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Experiences of self-management among young adults with type 1 diabetes in the context of a structured education programme: a qualitative study

Abstract

Aims

To explore the experiences of young adults towards self-management of type 1 diabetes in the context of a structured education programme.

Methods

Qualitative interviews and focus groups were conducted with young adults attending a structured education course promoting a flexible and self-directed format. Participants attending the structured education courses were recruited using purposive sampling to acquire a broad mix of participants based on age and equal numbers of males and females. Fifteen interviews were conducted at 12 weeks following each course, whilst 7 focus groups and observations of the course delivery were conducted at two course sites led by nurse/dietician educators representing two different diabetes centres (paediatric and adult). The interview and focus group data were audio recorded and transcribed, coded and analysed thematically in search of similarities and differences.

Results

The analysis revealed three themes, 'we're in it together', 'tacit benefits' and 'transitions beyond the structured education programme'. The findings show that structured education programmes can facilitate reflective critical thinking and greater engagement with diabetes self-management if they: a) foster maximal learning from fellow participants to decrease feelings of isolation, b) maximise engagement during the course by delivering the content in a flexible manner, and c) recognise the social and emotional needs of young adults.

Conclusion

Structured education courses can result in improved critical thinking and engagement with diabetes self-management by empowering young adults through a flexible and self-directed learning style that encourages peer group discussion.

Background

Type 1 diabetes is a long-term condition often diagnosed in childhood or adolescence, resulting from failure of beta cells in the pancreas to produce enough insulin to regulate blood glucose levels. The effective control of blood glucose, to avoid hyperglycaemia (high glucose levels) is important to avoid long term complications such as blindness, limb amputations, and kidney failure. Although sub-optimal control of blood glucose can lead to these long-term health problems, even when optimally controlled 'hypos' (hypoglycaemia, low blood glucose levels) can occur. They are usually relatively mild with symptoms such as sweating or confusion, but if severe can result in coma and occasionally seizures and death [1]. Consequently, the challenge for affected individuals is to attain a good balance of normal but not low blood glucose levels, and this is particularly problematic in young adults who are transitioning from paediatric to adult services [2]. As they move to adult diabetes care they are eventually expected to assume greater independence over their disease management, away from reliance on parents. This process can present a tension in the way they adjust to their disease, assuming more responsibility and navigating the healthcare system as autonomous decision makers. Greater ownership over their condition, however, could lead to stigmatisation identifying them as different from their peers.

The idea of care transitions has long been defined as "the movement patients make between health care practitioners and settings as their condition and care needs change during the course of a chronic or acute illness" [3, 4]. Studies investigating the transition of care by young adults from paediatric to adult diabetes services highlight personal, professional and system barriers. For example, one study found a divergence in approaches by paediatric and adult diabetes providers. Consensus in the literature is that a greater alignment is required between education provision to young adults transitioning into adult services and training for diabetes specialists in mental health and behavioural aspects of diabetes care [5].

Structured education programmes (SEPs) in diabetes and other chronic diseases have become widely implemented in the UK in adults following clinical trials demonstrating both improvements in glucose levels (shown by falls in HbA1c, a long-term measure of glucose control) and major

improvements in measures of quality of life [6, 7]. This has been attributed to an experiential learning approach with participants taught in groups who also learn from each other and provide mutual support, in contrast to traditional didactic courses [8, 9, 10]. One study concluded that people experience a 'transformation' in relation to what they described as 'insulin dose adjusting subjects', in which people recalibrated their 'risk thermostat' in light of insulin dose adjusting experiences of other people with diabetes [10]. Studies have also reported the high degree of unawareness of glycaemic control in the population as well as among families of those affected by type 1 diabetes [11, 12, 13, 14, 15], as well as the poor knowledge retention among younger adults with type 1 diabetes [15]. This contributes to the significant challenges of diabetes self-management among younger adults.

The purpose of this qualitative investigation was to explore 1) the views of young adults with type 1 diabetes in the context of a structured education course and their subsequent reported attitude and behaviour change towards diabetes management, and 2) the implications for care transitions between paediatric and adult care.

Methods

Setting

Qualitative interviews were conducted in the homes of the study participants 12 weeks after participants attended the WICKED course, whilst observations and focus groups were conducted at two course sites that were led by nurse/dietician educators representing two different diabetes centres. We interviewed participants after 12 weeks as we wanted to give them sufficient time to reflect on their experience of attending the course. Interviews and focus groups explored participants' views of the perceived impact of the course on their subsequent diabetes self-management behaviour, adherence to key messages and learning objectives, and expectations about their long term diabetes self-management in view of the knowledge and skills acquired from the course. Educators delivering the course at site A are based at an adult diabetes centre which provides a base for a dedicated team of specialist nurses and consultants who work closely with paediatric diabetes dietitians and paediatric clinical psychologists as well as with community colleagues, including GPs, district nurses and community case managers. Paediatric diabetes care is provided as part of an adult service. Thus, one of the potential challenges for educators was to integrate the course philosophy to younger patients within an adult diabetes care model. Educators delivering the course at site B belong to a paediatric diabetes centre, where the diabetes care team consists of doctors (consultants and specialist registrars), specialist and research nurses, dietitians, podiatrists, orthotists and clerical staff. The Centre offers care for younger patients with type 1 diabetes transitioning into adulthood. Each course lasted five full days (10am to 4pm), and two courses were observed at each site, amounting to 20 days of observations or 120 hours.

Course delivery and structure

'WICKED' stands for Working with Insulin, Carbohydrates, Ketones and Exercise to Manage Diabetes. The Wicked course is an educational intervention developed during earlier pilot work in South Yorkshire, demonstrating benefits to young adults in their transition from child to adult diabetes care. The WICKED course was adapted from both the DAFNE course developed for adults and the Kick-Off course designed for younger adolescents, structured specifically to enable a 'smoother' transition phase by equipping young adults to adopt a greater level of ownership and control over their self-management away from overdependence on parents and the diabetes team. This stage in the transition is particularly poignant as young adults experience many changes to their development from teenagers to adults and the challenges this entails with social, personal and professional relationships. They need to learn to adapt their health condition within a complex set of environmental and social circumstances. The course was designed to facilitate this process by providing additional information and facilitating greater understanding of the condition through a facilitative and evolving structure.

The WICKED course adopts a facilitative approach allowing participants to draw attention to their own risk of mismanagement, and the course philosophy allows the participants to find their own level in their diabetes management. The instructors use a non-judgemental teaching style to support diabetes self-management. Explanation of the small detail such as the significance of hand washing (to prevent infection risk) made a difference to participants' engagement with the key recommendations. Hence, they understood the rationale behind certain hygiene practices. The aim of the course was to promote equity in participants' ability to express an opinion in a safe environment. The course encouraged the value of listening to others' experiences of diabetes and the challenges others face in managing the

condition, not only the need to optimise glucose control. Clinical instructors delivering the learning material were encouraged to 'deviate' from the course order and to flexibly adapt the content in their own way that fits in with what participants preferred to discuss. Consequently, there may sometimes be a tension between covering the curriculum and responding to participant preferences. Also, the emphasis of the underlying self-directed philosophy of the course was that participants should not feel pressured to achieve perfect control. Calorie and carbohydrate counting skills were balanced against the desire to lead as normal a life as possible. The course included a series of group exercises during the 5-day course where participants tested knowledge and understanding acquired earlier. This was facilitated by a diabetes nurse and a dietician. This approach to learning was balanced against the wider social and emotional pressures discussed during the exercises. For example, a common theme was alcohol consumption in the context of glucose control, its likely adverse effects and best ways of minimising these.

A senior diabetes nurse who was involved in the initial design of the course attended each session at both sites to ensure trainers delivered the materials in line with the original course philosophy which included a self-directed learning approach. The 'coaching' was intended to be light touch, encouraging the trainers to gradually assimilate the course philosophy into their routine clinical model. This process worked well although initially at Site B trainers moved in and out of their established ways of delivering information and communicating with the YAs. Three themes were identified in the data which describe the social dynamics influencing delivery of the course and its receptivity by participants: 1. We're in it together; 2. Tacit benefits; and 3. Benefits beyond the structured education programme.

Interviews, focus groups and observations

We conducted 7 focus groups (between 6 and 9 participants in each group) immediately after each course with all participants, and 15 interviews with a maximum variation sample of participants 12 weeks following the course. Interviews and focus groups were facilitated by a researcher with qualitative research experience from a health psychology background. We sought to recruit an equal balance of both sexes and age groups. Interview participants were aged between 16 and 24, and so we recruited in equal proportion from the lower and the higher age band. 8 were female and 7 male, and all were White British. Average time since diagnosis was 9 years. We conducted both interviews and focus groups to explore experiences of the WICKED course from individual and from group perspectives. Focus groups encourage more detailed discussion and detect differences and similarities in people's views. The focus groups and interviews were designed to explore the perceptions and experiences of diabetes self-management, and whether course participation led to critical reflection and re-evaluation about their experiences. Observations were conducted verbatim by an experienced qualitative researcher. Detailed notes were recorded during the observation sessions, and additional reflective interpretations written up immediately after. This allowed for the verbatim data to be located in a broader interpretive context.

Analysis

The interview and focus group data were audio recorded and transcribed, coded in N-vivo 10 and analysed thematically in search of similarities and differences. The thematic framework was developed by two researchers who coded a sample of interviews independently and met to discuss areas of agreement and disagreement. The coding frame was refined and then used to code the remaining transcripts (both interviews and focus groups). Our approach to analysis was informed by the broad principles of grounded theory, particularly the constant comparative methodology [16]. This included immersion in the data to identify differences and similarities within interviews and focus groups as well as between participant views. The analysis process also included consolidating similarities between different data sets and 'negative' cases ('outliers'). The final analysis is presented below and illustrates the major themes arising from the analysis. Interview, focus group and observational data were coded independently by two members of the study team. Observations were conducted at two sites (A and B) on two separate occasions. Each course lasted 5 days (4 courses in total were observed, totalling 120 hours of observations). The observations were analysed alongside the focus groups and interviews, and provide the context of the delivery process, structure and interactions among the participants.

Results

Theme 1. 'We're in it together'

The social pressures of living with type 1 diabetes manifested during the group discussions and

provided an opportunity to identify potential solutions. In this respect the course offered an opportunity to engage in meaningful discussion and to compare experiences. As type 1 diabetes affects just 10% of all cases of diabetes, with type 2 the most common, participants struggled to place their experiences in a broader context, leading to feelings of isolation and inability to compare experiences with others with the same condition, as a means of making sense of their illness. The following is a verbatim quote from an observation.

L – When you're younger you feel isolated as you don't know of anyone else with diabetes. *Most people don't understand and others don't know how you are feeling, that's annoying.* They cannot know (Observation-Site A)

A major frustration observed across both sites was the view that young people are often labelled as different, a label to which they expressed resistance. This seemed to be an important obstacle to their transition from paediatric to adult diabetes care, as they placed the disease outside of their everyday experience. The diabetes became an irritation and an intrusion, blocking their desire to be normal like everyone else. The following respondent expressed a reluctance to inject in public signifying a preference not to make the disease 'visible'.

So for example one was like I don't like injecting in public and so we can talk about how that affects you, how you feel about that and then what we can do to avoid that (FG, Male)

Others claimed that struggle with control affected all diabetes sufferers, though many did not realise that this was a common experience, and only became apparent during the course.

Everyone's got their own story about diabetes. Some of it can be great, they can have you know perfect control but I think 9 times out of 10 most of us we really struggle with it (FG, Female)

Misguided views of friends about type 1 diabetes who often mistook it for type 2, led to feelings of blame, and hence the desire to hide the disease or 'detach' themselves from it. The following is a verbatim quote from the observation notes.

J – She knows others with diabetes, but its type 2 - and they act like they know what they are talking about. L – Almost everybody is ignorant about type 1, because all they have heard about is type 2 diabetes. In Tesco all they are focused on is type 2. It affects more people than they think – *10% of all diabetes cases is still a lot of people. There's a reason why it's called type 2!* (e.g. Less important than type 1?) (Observation-Site B)

The course was perceived to 'normalise' the irregular experiences of controlling diabetes.

I think as well when you go to the clinic they say how important it is for good blood sugar and you always learn how *poor blood sugar management will lead to problems later. So when I've had a good day and then the next day I have a bad day and like poor management and stuff but then when I come here I realise everyone has it. That its normal* (FG, Female)

The following young adult claimed that she wanted to distance herself from her diabetes by avoiding discussion particularly with people without diabetes.

...you feel more comfortable speaking to people who have got the same issue as you... when you come into a group you feel more supported and I think it gives you a bit of a boost up (FG, Female)

Not being understood by others who were unaffected by diabetes led to feelings of isolation and detachment. A similar frustration arose from parents' lack of understanding of diabetes control.

If I want to have a full fat coke which I don't really do but if I ever felt the need I could give insulin for it, I'll be fine. Like I can generally live a normal life. But my parents are like... if they see me eating a biscuit my mum like tuts cos she doesn't understand I can do this (Interview 3)

These views, taken as a whole, represent the external pressures contributing to the difficulty of self-managing type 1 diabetes, and the importance of critical reflection with their own peer group who have a shared understanding of living with the condition. The value of the WICKED course was its ability to promote shared discussion to encourage critical reflection.

Theme 2. Tacit benefits

Participants claimed that the spontaneity of the group discussions led to greater engagement since the participants set their own agenda encouraging 'tacit' learning; that is, learning from each other rather than formal or 'text book' learning. The WICKED Programme philosophy promotes the creative and critical delivery of educational materials and learning by encouraging trainers to 'deviate' from the course order and to flexibly adapt the material in their own way to fit in with the learning needs of participants.

It was just kind of more a spontaneous conversation just kind of broke out and that worked out better. It wasn't really planned I don't think to go off on such a tangent but because it did it just seemed real...we often went on a tangent to the social side more than the medical side (FG, Female)

The course appeared to fill a knowledge gap illustrating that even small adjustments to their insulin dose can make a big difference.

For me it wasn't to try and learn too much about what diabetes is and stuff it was more giving me a chance to feel comfortable at kind of changing my insulin doses and being able to do it whilst I'm with people (Interview 5)

They distinguished between informal (practical) and formal (technical) knowledge, with the former more difficult to access from books or the internet.

So the more practical things that are going to happen to you, they were the things that I found most valuable cos I haven't been through them yet and its not exactly something.... you'd have to search quite specifically to learn about those sort of things (Interview 5)

The observations highlight the ability of group learning to place irregularities of glucose control in a broader context. Group learning seemed to foster acceptance of 'imperfect' control, in contrast to 'didactic' care models which allowed less flexibility towards 'slippage' in glucose control. The following is a note made by the observer summarising the overall message conveyed by the psychologist.

The philosophy of Wicked is intended to be patient-led, and the session by the psychologist which emphasised the need not to over control and accept that degrees of failure are normal. (Observation Site B)

Trainers expressed empathy and had experience of dealing with situations discussed by the young people, and therefore their advice was perceived as trustworthy. This contrasts with unofficial sources of information such as internet forums which cannot be validated with the same level of confidence.

Cos its not on your part to find the information and you feel like if you go away and read about something or look it up on the internet there's a chance it's not right anyway. It could be outdated if it's in a book or everywhere on the internet has a different opinion or view of what this is or what that does, so its not like an official what isn't currently medically accurate (Interview 4)

Participants claimed that the information they obtained from the course had a greater credibility than information accessed from the internet such as online forums, and could be applied with a greater degree of confidence. It was evident that participants valued pragmatic or 'embodied' knowledge; factual knowledge did not hold the same meaning.

Yeah. Cos they're (diabetes nurses) not diabetics so they... they know that you're having a hypo and what that means but they don't know how that feels so if we tell them then they'll like share it with other people (FG, Female)

One diabetes nurse had diabetes, and the participants could relate to her since she shared their experiences. The less tangible benefits held the greatest value to young people, including listening to others' views, which enabled them to assess how their experiences compared to those of others, enabling them to find their own 'level'. Lawton and Rankin found that patients 'recalibrated' their risk thermostats based on the insulin dose adjustment experiences of others [10].

Theme 3. Transitions beyond the structured education programme

The structured education programme had implications for patient self-management and interactions with the healthcare system. The interviews and focus groups revealed a tension between the young adults' clinic appointments and the course philosophy.

I feel like now in this week if like I had a one on one session with (diabetes nurse) or something I could talk about it whereas in a clinic like I just never feel comfortable talking about that kind of thing. I don't feel comfortable in the clinic at all talking about emotional to be honest. At the clinic I feel when I go in like its just like what my actual numbers and readings are and stuff but I never feel comfortable talking about the emotional side when I go to my clinics at all (FG, Female)

Similarly, the following participant distinguished between diabetes as both a physical and a 'lived' experience.

Well that's it, its like the window thing again, they're looking through into diabetes, they're not living it (Interview 4)

The participants claimed that clinics were too target driven without sufficient recognition of the social and emotional obstacles to optimal glucose control.

I think there's, when you come to clinic there's a very... I wouldn't say they explain it really, its a case of its always sort of drilled into you that you have your target range blood sugars and you need to try and keep it in them. (Interview 2)

Participants claimed that attendance on the course helped to 'foreground' the key messages, increasing the likelihood that they would apply the learning. The implication was that 'technical' learning was far more likely to lead to a 'passive' response.

I guess its just when you do the course its in your head a lot and so rather than it just being in the back of your mind it doesn't seem like a big deal if you don't do it. When its in your head that you've been on the course it seems like... I guess its less in the back of your mind so you pay more attention. (Interview 6)

The course seemed to play an important part in encouraging a proactive response from the participants. It encouraged a greater acceptance of the risks of sub optimal diabetes control. Understanding the complexity of diabetes control, and the associated health risks, helped to reinforce the need to maximise effective self-management.

I think now we've been told how complex everything actually is with diabetes and how everything affects it I actually think about how dangerous it is to not check it. So I do check it if that makes sense. Like I used to just oh you know it doesn't really matter (Interview 4)

Discussion

We report three themes from the observations, interviews and focus groups. The first 'We're in it together', reveals the benefits of sharing experiences of diabetes self-management through the structured education programme. The group discussions revealed the pressures of managing diabetes, with participants expressing a desire for 'normality' and fitting into society. The desire to feel normal often outweighed the need for control. The findings are similar to another study where young people reported risk taking behaviours, which were easier to justify when parents took responsibility for negative health consequences [10]. The course, however, was designed to encourage greater individual responsibility for glucose control and therefore a readjustment of risk taking towards safer behaviours. Risk taking often included not taking insulin prior to socialising with friends or avoiding injecting in public spaces. The findings highlight how participants experienced common struggles,

suggesting that theirs was not a unique experience but a collective one. This helped to locate their individual experiences in a wider context and to recalibrate their 'risk thermostat' in light of the insulin dose adjustment experiences of other young adults [10]. The second theme, 'Tacit benefits', revealed how the structured education programme encouraged greater engagement with diabetes and its management through helping participants to acquire practical knowledge. This was achieved through the blending of clinical with emotional learning by listening to and reflecting on each other's experiences, a finding previously reported elsewhere [6, 7, 10]. At both sites trainers facilitated spontaneous and flexible learning. Young adults were able to view their self-management in a different light following the course, by expressing a desire to 'confront' their illness head on; something they were less willing to do previously. The notion of 'foregrounding' also seemed to play a part in this, since exposure to the course helped them to acknowledge the health risks of poor disease management whilst recognising the futility of perfect control. The third theme, 'Transitions beyond the structured education programme', reports resistance to a target driven medical model which was incompatible with encouraging greater responsibility for optimal control. A potential solution was to promote better integration of discussions about the emotional burden of diabetes alongside the clinical management. The importance ascribed to the social context of glucose control during the course delivery phase suggests that young adults may be better prepared to report their challenges during clinics. This raises the need for full engagement of clinic staff in recognising the importance of these concerns for young adults and greater engagement between those delivering the course and the clinic staff.

Broader implications of the WICKED course

The strengths of the structured education programme included the blending of clinical learning with non-clinical (social/emotional) challenges of type 1 diabetes control. It seems that these two elements are often addressed separately in clinic, and as distinct rather than integral concerns. A finding also reported previously [11]. The course philosophy which supports flexibility by encouraging the drip feeding of clinical knowledge in a way that is personally meaningful to participants was of importance. Establishing a balance so that clinical and non-clinical learning is promoted in a meaningful way, is perhaps the 'art' of course delivery. Young adults with diabetes will have different backgrounds and illness management experiences. As such the challenge for educators is to identify and 'tap-into' the group identity, identify the challenges faced by the group and employ tailored support through a sensitive and engaging style of learning [6]. This is where establishing rapport with the participants is critical. The limitations of the course on the other hand included the 'lead in' time required to establish a connection with the group of participants and build rapport. The way participants engaged in the course activities is one thing, and how they translate the learning for effective continuous self-management is another. Clearly, for some the course was less helpful than for others, and perhaps a perfect match with all young people with type 1 diabetes is an unrealistic goal. One practical way forward, however, is a novel care model in diabetes to encourage clinicians to build conversations with young adults by replicating the WICKED philosophy that combines clinical management with the emotional challenges linked to living with diabetes [11]. The entire clinical team have an integral, but differentiated, role to play in patient care, with nurses and dieticians perhaps well placed to take the lead in promoting WICKED through brokering clinical education with guidance on social and emotional self-management advice.

Strengths and limitations

The main strength of this qualitative study was the depth and breadth of experiences reported by participants during a stressful transition from childhood to adulthood in the context of living with type 1 diabetes. The methods provide insights into the key reasons why diabetes management and glucose control was difficult for young adults, and identified the way forward with potential solutions. The course observations provided insights into how participants talked about diabetes self-management and the public misunderstanding of type 1 diabetes; all of which placed added pressure on their ability to cope with the condition. Although not statistically representative, the findings are likely to reflect experiences of the broader population of young adults with type 1 diabetes, although the aim was not to generalise beyond the immediate study participants. The interview sample included 15 participants which may be viewed as a low number though we did reach data 'saturation' and did not require further data collection. In addition, the seven focus groups provided further in-depth information which gave us confidence that we captured a broad range of views and experiences in a lot of depth. As our participants were all White British, future studies need to explore the views of a broader range of ethnic groups in search of possible cultural differences regarding the benefits of structured education programmes.

In conclusion, clinical teams need to recognise that structured courses for young adults need to foster maximal learning from fellow participants to decrease feelings of isolation, maximise engagement during the course by delivering the content in a flexible manner, and lead to future consultations in clinic that more readily recognise the social context in which young adults are trying to manage their condition.

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