

# Meaning in life experienced by parents of children living with diabetes

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## Abstract

In this study, nine parents of children living with well-controlled diabetes participated in semi-structured interviews to explore how they make meaning of living with a child with diabetes. Creating a state of normalcy that incorporates the diabetes care plan, empowering their children to successful transition to independent care, positive relationships with their medical team as well as acquiring and sharing diabetes-related knowledge and skills add to the meaning in life of these parents. Health practitioners should facilitate conversations with parents to help them realise their motivation for adhering to the diabetes care plan.

## Keywords

adherence, children, diabetes, family, meaning in life

## Introduction

Diabetes is a chronic condition that requires various management behaviours to live a normal, active and high-quality life with few restrictions (Van der Merwe, 2015). The diabetes care plan involves regular blood glucose testing, injecting insulin, restricting food choices and regular exercise (National Diabetes Statistics Report, 2014; Silverstein et al., 2004; Van der Merwe, 2015). Young children are not able to make lifestyle choices or completely adhere to the diabetes care plan without the input or care of their parents. Parents play an invaluable role in reassuring their child that their condition is manageable, helping with testing and insulin tasks, renegotiating roles and preventing and intervening in family conflict relating to diabetes management (Chiang et al., 2014). For most children, their parents, more specifically their mothers, are the earliest and probably the most crucial source of support enabling them to manage their diabetes (Wiebe et al., 2005; Wysocki and Greco, 2006).

The negative psychological experiences of parents managing their child's diabetes are well documented. Parents are faced with the challenge that they must learn to balance their child's chronic condition with providing a healthy environment for the rest of the family (Barlow and Ellard, 2005; Cohen, 1999; Lewin et al., 2006; Waters et al., 2017; Wysocki et al., 2000). Resultantly, parents of children living

with type 1 diabetes report elevated levels of parenting stress, depression, anxiety and sleep problems (Hansen et al., 2012). These negative experiences falls well with traditional thinking in psychology: focused on pathology and the medical model of illness and pain. Within this paradigm, the focus is on understanding what is wrong with people in order to assist them to function better. This study, however, falls within the positive psychology paradigm, focusing on ways to enhance the quality of life and promoting optimal functioning (Wissing, 2014). Studies supporting this shift in research indicate that parents who have a collaborative relationship with their child living with diabetes experience improved emotional functioning as well as better treatment adherence (Delamater et al., 2014).

The central feature of human life is the pursuit of meaning and that people make their own meaning by seeking and creating their own understanding of the broader purposes in life (Baumgardner and Crothers, 2010; Frankl, 1964; Park, 2013).

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Even though meaning and purpose are sometimes used interchangeably, literature suggests that meaning is superordinate, consisting of two dimensions, namely: comprehension (understanding your life and how one fits into the world) and purpose (overarching long-term aspirations and the motivations towards those goals) (Steger, 2012).

Stressful events in some cases can challenge a person's meaning in life, and these circumstances can result in an effort to reintegrate the appraisal to an individual's meaning system. People thus create meaning in a process of meaning-making through 'the restoration of meaning ...' (Wissing, 2014). An outcome of this meaning-making process is successful adjustment and a meaningful life which acts as a buffer against personal distress and relates forward to enhancing physical, psychological and mental well-being of people (Park and George, 2013; Wissing, 2014). Jim and Andersen (2007) found that meaning mediates the relationship between social and physical functioning and related stress in cancer survivors. Furthermore, research has found that people who believe that their lives have meaning, appear to experience wellness in many aspects (Bonebright et al., 2000), including better self-related health and health-related quality of life (Scheier et al., 2006).

Studies relating to type 1 diabetes primarily have a quantitative approach and are conducted from a medical point of view with extensive reflection on global concerns about the illness and how to monitor and control treatment (Eppens et al., 2006; Marshall et al., 2009; Vollrath et al., 2007). While there are qualitative studies about the parental perceptions of children living with diabetes which contribute to our knowledge base (Hatton et al., 1995; Lowes et al., 2005; Miller, 1999), no significant study about the experience of meaning of parents adhering to the diabetes management regimen has been undertaken from a qualitative, positive psychological perspective. This study attempts to fill the gaps in literature by aiming to investigate how parents with children with well-controlled diabetes make meaning of living with diabetes.

## Methods

### *Rationale for qualitative design*

A qualitative approach with a subtle realist perspective (Cohen and Crabtree, 2006; Willig, 2001) was used to explore the experience of meaning in life of parents achieving good diabetes control in their children.

### *Participants and recruitment*

Purposive sampling was done to select participants who conformed to the following criteria: they had to be parents of children aged 12–18 years; the child had to be diagnosed with type 1 diabetes mellitus more than 12 months previously; were an enrolled patient of the abovementioned Centre for Diabetes and Endocrinology (CDE) and to have had maintained an HbA1c of 64 mmol/mol or less during

the preceding 12 months. Although the International Society for Paediatric and Adolescent Diabetes (ISPAD) prescribes an HbA1c of 58 mmol/mol, it was decided, in consultation with a team of medical experts to also include participants with an average HbA1c up to 64 mmol/mol. This was done to allow more participants to take part and is still within the prescribed guidelines of the CDE (2015) (HbA1c is also known as glycated haemoglobin, as it gives an indication of how well diabetes is managed). The researchers excluded individuals who were currently undergoing psychotherapy and those suffering from another chronic medical condition that could impact diabetes management.

Participants received either an information leaflet or saw advertisements placed on the 'Youth with Diabetes' Facebook page, in the Diabetes Lifestyle Magazine or the SA Journal of Diabetes. Potential participants could then contact the researcher for more information. Once the screening process was complete, a date for the interview was set. The final sample consisted of nine mothers (average age of the children in this group was 12 years), with an average HbA1c 55 mmol/mol.

### *Ethical considerations*

Ethical approval of the study was granted by the North-West University Institutional Research Ethics Regulatory Committee (NWU-IRERC), with reference number: NWU-HS-2016-0048. Independent informed consent was obtained from participants to as taking part of this project was voluntary. Participants were assigned codes to ensure confidentiality and anonymity, and consent forms were stored separately from the codes list. Data generated were stored securely, and statements used in reporting the research were also anonymised. Each participants received a summary of the findings.

### *Data generation*

Semi-structured interviews, on average lasting 45 minutes, were conducted by the researcher. These interviews were scheduled to coincide with their next scheduled visit with their healthcare professional. Informed consent was obtained by an independent person before the interview started, and interviews were conducted in a comfortable and private room. Interview questions included: can you tell me about your experience in terms of managing (the child's name) diabetes? how does managing (the child's name) diabetes influence your meaning in life? and how does managing (the child's name) diabetes influence your well-being? Data generation continued until data saturation was reached.

### *Data analysis*

All interviews were audio recorded and subsequently transcribed verbatim. Thematic analysis (Braun and Clarke,

2006, 2013) was used to identify themes within the data. ATLAS.ti version 7 (qualitative data analysis and research software) was also used to order data.

The co-coder independently analysed the transcripts in order to validate the analysis done by the researcher and reviewed all audio recordings to verify that findings were interpreted appropriately and interpreted within context. Several meetings were held with various experts (including medical professionals, nurses and dieticians) during the data generation and analysis phase to ensure the validity and reliability of the data and how it was interpreted. Results were also checked with participants after data analysis.

## Results

In exploring the experience of meaning in life of parents living with a child with well-controlled diabetes, a number of themes were identified. These themes not only provide insights into parental motivation for managing diabetes well (purpose), but also gives information on strategies they follow in managing diabetes that adds to their motivation or meaning-making.

### Theme 1: creating a state of normalcy

The participants in this study viewed diabetes as a manageable chronic disease that they had to adjust to in order to create a new normal. Very little reference was made to ‘illness’, ‘problem’ or ‘sickness’. One participant said, ‘it is not necessarily a death sentence’ (P4A), while another noted, ‘it’s just actually more a lifestyle management’ (P2C). Participants saw diabetes management as ‘a long journey ... and it’s changing and we’re up for it changing all the time’ (P3C). ‘Finding a new normal is important’ (P1A), and that others should ‘just treat him as a normal adolescent’ and that other’s behaviour towards him is ‘not in any way hypersensitive or hyper vigilant ... That’s important for A1 otherwise it just feels (like) a stigma ...’ (P1A).

Participants were motivated to create a new normal for their child and family. Participants felt that normalcy should be redefined when caring for a child living with diabetes and that they should raise their child to be as normal as possible and not be treated any differently. Participants’ beliefs about the condition of diabetes and the process of adjusting to it was prominent in achieving this normalcy, even though the participants knew that their child had to do things that other children need not do in order to manage their diabetes well.

### Theme 2: empowering their child to manage diabetes independently

Finding a new normal helps participants to empower their children to take over the management responsibility when they are old enough. One participant commented that she is ‘trying to get (him) to think for himself’ (P6A) and ‘... you

want to empower them ... experience the victories as they master and manage ...’ (P1A). Participants who manage to help their children take ownership of the condition, felt more relaxed and content over time.

Participants were motivated to empower their child living with diabetes to successfully transition from dependent care to independent care, and part of this journey entailed the transfer of beliefs about diabetes and the set of management behaviours that are necessary to achieve and maintain good diabetes control.

### Theme 3: positive relationships with the medical team

Participants noted the importance of the medical team, be it the endocrinologist, the diabetes educators or a nurse in hospital: ‘... have full trust in them, be open with them, make them your friends’ (P2A). Not only did these practitioners provide participants with the necessary information regarding the management of the condition, but they are also the people whose parents come to confide in when things are going wrong. One participant reflected,

anything that happened that I didn’t know the answer to I wrote down and when I first came to Dr. X I used to have lists of questions and that was my way of understanding ... My way of learning. (P2A)

The medical team does this by ensuring that parents can always reach them when they have concerns or problems. Another participant commented that,

it is important to know that you can contact Dr. X at any time of day or night if you have a problem, and he or someone in his team will tell you what to do in your crisis situation. (P3A)

Positive relationships with the medical team not only motivated participants to adhere to the diabetes care plan but also served as a resource, a strategy to assist them in adhering to the diabetes care plan.

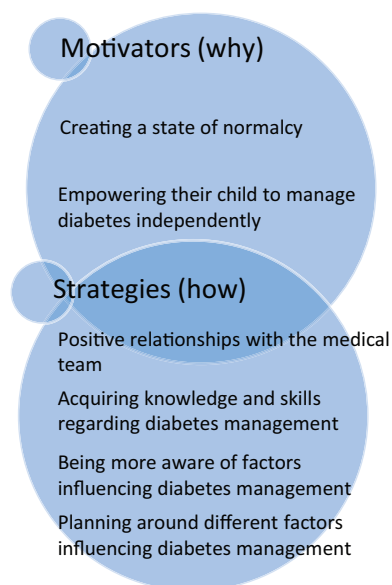
### Theme 4: strategies parents employ to successfully manage their child’s diabetes

Participants employed specific strategies in managing diabetes, which includes acquiring knowledge and skills regarding diabetes management, and being more aware of and planning around the different factors that influence their child’s blood glucose levels. Knowledge informed beliefs about diabetes and provided an avenue to seek out successful management behaviours. One participant said, ‘the more we learn and the more you know, the more empowered you will be to cope’ (P1A). Sharing knowledge also contributed to other’s understanding of the condition. One participant

commented that to educate others made ‘... a world of difference’ (P1C). Participants specifically focused their educational efforts on schools because when the school and the teachers receive training on diabetes and the management thereof, that it would give them some peace of mind as their child’s glycaemic levels will be monitored and better controlled. Having knowledgeable and supportive friends at school also added to participants’ peace of mind, ‘his friends also know how to use the emergency injection that is in his suitcase if anything should happen’ (P4A).

Participants always had a personal sense of awareness regarding their child’s condition. This awareness was reflected in being mindful about how the condition can be managed in terms of eating: ‘you are much more aware of what you buy to eat’ (P3A), and exercise: ‘I can see the difference when he’s done exercise’ (P6A). This increased awareness lead participants to plan ahead, which in turn alleviated pressure and helped to balance different roles, as one parent said that ‘having a plan helps’ (P1A). Different plans worked for different participants. For some participants, planning consists of capturing their child’s life on an Excel spreadsheet or spending time weighing and measuring food over weekends to take the load off of them during the week. For others, it might simply be to regularly consult with their child to see if the routine is still working or if something else could be done to make their lives and the management of the condition, a bit better.

The following diagram attempts to visually show the results as discussed above:



## Discussion

The aim of this study was to explore the motives and drivers of parents achieving good diabetes control in their children. The prominent themes identified can be divided into

two broad categories: what motivated parents to adhere to diabetes care plans (the why) and also which strategies they employed in adhering to diabetes care plans (the how).

The most prominent reason for parents to adhere to the diabetes care plans were their motivation to create a state of normalcy that incorporates the requisite diabetes behaviours. Parents in this study viewed living with diabetes as a long journey that they were willing to embark on. On this journey, meaning was restored (Wissing, 2014), and new reasons or goals for parents emerged as they reappraised the management of diabetes for their child. Successful education and transition of care from dependent parental care to independent care was seen as a specific goal worthy of achievement. This motivated parents to not only adhere to the diabetes care plan, but also to empower their child towards effective independent diabetes care.

Parents experienced positive relationships with the medical team as both a motivator and a strategy to adhere to the diabetes care plan. Positive relationships are at the core of experiencing meaning, especially where dreams or missions are shared between people (Wissing, 2014). Parents experienced the medical team as supportive in managing their child’s diabetes, which motivated them to adhere to the diabetes care plan. Parents further viewed the medical team as an important source of information, which formed part of their strategy to manage their child’s diabetes well.

Comprehension is one of the domains of meaning (Steger, 2012), which is evident in parents strategy of acquiring diabetes-related knowledge and skill to get a better understanding of the living with diabetes, for themselves, and also to create awareness and understanding for others. This understanding informed other strategies including being more aware of influences in diabetes management and planning to address these.

The question left unanswered by this study is how the reasons (motivations) and strategies interact to form a unique pathway or trajectory for each parent living with a child with diabetes in the process of making meaning of managing this disease.

## Conclusion and implications

Conducting parent-centred qualitative research allowed for the exploration of experiences of parents regarding the adoption and implementation of the requisite diabetes management behaviours in achieving good diabetes control. Meaning and meaning-making were identified as an important facilitator in this process. This research could potentially inform practitioners on how to support parents of children with diabetes to find meaning in the management of diabetes. Friedrich Nietzsche once said, ‘He who has a why to live for can bear almost any how’. Finding the meaning, finding the why could help to motivate parents to

adopt and maintain the demanding behaviours required to successfully manage diabetes – the how.

One of the major limitations of this study was the small sample size and that they were drawn from a privileged cohort that had access to a specialist multi-disciplinary care team. This is also one of the strengths in that we were able to interview parents managing to achieve good diabetes control in their children. Future research should endeavour to sample a broader demographic and include parents who are struggling to attain good diabetes control in their children. Further exploration could identify parent and patient-specific barriers and obstacles that are preventing parents from achieving good control while having access to the same specialist multi-disciplinary care team.

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