

The Long Road to Diagnosis: a phenomenological study

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Abstract

Aim: To explore the lived experience of a mother coming to terms with her child's diabetes. The research involves a phenomenological exploration of the impact on the parent of events leading to the traumatic hospitalization of a child before diagnosis.

Methods: One unstructured, in-depth interview was conducted, transcribed and analysed 'phenomenologically' in dialogue with the co-researcher participant. Themes were developed to describe the mother's narrative experience.

Findings: A narrative of the mothers lived experience was created revealing powerful themes concerning parental loss of a healthy child, and the changing identity of the parent throughout the child's diagnosis. The findings suggest that often parents know very little about the diagnostic symptoms of Type 1 Diabetes prior to diagnosis and parents identify strongly with feelings of frustration, fear and doubt during the early and invisible stages of this disease. Parents often feel that they are isolated in caring for their child as their family and friends often have minimal understanding. Normative childhood events are stressful, requiring parents to balance their own concerns whilst fostering their child's full participation. There are many support networks available for the diabetic child but support for parents seems to be very minimal. Appropriate parenting skills need to be seen as an important element of diabetes family management health care.

Introduction

Current research suggests incidences of child diabetes are rising. Within Europe, the UK has the highest diagnosis of children with Type 1 diabetes, 22,000 below 17-years¹ and a further 2,000 diagnosed every year.² The current UK estimate of child prevalence of Type 1 diabetes is one per 700–1,000.² Researchers analysing trends from 17 European countries over a 25-year period have concluded that by 2020 the incidence of diabetes could increase by 50% in children under 5-years and as much as 70% in children under 15-years meaning that more children and their parents will need access to specific health care services³.

1 p 24 National Diabetes Survey Research Report

2 p 7 Diabetes in the UK 2010: Key Statistics on diabetes

3 Abstract The Lancet 373 (9680)

These trends have implications upon improving parental knowledge of symptoms and the provision of support for vulnerable families. This study will concentrate solely upon Type 1 Diabetes although it is recognised that Type 2 Diabetes is also a major health care issue.⁴

Type 1 Diabetes Mellitus (T1DM) is an autoimmune disease that permanently destroys beta cells in the pancreas. The body can no longer produce sufficient insulin to absorb blood sugar. T1DM can be deadly without regular insulin injections to control blood sugar levels. T1DM is an insidious disease, for which no prevention is currently possible. Children affected by T1DM are often healthy before diagnosis. Diet and exercise have a role to play in T1DM management but they cannot reverse the disease or eliminate the need for insulin. T1DM treatment is a daily task and particularly difficult to control. Treatment requires a strict regime typically including a carefully calculated diet, planned physical activity, home blood glucose testing several times a day, and multiple daily insulin injections.⁵⁶⁷

The appearance of T1DM is suspected to follow exposure to an "environmental trigger," such as an unidentified virus. This stimulates an immune attack against the insulin producing beta cells of the pancreas in some genetically predisposed people. Unfortunately T1DM can muddle around in children for months undetected but the later symptoms such as above average thirst, feeling tired, needing to urinate regularly, losing weight, skin infections and itchiness need to be acted upon immediately.⁸ Without treatment this type of diabetes can be deadly. Diabetes UK, The Juvenile Diabetes Research Foundation⁹ and The International Diabetes Federation¹⁰ are the leading researchers addressing diagnosis and treatment into T1DM worldwide. Subsequently there are thousands of places to gain advice for children and how they can live with their diagnosis and daily coping mechanisms.

4 p2-4 Diabetes UK General Election Manifesto 2010

5 <http://www.diabetes.co.uk/diabetes-mellitus.html>

6 <http://www.nhs.uk/Conditions/Diabetes/Pages/Diabetes.aspx>

7 <http://www.diabetes.org.uk/Guide-to-diabetes/Introduction-to-diabetes/>

8 <http://www.diabetes.co.uk/type1-diabetes.html>

9 <http://www.jdrf.org.uk/> 10 <http://www.idf.org/>

For any parent whose child is diagnosed with this life-long, chronic condition, the tough job of parenting becomes even tougher. It brings an awful lot to consider and the responsibility can be very demanding. As a parent of a child with T1DM, the diagnosis can often be a much harder blow for the parent than for the child.¹¹ Having T1DM involves coming to terms with the diagnosis, getting used to treatments and making changes to everyday life. The patient can often still lead a normal and healthy life particularly with good parental support. Several researchers of parenting style and T1DM Glycaemic Control promote the importance of a supportive and child centred, emotionally warm but high demand parenting style for improved quality of life for T1DM children.^{12 13 14}

There are very few studies describing the parents lived experience of having a child diagnosed with T1DM. Personal accounts on many diabetes websites tend to focus on the personal experience of the patient rather than the people surrounding them. They seem to miss the complexity, ambiguity and ambivalence of the parents lived experience and little seems to be acknowledged about the psychological and social issues facing parents. What happens to parents as they learn to adapt to their new roles and what is the impact on their personal lives and their families?

Very little work stands apart from current research in this area however one particular study presented by Arlene Smaldone and Marilyn D. Ritholz,¹⁵ explores perceptions of psychosocial adaptations in parenting young children with T1DM from diagnosis through childhood. They have identified three significant sequential themes.

11 <http://www.diabetes.co.uk/diabetes-and-parenting.html>

12 Results. *Journal Of Pediatric Psychology* 26 (2)

13 Discussions and Conclusion. *Child Care, Health and Development* 34 (5)

14 Summary. *Diabetes Spectrum* 14 (4)

15 Abstract. <http://jpedhc.org/article/S0891-5245%2809%2900277-6/abstract>

Firstly “Diagnostic Experiences: Frustrations, Fears, and Doubts.” Here parents described inadequate diagnostic experiences with paediatricians where concerns were minimized and diagnosis was sometimes delayed. Although hospitalisation occurred abruptly, communication with specialists was more satisfactory.

Secondly, “Adapting to Diabetes.” Parents described isolation in caring for their child's T1DM. Family and friends had minimal understanding of T1DM care. Support groups lessened mothers' isolation, but fathers were less positive about this experience. Parental adaptation was more effective when responsibility for diabetes decision-making was shared. All parents reported never mastering diabetes management.

The final theme “Negotiating Developmental Transitions” revealed that normative childhood events were stressful, requiring that parents balance concerns to foster their child's participation. This research concluded that Paediatric providers can improve diagnostic and treatment experiences for parents of children with T1DM by recognizing feelings of isolation and lack of mastery, providing attentive communication, encouraging parental teamwork, and offering ongoing anticipatory guidance.¹⁶ They concluded that future studies of T1DM management will have much to gain from consideration of the role of the father and siblings in treatment, attention to the diabetic child's impact on family functioning, and recognition of sources of support and stress outside the family that affect adaptation to diabetes. Appropriate parenting skills should be an element of diabetes family management health care.¹⁷

Phenomenological research¹⁸ seems to be the best way to explore these questions and capture at least some of the issues through which parents must negotiate a path. On the basis of this information better informed health professionals may be able to offer advice designed specifically to be more responsive to any parental need for help and support.

16 Conclusion <http://jpedhc.org/article/S0891-5245%2809%2900277-6/abstract>

17 Findings Diabetes Care 3 (6)

18 p31-32 Relational-centred Research for Psychotherapists: Exploring Meanings and Experience

Recognising the likely significance of this relational realm I have set out to explore one parent's lived experience of her son's diagnosis of T1DM. This research provides an account of Sarah's story by presenting a co-created narrative alongside common themes. I offer simple psychotherapeutic analysis in my discussion using the following Transactional Analysis models: Functional Model of Ego states^{19 20} and Drivers.^{21 22 23}

Method

Existential Phenomenological research was undertaken collaboratively to explore Sarah's lived experience of coming to terms with her child's Type 1 Diabetes (T1DM) diagnosis. Sarah shared her story with me. The narrative was closely analysed and several themes were carefully chosen to best illustrate Sarah's story. Sarah took the opportunity to read the findings of this study and we discussed her thoughts and feelings about what had been written. Sarah then changed or added in aspects of the study to more closely match her experiences.

Co-researcher involvement and ethics

Sarah is in her early forties, married with three young children between ten and four years old. Sarah experiences her day as a stay-at-home mother looking after her family and their needs. She finds great support within the local Christian community volunteering regularly at the local church. Sarah and I have been friends for about seven years meeting through the attendance of various groups with our children. I know that we have a mutual understanding and trust of one another and knew that this was a good basis for this research.

Sarah knows that I am in Transactional Analysis Psychotherapy Training. She has always shown a great enthusiasm and interest about psychotherapy and my practise. I know some of what Sarah has been through and how very difficult these last few years have been for her and her family. I asked Sarah to be involved in this project as I know that her story has never really been heard. I believe that Sarah's story is an excellent example showing the difficulties for parents in recognising early onset T1DM.

19 Chapter 7 Transactional Analysis in Psychotherapy

20 Chapter 3 & 5 TA Today

21 Chapter 16 TA Today

22 Transactional Analysis Journal 4(1)

23 p120 Personality Adaptations

24 p31-32 Relational-centred Research for Psychotherapists: Exploring Meanings and Experience

I initially talked to Sarah about my proposal at our local toddler group. She showed her interest and I went on to draw up my research proposal form (Appendix 1). I offered her the choice of where she would like to meet to carry out the data collection and she chose my house. I sensed that my house was a quiet sanctuary away from her busy life and she wouldn't have to worry about tidying or preparation for our interview. Over a friendly cup of tea we chatted about the exact details of what was involved and she asked questions and voiced any concerns that she may have had. I had prepared a Research Written Consent Form that explained to her exactly what she was agreeing to, her rights and the ethical implications (Appendix 2).²⁵

She agreed to record a one-hour in-depth interview about her lived-in experience of the diagnosis and management of her child's diabetes.²⁶ I would then transcribe and analyse the interview phenomenologically. Together we would feedback about the interview process, the development of the research dialogue and the project outcomes. Sarah knew that she was in control of her level of disclosure and did not have to answer questions that she felt uncomfortable with. I ensured confidentiality by guaranteeing that all information relating to the project was locked away at my home. Copies of the project would only be available to her, the Research Co-ordinator and I. Participant permission would be sought for any other use after this time. Tapes would be destroyed after the project was marked and returned. Sarah knew that she had an absolute right to cancel at any time and she was given a Complaints Procedure should she require it.

I also offered to refer her to an appropriate source of help and support should she feel it necessary during our time together.²⁷ Sarah knew that our co research outcomes could form the basis of practise based evidence helping professional understanding and promoting therapist client relationships and therefore I may seek Supervision during this process. Sarah agreed to the project and we signed together the Research Consent Form each keeping a copy for our own records.

25 p78-80 & Chapter 11 Relational-centred Research for Psychotherapists: Exploring Meanings and Experience

26 p96-99 Relational-centred Research for Psychotherapists: Exploring Meanings and Experience

27 p82-85 Relational-centred Research for Psychotherapists: Exploring Meanings and Experience

Data collection and analysis procedure

Three weeks later we arranged the interview at my house. An hour beforehand I brainstormed the areas of research I would like to cover and any possible questions that might help my co researcher to explain her story. We spent some time getting comfortable and reminding ourselves of the focus of our research and the length of the interview. We started recording and I conducted an unstructured interview with my friend for one hour. My aim was to ask open, non-directive singular questions allowing Sarah to tell me her story. I sought to use my skills as a trainee Transactional Analyst to concentrate upon the ten core values underpinning relational centred research^{28 29}. At the end of the hour, I switched off the voice recorder and offered Sarah some time just to chat about her experiences. We said goodbye and then later on that evening I contacted Sarah to check out how she was feeling. She was pleased about the interview and felt relief from telling her story in more detail for the first time. I offered her support should she require it.

The second stage of data collection was the somewhat lengthy procedure of transcribing our interview in detail (Appendix 3). Using the transcript and the recordings I focused upon repeated systematic reading and listening to the narrative and so began to organise Sarah's story into a narrative sequence³⁰. I then began to pull out the thematic messages from the interview that would best illustrate the lived experience of Sarah coming to terms with her child's T1DM diagnosis.

Approximately three months after the initial interview stage of the project, I provided Sarah with a copy of the research project to date. In her own time she read through it with her family and made changes and added ideas in that were then incorporated into this report.

28 p36-39 Relational-centred Research for Psychotherapists: Exploring Meanings and Experience

29 p318-326 Transactional Analysis Journal 26(4)

30 Chapter 10 Relational-centred Research for Psychotherapists: Exploring Meanings and Experience

Findings: Sarah's story

The findings of this study are divided into four themes illustrating the chronological sequence of Sarah's story:

- Confusion and Denial
- Blame
- Terror
- Faith and Courage

Confusion and Denial

Sarah's story began in 2008 when her son was eight. Sarah felt that her son was "just not right". At times he seemed unusually tired, upset, out of sorts, which seemed out of character. Sarah's discovery seemed to mark the start of her confusing dilemma - was there really something wrong with her son or was she imagining it? She wanted to find out if this indicated a life threatening illness and a paediatric appointment followed. A thorough examination was carried out and despite some concerns about a possible iron deficiency, nothing was found. With hindsight Sarah remembers this was the first time she felt like she was "thrust into their [the medics] world". Sarah felt that the professionals took her seriously. She recognises that T1DM can be undetectable in the early stages. It can rumble around for months lulling parents into a false sense of security allowing them to deny their worries.

Blame

Due to other commitments Sarah cancelled a follow up appointment. With hindsight, she explains how difficult it is not to find fault and blame her self for this.

'Looking back I have slight guilt about this one. I mean I have guilt about all sorts of things but I do have slight guilt about this. It happened to fall on a day we were doing something special at Toddlers and I was needed there and I hadn't realised. And I actually cancelled the follow up appointment, not because I had double booked but mainly because they couldn't find anything wrong with him. And I thought, "You know, this is a doctor, a highly qualified doctor, they can't find anything wrong with him. I've got nothing fresh to tell her except I thought, I suppose at the back of my mind, the niggle was ... (pause) I don't think he's quite right but they can't find anything wrong with him.'" ^{Ap3 p30}

She now wonders if her son could have been diagnosed a little earlier. Sarah perceives the well being of her children as her main responsibility. She fears she may have failed her son when he needed her most. Sarah trusted medical opinion and although her son continued to be 'just not right' there seemed to be genuine reasons to explain his symptoms and serious illness seemed improbable.

'It's not until a child's better that you realise perhaps how ill a child has been leading up to it. We're talking about approaching May now and he'd been ill you know, almost 6 months so if it's gradual you don't realise. You think "Oh, Perhaps he's had a growth spurt, perhaps he's outgrown his energy, perhaps he needs some more sleep at this time in his life", and all those kind of things.'

Apx3 p31

Sarah didn't know what to do. It was very difficult to share her son's illnesses outside the family home as he showed no explicit symptoms and didn't complain of being unwell. As time past she began to share her confusion with her extended family and her son's teacher who was very understanding and took her seriously. As the main caregiver Sarah took on the burden of her son's dilemma. She is a very good mother and I sense that experiences that followed rocked the very foundations of her world and how she sees herself.

'You look back and you see these huge warning signs and I did... I was alerted to the fact that there was something wrong but I really didn't know what and you know the guilt will live with me that I didn't spot it. Although there was nothing that we could have done to cure it but we could have caught it quicker. I thought perhaps I'd started to think that it was diabetes but... I didn't realise how suddenly it could come on. And I thought that it was a slow onset disease. I did not realise that I should have acted *that* day.'

Apx3 p32

Sarah now expresses a great concern at the lack of public knowledge about T1DM and the onset symptoms like thirst, tantrums, and lack of appetite, cold legs, lethargy, frequent urinating. There is much publicity for Type 2 DM and the media do not seem to distinguish between the two types. She believes that educating parents could have helped her to make clearer decisions and seek medical help sooner. Guilt and blame continues throughout Sarah's story as a deep reminder to her of her experience.

Sarah's family and her parents holidayed in Wales in June 2009. Sarah explained how the horror and shock of the next days would live with her forever. During the holiday her son became poorly with what seemed like a routine sickness bug. Sarah nursed and quarantined him in fear of other family members becoming sick. However he deteriorated rapidly before his emergency admission to hospital and Sarah explains the crucifying guilt surrounding this for her.

'I got up with him each time [to be sick] but I kept saying to him "Don't forget to flush, don't forget to wash your hands, we don't want the girls to catch this". And you know again the guilt; I try not to dwell on the guilt cos if I did I think it would crucify me.' ^{Apx3 p36}

Terror and helplessness

The terrible fright of seeing her son in the morning light motivated her to get help very quickly. I felt very upset as Sarah described the pain and distress of her experience.

'S: I've got to get a doctor. This isn't right, I've got to go and get into a doctor. So I went downstairs and as soon as I got him in the light I have never seen anyone look so ill. My son was just fading. His cheeks were sunken, his eyes were black, and his lips were losing their puffiness. And he just looked, and he – the skin around his mouth was pulled across his teeth in the way that an old person does when their face is shrinking.

Me: How did that impact on you when you saw him like that?

S: Just... I can remember starting to panic. What if they don't take me seriously? What am I going to do if they don't take me seriously? What if they start saying "Look, just take him to the doctors" cos he doesn't need a doctor he needs to go to hospital but what if they don't listen to me? What do I do to convince them that he is not well?' ^{Apx3 p37}

Sarah was thrust into deep panic and fear as she realised her son was critically ill. She thought that the emergency services wouldn't believe her, she felt that she could not answer questions clearly, she felt numb and unable to mother him. Her guilt overwhelmed her.

‘I could almost remember almost being frightened to be near him in case something happened to him and I just wanted. And this sounds absolutely horrendous, not to be in the same room because I couldn’t...Because I couldn’t. I really thought, I thought I’m going to lose him and I don’t want, I know I should be there because I’m his mum and I know that I should be holding him because he’s mine but I don’t know if, I don’t know if I didn’t trust myself or whether it was just that I didn’t, but I thought that if he dies I know mine should be the last face he sees but I don’t think I can bear holding him while he dies (quiet and shaky voice).’^{Apx3 p37}

Sarah felt very grateful for her family being around her. Her husband, mother and father were strong and potent supporters giving Sarah the permission to believe and dial 999. Sarah’s mum held her grandson allowing Sarah the space and protection she needed for herself. The ambulance arrived swiftly but initial relief was swiftly replaced with absolute terror as she suddenly found herself wondering if her son could make it or had she been too late getting help? She recalls seeing her dying grandmother and could not comprehend how her son would pull through. Her sons’ life was now in the hands of the medical profession.

‘I can remember the female ambulance driver saying to me...“Why didn’t you call us before, why didn’t you call us before?” as if she was panicking. I felt like hitting her (laughs). I was thinking I’ve been onto this for months and months and months so now -why didn’t you call us before? But then remembering the night and thinking, “I should have phoned them last night I should have done that. Why didn’t I do it? Because I thought he had a virus.’^{Apx3 p38} I was with my grandmother when she died and he looked more like death than she ever, even though she was 90 odd, he just looked like that. He looked like death and I thought, “He’s not going to make this.”’^{Apx3 p39}

They were taken at speed to the nearest hospital which was forty five minutes away. Time seemed to stand still. Sarah remembers feeling helpless but somewhat relieved as a huge team of doctors and nurses sedated her son and arranged cannula lines in his arms and groin. All they could do was stand and watch – it felt like when she had given birth.

'I'd had an epidural so I couldn't move and I can remember saying, "Like can't he come a bit nearer to me". And it felt a bit like that. Cos he was probably only a metre, a metre and a half away from me but with all these doctors and nurses around him in a flap, an absolute flap... You could just see all these cannulas into him and it was horrible and a blanket to protect his modesty a little bit. And feeling that this boy is just nine and you know he's just, it's just awful but relief cos I thought he was there.'^{Ap3 p41}

The hospital was small and Sarah sensed that everyone seemed to know what was going on. Sarah found this a little comforting but mostly overwhelming. There was nowhere to escape from the enormity and seriousness of her son's condition.

'S: As I came through A & E,...I just remember every single person in that A & E looking at me as if they knew. They knew that this child was so ill and even eventually people waiting outside A & E to go in, when I went to see, I can remember them looking at me too.

Me: What did that feel like them looking at you, what did you think?

S: I thought this is very serious; this is not a common occurrence. I don't think diabetes it usually like this because this just seemed to be sort of a condition that perhaps doctors and nurses never quite see like that. It just seemed to come across like, you knew, that people were watching, I knew people were watching me, feelings for me. Erm. Just feeling for me I think. Worried for me...us... but you could tell that they knew. The doctors and everybody knew. I remember the whole hospital, really in relation to the size of it; it had poured resources into our situation. I couldn't have, you couldn't have asked for more really.'^{Ap3 p42}

An emergency retrieval team then arrived from The Children's Hospital of Wales, Cardiff. Sarah's instincts were razor sharp and she sensed that the new doctors seemed to be very concerned. Without explanation the new doctors removed the parents from their son's bedside. They had an excruciating two hour wait before receiving dreadful news. Their son had had to be rehydrated very quickly, fluid had rushed to his brain and he had swelling of the brain cortex. There was a high chance that he would be brain damaged and he was critically ill. The effect on Sarah and her husband was immediate and devastating.

‘And G was sitting there rigid and I (pause) didn’t know what to do with my body, I didn’t know what to do with my body and I just thought, “This is just like being on Casualty”, which is not something I particularly watch but I just thought and then I It didn’t feel surreal enough. I wanted it to be surreal; I wanted it not to be me. I wanted it to be as if I was looking at me and not really me. And I couldn’t escape it and at the same time I didn’t know what to do with myself, didn’t know where to put my arms and legs. I didn’t know whether I should cuddle G. I didn’t know whether I should cuddle the nurse, I just didn’t know. I just didn’t know if I wanted to roll into a ball. I just wanted never- not to be there. And they were going to move him quite quickly, it became, they were going to take him then [to Cardiff hospital]. We weren’t allowed to go in the ambulance with him.’

Apx3 p43

Sarah and her family stayed with their son until the very last moment. As Sarah described this moment to me I felt a deep and profound sadness for her loss and how she might endured it mixed in totally with thoughts about my own children. How can we ever imagine as parents that our children may not outlive us and that we may have to say goodbye?

‘So as a family – the four of us and my mum and dad, we walked behind his trolley to the ambulance entrance and I kept kissing him and hugging him, trying to hug him but you cant hug him cos he’s surrounded by tubes but. They put him in this ambulance and I can remember they closed the doors and I thought, “I may never see that child again alive”, (long pause) and that was really, really, that was the hardest part of the whole day (choked words) just thinking, “I don’t think I’m ever going to see him again.” (Long pause)’ Apx3 p44

Faith and Courage

As they travelled to Cardiff hospital Sarah found herself having thoughts of organising her son’s funeral.

‘If I have to plan a funeral, perhaps I should have a rock song like this because this is a bit more suitable for a 9 year old than a full-blown hymn. Which is just crazy? I was already starting to plan a funeral but how do you have a funeral for a 9 year old? How do you do that? And what do you have for a 9-year-old funeral? I’ve never been to a child’s funeral.’ Apx3 p45

I believe that Sarah's faith helped her to gain access to unprecedented courage, conviction and bravery. Her strong Christian belief and complete conviction in the power of prayer enabled her to actively seek the support of her Church Home Group. She phoned and asked them to pray for her and her family. Sarah's prayers were answered. Within minutes of their arrival at Cardiff, Sarah and her family were informed that their son had a very positive brain scan and was being brought out of sedation. The relief experienced by Sarah and her family was palpable.

'Everything changed. It just changed. In minutes he came out of sedation and started joking with the nurse! They called me, I'd gone back to, we'd had this little room slightly off the ward that they'd given us; just a sitting room and they called us in. He was awake and he was normal. I just thought that's it, people have prayed for me and he's right and it's going to be okay.'^{Apx3 p46}

Sarah and her family had come through a severely traumatic experience and despite everything their son was alive and unharmed albeit with a diagnosis of diabetes. Sarah found herself confronted with the reality of her son's life long illness. It soon became very clear that the diagnosis was only the very beginning of their long journey with diabetes. T1DM was a virtual unknown to them and within hours they had to make quick decisions about their son's injection regime, medication and treatment.

Today, Sarah is a mother and a registered carer. It will come as no surprise that Sarah is utterly devoted to her new role. She must be 'on call' at all times for her son. She must provide support and vital information about diabetes to anyone else who has care of her son. Medication regimes and access to emergency medical treatment must be prioritised. Diabetes UK Support groups need to be attended. Sarah has had to learn very quickly but even today she keeps herself going in the knowledge that her son's diagnosis and medication is really incidental. The event that will live with her forever is how the illness presented itself and how she very nearly lost her son and the part that she played in that. Sarah acknowledges how very difficult her son's diagnosis is and how much of an impact it has had on all of her family. It has brought other worries such as the

fact that her son's diagnosis with no family history greatly increases the chances of his siblings developing the disease. She also feels guilt as well as obvious relief that her son survived whilst others have not.

'Living with it is hard. Living with it is really hard. Well, you pull together. Oh I think that unless you've been there you can't appreciate what its like and how much of an impact it has and how we've had to all work together. I don't, didn't, live on my mobile phone, I do now. Erm... that's one of the changes.'^{Apix3 p47}

Sarah has shared the very intimate details of how her and her family discovered her son's life long diagnosis of Type 1 Diabetes. Her story is one of confusion, doubt, terror, relief, faith, courage, loyalty and utter devotion.

Discussion

Reflections on earlier literature review

The research project that Sarah and I have undertaken seeks to explore the lived experience of a mother coming to terms with her child's diabetes. Our findings have the potential to raise awareness of T1DM in the public domain and deepen the understanding of the dilemmas that parents may face. It is reassuring that, despite the limited amount of literature available on this subject, Sarah's experiences and the findings of this research project reveal elements found in some of the literature discussed at the beginning of this article. There are particular similarities with the study by Arlene Smaldone and Marilyn D. Ritholz,³¹. This study identifies three main parental experiences of children diagnosed with T1DM.

Diagnostic Experiences: Frustrations, Fears and Doubts. The study suggests that many parents faced an inadequate diagnostic experience. Paediatricians minimized concerns and diagnosis was sometimes delayed. This was not entirely echoed in Sarah's lived experience. Sarah's G.P. had organised every test that he could for her son, including blood sugars which were normal. They were referred for a lower than normal iron count but otherwise no abnormalities were found with her son's health. However, Sarah did identify strongly with the

31 <http://jpedhc.org/article/S0891-5245%2809%2900277-6/abstract>

feelings of frustration fear and doubt felt during the invisible early stages of the disease. In Smaldone and Ritholz's study,³¹ parents agreed that although hospitalisation occurred abruptly, communication with specialists was more satisfactory. Sarah and her family received tremendous support after hospitalisation by the specialists in Cardiff and her local area team.

Adapting to Diabetes In Smaldone and Ritholz's study,³¹ parents described isolation in caring for their child's T1DM as their family and friends had minimal understanding of T1DM care. Sarah did not feel isolated from a medical perspective but rather more from life in general due to her new parental role, care regimes for her son and the difficulties in parenting the diabetic child's siblings fairly. As Sarah told her story, I had a real sense of how much she has hidden about what has actually happened to her and her family. This self imposed isolation has ensured her family's protection from the scrutiny of outsiders who could make ill-conceived judgements about the issues she is facing. Sarah has found Diabetes UK Support Groups very beneficial as she has been able to talk to other parents who have experienced children with diabetes.

Negotiating Developmental Transitions Smaldone and Ritholz's study revealed that normative childhood events were stressful, requiring that parents balance their own concerns to foster their child's full participation. Sarah agrees strongly with this as a new registered carer. She feels that the balance between a normal life and managing diabetes can be a constant stressor on family life. Sarah feels that there is a very obvious predicament between acknowledging that glycaemic highs and lows or multiple lows can have serious effects on her son's behaviour and at the same time not wanting to use diabetes as a constant excuse for generally poor behaviour. Balancing parental fears with the desire for a normal life is an ever present challenge especially concerning events such as school days trips and residential.

Sarah agrees that key issues for parents of children with diabetes include avoidance of punishment when dealing with diabetes issues, arrangement of nontraditional households to better facilitate diabetes management, awareness of the potential negative effects of parental overinvestment in helping children with diabetes, and the appropriate transference of diabetes management from parents to older children.³²

Perhaps the main difference between this research and other accounts is Sarah's view about her son's diabetes. The daily management and diagnosis of T1DM seem to be the stressor point for most parents but Sarah and her husband took to reading food labels and measuring insulin very quickly. More importantly, Sarah still feels that the terrible trauma of her son's hospitalisation far overshadows any other trauma surrounding their son's T1DM daily management.

The findings in this research agree with the conclusion reached by Smaldone and Ritholz³¹ that paediatric providers can improve diagnostic and treatment experiences for parents of children with T1DM by recognizing feelings of isolation and lack of mastery, providing attentive communication, encouraging parental teamwork, and offering ongoing anticipatory guidance.³³ Sarah's lived experience particularly supports the work of Anderson and Aulander in that appropriate parenting skills should be an element of diabetes family management health care.³⁴

Diagnosis of chronic illness can have a potentially devastating impact on a person's life. Some of the most basic underlying existential assumptions that people hold about themselves can be thrown into disarray.³⁵ Sarah's sense of embodiment is unique to her story. Sarah conceived, carried and gave birth to her son. It is an inescapable fact that there is a unity of bodies as her genes are his genes. How can a mother accept that her body may have let her child down in some way?

31 <http://jpedhc.org/article/S0891-5245%2809%2900277-6/abstract>

32 Conclusions. *Diabetes Spectrum* 14 (4)

33 Conclusions. <http://jpedhc.org/article/S0891-5245%2809%2900277-6/abstract>

34 Conclusions. *Diabetes Care* 3 (6)

35 p9 *Theory and Psychology* 10(4)

It is likely that Sarah will blame herself at a very deep and subconscious level for the genetic predisposition her son may have inherited. She is able to blame herself as he is a part of her. Sarah experienced a very spontaneous reaction when told about possible brain damage and the chances of her son's survival. Suddenly her embodied experience of the self-other relationship was severely disrupted. Sarah did not know what to do with her body. She felt surreal. She felt like rolling into a ball and disappearing. Her sense of self was rocked at its very core. ^{Appendix 3 p43}

The main themes in Sarah's story could help to behaviourally identify her dominant functioning ego states. ^{36 37} Sarah's initial experiences of confusion, denial and later terror could suggest a conflict back and forth between her Adapted Child and Critical Parent ego states. In her Adapted Child she needed reassurance that her son *was* actually ill, she felt that she wouldn't be believed by medics and she needed permission and support from her own parents to ring 999. Sarah's Critical Parent ego state can be experienced as she begins to blame herself for what has happened to her son. She projects feelings of anger out at the ambulance driver and nurses for their inappropriate comments regarding earlier contact and their messages of good luck. TIDM diagnosis must be incredibly scary for any parent and accepting it must be almost unbearable. A way in which Sarah searched for acceptance about her son's future was by looking towards her faith for nurture. Sarah began to share her experiences and received positive strokes through prayer. Her Nurturing Parent ego state strengthened allowing her to return to her Adult ego state functioning at some level. Sarah could then make vital decisions about her son's medication regime and put necessary plans into action.

Sarah recalled her story in great detail, using many parentheses, with little external emotional feeling. This could indicate aspects of a Be Perfect and Be Strong Drivers ^{38 39 40}. Sarah blames her self for not getting her son's medical treatment right at an earlier stage and that guilt will stay with her forever.

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37 Chapter 3 & 5 TA Today

38Chapter 16 TA Today

39 Transactional Analysis Journal 4(1)

40 p120 Personality Adaptations

There is a chance that whatever Sarah does for her son now she may feel like it is never enough. Sarah has recently experienced aversion towards treating her children's cuts and grazes. She suspects that she will not get the treatment right and something terrible could result. This could be a physical and psychological defence against her blame and guilt. I sense that if Sarah were actually to allow herself to feel her guilt it would seriously debilitate her. She is protecting herself and her children from her incapacitation by being strong. Sarah's Be Perfect driver is fundamental to managing her son's daily regime as the worst case consequences could be death.

2. Acknowledgement of my own position in the construction of knowledge

As main researcher in this project I recognise that I have had a large part to play in the construction of knowledge appropriate to this study. As a mother myself, I am very interested in other mother's experiences of their children and I have discovered that, rarely, do I hear such thought provoking scenarios as the ones presented here. I have been distinctly aware of my own reflexive bodily responses to Sarah's story throughout data collection and also the analysis. I have attempted to distinguish my own bodily responses from Sarah's real experience, bringing into my awareness the difference between how I feel, think and behave concerning my children and parenting styles and Sarah's children and her parenting styles. This links to the theory of transference and countertransference within Transactional Analysis.⁴¹

As Sarah is my friend, I have found that at times, it has been difficult to separate my own experiences as a friend apart from Sarah's lived-experiences. This could have somewhat clouded my judgements at times. For example Sarah described her isolation from family and friends throughout her son's T1DM diagnosis. I began to feel guilty and wondered if I could have done more to help her. I felt that I had to check out how she had seen my role over those initial months and possibly apologise for any wrongdoings. In the initial stages of data collection, I began to feel very nervous about our interview. I felt scared that I might offend Sarah or not provide enough protection for her to tell her story. I felt worried about whether I would be able to get this

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research right so as to truly tell her story. Despite having brainstormed some ideas I didn't look once at my crib sheet and at several times I became acutely aware of trying not to be a therapist. As I wrote up the transcript I was aware of how empathetic I was but also how I didn't really ask a variety of questions. The most regular question seemed to be - How did you feel when that happened? This exemplifies my own Concordant Proactive Countertransference.⁴² I am experiencing Sarah's story based upon my own past history rather than the here and now reality. My Adapted Child ego state is very scared of not getting this perfect and disappointing others. The reality is that Sarah felt that I have been someone who *has* understood and supported her. As the interview progressed I did indeed relax and my natural therapeutic skills such as actively listening and helping her to express herself did come back into play. Perhaps as Sarah is my friend I have felt an unusual level of perfection and loyalty towards her in getting this research to be a true reflection of her incredible story.

At times during Sarah's story I found myself experiencing profoundly strong emotions despite Sarah impassiveness. Shock overwhelmed me when Sarah described seeing her son in the morning light the day he was hospitalised. I felt huge sadness when Sarah and her family had to say goodbye to their child without knowing whether they would ever see him alive again. I believe this is Concordant Reactive Countertransference.⁴³ I experienced the co researchers avoided experiences and/ or resonated empathically with her experience.

I became so absorbed in the interview and story unfolding that when I looked at the clock we only had ten minutes to go and we hadn't even got to the end of Sarah's son's hospitalisation. I had a real sense of Hurry Up and began to panic about whether or not I'd got the answer to my question and notified Sarah of the time we had left. Her response was a Complimentary Reactive Transference.⁴⁴ Sarah's response suggested that she began to feel that she needed to look after me and apologise and provide me with the results I needed.^{Apx 3 p46} With hindsight I would like to have another chance of interviewing so as to complete her story and be able to share some of my experiences back with Sarah at length.

Sarah's stories hit me very hard as a mother and parent particularly the denial, terror and horror that she experienced in isolation. Hearing Sarah's story has made me recognise how very lucky I have been that I had not had to go through similar trauma with my own children as yet.

3. Methods and overall usefulness

As co researchers in this admittedly small scale project we accept that these findings remain tentative, partial and emergent. A study such as this cannot make large claims or generalise people's experiences but at the same time it does have wider resonance such as to health professionals working with clients from similar backgrounds. These findings could enable health professional to 'see' and 'hear' the individuals that they are working with thus gaining important insights into their life and relationships. These research findings provide small scale practise based evidence that could help promote understanding and give voice to lived experiences of parenting T1DM children. This could aid and promote the development of therapeutic relationship with such clients.

It could be said that one of the strengths of this research project is that it has further clarified some existing but embryonic findings on the perceptions of parenting children with T1DM. Therefore it could continue to raise awareness of the parent's plight in T1DM diagnosis. Secondly, this project was systematically planned from the beginning prior to data collection with the main aim of discovering the lived in experience of a mother coming to terms with her son's T1DM diagnosis. Planning the project in this way allowed both the co-researcher and author to have the maximum amount of time available. The time factor was very important as we had to take into consideration the fact that we are both working mothers with little time on our hands and often a child's crisis to deal with little notice.

I believe that the goals of this project were realised but subtle differences occurred between the initial plan and what was actually found because of what else I discovered on the way. I did have some pre-conceived ideas of what I might hear because I had heard part of Sarah's story before. I expected her to report the difficulties of

daily regimes, being constantly on call and never having any time for her self. I recognise now that my pre-conceived ideas fit almost exactly with Sarah's experiences of those around her soon after her son was diagnosed. Thus the findings of this study truly illustrate the real isolation Sarah felt in being able to talk to other adults about her experiences. Another discovery was the alarming fact that I know very little about T1DM and the delicate nuances involved in the arrival at its diagnosis.

Overall the research methods used enabled us to meet our goals and also provided much more food for thought. I encountered some difficulties with the interview technique when collecting together the findings. The unstructured manner of the interview permitted the co-researcher to go into more detail about certain events in her story than was probably necessary to satisfy our goals. The dialogue provided such a wealth of information that it was at first very difficult to decide which parts of the story to take as evidence. However despite this, I do feel that we discovered far more of Sarah's lived in experience than if I had asked her to answer structured questions. Phenomenological research is of course qualitative research. And so perhaps it would be possible to add in an element of quantitative study such as a questionnaire scoring system about parent's diagnostic experiences of children with T1DM for comparable results. On the other hand, I recognise that this would have impinged on my experiences of actually 'being' with my co researcher and hearing the story she chose to give me.

I have thoroughly enjoyed my experiences with my co researcher; the end of the interview seemed to come far too soon, I wanted to hear more. To modify this project I would have liked to organise two more interviews of the same length with the same co researcher. The purpose of this would be to allow her to discover more about how relative all their experiences are now to every day life, a year and a half after diagnosis. To further this study it would be very interesting to attend a Diabetes UK support group and perhaps ask for volunteers to go through a similar process as Sarah to ascertain whether Sarah's experience is familiar to others or is in fact, unique.

For eight years Sarah had lived safe in the knowledge that her children were fit, healthy and progressing well. Suddenly she was plunged into a world where uncertainty clouded her thinking and life changed beyond what was imaginable. Many studies show that disruptive traumatising experiences of chronic or serious illness have potentially devastating impacts on a person's life. This trauma throws into disarray the underlying existential assumptions that people hold about themselves and the world around them. The experience of traumatisation often serves to fundamentally disrupt the routine and orderly sense of existence, throwing into radical doubt our taken for granted assumptions about time, identity, meaning and life itself.⁴⁵ I would argue that this study highlights similar effects on the parents of children with other serious illnesses. Sarah has at times seriously questioned her abilities as a mother and in so doing has felt guilty and blamed herself. She has had to face the reactions of others around her reminding her of her son's illness and any mistakes she makes. Sarah recognises that she still has a lot to learn and will probably continue to adapt as her son's carer until he is an adult and can go his own way. Sarah's 'lived' sense of time and identity has been severely disrupted and I feel that her telling her story is an important way of her rebuilding her sense of connection and coherence.

I would like to thank Sarah for agreeing to take part in this project and for sharing her amazing story with me.

References

Anderson, B.J., Auslander, W.F. (1980) Research on diabetes management and the family: a critique. *Diabetes Care* 3 (6) 696-702 November 1980

Berne, E. (1961) *Transactional Analysis in Psychotherapy* New York. Grove Press.

Botello-Harbaum, M., Nansel, T., Haynie, D. L., Iannotti, R. J., Simons-Morton, B. (2008) Responsive parenting is associated with improved type 1 diabetes-related quality of life. *Child: Care, Health and Development* 34 (5) 675-681 Sept 2008

Clarkson, P. (1991) Through the Looking glass: Explorations with Transference and Countertransference. *TAJ* Vol 21(2) April 1991

Crossley, M.L. (2000) Introducing Narrative Psychology: Narrative psychology and the study of Self/Identity. *Theory and Psychology* 10(4) 527-546

Davis, C.L., Delamater, A.M., Shaw, K.H., La Greca, A.M., Eidson, M.S., Perez-Rodriguez, J.E., Nemery, R., (2001) Parenting Styles, Regimen Adherence, and Glycemic Control in 4- to 10-Year-Old Children With Diabetes *Journal of Pediatric Psychology*. 26 (2) 123-129

Diabetes UK (2010) Diabetes in the UK 2010: Key statistics on diabetes.
http://www.diabetes.org.uk/Documents/Reports/Diabetes_in_the_UK_2010.pdf

Diabetes UK (2009) Diabetes UK general election manifesto 2010
http://www.diabetes.org.uk/Documents/Reports/Manifesto_for_web_2010_uk_version.pdf

Erskine, R.G., Trautmann, R.L. (1996) Methods of an Integrative Psychotherapy. *TAJ* 26(4) 316-28

Finlay, L., Evans, K. (2009) *Relational-centred Research for Psychotherapists. Exploring meanings and experience*. Wiley Blackwell

Harris, M.A., Mertlich, D., Rothweiler, J., (2001) Parenting Children With Diabetes. *Diabetes Spectrum* 14 (4) 182-184 October 2001

<http://www.diabetes.co.uk>

<http://www.diabetes.org.uk>

<http://www.idf.org>

<http://www.jdrf.org.uk/>

<http://www.nhs.co.uk>

Kahler, T., and Capers, H. (1974) The Miniscript *TAJ* 4(1) 26-42

Joines, V., Stewart, I. (2002) *Personality Adaptations: A new Guide to Human Understanding in Psychotherapy and Counselling*. Nottingham. Lifespace

Patterson, C.C, Dahlquist, G.G, Gyürüs, E, Green, A, Soltész, G. (2009) Incidence trends for childhood type 1 diabetes in Europe during 1989—2003 and predicted new cases 2005—20: a multicentre prospective registration study. *The Lancet*, 373 (9680) 2027 - 2033, 13 June 2009 Published Online: 28 May 2009

Royal College of Paediatrics and Child Health. (2009) *National Diabetes Survey Research Report: Growing up with Diabetes: Children and young people with diabetes in England*.
<http://www.rcpch.ac.uk/Research/Research-Activity/Completed-Projects/National-Diabetes-Survey>

Smaldone, A., Ritholz, M.D (18 January 2010 online) Perceptions of Parenting Children With Type 1 Diabetes Diagnosed in Early Childhood. [www.jpedhc.org/article/S0891-5245\(09\)00277-6/abstract](http://www.jpedhc.org/article/S0891-5245(09)00277-6/abstract)

Stewart, I., Joines, V. (1987) *TA Today: A New Introduction to Transactional Analysis*. Nottingham Lifespace.

