

“Not just a diabetic”: Exploring the service needs of young people with diabetes.

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Introduction

Service Evaluation Context

The Mid Yorkshire Hospitals NHS Trust is a large organisation comprised of Dewsbury and District Hospital, Pinderfields Hospital and Pontefract Hospital. The trust has diabetes centres at all three sites and offers a specialist service to paediatrics and adolescents (0 – 15 years old) and adults (16 and over) who are living with diabetes. There is a large medical team across the services, including consultants specialising in diabetes, clinical nurse specialists and dietitians, alongside clinical psychologists and family support workers. NICE (2015) guidelines stipulate that psychology services mirror the physical health management of diabetes, in that there are separate services for children and adolescents and adults. This means that when a child reaches 16, they transition to adult diabetes care management, and will therefore access a different psychology service.

Reflecting the literature this service has also noted increased risk of psychological difficulties, sub-optimal self-care and poor engagement with services in young people with diabetes (Davies, 2019; Dovey-Pearce et al., 2005). All of which have been associated with a detrimental impact on biomedical outcomes (blood glucose/HbA1c levels) and significant risk of complications related to diabetes (Wentzell et al., 2020; Northham et al., 2010). In light of this, and in line with trust and national priorities to improve diabetes care management (NHS England, 2016/2017) and streamline resources, the Department of Clinical Health Psychology and the paediatrics and young people's diabetes team are working in collaboration. They aim to develop a business plan to better integrate current services and develop a specialist psychology service aimed at young people (16-25).

This SEP was commissioned to understand young people's experiences of living with diabetes, the kind of support they may require, and the best way the service can be designed and developed to meet these needs.

Literature Review

Diabetes is a complex chronic condition that affects approximately 15,000-25,000 children and young people (YP) in the UK (www.diabetes.org.uk; NHS Digital, 2018). Alongside the significant impact for the person living with diabetes and those around them, it is estimated that complications arising from diabetes account for approximately £10bn each year (www.diabetes.org.uk).

Young adulthood is characterised as a complex transitional and developmental period. Arnett (2001) proposes that this stage is divided into two phases: an early transitional phase (18-22) and later transitional phase (23-30). Each phase consists of development, psychosocial and lifestyle changes, such as in residence, education status, occupation and interpersonal relationships. In a population of YP living with diabetes the competing demands on health, the added transition of a move from child to adult health care systems, and normal developmental activities may lead to a greater sense of burden and a greater risk of poor psychological wellbeing.

In light of this there is a large amount of research dedicated to optimising diabetes management in YP, however it continues to represent a significant challenge to service users and healthcare systems. A recent integrative review in emerging adults (18-29) found an increased likelihood of hypoglycaemia and more frequent diabetic ketoacidosis than other age groups with diabetes (Wentzell et al., 2020). This period is also associated with poorer outcomes in terms of diabetic complications (Northham et al., 2010; Bryden et al., 2003) and psychological wellbeing (Baucom et al., 2018; Berg et al., 2018). These outcomes suggest there remains a pressing need to improve transition to this group, integrate mental health support with diabetes care provision and take into account YP views about the services they are accessing.

Mismanaged or missed psychological difficulties can have significant implications on diabetes management (Peters, 2011; Hislop et al, 2008; Anderson, 2001) and several reviews have suggested the importance of including psychological support alongside lifestyle and educational interventions often implemented in this population (Sturt et al., 2015; Chew et al., 2017; Harkness et al., 2010).

Aims

Alongside better integration of physical and mental health service provision in diabetes care, there has been a call for increasing service user input in service design and provision in order to best reflect their needs. In line with this, the SEP aims to:

1. Understand the lived experience of diabetes for young people accessing the service.
2. Explore the service needs of young people with diabetes.
3. Provide recommendations to support the development of a psychology service.

Method

Design

A qualitative design was used to elicit the young people's experiences. A semi-structured topic guide was developed (Appendix 1) which included open-ended questions designed to map on to the SEP aims.

The study was initially designed to include two focus groups, dividing YP into two age brackets (16-20 and 20-25). This was designed to manage group size and ensure participants were grouped with peers of a similar age and potentially at similar stages of life, and therefore have some common experiences related to their diabetes management.

Participants and procedure

Participants were recruited via opportunity sampling from the Young People's Diabetes service from a database of individuals who had been invited to participate in the Trust's experts by experience group (Appendix 2) and provided consent and contact details (Appendix 3). Service users who had consented were provided with a participant information sheet (Appendix 4). All participants were given at least 24 hours to consider if they would like to take part or not. This was followed by a telephone call to answer any questions and offer dates of the focus groups. Non-English speakers were excluded as the project had insufficient funding for interpreters or translators.

Two focus groups were offered in November 2019, but there were no attenders. Another group was offered in January 2020, with one. In light of this poor recruitment, a minor ethics amendment was submitted in February 2020 to include telephone interviews using the same semi-structured topic guide.

After written consent (Appendix 5) was obtained, the single attender of the focus group in January 2020 was interviewed face-to-face. Although they were outside of the age bracket (older by 5 years), it was felt they could make a valuable contribution of their reflections of living with diabetes and accessing both child and adult healthcare services. Subsequently, seven telephone interviews were conducted in March 2020 after verbal consent was obtained. The face-to-face interview lasted approximately 45 minutes and the seven telephone interviews lasted between 20 – 30 minutes. During the interview process, basic demographic information was collected to describe the sample. All interviews were conducted on hospital premises in a private room. All interviews were digitally audio recorded and transcribed verbatim either by the researcher or a University of Leeds approved transcriber. To ensure anonymity, all names were removed during the transcription process.

As the recruitment and data collection period was time sensitive, it is unlikely that data saturation was reached. This is defined as the point where no new information or themes are being identified in the data (Guest et al., 2006).

Analysis

Thematic analysis as described by Braun and Clarke (2006) was used to distil themes. This was considered appropriate due to its descriptive rather than interpretive function for the exploratory purposes of this SEP.

Each transcript was repeatedly examined in depth and coded by the author. Each unit of coding was given a label, where possible reflecting the service users' own vocabulary. The preliminary codes were continuously reviewed for salience and importance and for clustering or grouping into themes by content. A conceptual map was produced to help identify and illustrate where codes and themes were interconnected (Appendix 6). The author used the method of constant comparison in order to reduce and condense the themes into the most important categories. Through this iterative process, the most salient themes were identified.

Superordinate themes were chosen on the basis of forming ‘umbrella’ themes that covered various subordinate themes. Themes were repeatedly checked against the transcripts to ensure they were well grounded in the data.

To ensure trustworthiness and credibility, in line with quality assurance guidance (Elliot, Fischer & Rennie, 1999), two of the eight transcripts were independently coded by an experienced colleague. Joint discussions were held to consider differences until a consensus was agreed and to ensure the themes were adequately grounded in the data.

Ethical considerations

This SEP was approved by the Faculty of Medicine and Health Research Office, School of Medicine Research Ethics Committee (SoMREC) in September 2019 and an amendment was approved in January 2020 (DClinREC 19-001). Approval was also obtained from the head of service. The trust R&D department did not classify this SEP as a research study and provided confirmation as such.

Results

Overall, eight interviews were conducted (see Table 1 for participant demographics).

Table 1. Participant demographics

Participant ID	Diagnosis	Age of Diagnosis	Current Age	Ethnicity	Gender
1	Type 1	7	30	White-British	F
2	Type 1	5	21	White-British	F
3	Type 1	19	25	White-British	F
4	Type 1	21	25	White-British	F
5	Type 1	3	23	White-British	M
6	Type 1	11	25	White-British	M
7	Type 1	16	19	White-British	M
8	Type 1	15	24	White-British	M

Five themes were identified in the data: 1) Diagnosis, 2) Day-to-day management, 3) Self-identity and concept, 4) Interactions with staff and 5) Peer support. The themes were partly shaped by the interview questions and partly identified from the data. All superordinate and subordinate themes were intricately linked to wider codes and each other (see conceptual map, Appendix 6).

The following section will present the themes identified in the data in the context of key recommendations for the service and use excerpts from the transcripts to illustrate.

Experience of diagnosis

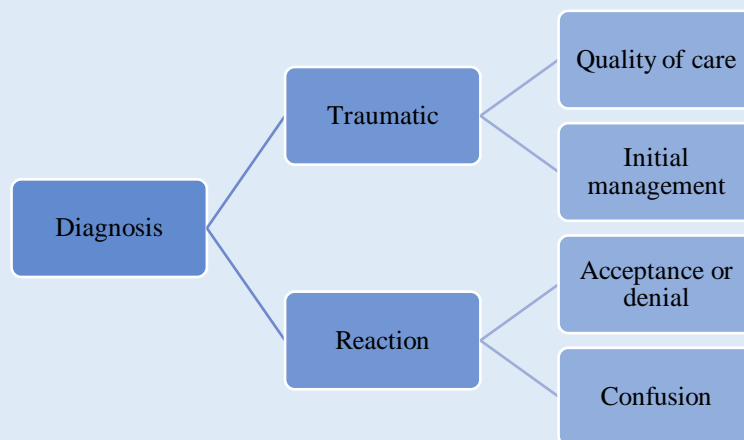


Figure 1. A thematic map illustrating the superordinate theme of diagnosis and related subthemes.

The superordinate theme related to the experience of diagnosis captured two subthemes of trauma and reaction to a diagnosis. Participants described an initial medical management of the symptoms and very little attention to the traumatic circumstances of presenting in a critical state and receiving a diagnosis of a chronic condition at a young age. There was general consensus that psychological input at point of diagnosis is required.

“but I think it [psychology] should be offered to you like the minute you’re diagnosed, especially the, as a young person ... I-well it’s such a huge change; like you’ve got to live your life completely differently. Like your mentality changes and everything, you know you see yourself so differently I think it’s important for young people to talk to someone.” P3

“psychology should have been way way before. I think that it could have helped me totally.” P1

Participants described that receiving a diagnosis as a young child meant that responsibility for diabetes management was often placed on parents/carers. Some participants reflected on the effect of this on acceptance or denial of the condition and the implications for self-management when they were older.

“I didn’t realise what were going on kinda thing, I didn’t know anything about it or really, I mean I were 7 so, but that’s it not really anything much about... I think it were coz me mum that dealt with it.” P1

“it didn’t really phase me ... umm, but I think that’s cause I didn’t really accept it ... was just kinda like coping with it, I didn’t really realise the implications of what I had so I didn’t realise like how much I could damage myself by not looking after, I didn’t realise any of this.” P8

Most participants described a complex reaction to receiving a diagnosis, and some felt that a poor understanding of diabetes and its impact, on the general ward, had a significant effect on their perception of the quality of care and emotional wellbeing.

“um, to be honest I think if the hospital were a little bit better about er, diabetes care... umm, and I-I was there for about twelve days ... And there was an instance where I had a hypo and um, they didn’t really know how to treat it ... and I felt rubbish for about an hour and it just didn’t, it didn’t feel like I was very well looked after... I spent a good week or so feeling really confused ... and obviously nobody there to explain it yet” P4

“at the beginning again, like I said, I was very scared and like unsure and anxious about it” P2

Day-to-day management

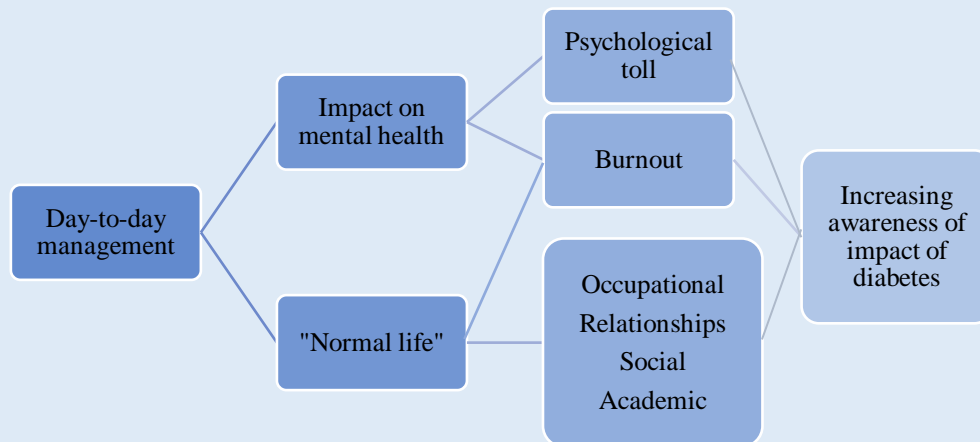


Figure 2. A thematic map illustrating the superordinate theme of day-to-day management and related subthemes.

The superordinate theme of day-to-day management of diabetes reflected two subthemes related to its impact on mental wellbeing and leading a “normal life”. In general participants described high emotional and physical demands related to diabetes, however, there was typically a disproportionate focus on medical management over psychological wellbeing by staff and the bidirectional relationship of mental health and blood glucose was felt to be overlooked. Some participants described the complexities of the transfer process of diabetes management from parent to child and during transition from child to adult healthcare systems. The potential significance of having psychological input during key transitions was noted.

“I don’t really think there was much more cause obviously I were only young so my mum and like dad were doing everything for me. So I didn’t really have to worry about quite a lot of things ... as soon as I reached that age it were all, it were all me then when I was about 16 but I had, when I was speaking to [psychologist] about it I was saying there were times like when I was at the doc, well I’d gone obviously to see the consultant; but he was really horrible. He was like . . . shouting at me cause I’d forgotten my readings; but I didn’t-cause obviously I’d gone from school straight to the hospital so then I just like everything, I just, everything went back to me mum then cause I were just like, ‘No, I’m not having this. So I were just like, so then it got to

when I were actually cause then my mum still like came to hospital appointments with me afterwards cause I was saying I won't go" P2

There appeared to be a high risk of burnout due to the time and energy expended on monitoring diabetes (calculating and restricting diet). Participants described the impact diabetes had, both psychologically (emotional, cognitive, personality and fatigue and stress) and on leading a "normal life", in terms of their occupation, forming relationships, academic work and socialising.

"socialising becomes quite an issue; I've been in gigs where I've been in the crowd and I've ended up having a low blood sugar so I've gotta get out there and do stuff like that so stop going to gigs as much . . . after that experience. And especially if you get diagnosed and you're like in mid-teens and everyone starts to go out drinking, stuff like that and . . ." P8

"you're always told when you go to clinic that you can do all these normal things and yada, yada, yada. And as much as that sits in your head, it's, , you know it's a little bit of your life but it doesn't feel like that. it feels like a massive, massive part of your life." P5

This was interrelated with a subtheme of increasing public awareness of the different presentations of someone living with diabetes and addressing some commonly held underlying assumptions of the condition such as poor weight control, diet and unhealthy lifestyle which led to shame, guilt and stigma.

Self-identity

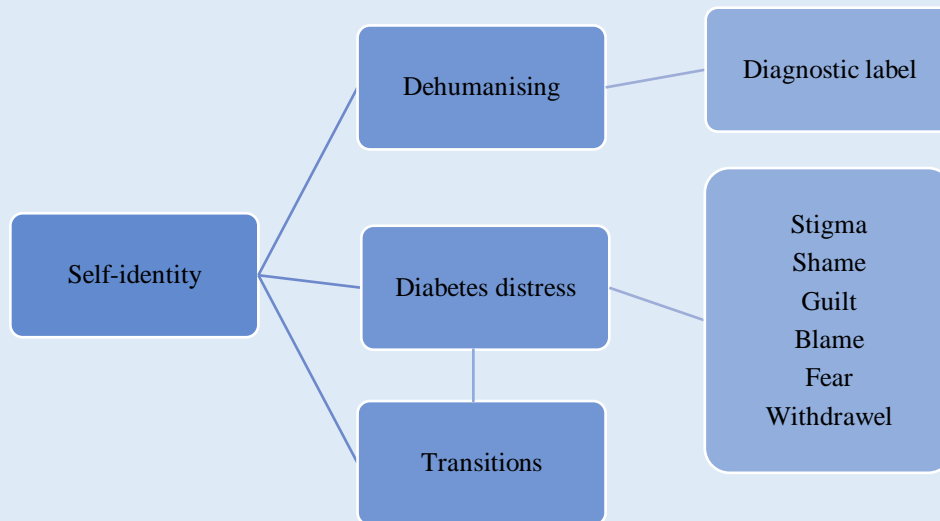


Figure 3. A thematic map illustrating the superordinate theme of self-identity and related subthemes.

Several references were made to a change in self-identity and its impact on acceptance and/or denial following diagnosis. Under this superordinate theme, three subordinate themes were identified: 1) dehumanising, including diagnostic overshadowing, the label of “diabetic” and focus on biomedical information above overall wellbeing, 2) psychological distress related to diabetes and 3) transitions.

Participants described the dehumanising of the self and one’s personal identity once they were labelled as “a diabetic”. For one participant this had a significant impact on their acceptance of the condition and was linked to the development of diabulimia.

“But everything gets boxed diabetes, even if you go, its literally oh are you diabetic, oh well I’m not here for that I’ve got a broken foot ... I’m not just a diabetic, I’m also, I’m a person with diabetes. It took a long time for me to, oh what’s the word erm, kinda accept that I were diabetic. I don’t think I ever accepted it, it were always the case that I don’t want to be diabetic, I don’t like being diabetic, so I’m not gonna do everything that a diabetic does and I will go completely the other way.” P1

Participants described how there was a sense of self-blame and guilt that appeared to be an ingrained feature of diabetes management routines, and these feelings were heightened when blood glucose management was pointed out as suboptimal by healthcare professionals (HCP)

and often seen as a personal failure. Most participants described striving to manage diabetes and meet social and normal developmental goals which was perceived to be somewhat at odds with the singular goals of HCPs to control blood sugar levels. Balancing this and a general shift in personal identity was linked with the stigma and shame of being a young person with a chronic health condition, publicly often associated with older age and other assumptions noted earlier.

“I wouldn’t want to, you know I wouldn’t want to talk about it, and would probably try keep it hidden cause I do tend to do that when I’m around people that I don’t know very well ...I think I did have quite a bit of shame for having it; and you do get dirty looks and things like that.” P4

The psychological impact of diabetes was described in relation to general psychological factors such as changes in temperament or cognitive functioning but also more specifically to some form of worry, fear and anxiety associated with the management of diabetes, for some leading to social withdrawal and disengagement with services. This ‘diabetes distress’ was often heightened at key transitional points including from child to adult services or transitioning through education and into working life.

Interactions with staff

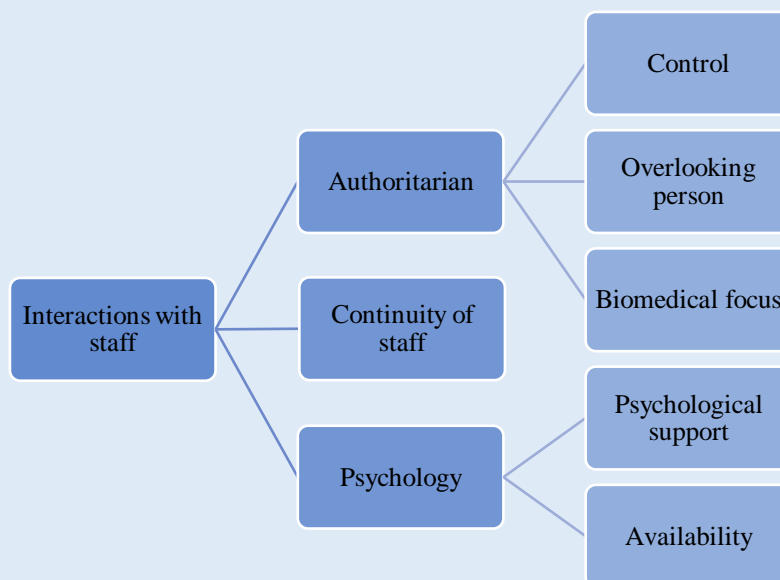


Figure 4. A thematic map illustrating the superordinate theme of interactions with staff and related subthemes.

The superordinate theme of interactions with staff reflected three subthemes regarding authoritarian interactions with consultants, difficulties related to the continuity of staff and psychological input. Appointments with doctors were generally described as brief, biannual with a singular focus on biomedical data and control, and typically with a different consultant each time. Some participants described the effects of being overlooked and a sense that consultants do not truly understand the complexities of the lived experience of diabetes.

“Umm, something I’ve always, always thought and always said, is when you go for, when you go for your standard, your standard clinic, it’s like, especially if you having like tough times, like these people don’t know what it’s like to, to live with it. They don’t know what it’s doing to, to my head, to this, to that, to whatever.” P5

Participants described the disproportionate focus on biomedical data collection and a consistent emphasis on poor management and control left them striving for perfectionism. Often leading to guilt and self-blame if glycaemic control was not achieved. This perception of complete control was adopted in other parts of life for one participant.

“There’s no human interaction. It is right well, you’re not doing this, there’s no right well I can see where you’ve tried with this. You’re never going to win and they don’t, it’s like nothing is ever good enough, they’re just bothered about the numbers ... when I were first diagnosed and how they’d speak to you and say you need to control, you need to control this ... It were almost like I’d took that into every other aspect of me life for trying to control stuff whereas it’s like I shouldn’t have had to control it, I should have just... It’s alright for it not to be okay, that I’m not just a diabetic, I’m also, I’m a person with diabetes.” P1

All participants were aware of psychological support, with six out of the eight participants accessing it at some point. Some participants mentioned that psychology support can be delivered by psychologically informed HCPs to improve access.

“A nurse possibly, coz I’ve just got a new nurse from [location] and she’s doing mindfulness so I were like oh wow that’s really great that you’re doing that ... I feel like if they’ve got that then people are not gonna be going into hospital and you don’t

have to see them every three weeks, you can see them every three months because you know that your patients are alright.” P1

Of those that had accessed support, psychology seemed to provide a space for participants to reframe diabetes management, take some ownership and help navigate the complexities of undertaking developmentally appropriate activities whilst having a chronic health condition. For some, the support was for factors outside of diabetes self-care and it felt important to participants that everything was not always related to their condition.

“So she’s completely spun, even if we don’t talk about diabetes related things it has an impact on me diabetes the way I feel about it whereas before it were like just ignore it and it’ll go away whereas now I’ll just do it without thinking about it coz it’s not such a diabetes this big thing that controls me life completely, I’m more than that, I’m more than just diabetic.” P1

Most participants preferred one-to-one therapy, due to concerns with confidentiality, but were open to the idea of group support, to check-in with others either monthly or biannually.

“They could be umm, one-on-one sessions and then also if you want to join umm, a group that could be good cause then you could meet people who also have it and understand it, your own age, so both of ‘em would be good... I think having diabetes is enough of something to have in common. Like the people that I have met you sort of understand them straightaway when they tell you they’re diabetics.” P3

Peer support

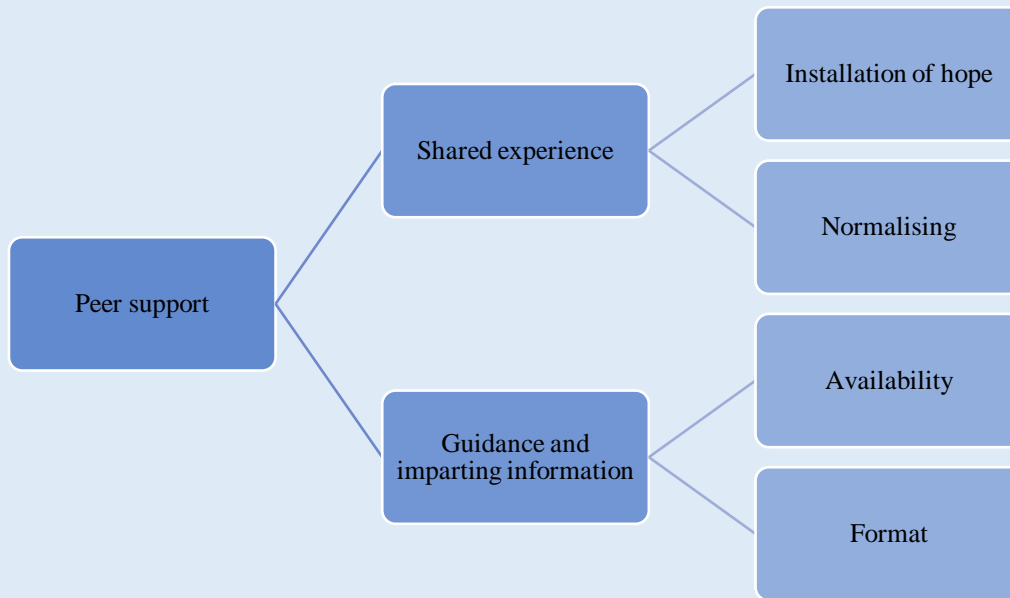


Figure 5. A thematic map illustrating the superordinate theme of peer support and related subthemes.

The superordinate theme of peer support covered two subthemes related to having a shared experience with others and peers as reference points for guidance and information. Some participants described that more formal diabetes education did not often translate well into everyday life and noted that practical learning was more likely to come from peers also living with diabetes, whom they were able to exchange ideas with. Peer support was generally viewed as a valuable resource and an opportunity to increase their social network and a sense of community, alongside normalising experiences related to diabetes management and instilling a sense of hope. Most participants reported that there was currently limited availability of peer support via the service, and recommended it should be offered at the point of diagnosis to help regulate emotions, and that it should continue into young adulthood. Some participants felt access to monthly peer support groups or having a buddy system would be helpful. There were no particularly preferences for age bands but nearly all participants preferred splitting peer support for people with Type 1 and Type 2 diabetes.

“I don’t know really cause umm, one thing that I did find helpful was my er, my um, my dad had a friend that er, also got it at a similar age to me and he’d umm, it were a little, maybe a month or two after but we went for like a meal, we-we discussed it a little bit. It was, I found that quite helpful.” P7


“Them putting them with other people that were going through the same thing I feel personally like I’m doing really well, like I was doing really badly with my diabetes but to even see some people – oh yeah they’re doing really well or wow they’re doing worse than me. It’s nice to know you’re not the only one going through it all, coz you’ve got a nurse and a doctor telling you that you should be doing this but they’re not doing it. It’s so easy to preach when you’re not having to live the life that we are, it’s difficult. Even if it were every six months, do you know what I mean, it wouldn’t have to be a monthly thing, if you’d got a couple of people who were down for it. I’d love it, I only know two other diabetics but we’re not on like talking terms or anything like that. Just to speak to somebody that kind of goes, ah I get ya. ... so it’s people understanding what you’re going through and being able to speak to em. Erm, but just to know you’re not alone, I think it would be lovely.” P1

Recommendations

Given that this research was conducted as a service audit, service users were asked what they would like from a new psychology service and several suggestions were made (see Table 3a). Participants described various preferences related to what the service could look like, how awareness of psychology services could be increased, and methods to help engage young people. Most participants advocated for psychology input to be available at the point of diagnosis. Some people felt that clinicians should be aware of the normal development challenges YP face and recommended increasing visibility of psychology services at points of transition; particularly from child to adult healthcare systems and also during other developmental transitions e.g. college to university, or academic to occupational.

Several recommendations were also identified for providing a psychologically informed general diabetes service, including having developmentally appropriate consultations and ensuring an equal focus on psychological wellbeing alongside biomedical information collection (see Table 3b).

Table 3a. Recommendations for the new psychology service

*Preference	Location of appointments	Increasing awareness	Communication for appointments	Type of support	Referral
High  Low	Hospital	Via social media platforms – Facebook (FB), Instagram, Twitter	Social media platforms e.g. FB messenger	One-to-one therapy	Clinician
	Home	YouTube videos about diabetes and psychological wellbeing	Text	Service user advocates - organising buddies	Self
	School/University	Information sheets/leaflets/posters in hospital and GP waiting rooms about psychology service and referral process	Email Letters	Peer support /network groups – face to face and virtual via social media “Check-in” groups / drop-in clinics Structured psychological support from other HCP’s Telephone support	

* Participants’ preference was identified by analysing participant ranking of options.

Table 3b. Recommendations for wider diabetes care management support

Improving clinic organisation	Improving the consultation	Improving informational care
Seeing the same person during consultations	Be attuned to emotional wellbeing of patient e.g. screening for diabetes distress	Make information relevant to young person and developmentally appropriate
Drop in clinics	Change in language from “a diabetic” to “person with diabetes”	Make information available at point of diagnosis
Flexible timing of clinics e.g. after work ones	Staff discussing psychological support with patient and referring where appropriate	Make patient aware of availability of psychological support at point of diagnosis
More colourful design of waiting room e.g. with positive posters	Style and attitude of health care professional – not authoritarian and judgemental.	Information via YouTube video of living with diabetes
Appointment confirmation and reminders via text and email.	Medical staff consulting with psychology to understand patient formulation Encourage patient empowerment Talk directly to the young person	Posters with support resources

Discussion

This SEP provides an insight into the experiences of young people with diabetes and how they believe the paediatrics and young people's diabetes service can be developed to best meet their needs. In general, most participants felt that diabetes is a life changing condition to have and it comes with a high degree of demands and psychological burden. However, participants described a disproportionate focus on biomedical impact over mental health, even though they themselves identified a unidirectional relationship between mental, social and physical health (HbA1c levels), consistent with other accounts (Ascher-Svanum et al., 2015; Penckofer et al., 2012; Lawrence et al., 2006).

Consistent with earlier findings, this evaluation identified that young people with diabetes often had a traumatic or emotionally challenging experience at point of diagnosis (Simms & Monaghan, 2016). Most participants also described some form of diabetes distress, a general term that refers to the emotional burdens, stressors and frustrations that come from managing diabetes (Fisher et al., 2014). All of these experiences have been linked to poorer diabetes self-care management (Balfe et al, 2013; Hagger et al, 2016; Stahl-Pehe et al, 2019).

There were also consistent reports of challenging interactions with staff, a focus on control and a sense of disempowerment, which have been reported elsewhere (Davies, 2019; Scholes et al, 2013; Dovey-Pearce et al., 2005). Unfortunately, in this sample participants described this contributing to withdrawal and/or transferring diabetes management back to parents/carers. For one participant was linked to the development of diabulimia, an eating disorder with high prevalence in this population (Coleman & Caswell, 2020).

Overall, and reflecting findings in the literature (Maidment et al., 2019; Bailey & White, 2017) accessing psychological support was viewed positively. For those that had accessed psychology, they described a change in their attitude towards diabetes management. For some, psychological support helped to take some ownership of their care and learn skills to better navigate and balance leading a "normal life" whilst having a chronic health condition. Similarly, peer support was largely viewed positively and several participants advocated for increasing its availability and access; a finding that has been identified in previous research in this population (Fisher et al., 2012; Simmons et al., 2010).

Recommendations to the service

- A key finding was a largely positive perception of psychological support, suggesting a new psychology service would be valued by YP. Most participants requested psychological input at the point of diagnosis and/or during transitions, particularly from child to adult healthcare systems and other typical developmental transitions such as from academic to occupational. Therefore, it may be useful have a psychologist available for more specialist input on the general wards, and perhaps provide additional training to HCPs in psychologically informed practice.
- Most participants reported a preference for one-to-one therapy, and described the impact it had on their self-care management. Early psychological input may help increase self-care skills and promote empowerment to reduce worries, concerns and fears related to diabetes. It may also help the MDT to formulate and understand the service user's life circumstances, how diabetes is fitting in with other aspects of their life and any underlying factors that could be associated with poor management of diabetes.
- Most participants reported a general sense of disempowerment present in interactions during consultations and a high focus on biomedical control. This may reflect an opportunity for the psychology service to facilitate MDT reflection on practice and its delivery in relation to mutual goal setting, understanding the YP's perspective and increasing patient empowerment. It may also help develop creative and innovative ways the service can integrate physical and mental healthcare with this client group.
- In a similar vein, based on the service users' views, it may be helpful to further explore contact vs. content of clinical time. Whilst participants appreciated that clinics were time sensitive due to resources, there appeared to be frustration around mismatched goals of consultation, repetition of information and a disproportionate focus on negative medical outcomes. For example, some participants described the limited efficacy of the 'scare tactics' often used during consultations. Dovey-Pearce and colleagues (2005) note that in this population, these tactics may not be meaningful and in fact lead to denial and withdrawal, due to still developing abstract thinking related to long-term implications of diabetes, something reported in this

evaluation. There is a role for psychology here to help the MDT provide developmentally appropriate and psychologically informed clinical practice via training, supervision and consultancy to help diabetes specialists understand the impact of the developmental stage on diabetes management and to formulate presentations.

- Most participants struggled with diabetes distress at some point (although not directly labelled as such). It may be useful to screen for this during consultations alongside biomedical data collection, as this was reported to have an impact on self-care management in this sample. As noted earlier, the new psychology service can play an important role in bridging the fragmented perception of physical and mental wellbeing that participants felt some HCPs held.
- Some participants valued support regarding general life problems. It may be useful to provide additional training to HCPs in structured basic counselling or other psychological intervention e.g. mindfulness.
- Most participants noted an absence of peer support, but advocated its value for wellbeing. It may be useful to set up some groups or a buddy system so that participants are empowered to speak of their diabetes, but also to provide guidance and information sharing from those with lived experience e.g. diabetes and travelling, sports, or tips and tricks, or alcohol consumption. Given participants frequently described a sense of isolation and an impact on self-identity, peer support groups may also serve to increase social connection and identity development. In light of the current situation, there is potential to use remote technology in this manner e.g. social media applications (e.g. Young with Diabetes and MyT1DHero) which have received positive feedback (Husted et al., 2018; Castensøe-Seidenfaden et al., 2018).
- Most participants identified the benefits of accessing pump technology on the physical and psychological demands of diabetes. Therefore, increasing access to this technology may be helpful.

It is important to acknowledge here that there are cost and resource implications for implementing some of these recommendations successfully.

Dissemination

This report and recommendations of this study will be provided to the commissioner to inform the business case in the development of the psychology service.

Limitations

There were several limitations with this SEP. There was an issue with recruitment to focus groups and therefore the design was changed to individual interviews. Participants consisted of a small, self-selecting homogenous group from the same geographical location which therefore limits the conclusions that can be drawn. Future research may wish to broaden the sample to include a more diverse representation of the population, and perhaps seek to identify the views of those who had not accessed psychology services. Furthermore, as the sample size was small it is unlikely that data saturation was reached and views of other YP with diabetes who may have different experiences and recommendations may not have been captured in this analysis.

As the primary aim of this SEP was to explore service needs and development, the semi-structured guide consisted of potentially directive questions which may have introduced an element of bias in responses. Additionally, the presence of a staff member from the YP diabetes team during one interview could have introduced social desirability bias. However, the remaining interviews were conducted by the author, who is independent from the service and therefore this bias will have reduced.

Lastly, it can be argued that the author's prior knowledge of literature concerning YP's experience of diabetes may have narrowed the focus of the analysis and potentially resulted in the salience of certain themes reported, with less focus on alternatives. However, two transcripts were analysed independently by an experienced colleague and similar themes were noted. Additionally, Tuckett (2005) suggests that engagement in literature can enhance analysis by sensitising the researcher to more subtle features of the data.

Conclusion

Overall, the findings of this evaluation indicate that YP find navigating and balancing the demands of diabetes and engagement in typical developmental activities a challenging process. These can sometimes be at odds with the priorities of HCPs, and lead to a differences in the perception of optimal diabetes management. This in turn can have significant implications on engagement and diabetes self-care. However, there is an important role for a psychology service to support the psychological wellbeing of YP with diabetes and to create a shared understanding between YP and HCPs to help increase engagement, collaboration and self-management.

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Topic Guide

[ICE BREAKER – e.g. if you had as much money as you could possibly spend, what would you spend it on?]

1. How would you describe your earliest memories of having diabetes?
2. Thinking back, what do you think would have been most helpful for you during that time?
3. What are the main challenges of having diabetes?
 - a. Impact on personal life (family, relationships), college/university, work
4. The young people's diabetes team are made up of several people, can you think of who they are and what they do?
 - a. Is there any other type of professional you would like to see? Why?
 - b. Do you think it would be useful to have a psychologist in the team? Why?
[Outline role of psychologist if YP are unsure]

Questions about the new psychology service

1. What other kinds of professional do you think would be best to deliver this service?
2. What information would you like about the service in order to help you decide if you would like to access it?
3. How would you like the team to communicate with you? (*Prompts: these could be face to face, telephone [clinic/ school], email, Whats App, Facebook*).
 - a. Which ways do you think are the most effective?
 - b. When we communicate with you, which ways do not work so well?
 - c. What other ways can the team get in touch with you that would be more effective?
4. What would be the best way to provide this information
 - a. Leaflets, YouTube videos, other social media (Instagram, FB, Twitter).
5. What kind of challenges do you think there might be in accessing this service?
 - a. Helpful / unhelpful aspects of having a psychology service?
 - b. Timing of clinics
 - c. Transport
 - d. Convenience
 - e. Location of clinics?
 - f. Fitting with current lifestyle?

6. How would you want to be referred into the service?
 - a. Self-refer, Referred by clinician (doctor, nurse, dietician)
7. Where would you prefer to be seen e.g. in clinic, home visits, in community? Why? Possible advantages, disadvantages?
8. What form of support would you like prefer?
 - a. 1:1, group (therapy/peer support), over the phone, skype/facetime, online or other apps?
 - b. If you were seen in a group, what kind of people would you like to be seen with, same age, diagnosis, treatment? Why?
9. What other ways could the Young People's Diabetes Team help you with your diabetes?
10. If you had X amount of money to spend on the diabetes team what would you spend it on?

The Mid Yorkshire Hospitals NHS Trust

YOUNG PEOPLE'S DIABETES SERVICE

INVITATION TO GET INVOLVED



We are looking to get the views and opinions of young people with diabetes to help us set up a new service. This service will aim to help young people with diabetes manage any psychological difficulties they may be having associated with living with diabetes.

If you would like to get involved and have your say, then please give us your name and contact details using the attached form. We will contact you in the next few weeks with further information about how to get involved.



Consent to be contacted for involvement with an 'Experts by Experience' group

I agree that I may be contacted about involvement as an 'Expert by Experience' with the Department of Clinical Health Psychology for the purposes explained to me.

I also agree my contact details may be kept by The Mid Yorkshire Hospitals NHS Trust for the purposes of contacting me only.

Name of individual giving consent: _____

Signature _____ **Date** _____

Address: _____

Email address: _____

Phone number: _____

Thank you for giving your consent. If you wish to withdraw your consent at a later date, please contact the Clinical Health Psychology team on 01924 816032.

Chairman – **Jules Preston MBE** Chief Executive – **Martin Barkley**

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23/09/2019 V2.1



Participant Information Sheet

Exploring the service needs of young people with diabetes

Thank you for taking the time to read this. You are being invited to take part in a service-evaluation project (SEP). Before you decide it is important for you to understand why the SEP is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with family members or friends if you wish. Please contact us if there is anything that is unclear or if you would like more information. After reading this information sheet take at least 24 hours to consider if you wish to take part.

Who is conducting the SEP?

This SEP is being conducted by Krisna Patel, Psychologist in Clinical Training at the University of Leeds, in collaboration with the project commissioner Dr Daniel Stockton, Senior Clinical Psychologist at The Mid Yorkshire Hospitals NHS Trust. The SEP is supervised by Dr Ciara Masterson, University of Leeds.

What is the purpose of the project?

As you know, diabetes is a condition that requires self-management of diet, exercise, and medication. Guidelines for optimising treatment for Type 1 and Type 2 diabetes in young people advocates emotional and behavioural support from the health care team. The Department of Clinical Health Psychology is developing a service to help young people manage any psychological difficulties they may be having, associated with living with diabetes. We are interested in exploring your views about the diabetes service currently on offer to you and the type of things you might find helpful and unhelpful or would like in a psychology service. At the conclusion of the SEP, I will provide a written report and a short presentation to the team, and university peers, summarising the main findings. Your participation will increase knowledge in this area and feedback into developing the diabetes service for young people.

Why have I been chosen?

You have been approached about this study because you have diabetes and are currently known to the young people's diabetes health care team at The Mid Yorkshire Hospitals NHS Trust. You have also previously provided your contact details and consented to being



contacted for service user projects. We are inviting young people who are between the age of 19 and 25 to take part in a focus group to help us gain different perspectives.

A focus group is a form of qualitative research where a group of people, who may share similar experiences, are asked about their perceptions, opinions, beliefs, and attitudes regarding that experience. The researcher (Krisna) will ask questions in an

interactive group setting where participants are free to talk to one another about their experiences of diabetes.

We aim to recruit around 12-20 young people with a variety of experiences of diabetes to gain a better understanding of what kind of challenges they experience and how the psychology service can provide support.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form) and you can still withdraw at any time without it affecting the care or service you are provided in any way. You do not have to give a reason.

What do I have to do? / What will happen to me if I take part?

After reading this information sheet take at least 24 hours to consider if you wish to take part. If you do agree to take part you can let a member of your diabetes team know or call (Tel: 01924 816032) or email (Daniel.stockton@midyorks.nhs.uk), Dr Daniel Stockton.

We will then provide you with the time, date and location of the focus group. You will be asked to provide written and verbal consent before starting the focus group. The focus group will last between 60 and 90 minutes. Krisna Patel, will be facilitating the focus group and is in no way connected with The Mid Yorkshire Hospitals NHS Trust. Daniel Stockton will also be helping to facilitate the groups, Daniel is a clinical psychologist at the Trust. Krisna will ask you some questions about your experiences of living with diabetes and what kinds of things you would like from a psychology service. There are no right or wrong answers - the SEP team really want to glean your views and experiences. The focus group will be digitally audio recorded so that Krisna can transcribe it. During the transcription process Krisna will convert the audio recordings (speech) to text, word for word. You will be able to withdraw from the focus group at any point and will have one week after the focus group to withdraw your data should you wish. After this time your focus group will be transcribed and analysed and withdrawal will no longer be possible.



Will you compensate me for my time?

No. While we very much appreciate your help and time, and you may find the experience useful, you will not benefit financially from the SEP.

Are there any costs?

The focus group will take between 60 to 90 minutes of your time, but otherwise there are no costs associated with the SEP.

What are the possible disadvantages and risks of taking part?

The risks involved in participating are minimal. It is possible that some participants might find it distressing to talk about their experiences of having diabetes or challenges they have faced. If you get upset you can skip questions and choose not to answer, take a break or decide not to continue with the group. If you become distressed you can speak to Daniel Stockton, who will direct you to sources of support.

What are the possible benefits of taking part?

There may not be any immediate or direct benefits to you by taking part. However, some people may find it helpful or interesting to talk about their experiences of diabetes and how it affects them and share this with others who have had similar experiences. Your participation will help us to develop a better idea of how we can improve care for young people who have diabetes. At the conclusion of the SEP, we will present findings to your team describing the major findings. The team may alert you to any research publications we have generated from the project, if you wish to be informed.

If this study has harmed you in any way...

In the unlikely event that you are unhappy with the way that the SEP is conducted complaint mechanisms are available to you. In the first instance please contact Dr Ciara Masterson Ciara.masterson@leeds.ac.uk.

If you feel distressed after your focus group with Krisna, we suggest you access the following sources of support:

- If you feel you can, perhaps initially discuss any issues with a member of your diabetes care team or Daniel Stockton
- Contact your GP



Will my taking part in the study be kept confidential?

Yes. All information about your participation in this study will be kept confidential in accordance with the Data Protection Act 1998.

All the contact information that we collect about you during the course of the research will be kept strictly confidential and will be stored separately from the research data.

As you are taking part in a focus group, full anonymity cannot be guaranteed on behalf of the other focus group participants. However, we will make it clear at the start of the group that any discussion between focus group members should not be shared with others outside of the room after the group has finished.

Once the focus group is completed, your name on the digital recording and the transcript data will be replaced with a participant ID number making it anonymised. Your personally identifiable information will only be available to members of the research team and be initially stored on an encrypted recording device whilst in transit and then a secure drive at Leeds University. This information will only be used for the purposes of the current study. Your digital and transcript focus group data will be retained for a maximum of 3 years, from the completion of the project and subsequently disposed of securely. Quotes from your focus group may be used as examples of what people have said but any potentially identifiable information will be removed and your anonymity will be preserved.

Your responses to our questions will remain confidential unless you tell us something to indicate risk to yourself or others. If so, confidentiality will be broken and relevant information shared with Daniel, your health care team and/or appropriate agencies. If this happens, Daniel will contact you first to let you know what the team plan to do in response to your disclosure. The deadline to request withdrawal of your data from the study will be one week after your focus group. After this point your focus group will be transcribed, and it will not be possible to withdraw your data.



What will happen if I don't want to carry on with the SEP focus group?

You are free to withdraw from the study before or during the focus group without having to give a reason even if you decide to take part initially. However, due to the nature of a focus group it will not be possible to withdraw any contributions already provided.

Your consent form and ID linking to your focus group data and demographic information will be deleted after the data has been analysed and report completed. After this time, we will be unable to link your ID with your data in order to withdraw it.

What will happen to the results of the SEP?

The results will be used to help the researchers better understand the service needs of young people with diabetes. The study will be presented at a student conference and may be written up for publication in a practice-based journal.

Who is organising and funding the research?

The SEP is not funded. It is being organised and conducted by Dr Daniel Stockton, Consultant Psychologist, The Mid Yorkshire Hospitals NHS Trust, and Krisna Patel, Psychologist in Clinical Training, University of Leeds.

Who has reviewed the study?

The study has been approved by the SoMREC DClInPsych sub-REC (ref: DClInREC 19-001).

What if I have questions about the project? Contact details for further information

If you would like to discuss your potential involvement in this SEP further, please contact:

Name: Dr Daniel Stockton
Job title: Consultant Clinical Psychologist

Email address: Daniel.stockton@nhs.net

The Mid Yorkshire Hospitals NHS Trust
Department of Clinical Health Psychology
Staincliffe Wing
Dewsbury District Hospital
Halifax Road Dewsbury
WF13 4HS

Telephone: **01924 816032**

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If you would like to discuss your involvement in this SEP with a member of staff from Leeds University, please contact:

Name: Dr Ciara Masterson

Job title: Academic Director, Clinical Psychology Training Programme

Email address: Ciara.masterson@leeds.ac.uk Telephone: **0113 343 2712**

Leeds Institute of Health Sciences
University of Leeds
1093, Worsley Building
Clarendon Way
Leeds
LS2 9NL

Please retain this information sheet.



UNIVERSITY OF LEEDS

Doctor of Clinical Psychology Programme



Participant Identification Number for this SEP:

CONSENT FORM (23.09.2019, version 2.0)

Title of Project: Exploring the service needs of young people with diabetes

Name of Researcher: Krisna Patel

Please initial
box

1. I confirm that I have read the information sheet dated 23/09/2019 (version 2.1) for the above Service Evaluation Project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. In addition, should I not wish to answer any particular question/s, I am free to decline.
3. I understand that I may withdraw prior to or during the focus group. However, due to the nature of a focus group it will not be possible to withdraw any contributions that I have already provided.
4. I understand I will have up to one week after this focus group to withdraw my anonymised data. After this time, this focus group will be transcribed and anonymised and analysed, and I will no longer be able to withdraw my data.
5. I understand that the focus group will be digitally recorded.
6. I understand that as I am taking part in a focus group, full anonymity cannot be guaranteed on behalf of the other focus group participants.
7. I understand that the focus group will be transcribed by the SEP researcher and this will be kept confidential.

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

8. I give permission for members of the SEP team to have access to my anonymised responses. I understand that my name will not be linked with the SEP materials, and I will not be identified or identifiable in the report or reports that result from the SEP. I understand that my responses will be kept strictly confidential unless I disclose information about risk to myself or others, or unprofessional practice. I understand my consent form, digital and transcript data will be securely stored and destroyed after 3 years.
9. I understand that relevant sections of the data collected during the study, may be looked at by auditors from the University of Leeds where it is relevant to my taking part in this SEP. I give permission for these individuals to have access to my records.
10. I understand that any quotations used within the SEP report or any presentations as part of the SEP, will be anonymised to maintain my confidentiality.
11. I agree to take part in this focus group.

 Name of Participant Date Signature

 Name of Trainee
 Clinical Psychologist Date Signature

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

