change research suggests that although direct persuasion is perhaps the most straightforward approach, it increases the potential for disagreement.31

‘Never make a throwaway comment, never say “Oh just bring your blood sugar down or just lose weight or just do this,” because it has a real significant impact and it is hard,’ (Karen).

**Adjustment processes**

‘Accepting limits of personal control and finding a healthy balance.’ As the participants’ stories unfolded, they told of critical moments where they experienced their first empathic and understanding exchange with a health care professional, which assisted them to discover their capacity to change misconceptions and to develop more positive representations of diabetes.

‘I was having a really terrible time and I said something like “If this was a war, I would be surrendering. At the moment, I feel like I really am losing”; and he said to me “I bet you would just like a couple of weeks off wouldn’t you?” And that was one of the most understanding things a doctor has ever, ever, ever said to me … It was like he understood me … rather than getting a tick or a cross depending on my HbA1c,’ (Laura).

For the first time Laura’s battle with diabetes is recognised as her personal reality. The emotion in her narrative highlights further the significance of this encounter in assisting her to discover important insights, and thus enabling her to acknowledge her personal efforts.

‘It’s made me realise that it’s not my fault, there isn’t really shame attached to not getting it right … it’s hard work and it takes up an awful lot of my time and energy,’ (Laura).

These discoveries enabled the participants to access the help they required through diabetes education courses, allowing them to make long sought-after changes.

‘Becoming a self-manager.’ Health care professionals leading with a patient-centred and collaborative approach appeared to help the participants to discover new meanings, and assisted them to become more proactive in their self-management.

‘Cos of the way she’s re-educated me … I feel a lot happier. I know there are good reasons for carrying out blood tests … I don’t have that rebellious streak anymore, because I know she is real proud of what we have achieved together,’ (Jannine).

Being re-educated by her diabetes nurse in a supportive and encouraging manner increases Jannine’s motivation for change. The participants spoke of the benefits of being given choices and setting their own treatment goals, reducing their sense of isolation and giving rise to a sense of mastery and control.
'Rang around about 10 different doctors until I found someone who gives me the service I want. I go and search for things that make life easier to deal with ... I feel more in control,' (Jannine).

'Now I feel it’s me that is in charge. I have the knowledge to make much better informed decisions. I still get things wrong ... but I have a lot more control,' (Laura).

Frequent, regular appointments with the same clinician were also felt to be an important source of motivation for at least half of the participants, consistent with the findings of Dové-Pearce et al.1 Other research has noted how supportive and understanding interactions with health care professionals marked major turning points in the participants’ illness trajectory.22,35

‘Accepting being different.’ Over time and with the help of positive re-affirming experiences from professionals and close friends and family, the participants were able to accept being different and to incorporate it into their sense of self.

'I see myself as just being normal, I’m me. I have diabetes but I don’t consider it to be a huge problem. If you had asked me the same question when I was 16–20, I would have said it was a pain and I wish I didn’t have it, and it restricted me from doing things,' (Tony).

Meeting other people with diabetes and being part of a support group assisted participants to find a shared identity, reducing feelings of isolation and difference.

'Going to the support group was quite life changing for me. It was astonishing to know that everyone else had problems too,' (Laura).

Conclusions
These findings support the suggestion that chronic conditions can alter existence and undermine notions of self that are taken for granted.22 However, the study also demonstrates that over time, through helpful relationships and processes of learning and discovery, young people are able to develop a more integrated sense of self suited to living with diabetes. The participants’ narratives have led to the emergence of an explanatory model describing the ways in which family, friends and health care professionals can influence the individual’s adjustment to diabetes by providing support and encouraging the adoption of adaptive and helpful understandings of diabetes (Figure 1).

The initial impact of diagnosis depended on how the young people were able to make sense of the experience, which was largely influenced by their biographical and contextual situations. This was mainly captured by powerful, vivid emotions resembling typical responses to traumatic experiences. These findings highlight the importance of family support and the need for health care professionals to consider the timing of diagnosis in relation to other concurrent factors such as school transitions and parental divorce. This may inform health care professionals in terms of the kind of losses experienced by the individual and of past frames of reference to which the individual may still look.

The impact of diabetes on certain developmental tasks, such as the emergence of concepts of death, seems a theme worthy of further attention. There is no doubt that the participants felt very much at odds with their peers and such frightening concepts may be linked to subsequent denial and mismanagement due to excessive anxieties about growing older.34 Unable to understand what was going on in their bodies or to contemplate the value of life or the relevance of long-term blood glucose readings, the participants sought to maintain their identity as a well person, resulting in them rejecting their diabetes in favour of continued adolescent freedom. Health care professionals need to consider that young people may be negotiating certain developmental tasks both prematurely and simultaneously, and should try to grasp an understanding of the young person’s thoughts and feelings regarding concepts of death, the consequences of diabetes, and the perceived impact of the condition.

This study highlights the powerful role of health care professionals in influencing and shaping the beliefs of young people during the formative years of adolescence, and provides support for the Self-Regulatory Model and the role of illness representations in predicting health outcomes and psycho-social adaptation.11 The model proposes that problems may arise when individuals adopt inappropriate models or representations based on whatever previous knowledge or beliefs they have about illness they have encountered.35 In fact the way in which diabetes was explained at diagnosis has been documented as the strongest predictor of illness representations, predicting emotional responses to diabetes two years later.30 This emphasises the need for health care professionals to be careful in their interactions with patients, ensuring that they are conveying messages and beliefs concerning diabetes which are both accurate and helpful to the patient.

The study is limited to a small sample. The participants who volunteered to take part in the research were mainly experienced self-managers of diabetes, who were open to talking about their experiences. They favoured a holistic approach to care based around the emotional needs of the individual, developing a positive rapport, practising empathy and collaboration, and providing consistent and regular care irrespective of how long the individual has been diagnosed. This mirrors current-day approaches to health care and is something that health providers need to continue to build upon in order to meet the ongoing psychological needs of these young people as they embark upon the increasing demands and responsibilities of adulthood. Somewhere between their mid-20s and 30s marked a turning point in the participants’ lives when they began to recognise the permanency of diabetes and to take the consequences of diabetes more seriously. This has been found to impact positively on adherence in adults.37 Designing educational refresher courses specifically for this age group may be an effective and resourceful way of addressing this need at a time when patients are experiencing shifts in attitudes towards their health and demonstrating increased motivation for change.
The language used by health care clinical health psychology teams can be poorly managed with high drop-out rates, poor attendance and sub-optimal control. Clinical health psychology teams can be approached to provide consultation, training and supervision to diabetes teams to assist in the setting up of age-appropriate services based on developmental theories and tailored towards the needs of adolescents and young people. Developing a helpful and realistic lifestyle and self-concept, and to develop adequate models of self-care.

Currently, transition to adult care for young people with diabetes is poorly managed with high drop-out rates, poor attendance and sub-optimal control. Clinical health psychology teams can be approached to provide consultation, training and supervision to diabetes teams to assist in the setting up of age-appropriate services based on developmental theories and tailored towards the needs of adolescents and young people. Developing a helpful and realistic lifestyle and self-concept, and to develop adequate models of self-care.

Resources for health care professionals

- www.diabetescounselling.co.uk

Resources for young people with type 1 diabetes

- https://www.youtube.com/user/type1uncut
- https://twitter.com/OurDiabetes

Box 1. Resources for health care professionals and for young people with type 1 diabetes

Applications to psychology

This study highlights the need for routine integrated psychological support in diabetes clinics to help patients integrate diabetes into their lifestyle and self-concept, and to develop adequate models of self-care. Developing a helpful and realistic meaning of diabetes seems to be a key task that the individual must negotiate as part of the ongoing task of adjusting to diabetes. Individual and group therapy can be provided by psychologists to help identify maladaptive models of self-care based on faulty illness appraisals, while facilitating the adoption of healthy beliefs and specific diabetes processes, such as accepting being different, becoming a self-manager and recognizing limits to personal control.

Currently, transition to adult care for young people with diabetes is poorly managed with high drop-out rates, poor attendance and sub-optimal control. Clinical health psychology teams can be approached to provide consultation, training and supervision to diabetes teams to assist in the setting up of age-appropriate services based on developmental theories and tailored towards the needs of adolescents and young people. Examples cited in the literature include the need for more frequent appointments and more active follow up, continuity of health care professionals, and the introduction of measures of diabetes distress and depression to identify at-risk individuals who could benefit from targeted education or referral to psychology services.

Resources

Box 1 provides a list of training and educational resources for health care professionals and for young people with type 1 diabetes.

Key points

- The language used by health care professionals has the power to shape, change and reinforce the beliefs and behaviours of young people, particularly during the formative years of adolescence.
- Health care professionals should be mindful in their interactions ensuring that they are conveying messages and beliefs concerning diabetes which are both accurate and helpful to the young person.
- Clinical health psychology teams can be approached to provide consultation, training and supervision to diabetes teams to assist in the setting up of age-appropriate services based on developmental theories and tailored towards the needs of adolescents and young people.

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Declaration of interests

There are no conflicts of interest declared.

References

References are available online at www.practicaldiabetes.com.

POEMs

Bariatric surgery in obese patients with T2DM: more achieve partial remission at five years

Reference


Synopsis

These researchers studied 60 adult patients who were obese (body mass index of at least 30kg/m²) and who had type 2 diabetes for at least five years with a glycaemia (53mmol/mol) at the time of enrolment. The researchers randomised the patients to receive medical treatment or surgery by Roux-en-Y gastric bypass or biliopancreatic diversion. After five years, more patients began to revert, so the rates for partial remission in the surgically treated patients were 37% and 63%, respectively. After five years, no patients had complete remission of their diabetes. Approximately 25% of patients treated with biliopancreatic diversion developed iron-deficiency anaemia and patients in the biliopancreatic diversion group were also more likely to develop renal calculi.
References


