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Multidisciplinary healthcare teams' challenges and strategies in supporting people with type 1 diabetes to recover from disordered eating

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What's new?

- People with type 1 diabetes and disordered eating experience high complication rates and are difficult to treat because there are no evidence-based care pathways for this dual condition.
- This study offers insights into the challenges of treating people with type 1 diabetes and disordered eating and the self-acquired strategies used by healthcare teams in tertiary diabetes and eating disorder centres to overcome these challenges. We identified the gaps in professional consensus, training and guidance for healthcare professionals.
- The findings will be used to develop the STEADY intervention (the Safe Management of People with Type 1 diabetes and Eating Disorders Study)

Abstract

Aim To examine the challenges healthcare teams face when treating people with type 1 diabetes and disordered eating and the strategies these teams have developed to facilitate effective treatment.

Methods Four semi-structured focus groups were conducted including two tertiary diabetes specialist teams and three tertiary eating disorders specialist teams between July and December 2018. Thematic analysis of the transcripts followed a six-phase process.

Results Twenty-nine experienced healthcare professionals (16 diabetes and 13 eating disorder specialists, 16±12 years' professional experience) were interviewed. The challenges identified in treating people with type 1 diabetes and disordered eating included subthemes the 'challenges specific to the healthcare professional' (feeling not competent enough and perceived emotional burden), 'challenges pertaining to patient factors' (e.g. difficulties with

engaging in therapy) and ‘challenges created by the healthcare system’ (time pressure and staff shortage). Healthcare professionals expressed the need for a consensus on diagnosis and the definition of disordered eating in type 1 diabetes, as well as the need for training and educational resources specific to type 1 diabetes and disordered eating. Healthcare professionals gave practical examples of strategies of communication for better patient engagement and felt that multidisciplinary working in joint clinics with the other specialty were facilitators for recovery.

Conclusions Healthcare professionals require multidisciplinary team support when treating people with type 1 diabetes and to improve their own competencies. The development of effective screening and assessment tools, educational resources and training for healthcare professionals, and developing multidisciplinary treatment pathways will be key to improving outcomes for their service users with type 1 diabetes and disordered eating.

Introduction

Psychiatric comorbidity impacts diabetes self-management and there is an established association with acute and long-term complications including increased mortality [1]. Eating disorders are twice as common in people with type 1 diabetes compared to those without [2].

Intentional insulin restriction in order to lose weight or avoid weight gain is a type 1 diabetes-specific disordered eating behaviour [3], occurring in up to 40% of young women with type 1 diabetes [4].

This accelerates development of late complications of diabetes [5], increases risk of acute complications such as diabetic ketoacidosis [6], and triples mortality risk [7].

Healthcare professionals have difficulty detecting and treating people with type 1 diabetes and disordered eating because of a lack of guidelines and integration across specialist care pathways, and have described the detriments of insufficient awareness and lack of skills [8].

In previous studies exploring healthcare professionals' and service users' individual perspectives, it became evident that an integration of type 1 diabetes and eating disorder specialism in multidisciplinary teams would be desirable [8,9]. The experiential perspectives of multidisciplinary healthcare teams are therefore extremely valuable for developing future clinical care pathways and effective interventions for people with type 1 diabetes and disordered eating.

Although there are currently no evidence-based treatment pathways or effective interventions that improve diabetes outcomes and mental health in people with type 1 diabetes and disordered eating [10], it is likely that highly experienced healthcare teams have developed their own strategies.

This semi-structured focus group study has been conducted as part of the STEADY project (Safe Management of People with Type 1 Diabetes and Eating Disorders Study), with the aim of developing a complex intervention using experience-based co-design [11].

We examined the experiential perspective of healthcare teams at tertiary National Health Service (NHS) centres to identify the specific challenges they face when treating people with type 1 diabetes and disordered eating, and to capture strategies they have used to improve the health of this group.

Participants and methods

Recruitment and sample

Healthcare professionals were recruited from tertiary NHS centres: two diabetes specialist teams (King's College Hospital and Royal Bournemouth and Christchurch NHS Foundation Trusts) and three eating disorder teams (South London and Maudsley NHS Foundation Trust, Chelsea and Westminster NHS Foundation Trust, and Royal Bournemouth Hospital). Healthcare professionals from relevant disciplines with a minimum of 6 months' experience working with people with type 1 diabetes and disordered eating were invited to participate.

Data collection

The semi-structured topic guide consisted of open-ended questions regarding the challenges and therapeutic strategies of healthcare professionals when treating people with type 1 diabetes and disordered eating.

Focus groups were held in-person by two researchers (M.S. and N.Z.) between July 2018 and December 2018 and lasted approximately one hour. The focus groups were audio recorded, transcribed and fully anonymized.

Data analysis

The data were stored, managed, and analysed through NVIVO® version 12 software [12]. A thematic analysis was conducted according to Braun and Clarke' six-stage framework [13] using a semantic top-down approach to identify healthcare professionals' challenges and strategies. The initial coding was undertaken by two independent researchers (A.W. and N.Z., specialized in mental health and health psychology, respectively), who created initial codes and classified emerging themes. A third researcher (M.S., a diabetologist) was included in the process to compare findings, review and refine the themes and subthemes and create thematic maps until saturation was reached. Themes and sub-themes were discussed and further refined with the multidisciplinary team of co-authors. A multidisciplinary approach was used in this analysis to reduce researcher bias.

Ethics

Ethical approval was granted by the London and Surrey Borders Research Ethics committee (18/LO/0812/AM02).

Results

Twenty-nine healthcare professionals (four men, 25 women; 40 ± 11 years), who had worked in their professions for 16 ± 12 years, delivering care for people with type 1 diabetes for 7.3 ± 8.9 years, participated in four focus groups (four, 13, five and seven participants). Fourteen participants (P01–P14) were diabetes specialists, and 15 (P15–P29) were eating disorder specialists (Table 1) .

Two sets of themes emerged that aligned with the structure of the topic guide: (1) the challenges of treating people with type 1 diabetes and disordered eating, and (2) strategies for treatment (Fig. 1a,b).

Challenges of treating people with type 1 diabetes and disordered eating

Three main themes of challenges of treating people with type 1 diabetes and disordered eating were described (Fig. 1a).

Challenges specific to the healthcare professional

Diabetes specialists described the difficulties in recognizing this complex diagnosis, partly because of lack of education and resources on type 1 diabetes and disordered eating and partly because of absence of validated screening tools adapted to diabetes, resulting in insufficient awareness and feelings of confusion around diabetes and disordered eating.

Healthcare professionals alluded to the fact that people with type 1 diabetes and disordered eating do not always meet the standard eating disorder criteria described in diagnostic manuals. They felt that insulin manipulation to control weight can be more challenging to detect than more typical behaviours like food restriction or purging. They also mentioned that people with type 1 diabetes and disordered eating are also more likely to have a normal BMI and can go undiagnosed because of this.

Consequently, healthcare professionals felt they lacked competency to treat disordered eating in type 1 diabetes.

...a lot of the patients [with diabetes] that have eventually been referred to us actually don't meet the criteria in terms of weight and BMI, and so I think, actually, there isn't that obvious sense that there might be an issue. [P26]

...we probably see people with eating disorders and diabetes but don't quite pick it up when they come in. [P07]

I didn't feel I had the skills to address it and I didn't know where to then, sort of, signpost them to, to get those skills. [P14]

Treating people with type 1 diabetes and disordered eating was very emotive for both eating disorder and diabetes teams. They described feeling out of their depth and a significant emotional burden.

Healthcare professionals described being fearful and lacking confidence in their abilities to work with patients without exacerbating their difficulties. Healthcare professionals felt demoralized because of the complexity and the lack of support in treating this group.

... you're afraid of making it worse because you feel, mental health things, you might push somebody over the edge because you don't know what you're doing.

[P04]

...there was a lot of sense [on the eating disorder inpatient unit] that they didn't feel confident in managing diabetes [...] then you get into a, kind of, 'Well, his regime needs to be stable before he comes,' but how can it get stable without the support of a specialist team? [P20]

This perceived incompetence and the emotional responses to this patient group led to unhelpful behaviours such as avoiding the topic altogether and insecurity in supporting diabetes care when treating the patient in an eating disorder ward.

... I suspected [my patient] did have underlying eating disorders but, you know, almost, sort of, tried to ignore it, being quite honest, because I wouldn't know what to have done with it. [P14]

I always, kind of, play ignorant early on in therapy, like, asking the patient to educate me about diabetes and how it's managed, and how it should be managed, and what you know about the risks rather than trying to educate them, because they know a lot more than I do. [P17]

Patient-specific challenges

Healthcare professionals felt challenged by the fact that disordered eating can be very diverse in the context of type 1 diabetes, with each person having individual reasons for insulin manipulation.

There was a strong sense of uncertainty around when compensatory behaviours should be clinically diagnosed.

... there will be a lot of people who perhaps don't quite take their insulin properly for whatever reason every now and then, but at what point does it become a diagnosable eating disorder? [P22]

... they hate having diabetes and they have recurrent DKA. Some people it manifests by, 'I've got a needle phobia,' and I wonder if for some people it manifests that, 'I've got eating disorders'. [P01]

Healthcare professionals described their patients not being ready to disclose their behaviours or engage in therapy, as well as insufficient diabetes education as key barriers to supporting their patients. They struggled with waiting until their patients were ready to engage.

... you might start the conversation now, and in 2 years' time that's when that conversation bears fruit [P21]

... even jumping from seeing them to a referral to us was too quick and too fast, and that there was more work to be done about getting them ready to even accept a referral. [P19]

Healthcare professionals identified unhelpful traits in some of their patients that make recovery more challenging, such as perfectionism, lacking self-awareness about their behaviours and not being able to see a long-term perspective. They identified behaviours such as avoidance, risk-taking, and making attempts to deceive healthcare professionals or split between different teams.

... whenever they try to start insulin, they gain some initial weight, and then that puts them off, and this is the perfectionist mindset. [P01]

... they're mostly adolescents, and in the same way as you talk to them about anything in the long term, they don't really see it, they don't really believe it. [P20]

... people then can start doing really extreme things as well, like deciding they're never going to eat carbohydrates again, at all so that they can omit insulin for the longer term. [P19]

... if they are seeing different healthcare professionals, well it's much easier then to manipulate the situation, you can play people off against each other. [P14]

Healthcare professionals acknowledged the impact of family and social environment as well as social media trends on diabetes and illness management and how people feel about their condition.

There's a 'clean eating' trend, and becoming vegan, and all your meals being on Instagram and things, that's very, very popular amongst young people, and again, that fixates people on the food and what they eat. [P14]

... no-one is taught how to parent a young person with a chronic illness, or a chronic condition, and it's just such a crazy dynamic that I don't think anyone's really prepared for. [P11]

Challenges related to the healthcare system

Diabetes specialists felt that the healthcare system does not accommodate the needs of people with type 1 diabetes and disordered eating. The rigid framework makes it difficult to retain continuity and does not allow for the increased time demands of complex patients.

... the vast majority of diabetes appointments are done probably by a person who you're never going to see again, because 50% are done by registrars. [P14]

It's no good saying, 'I'm going to have five minutes with this patient because that's what I'm allowed, so five minutes and that's the end.' [P04]

While the aim of clinical targets is for patients to have a healthy weight and HbA_{1c} concentration, diabetes specialists felt that they needed more flexibility in their targets to help in the recovery of people with type 1 diabetes and disordered eating.

... [People are told] 'The A1c is 7.5 [%] -- make it better,' and no-one's really given the tools to make it better and the only way people can find to make it better is by carb-restricting. [P01]

... the agenda of the healthcare professional is so diametrically opposite to the patient agenda [...] your consultation is focused around a short negotiation around, 'Take one, or two, or three,' [...] how much insulin can I convince this patient to take? [P01]

... we are a diabetes service, and we are supposed to be delivering better diabetes outcomes [...] you're not going to take someone who has got a really significant eating disorder and suddenly find that, you know, they will suddenly accept a BMI of 25 in order to get an HbA1c of 6.9[%]. [P04]

Both specialist groups found it difficult to collaborate with one another to support patients without a defined collaborative care pathway. This often leads people with type 1 diabetes and disordered eating to be passed from one team to another and to be given conflicting advice.

You meet a patient who is trying accept and come to terms with two potentially long-term illnesses that are very, very interlinked, and they can be given advice from two different services which sometimes can make things a little bit worse and more complicated for them. [P19]

... the management of diabetes is very detail-focused [...], whereas actually we want to try and look at the much wider, bigger picture and not focus on the details. So, they're almost, sort of, at opposite ends to each other. [P26]

Lastly, eating disorder specialists identified challenges of having a person with type 1 diabetes in their inpatient service, such as this person having different needs from the other patients, feeling isolated from other patients, and not having the right support in their service.

... sometimes the pathology is quite similar to a, kind of, classic anorexia nervosa, sometimes it's quite different, and actually wouldn't sit that well on our ward here with the other patients we've got. [P20]

Strategies for treating people with type 1 diabetes and disordered eating

When identifying strategies for treating people with type 1 diabetes and disordered eating, two main themes emerged (Fig.1b); these are set out below.

Need for training and resources for the basics of understanding diabetes and eating disorders

Healthcare professionals in both specialties suggested that specific diagnostic criteria in addition to screening questions to identify people with diabetes at risk of developing an eating disorder were needed.

... we like to treat our people as individuals, but maybe it is helpful to have a sense of who's vulnerable, actually, in quite a scientific way rather than [...] just form a, kind of, vague impression. [P03]

...when they're either losing weight, [...] struggling to stabilize their blood sugars, [or] having frequent hospital admissions. [P19]

I'd like to have just the right questions to ask in the first place. [P12]

Healthcare professionals identified a need for biomedical measures to help them stratify their patient's risk, but they were unsure how to assess these without distressing their patients.

... maybe it's just about putting it in red and green, or red, amber, green without having a number on it. [P01]

If you're going to make food intake one of your measurements, is that something that you do or do not want to focus on with these patients? [P04]

Healthcare professionals wanted algorithms to follow and access to other specialists who have had similar experiences to look for guidance in making treatment decisions.

I think we need various strategies, and maybe a flowchart, something that says, 'If you've got a yes answer to this, do that.' [P09]

Lastly, healthcare professionals identified specific skillsets that would help them treat this group more effectively and confidently. Eating disorder and mental health specialists wished for education on carbohydrate counting and understanding type 1 diabetes management, while diabetes specialists expressed a need for training in psychological skills and therapeutic techniques.

... it's really difficult when we're signing off, saying that someone's administering the right amount of insulin when they're saying, 'This is the number of carbs we've had,' when the meal plan says that it's a different number. [P25]

...[education] about what the different eating disorders are, because I'm going to have to identify them as well, but I don't necessarily have the basics on what the different disorders or disordered behaviour might be. [P08]

Strategies healthcare professionals have used successfully

The healthcare professionals repeatedly emphasized the advantages of multidisciplinary clinics allowing both aspects of the patient's care to be addressed at once, whilst complementing each other's skillsets and improving competencies. Clear communication between teams created unity in the messages patients were given and the information available to the healthcare professionals..

... adding into eating disorder therapy but with [...] add-ons that are specific to diabetes care. [P15]

It's also allowed us to learn more about how you can talk, and how you can open up things [...] I'm not that scared to open up that can of worms because there is somewhere to go if you find something. [P02]

Creating individualized care plans collaboratively with the patient was a key strategy for healthcare professionals. Healthcare professionals felt that it was important to implement flexibility with

standard approaches to diabetes management, such as carbohydrate counting and the use of technology. Small practical adjustments like using different injection techniques or working with an occupational therapist to make changes in real-world settings can be included in these care plans.

... sometimes, you actually do have to go really simple and just go back into fixed dosing on a very basic, basic diabetes level which again feels very counter-intuitive, but has worked. [P002]

... [Our patients] very much valued staff being able to initially go out, and then taken those slow steps back and enabling them to do that independently. [P026]

Having an open, communicative relationship was the most consistent strategy that allowed diabetes specialists to both diagnose and treat people with type 1 diabetes and disordered eating. Ensuring their interactions were non-judgemental and their patients felt comfortable sharing their experiences and behaviours encouraged patients to come back once they felt ready to engage in therapy and seeing the same patients consistently were key to building this trusting relationship.

...being as open as possible, and letting them know that it's okay to say whatever it is they need to say [...] and building on that until you can then stop and have the really difficult conversations. [P02]

... initially when they come to us they bring their monitor, their meter, and they stick it on the desk, it's there to download and I'm, like, 'Whoa, hang on a minute, we're not ready for that yet. How about you? What are you doing? How's life been treating you? [P09]

Eating disorder specialists identified helpful treatment strategies from established therapies. Using food or event journals, facilitating self-discovery, and addressing emotions such as isolation or grief, are elements from cognitive behavioural therapy, commitment and acceptance therapy, and dialectical behavioural therapy.

... acknowledging a lot of the distress around, you know, what might happen if you do take your insulin diligently, and how do you cope with that? [P11]

... in some ways it's a bit like bereavement work, that whole sense of their life's never going to be the same [after the diagnosis of type 1 diabetes]. [P26]

When setting goals with patients, taking small and achievable steps was essential for success.

Achieving smaller goals led patients to begin taking small, healthy risks in confronting their fears around recovery.

...they, sort of, go from, 'Oh, I'm not going to do any of the blood glucose measurements,' to, 'I want to do four blood glucose measurements a day,' [...] I'd say, 'Let's be realistic, I know you really want to do four, but I want to bring you back'. [P11]

... try and work out where the motivation lies, and saying, 'What is it? What sort of change can you possibly make at this moment in time?' and making those small steps. [P26]

Discussion

This focus group study with healthcare teams in tertiary diabetes and eating disorders services examined the challenges healthcare teams faced when treating people with type 1 diabetes and disordered eating and the strategies they developed to facilitate treatment.

Challenges were found in relation to the healthcare professionals' training and education, the lack of consensus on what defines disordered eating in type 1 diabetes, and lack of established evidence-based clinical guidelines and algorithms. They also identified patient-specific factors and broader healthcare system challenges.

Strategies for treating disordered eating included specific training for healthcare professionals in addition to multidisciplinary and patient-individualized approaches. Collaboration between diabetes and mental health specialists was key for increasing the confidence and competence of both teams. Having an open relationship with patients was helpful in building trust and ensuring patients had a positive experience and were willing to engage in treatment.

Current National Institute for Health and Care Excellence (NICE) guidance on treating eating disorders with comorbid diabetes emphasizes a team care approach [14,15], but does not include consensus on how to define and diagnose disordered eating in a person with diabetes, or clinical pathways or standardized treatment strategies. International guidelines for eating disorders are similarly limited in their classification of disordered eating in type 1 diabetes: although the *Diagnostic and Statistical Manual of Mental Disorders, 5th edition*, includes insulin manipulation as a diagnostic criterion for anorexia nervosa and bulimia nervosa [16], the International Classification of Diseases, 11th revision, does not include any diabetes-related diagnostic criteria in its categorization of eating disorders [17]. Unsurprisingly, healthcare teams are struggling with the basics of this dual diagnosis despite working in highly specialized tertiary centres. Clear classification guidance is the first essential step in removing one of the largest challenges for healthcare professionals to diagnose and treat people with type 1 diabetes and disordered eating.

The strategies for treatment expressed by healthcare teams consistently echo the need for an interdisciplinary care model with shared expertise across diabetes and mental health disciplines [8,9]. Physical and mental health have been successfully integrated in a number of care settings for patients with chronic liver disease and mental health comorbidities, improving treatment adherence and clinical outcomes, and reducing the stigma of mental healthcare [18]. Working closely on shared goals also has benefits for healthcare professionals including higher satisfaction, higher efficiency, and lower risk of burnout when treating chronic conditions [19]. Healthcare teams also expressed the need for supervision to confidentially debrief and reflect on their practice, whilst developing competencies [20].

Healthcare professionals in this study expressed a need for greater understanding of the risk factors associated with type 1 diabetes and disordered eating and more guidance on how to tailor treatment to individuals. Patient personality traits (e.g. perfectionism) were identified as a challenge by healthcare professionals. The role of perfectionism in eating disorder aetiology and maintenance in patient groups without diabetes has been firmly established [21,22], and eating disorder interventions tailored to perfectionistic personalities have been developed, focusing on increasing flexibility, reducing rigidity, and minimizing focus on food [23]. This suggests that strategies such as food diaries/smartphone apps or an over-focus on meals and insulin doses could be detrimental for people with type 1 diabetes and high perfectionism in eating disorder treatment. Difficulties with self-regulation and insight (e.g. impulsive behaviour and lack of awareness or consideration of long-term consequences) were also significant challenges in this group. These difficulties are characteristic of the adolescent and young adult period, during which higher-order cognitive and emotional functioning are still developing [24]. This developmental context, coinciding with the challenges related to diabetes management, can create a significant burden for patients [25] and a clinical dilemma for healthcare professionals. Although preliminary research has begun to address this [26,27], there is a need for further research on the cognitive and developmental risk factors for disordered eating in type 1 diabetes. This could assist in identifying vulnerable individuals and developing treatment approaches tailored for the individual's cognitive and emotional capacity.

A major limitation of the present study is that the sample of healthcare professionals in this study will not be representative of all clinical teams and workplaces in and outside the UK. We deliberately chose the tertiary centres to learn from teams who have had the greatest exposure to providing care for people with type 1 diabetes and disordered eating.

A major strength of the present study is that these findings will directly feed into the development of the STEADY intervention, and healthcare professionals who took part in the present study have been invited to the co-design process. More broadly, these findings may help to inform future care pathways, screening tools, and diagnostic criteria for people with type 1 diabetes and eating disorders.

In conclusion, the most fundamental challenge for healthcare professionals treating disordered eating in type 1 diabetes is the lack of specific diagnostic criteria and evidence-based clinical guidance, screening and assessment tools, training, and interdisciplinary support.

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Competing interests

None declared.

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Table 1 Participant characteristics

Participant ID	Clinical area	Role	Years in profession
P001	Diabetes	Diabetes consultant	20
P002	Diabetes	Diabetes consultant	23
P003	Diabetes	Diabetes consultant	20
P004	Diabetes	Diabetes consultant	40
P005	Diabetes	Diabetes specialist nurse	8
P006	Diabetes	Diabetes specialist nurse	20
P007	Diabetes	Diabetes specialist nurse	15
P008	Diabetes	Diabetes specialist nurse	32
P009	Diabetes	Diabetes specialist nurse -- transition clinic	39
P010	Diabetes	Diabetes research nurse	5
P011	Diabetes	Diabetes dietitian	8
P012	Diabetes	Diabetes dietitian	29
P013	Diabetes	Other diabetes specialist	11
P014	Diabetes	Diabetes specialist (other)	10
P015	Eating disorders	Clinical psychologist	15
P016	Eating disorders	Clinical psychologist	4
P017	Eating disorders	Clinical psychologist	8
P018	Eating disorders	Consultant psychiatrist	23
P019	Eating disorders	Consultant psychiatrist	11
P020	Eating disorders	Outpatient consultant	12
P021	Eating disorders	Eating disorder specialist nurse	40
P022	Eating disorders	Mental health nurse	6.5
P023	Eating disorders	Mental health nurse	2
P024	Eating disorders	Mental health nurse/CAT psychotherapist	17
P025	Eating disorders	Charge nurse in Eating Disorder Service	6
P026	Eating disorders	Specialist physical health nurse	30
P027	Eating disorders	Assistant psychologist	2

P028	Eating disorders	Assistant psychologist	1.5
P029	Eating disorders	Occupational therapist	2

CAT, cognitive analytical therapy.

FIGURE 1 Themes and subthemes of (a) challenges and (b) strategies in delivering care to people with type 1 diabetes and disordered eating. ED, eating disorder; HCP, healthcare professional.

Figure 1A

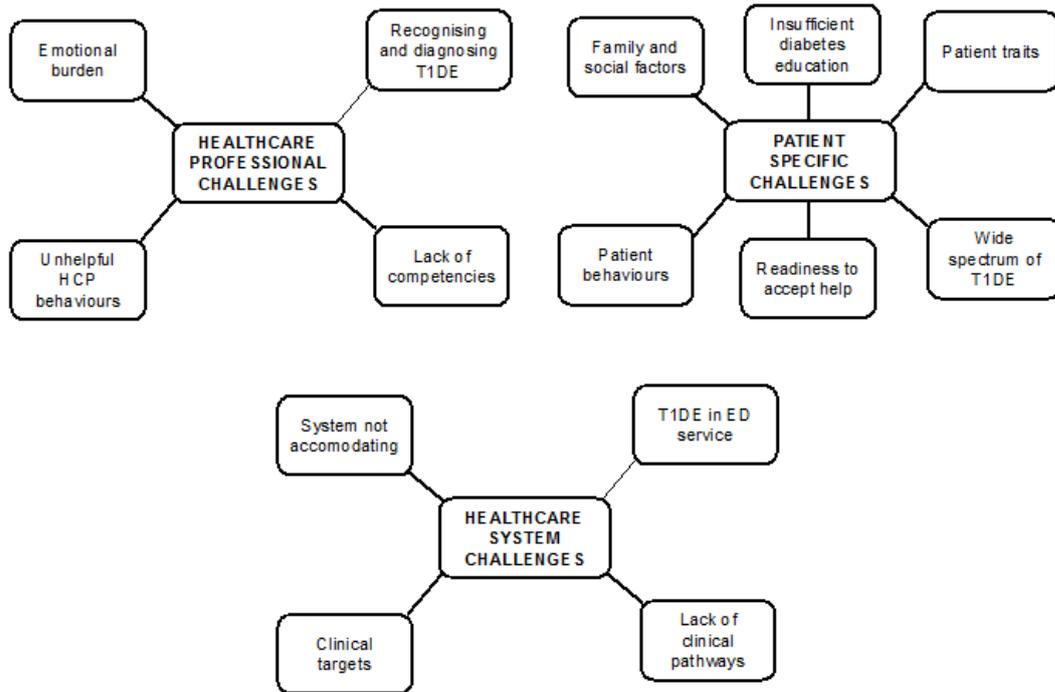


Figure 1B

