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RESEARCH ARTICLE

Parenting a child with 'Diabulimia': A systemic interpretative phenomenological analysis

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Abstract

The aim of this paper is to examine the experiences and views of parents whose child lived with type 1 diabetes (T1DM) and eating disorder (ED), specifically 'diabulimia' and the professional support offered to them. Interpretative phenomenological analysis (IPA) was employed as a methodology to explore the experience of three parents (mothers) living in the United Kingdom, regarding their chronically ill children. Four themes emerged from the analysis: battling, blaming, surviving and loss. These were interpreted through the lens of systemic theory. Within the framework of the results and the discussion, further research and the provision of systemic family therapy for children, parents and families in both paediatric and adolescent-to-adult transition diabetes clinics is recommended.

KEYWORDS

adolescent-to-adult transition, diabulimia, eating disorder (ED), parenting, systemic family therapy, type 1 and eating disorder (T1ED), type one diabetes (T1DM)

INTRODUCTION

More than a quarter of people with type 1 diabetes (T1DM) also have an eating disorder – a statistic higher than that of the non-diabetic population (Troncone et al., 2022). Standard eating disorder (ED) treatments for this population offer disappointing results (Staite et al., 2018).

If you would like to share ideas about the article, or how we might enable change, please contact Fiona at fiona.kennon68@gmail.com.

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Practitioner points

- A high proportion of females living with T1DM will also experience an ED; morbidity in this population is extremely high.
- Understanding T1DM and its implications relating to ED is important for practitioners in supporting management and recovery.
- Systemic support to enable families to explore their relationships and responses to diabulimia is recommended within diabetes clinics.
- Further research into how families experience the support offered is recommended.

Complications associated with poorly managed diabetes are wide-ranging and potentially fatal (Larrañaga et al., 2011). Existing literature suggests that the support for families is crucial in management and recovery from this complex co-existing condition (Lock et al., 2010; Schmidt & Treasure, 2006).

Type 1 diabetes (T1DM) is an illness which results from the body's inability to produce insulin, a hormone necessary for the regulation of blood glucose levels (Akil et al., 2021). T1DM is managed by injecting insulin. Poorly regulated blood glucose levels can have a devastating impact on quality of life and lead to premature death (Larrañaga et al., 2011). EDs are complex mental health conditions affecting people of any age and gender and are still little understood (Bullivant et al., 2020). Studies suggest that individuals with an ED, particularly with anorexia nervosa, are at a significantly higher risk of early death (Arcelus et al., 2011). Young women with a diagnosis of T1DM are two and a half times more likely than their non-diabetic peers to develop an ED and are at higher risk of relapse (Colton et al., 2015). T1ED and 'diabulimia' are not the same thing; T1ED is the term for living with type 1 and any type of ED, whereas 'diabulimia' is used for the intentional omission of insulin to lose weight (Coleman & Caswell, 2020). This term encompasses the morbid fear of injecting insulin due to its weight-gaining impact. Any eating disorder carries the possibility of potentially fatal consequences; however, the researchers' specific interest was in the potential afforded by being able to omit insulin to lose weight because only people living with T1DM have this opportunity. Despite the prevalence and repercussions of 'diabulimia', it is not yet recognised in either the International Classification of Diseases 11th Revision [ICD-11; World Health Organisation (WHO), 2022] or the Diagnostic and Statistical Manual Version 5 [DSM-5; American Psychiatric Association (APA), 2013]. Moreover, little specialised help is available to treat both T1DM and ED together, yet evidence shows that this joint understanding is crucial to successful treatment (Bermudez et al., 2009).

Over the last twenty-five years, research has explored the concept of 'diabetes distress' (Strandberg et al., 2014, 2015) and, more recently, an understanding that distress can lead to diabetes burnout (Abdoli et al., 2020). Systemic therapy has been evidenced as effective in the management of T1DM (Carr, 2019) and is the first line of treatment recommended for children and young people living with both anorexia and bulimia [National Institute for Health and Care Excellence (NICE), 2017]. Throughout the guidelines, it is recommended that support be offered to families.

Despite the lack of literature on T1ED, the literature search offered three main themes. First to be highlighted is the importance of a multi-disciplinary team (MDT) treatment approach, with professionals holding a joint understanding of T1DM and ED (Staite et al., 2018). Second, family

involvement in treatment is mentioned in every article, including a review of the perspectives that clients and healthcare professionals have regarding treatment models (Macdonald et al., 2017). Family involvement is deemed equally crucial in inpatient treatment (Dickens et al., 2014). Third, several studies went a step further, eschewing conventional ED treatment in favour of specific interventions tailored to T1ED (Treasure et al., 2015), with Romi and Kowen (2006) advocating early intervention in supporting families living with T1DM before the advent of an ED. However, before highlighting what support might look like, it is important to understand the experiences of families encountering this co-existing condition, which is where this project is positioned. A complete lack of existing literature on parental experiences of T1ED generated the focus of the research project.

An ontological position that there is no single reality, and that meaning is created through the social interactions of language, family and culture (Hoffman, 1990), offers the lens of social constructionism to this research. A postmodern epistemology, accentuating the co-existence of multiple realities (Burr, 2003), suggests that qualitative research is more suited to the aims of a systemic thinker. Qualitative research examines reality from different perspectives and seeks to understand the context by considering gender, culture, spirituality and other Social GRRAACCEESS[1] (Burnham et al., 2008). The question 'what is it like?' is an invitation to explore subjective experience, which Burck (2005) describes as pertinent to systemic family therapy. Systemic therapy is influenced by Milan's ideas of curiosity and circularity (Cecchin, 1987; Selvini et al., 1980), exploring and drawing on the resources of the whole system to help effect change. Systemic therapy also acknowledges the individual as 'the expert in their own life' (Anderson & Goolishian, 1992). It seeks change at the level of meaning and understanding, rather than simply at the level of behaviour (Hoffman, 1981). Research states that this second-order change is longer lasting (Levy, 1986). When considering the cost to the National Health Service (NHS) of diabetes-related complications, sustained change is critical (Alderwick et al., 2015).

In summary, to develop effective family interventions for this population, to lower the risks of associated complications and early death, it is important to first understand the experiences of family. The research project's aims were to understand the lived experiences of the mothers and learn of the professional support offered. It was hoped that the study would offer 'Outside Witnessing' (White & Epston, 1990) in relation to the experiences of parents living with diabulimia.

METHOD

A descriptive study was conducted using interpretative phenomenological analysis (IPA; Larkin & Thompson, 2012; Smith et al., 2009). IPA privileges examining the meaning of lived experience (Van Manen, 1997) by asking what happens when the everyday flow of life takes on a particular significance for a person(s). IPA enables researchers to attend to and privilege the participants' experiences of the phenomena, whilst acknowledging the researcher's position in interpreting the data (Duffy et al., 2023).

Ethical approval was received from the University of Derby. Participants and their children provided consent, although the latter group were not interviewed.

[1]GRRAACCEESS: gender, race, religion, age, ability, class, culture, education, ethnicity, spirituality and sexuality.

Researcher reflexivity and positionality

It is important, within IPA and in line with systemic research, to consider the person of the researcher(s), and how their positioning may impact the analysis of the data. Both authors were involved in this research. FK, the lead researcher and first author, planned and undertook the project, including data collection and analysis. The second author (GR) acted as research supervisor. FK has lived with T1DM since childhood and, as a white British woman, has been privileged to receive excellent healthcare and support. She became curious about the number of people with T1DM she encountered being admitted to the ED unit where she worked as a systemic practitioner. This led her to volunteer with charities and other special interest groups to support those impacted by this co-existing presentation. As a parent she wondered what it might be like for those living within the T1DM/T1ED family system without being directly able to manage it, and she saw a need for support for families. Qualitative research is an interactive process (McDowell, 2011); therefore, it was deemed important for participants to understand the lead researcher's context of living with T1DM, but not with ED. The research project was developed from a desire to both acknowledge the lived experiences of the lead researcher whilst privileging the lived experience of the participants.

Context and participants

Participants were recruited through the UK charity Diabetics with Eating Disorders. This small charity uses social media to offer support to people living with T1ED, families and friends and researchers. Diabetics with Eating Disorders acted as gatekeepers for the research by posting ethical approval for the study on the Facebook page and connecting interested participants with the researcher. Inclusion criteria were met if the child of participants was at least two years recovered, this being the protocol for both Beat, a UK Eating Disorders Charity, and Diabetics with Eating Disorders when recruiting ‘experts by experience’. Three mothers came forward to participate; none were known to the researchers before the study took place. Interviews were conducted in the homes of each participant, to which the main researcher was invited.

Data collection

A semi-structured interview (Reid et al., 2005) was developed on the basis of hypotheses held by the lead researcher, and therapeutic conversations with families in the researcher's work context. The interview schedule is shown in Table 1. Participants were given pseudonyms to ensure confidentiality and are introduced in Table 2.

Analysis of the data

Data were transcribed using software and listened to for accuracy (Davidson, 2009), and analysis was undertaken following the step-by-step process detailed by Larkin and Thompson (2012). The interviews were analysed, emerging themes were listed (Smith et al., 2009) and four superordinate themes were identified.

TABLE 1 Semi-structure interview schedule.

1. What might you want people to know about being a parent of a child with T1ED?
   - What was it like for you?
   - How did it affect your everyday life?
2. How did you experience help?
   - What approaches worked and didn't work for you in professional contexts?
3. Tell me a little about how this impacted on your relationships with wider family and friends.
4. Can you tell me a little about how Diabetics with Eating Disorders figured in this?
5. What about present day?
   - Would you say you have started to recover from this?
   - What's that been like?
6. Can you tell me a little about the sorts of things that helped you get through the experience?

TABLE 2 Participants' characteristics.

Participant name and ethnicity (marital status)	Child name, gender, age at T1DM diagnosis and ethnicity	Nuclear family details	Diabetes context at time of study
1. Katie, white British (single parent)	Tia, female, 12 years old at diagnosis of T1, white British	Tia, the eldest of three children, has younger brother and sister	In recovery from 'diabulimia' for five years
2. Ruth, white British (married to Gerry)	Susie, female, 8 months old at diagnosis of T1, white British	Susie, younger of two daughters of Ruth and Gerry	In recovery from 'diabulimia' for four years
3. Wendy, white British (married to Sunbeam)	Rob, male, 8 months old at diagnosis of T1, white British	Rob, middle child of three, has older brother and younger sister; brother and Sunbeam (dad) also have T1	Died at age of 21 years of 'diabulimia' ten years ago

Ensuring trustworthiness and reliability

Following transcription of the data, transcripts were returned to each participant for verification and to ensure validity (Mero-Jaffe, 2011). No inaccuracies or corrections were reported. In choosing a phenomenological methodology, the researcher explicitly aimed to 'give voice' to the participants. In IPA this is achieved through the use of confirmed verbatim extracts from transcripts within the analysis (Brocki & Wearden, 2006). A reflective journal was used by the lead researcher (Alsaigh & Coyne, 2021). This was considered with the research supervisor within the analysis of the data. The data and analysis were also explored by a 'critical friend' (Smith & Sparkes, 2006) as a further independent audit (Smith et al., 2009) of the emergent and superordinate themes. Further peer review in relation to the project was achieved through sharing aspects of the research with systemic colleagues (Kennon, 2020).

FINDINGS

Four major themes emerged from the research: battling, blaming, surviving and loss. The superordinate and emergent themes are presented in Table 3.

Battling

The nouns used by the participants to describe their experiences recalled stories of combat: 'trauma', 'fight', 'battle', 'conflict' and 'carnage'. No one knew where to turn for support, and it was not always clear who was on whose side.

> You're not just fighting the system; you're fighting everybody else as well.
>
> (Katie)

> But Gerry hacked into their system and found ... well this is what you have to do.
>
> (Ruth)

> The nurses and doctors were against me from that moment.
>
> (Wendy)

All participants described battling for a hospital bed for their child, for support and to be heard. This included Katie's experience of being taken seriously.

> I would spend hours at A&E, hours and hours and hours ... trying to get her admitted. I mean, thankfully her consultant was really good. He was understanding.
>
> (Katie)

Whether this was a consultant who understood 'diabulimia' or a consultant who empathised with Katie, or both, his approach and the value of 'understanding' seemed important.

TABLE 3 Super-ordinate and emergent themes.

Super-ordinate themes	Emergent themes
Battling	Battling without clearbattle lines
	Battling the hidden
	Battling for understanding
	Battling on beyond
Blaming	Are mothers to blame?
	Am I to blame?
	Who is to blame?
	The fault lies here
Surviving	Survival of their child
	Survival of themselves
	Survival in the moment andbeyond
	Diabetics with Eating Disorders
Loss	Shared loss
	Individual loss: Katie
	Individual loss: Ruth
	Individual loss: Wendy

Fighting to make sense of what was happening was a strong theme for all three participants. Seeking professional help was not straightforward and resulted in all three having to beg, argue or complain. This seemed to lead to fractures in trust in relationships with professionals. All participants described feeling frustrated to encounter a lack of a joined-up approach when seeking help from diabetes and/or mental health experts.

> You go to the diabetes people, and they say, 'we don't do mental health'; you go to the mental health people and they say, 'we don't do diabetes'.
>
> (Ruth)

For all the participants and their families, what happened had a lasting impact:

> I was suicidal, definitely, for a long time. There were points where I would just sit and think 'If I just get in this car, now, and drive... I don't have to think about it anymore'. And I felt like that for many, many years because you're screaming for help and there's no help.
>
> (Katie)

Death was ever-present for all three participants, who described battling then and since to educate others and to stop the deaths.

> I'm angry with the coroner ... if he had said there were mistakes made in mental health, there have been two more people that I know since Rob died, that have died in this county, at least two, because of the type one diabetes and what was possibly an eating disorder.
>
> (Wendy)

> I said 'I'm on a ticking clock with my daughter. If I don't get help with the fact she's not taking her insulin, she's going to die'.
>
> (Ruth)

For Katie the ripples of the trauma appeared to reach everyone near to her. She was able to affirm Tia's 'amazing' journey of recovery while acknowledging that she and her other children had been left traumatised. Ruth was quite pragmatic in learning to live with uncertainty, believing this to be their ongoing situation. Wendy's battle had a different ending because of Rob's death.

Blaming

Blame was something all participants described experiencing. They all spoke of their parenting coming under scrutiny from outside and from within. Helplessness and a lack of understanding of the connection between disordered eating and diabetes seemed to position everyone, possibly contributing to the strong narrative of blame, voiced and unvoiced. This included professionals, parents and patients. The blame each mother felt and accepted differed. Katie 'refused to accept' the blame she felt was levelled at her. Ruth had a strong story that she, as Susie's mother, was held to blame. This seemed to connect with her training as

a psychiatric social worker and her experience of being responsible for an 8-month-old with T1DM:

> I mean, I remember them saying on the social work course things like: schizophrenia was caused by mothers who were ambivalent towards their children; autism was caused by refrigerator mothers – which is a really horrible terminology isn't it? And at the time when I was doing my training, I was only 18, and I thought 'That's complete crap!'.
>
> (Ruth)

Ruth and Katie recognised that they were not to blame for what was happening, yet there remained a part of all three mothers which sought absolution. In Ruth's case, this came when she attended a course at the hospital where her daughter was an inpatient.

> Then what you realised was they were just mums and dads like us, who'd all had to fight so hard and there was nothing wrong with them as parents.
>
> (Ruth)

For Wendy, even after Rob's death, she wanted to understand:

> That's all I ever wanted was the truth. If any mistakes had been made by them or by me. I wanted to know. Apart from the fact that they blamed me because I was his mother and I was the only one, you know, that could have put it right.
>
> (Wendy)

A lack of depth of understanding from professionals and family members often led to blame of the young person.

> My father said, and he had always said, he should be looking after himself and he couldn't see a problem. He didn't see all the carbohydrates, the everything that went into diabetes, and he was cross with Rob.
>
> (Wendy)

> It was the same response: 'Why are you doing this to yourself?' There was no one saying 'this is happening, how do we work together as a team?' I had to go to one clinic for one thing, one clinic for another and I got the same response: 'Yeah, but why are you doing this, Tia?'.
>
> (Katie)

Surviving

Each participant spoke of a constant fear of finding their child dead:

> I just remember having to stop my son ever going into her bedroom, because I didn't want him to find her dead. And I never knew whether that was going to happen or not, because it was so close all the time.
>
> (Katie)

> If it wasn't for Diabetics with Eating Disorders, my child would be dead, and probably me.
>
> (Katie)

> You can't leave her at home in case she kills herself.
>
> (Ruth)

Ruth's comment, offered in a very matter-of-fact tone, suggested the reality of everyday life with 'diabulimia' and how acclimatised she and Gerry had become to the situation.

Participants all developed ways to carry on, and for each of the mothers, value seemed to be associated with any acknowledgement that they were doing their best. For Ruth, this took the form of validation from staff in one of the inpatient wards where Susie was. Ruth's description of this seemingly different experience was delivered in a tone that suggested she was surprised at its importance:

> This was the first time anybody had ever said anything nice to me. And this nurse said 'Susie's mum's here. She must have a chair'. And they spoke to you like you actually were somebody of value.
>
> (Ruth)

Katie said she often returns to a conversation she had with Tia about the possibility of Tia's death. Katie struggled to make sense of even having to have that sort of conversation with her child, yet still valued its honesty, perhaps accepting that this was all she could have:

> It's the hardest conversation in the world to have with your child but I had to have it, and I said to her 'Has there been anything else that I could have done to save you or to make this better or done differently, to make you change your mind and fight to get better?' And she took my hand and said 'Mum, there's absolutely nothing that you can do.' And I said to her 'You know that, uhm, if you die, that, because it will happen, because there's no other way round it, you know', ... 'You know that I love you ... uhm ... and there will be a part of me that'll die with you' [tears]. 'But I have to, I have to do this for them, you know'. And she said, 'I get it, I understand it'. And I said 'So, can you just, can you just give that back to me, that I've done everything I can', you know. Because I thought, if she dies, I need to know, because that's the depths it takes you.
>
> (Katie)

Wendy found validation primarily after Rob's death from her involvement with Diabetics with Eating Disorders. Her conversations with others from the charity seemed to allow her to find a level of closure from the guilt she described:

> I will always live with guilt. It has made such a difference because I, I was talking to young women that could relate to Rob's feelings, I could find out how my child had felt. That helped me so much. To be aware that there was probably nothing I could have done to help.
>
> (Wendy)

Although Ruth and Katie were able to speak of their daughters' recovery, both rejected the word recovery for themselves. 'I don't think you ever do recover, really' (Ruth). Spirituality was

a support for all three mothers, and the connection to a broader world seemed to offer hope. For Ruth, daily meditations from Stoic philosophy along with her Christian faith helped her accept she could only control her own approach. Wendy described finding the courage to visit a medium where Rob 'came forward'. Katie openly bargained with God in St. Paul's Cathedral, before Tia's operation to try to restore her sight.

Humour also helped the mothers through and beyond. Ruth and Katie made sense of needing to connect to the absurd to stay grounded both then and now. Today Wendy held onto little things to remember Rob.

> Somebody came up behind me and did this [put their hands over her eyes] and said, 'Guess who?' and kept their hands there for a long time and I put my hands, 'cos I knew it was Rob. And it's funny because after, since his death that has been such a comfort to me to remember that.
>
> (Wendy)

Loss

> We buried her and there was about four others from diabetics with eating disorders after that .... We buried a lot.
>
> (Katie)

There were many similarities in each participant's experiences of loss. All the participants spoke of at least one relationship within the wider family which suffered, of losing confidence in the system, of the loss of current and future hopes and a loss of trust.

There were examples from all three mothers of their belief that the system had let them and their children down. Wendy spoke of only discovering that the local mental health team had withdrawn Rob's promised support on the day he died, and yet 'I trusted them'. Ruth's anxiety was raised with every admission Susie had. The lack of understanding from ED teams about Susie's diabetes seemed to be a particular worry for her. Everyone spoke about the loss of what they might have expected normal life to be like for both them and their other children.

> I would spend hours at A&E ... We would have to take [10-year-old] E with me, this poor little boy, sitting in a bucket seat late at night, you know, for another episode. And he lost his childhood.
>
> (Katie)

> I don't know who Rob's sister Kim might have been. She changed her mind about going into the Royal Navy when Rob died. She gave up her chance for a good career and Sunbeam felt that very strongly because he'd always wanted to go into the Royal Navy but had been diagnosed with diabetes just before he was due to go in. So he felt that very strongly. And because his father was in the Royal Navy, my father was in the Merchant Navy, so my father felt it strongly.
>
> (Wendy)

It seemed to the mothers that their expert knowledge of parenting their child was often dismissed or lost. Similar to Wendy with Rob, Ruth had managed Susie's diabetes since the age of

8 months, but her expert parenting seemed to contribute to her anxieties at times when faced with professional expert knowledge.

> I said 'Oh, can you liaise with the diabetes unit as to how the diabetes is managed?' And he said 'No, no we don't need to do that. We have our own doctor here'. And I said, 'But is that person a diabetes specialist?' And he said 'No, we don't need a diabetes specialist. We can manage the diabetes here'. Well of course, my anxiety is rising.
>
> (Ruth)

Katie told of her self-sufficiency in providing a home for her children, wanting to have a career and a pension. She had started to invest in new relationships. All of this appeared to collapse around her in the face of diabulimia. 'Just living' became her highest context marker. She held a view that, although Tia had now recovered, much was lost in the process:

> All my children are on antidepressants; I'm on antidepressants. That didn't come from nowhere. You know, the trauma, the rippling ...
>
> (Katie)

Keeping Susie alive was Ruth's highest context marker, as one problem overtook the next. Smoking, drinking, missing school and self-harming – all these things seemed to take on a different meaning when they were put in the context of Susie's health:

> It was almost like everything that came along could then get supplanted by a worse problem. So things that would bother other people ... I thought 'well actually that doesn't matter' because the health's more important ... and Gerry was the same. Our one thing was the health, we didn't care what got thrown up, it was the health.
>
> (Ruth)

In Wendy's story, the fear expressed by all three mothers was realised. What could prepare her for the death of her son? It felt as though she lived on the edge of that fear for so long until 'they told us'. Wendy described the ripples of Rob's death. Not only was she trying to grieve for her son, but she also mourned with her other children in their grief:

> How could my 23-year-old son and my 19-year-old daughter just have to see their brother like that? How could they see their brother dead?.
>
> (Wendy)

Although Susie and Tia were still alive, no happy endings were anticipated:

> Well, we've changed. We won't ever be the same people again, ever. It's ... none of us.
>
> (Wendy)

DISCUSSION

In this study the views and experiences of parents of children with diabulimia were explored and analysed. This discussion further explores each of the four super-ordinate themes which

emerged and considers conclusions in relation to children, parents and families living with diabulimia. Limitations of the study, implications for professionals and recommendations for further research and service provision are highlighted.

Battling

A main theme was that of battling, which encompassed the battle for professionals to understand and offer appropriate help in both acute and outpatient services. It is important to recognise that, while the measure of severity of ED in the United Kingdom remains body mass index (BMI), people living with T1DM are on average slightly heavier that non-diabetic peers (Domargård et al., 2007), suggesting that it can be more difficult to recognise how unwell those living with T1ED are, and for them to access ED treatment.

Diabetes literature was recognising this concern as early as 1989 (Steel et al., 1989), yet there still remains no formal recognition of the problem with a name. Similarly, the scale of the problem and its dangers are only anecdotally recognised. With over sixty per cent of females with T1DM meeting the criteria for a diagnosable ED by the age of 25 years, the problem is in urgent need of recognition (Colton et al., 2015). New nomenclature for this co-existing condition was recommended by a focus group in 2008 (Colton et al., 2009); however, this is still to be implemented in a way which allows all medical professionals to have a frame of reference. NICE (2017) guidelines stipulate a joined-up approach in managing any eating difficulties in T1DM; however, the mothers in this study struggled to find any meaningful support.

Blaming

A lack of recognition and appreciation of 'diabulimia' led to the mothers having to explain the dilemma to professionals, often in an urgent care setting, while managing their own immediate fears about their child's health. A mixed response was experienced from medical teams, and this was often felt by the mothers to be blaming of them or their child, or both. Parents who had managed their child's T1DM since diagnosis in babyhood felt displaced or excluded from being part of the system of support. Diabetes is a family disease (Anderson et al., 1981), and it is recommended that families are enlisted as support early in treatment (Carr, 2019; Dickens et al., 2014; Jewell et al., 2016). Family therapy is recommended by NICE (2017) as front-line treatment for ED, but there remains no requirement for families to be considered in the treatment of T1ED.

Much is now understood about the psychological burden of 'diabetes distress' (Dennick et al., 2017). Recognition that, by 'doing with' rather than 'doing to', health professionals can support optimum results in their patients living with T1DM (Skinner et al., 2019). The blaming which the mothers in this study described encountering might have been less had they experienced professionals understanding the pressures of living with T1DM. Current societal narratives often confuse type 1 and type 2 diabetes, or do not distinguish between them. Lack of understanding of the difference, combined with societal stigma, can add to the blame many with T1DM experience (Browne et al., 2014).

Surviving

An important theme for participants was survival. Mothers were focused on keeping their child alive at all costs, with other important occurrences often taking a back seat. Katie reported that both she and her other two children were on anti-depressant medication following the experiences of living with 'diabulimia'. The reality of their child not waking up in the morning was ever-present, and two of the three participants forbade siblings from entering each other's bedrooms in case they discovered their brother or sister dead. The consequence of living with this level of anxiety led one mother to consider whether the only way out was to end her own life. This suggests that psychological support would be beneficial to all those in the system supporting T1DM. The mothers spoke with relief and gratitude about the charity Diabetics with Eating Disorders and recounted the difference this organisation made to them. Even though she did not come into contact with the charity until after Rob's death, the connection allowed Wendy to make sense of many of her questions. They all described Diabetics with Eating Disorders as offering hope through understanding; for the mothers, hope was often absent in their search for professional support.

Loss

Loss was described poignantly by all three mothers. They described losing future plans, confidence, home, job, trust, relationships and more. This was for themselves, for their partners and for their other children. Wendy also spoke of a loss of pride – that, to support Rob, she had to visit a food bank, which she found humiliating. Rob's death was recorded on his death certificate as being due to 'natural causes'; for Wendy this was unacceptable, although she was unable to change it. She suspected Rob was living with an ED, and she knew he had very poorly-managed T1DM, but she did not know of T1ED. Systemic therapy, which recognises the expertise and experience of family members (Anderson & Goolishian, 1992) could offer a way for families to explore any concerns, navigate difficult conversations and thicken an alternative narrative of strength and hope (White & Epston, 1990). An exploration of family beliefs regarding illness and hopes (Altschuler et al., 1997) and life cycles stages (Carter & McGoldrick, 1980) might also allow families to recognise and differentiate between the signs of diabetes distress and diabetes burnout (Abdoli et al., 2020) before difficulties become entrenched. Statistics confirm that the combination of T1DM and ED can bring with it a fivefold increase in the risk of death (Nielsen, 2002). This begs the question, already asked in this discussion, what difference a name for, and recognition of, this co-existing condition could make.

Limitations of the study

Our sample size consisted of three participants, allowing the researcher to take an idiographic approach and to micro-analyse similarities and differences between each interview (Smith et al., 2009). However, a significant limitation of this study is the small sample size and a lack of diversity in 'diabulimia' representation. Moreover, there was little diversity in our participant sample, resulting

in low information power (Malterud et al., 2016). People of all genders, sexual orientations, ages, ethnicities and socio-economic status suffer from a range of EDs (Qian et al., 2021). This research project is an in-depth exploration of three mothers' experience of diabulimia. It does not aim to generalise findings beyond the scope of this project. However, the lack of research in this area adds fresh impetus for further research. An additional limitation is the similarity between the mothers' experiences of battling, blaming and surviving. Their experiences of loss offered most difference, specifically at a practical level – possessions, freedoms and hopes and because of the loss of Rob's life. The death of their child was an ongoing fear for Katie and Ruth but only a reality in the case of Wendy; however, there remains much similarity between the mothers within this theme.

CONCLUSIONS AND IMPLICATIONS

NICE (2015) recommends offering children and young people with T1DM and their families or carers timely and ongoing access to mental health professionals with an understanding of diabetes. Diabetes is a family disease (Anderson et al., 1981). This statement, published forty years ago, is yet to impact upon psychological interventions in many diabetes clinics. There is a wealth of literature both referencing the impact of a diabetes diagnosis on the family system and confirming the view that families and family-based interventions can make a difference for the whole system in relation to T1DM (Dickens et al., 2014). This includes diabetes-related family conflict, the difficulty in managing life cycle stages of separation and the impact on parental mental health. Taking a systemic position that everyone in the family has a relationship to the problem and the opportunity to make a difference makes a strong case for family therapy to be offered within diabetes services.

It is impossible to say whether family therapy in a diabetes clinic would have prevented the onset of T1ED for the children of Katie, Ruth and Wendy; however, their experiences of battling and blaming could have been explored constructively within a systemic setting. One of the strongest narratives weaving throughout the interviews and each theme was that ED professionals did not fully understand diabetes and vice versa. This research has begun to evidence that families, and specifically parents, are greatly affected by their child's diagnosis of T1ED and that they hold a great deal of knowledge and expertise. It is important to consider them as crucial elements within support and treatment systems.

RECOMMENDATIONS

Any research, including systemic research, should focus upon utility and offer an answer to the 'so what?' question (Dallos & Vetere, 2005). The review of the literature, feedback from colleagues and, most importantly, the voices of participants in this project support:

- Greater understanding of both T1DM and ED in relevant MDTs and services;
- Training in the physical and psychological impact of T1DM for all ED professionals;
- Recognition of 'diabulimia' as a chronic and life-threatening condition;
- Further research into the experiences of a larger number of parents living with diabulimia, including parental dyads;
- Further research studies exploring the experiences of children and extended family members living with diabulimia;

- Future qualitative studies should employ purposive sampling to recruit larger and more diverse samples of participants, including people from minoritised ethnicities;
- Provision of systemic parental and family support to enable families to explore their relationships and responses relating to diabulimia within diabetes and ED services.

FINAL COMMENTS

> 'You're not just fighting the system; you're fighting everybody else as well'.
>
> (Katie)

This project set out to explore the impact of type 1 diabetes and an eating disorder on parents, with the literature confirming the prevalence and implications of the problem. It detailed some of the experiences of parents struggling to get help and some of the long-lasting effects on family members. It highlighted a lack of understanding and provision within support systems for this group of people and their families. T1DM was a fatal illness until the discovery of insulin in the early 1900s (Vecchio et al., 2018). Since then, and particularly in the last twenty-five years, progress in understanding and management of the physical aspects of the illness has been rapid (Speight et al., 2020). T1DM remains an illness to be managed, rather than controlled, requiring a robust system supporting the individual and family. 'Diabulimia' only exists in relation to T1DM. Progress in recognising, understanding and managing this illness, is slow and costly, seemingly on both an economic and an emotional level.

FOOTNOTE

As we neared the end of our collaboration, GR, as research supervisor, asked FK, as primary researcher, what had been helpful or unhelpful about their contribution. The following list was generated:

- Being accompanied, supported and witnessed from the beginning of the journey to the end;
- Offering an outsider witness perspective, having one foot in the river and one on the bank;
- Encouraging and believing that a difference could be made and change happen;
- Not taking over, doing it for or telling what to do;
- Being a constructive, 'critical' friend, not just being superficially 'nice';
- Getting to know the person, before any problems or possibilities;
- Listening and not rushing or pushing.

With tears, we realised that this mirrors what the mothers highlighted about what they and their families needed from the professionals and services supporting them.

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CONFLICT OF INTEREST STATEMENT

There are no conflicts of interest associated with this study.

DATA AVAILABILITY STATEMENT

To protect anonymity, participant data are not publicly available.

PARTICIPANT CONSENT

Informed written consent was gained from all participants for this study.

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