

Caregivers of children with diabetes mellitus: challenges of caring for and perceptions of consultations in a South African public sector context

BL Dhada^{a,b*} and DR Blackbeard^{c,d}

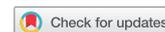
^aDepartment of Paediatrics & Child Health, Grey's Hospital, Pietermaritzburg, South Africa

^bDepartment of Paediatrics & Child Health, University of KwaZulu-Natal, Pietermaritzburg, South Africa

^cDepartment of Clinical Psychology, Grey's Hospital, Pietermaritzburg, South Africa

^dDepartment of Psychiatry, University of KwaZulu-Natal, Pietermaritzburg, South Africa

*Corresponding author, email: dhadab@gmail.com



Background: Understanding caregivers' challenges in caring for children with diabetes mellitus (DM) and their perceptions of consultations with the multidisciplinary team (MDT) may be valuable in assisting in achieving control.

Methods: Using a qualitative descriptive design, anonymised, transcribed recorded data from semi-structured interviews with a purposive sample of caregivers were thematically analysed in three areas: (a) challenges experienced in caring for their child, (b) feelings around MDT consultations pertaining to helpfulness, support and diabetes education, and (c) suggestions for clinic improvement. University of KwaZulu-Natal ethics committee approval and informed consent were obtained.

Results: All caregivers ($n = 14$) were female with a mean age of 38 years. Total diabetes caring experience was 47.4 years. The primary caregiver was the mother in nine interviews. Ten interviewees were unemployed. The children's ages ranged from 3 to 15 years with mean age at diagnosis of 6.7 years. Caregivers' challenges in caring were reflected in two global themes: 'DM care is difficult' and needs a 'process of adjustment' over time to accept and meet demands. These included emotional, practical, financial, behavioural and social challenges. Caregivers' feelings regarding overall consultations were mostly positive, including satisfaction. The MDT's helpfulness and support were perceived as patient-centred and meeting education and care needs. Negative feelings were frustration and boredom. Clinic improvement suggestions included shorter waiting times and seeing the same doctor for continuity of care.

Conclusion: Caregivers in South Africa experienced caring for children with DM as difficult, requiring an adjustment process. Perceptions of consultations were mostly positive. Relevant clinic improvements were suggested.

Keywords: caregiver; care consultations; children; challenges; diabetes; perceptions

Background

Diabetes mellitus (DM) care in children is complex, and requires the active support and involvement of parents or primary caregivers along with healthcare providers (HCPs) to effectively manage this chronic, life-limiting disease. A primary caregiver may be defined as 'a person who cares for, nurtures, loves and looks after one or more children; the role is similar to that of a parent'.¹ Primary caregivers may be members of the immediate or extended family, foster family or other guardians. The diabetes-specific and general support needs of children living with this long-term health condition (LTHC) vary according to growth and developmental stages, individual characteristics, and characteristics of family and social environments. Diabetes-specific tasks are an additional care burden above the usual emotional and practical support offered by parents or primary caregivers.^{2–4} Caregivers therefore carry the responsibility for demanding daily care, support and supervision. Hence, interactions with HCPs such as a multidisciplinary team (MDT) include not only clinical care but also addressing challenges of support and supervision.^{4–6} More research and international standard treatment guidelines for DM are recognising this aspect of care and include information on psychosocial, educational and support considerations and interventions for the children and their families.^{2–6}

Whereas acute illnesses have a defined endpoint or cure with return to normal pre-morbid state after recovery, LTHCs such as DM involve gradual shifts in responsibility of care from the

adult caregiver to the developing child and adolescent with life-long care goals. Providing appropriate support and supervision for the child's developmental needs can lead to caregiver stress, diabetes-related distress and other sequelae.^{7–14} Much more research into parents' or caregivers' lived experience in caring for a child with a LTHC, including DM, has been reported from the developed world compared with developing world countries. Findings from the review of qualitative studies from high-income countries (HIC) included themes around 'parental impact, family disruption, difficult diagnosis, illness management and social context'.⁷ In summary, 'immediate concerns' were 'making sense of the condition, loss and grief, learning about the condition, monitoring symptoms and responding to changes in child's condition, interacting with health professionals, and managing disruption'.^{7–9} 'Ongoing challenges' identified were 'chronic sorrow, adapting and coping, physical and emotional overburden, mastering technical aspects of care, collaborating and working in partnership with health professionals, co-ordinating services for the child, maintaining normality, seeking social support systems and maintaining relationships'.^{7–9} Additional themes recorded include: 'fear of child's failing health, information sharing, service transition, other family member with chronic illness, shielding or avoidance and language and cultural barriers'.^{7–9,13,14} Studies on caregivers' experiences in low- and middle-income countries (LMIC) have similar themes and also report experiences of shock, anxiety, depression, fear, guilt, shame, poor quality of life (QoL), psychological problems and inadequate care and

support in schools.¹⁵⁻²¹ The role of caregivers and their coping mechanisms are therefore essential aspects of MDT-based, patient-centred care for childhood DM.^{18,22-25}

Successful communication, which starts with listening to and understanding the experiences of caregivers, can be important for improving patient outcomes such as metabolic control and QoL. The clinic consultation, a regular face-to-face care interaction with principal members of the MDT, serves as an extremely valuable opportunity to review care and to implement plans to achieve treatment goals.²⁶ In this study of parents' experiences and views on consultations the following issues were identified: 'styles of communication, complex medical language, contradictory advice, variations in practice, anxiety and poor recall of information with preference for written instructions, feelings of being cross-examined and judged leading to non-disclosure, disengagement and non-attendance, the child's presence in the consultation being distracting, structural and organisational features of clinics like time pressures preventing questions, and parents want and appreciate consistent messages from HCPs'.²⁷ To ensure that MDT consultations meet the intended goals, enquiring about consultations from caregivers was identified as a possible area for care improvement.²⁸

There is clear evidence that health and QoL outcomes for citizens in under-resourced countries are worse, including for those with DM. Management of non-communicable diseases (NCDs) is especially affected by constraints in health system design, funding and functioning. These constraints include people, institutions and resources, organised by policy and with appropriate responsiveness to the needs of the people served by that health system.^{19,26,29-32} In acknowledgement of the constrained and variable availability of resources in current health systems, the International Society for Paediatric & Adolescent Diabetes (ISPAD) consensus guidelines cater for these differences by offering three resource-based care guidance options. These are (1) state of the art, 'comprehensive care', (2) the standard of care, 'recommended care' guidelines and (3) the basic, 'limited care' option.

The limited care guidance appendix describes factors that contribute to poor DM care and high-risk glycaemic control. These factors are: 'imbalances in geographic, economic and scientific development, gender discrimination, limited access to insulin and supplies, inadequate transport and storage of insulin, limited access to care, cost of care linked financial burdens, psychosocial instability, detrimental health beliefs, shortage of HCPs with DM expertise, lack of awareness and knowledge among HCPs, lack of family or peer DM awareness and education, poverty, food insecurity, diet lacking diversity, illiteracy, little or no job security and poor education status of family. Some positives are robust family structures with support from extended family members and limited "junk food" availability.^{26,32} Therefore, research to explore patient and caregivers' experiences was relevant to understanding such challenges and to potentially inform healthcare improvement (HCI), health systems design, funding and functioning to address needs adequately in our setting.

Motivation for the study

The researchers wanted (Aim 1a) to describe the experiences of caring for a child with DM and care consultations with the MDT from the caregivers' perspectives in the South African public health sector in order (Aim 1b) to confirm and provide a more

detailed picture of previously published focus-group local needs assessment.¹⁸ As reported in similar studies, the data could also (Aim 1c) help the MDT better understand the challenges faced by our caregivers and their children. This knowledge can (Aim 1d) inform clinical practice including communication with patients and caregivers, guide support systems, and contribute to HCPs' as well as community awareness and education concerning the experiences of living with DM in this treatment context. Furthermore, it would (Aim 1e) enable an evaluation of similarities to and/or differences from experiences reported in other settings.^{7,8,11,13,27}

The researchers were concerned with the caregiver's perceptions of clinic consultations for several reasons. Sensitive communication with accurate information about DM (Aim 2a) has been found to be an important factor in the successful emotional adjustment to newly diagnosed DM in children.²⁶⁻²⁸ This then sets the scene for effective future DM care. The paediatric diabetes consultation with the child-caregiver dyad is mainly for (Aim 2b) reviewing clinical progress and problem identification. This time is also (Aim 2c) an opportunity for updating diabetes education and adjusting treatment regimens. In addition, it is an important context for (Aim 2d) supporting and motivating the children and caregivers with treatment adherence.^{23,28} Therefore, understanding caregiver perspectives on what quality and how we provide care can assist with (Aim 2e) directing improvements to make consultations more productive and possibly influencing adherence towards better metabolic control and good QoL.^{33,34}

Hence, the purpose of this study was to generate findings that were not only relevant for DM clinical practice and further research but also to contribute informatively towards integrating care into daily living, improving the experiences and QoC and assisting in directing clinic improvement in our paediatric DM service.^{33,34}

Methods

Ethics

Study approval (BE514/15) was obtained from the Biomedical Research Ethics Committee of the University of KwaZulu-Natal (UKZN) with site approval from Grey's Hospital and KwaZulu-Natal (KZN) Department of Health (HRKM70/16).

Study design

Qualitative research can be useful in documenting what living with a condition, caring for a loved one and interactions with HCPs means for individuals, caregivers and families, as this experience cannot be numerically measured. Qualitative descriptive (QD) design is an appropriate approach for describing experiences of individuals and groups in their natural settings such as at home, in school, in a clinic or hospital.³⁵⁻³⁷ QD is based in a realist framework; the conceptual basis for QD is to develop detailed naturalistic accounts that describe phenomena in their context without imposing theoretical constructs. The data produced are therefore an attention to the details and unique qualities of the transcript with a process of analytic induction through which theoretical constructs can be developed. This is the process of finding the themes and concepts in the collected data and revising these until they best express the data.³⁶⁻³⁸

Qualitative research also has a role in gauging quality of care (QoC) as measured by patient satisfaction with services or as

reported by user (patients or caregivers) experiences of care and therefore a role in informing HCI towards high quality health systems.^{16,21,22,33,34,36,39} QD was thus carefully selected as the approach for this study, in order to give close attention to the detailed experiences of the caregivers and from this develop a conceptualisation of the data to better understand caregivers' challenges and their perceptions of care consultations offered in this clinic, in order to meet the aims of the study.^{25,36}

The arrangement of care in this clinic was guided by previous research. It follows a local adaptation of the 'Patient-Centred Care Model for Childhood Diabetes (PCCM-CD)' and the more detailed 'Chronic Adaptation Model for Chronic Illness—Diabetes Mellitus (CAMCI-DM)'.¹⁸ In this study, we are focusing on a deeper description of the caregivers' lived experience, loosely guided by the 'mediating variables' in the PCCM-CD and 'characteristics and responses towards adaptation' in the CAMCI-DM. In addition the study design was guided by the 'Study' component of the Institute for Healthcare Improvement's (IHI) 'Model for Improvement' using iterative 'Plan-Do-Study-Act' (PDSA) quality improvement cycles and especially the aim of improving the experience of care as expounded in IHI's Triple Aim.³⁹⁻⁴³ A detailed explanation of these models is beyond the scope of this paper.

Site

The Paediatric Endocrinology clinic at Grey's Hospital, a tertiary, public sector hospital in Pietermaritzburg (PMB), KZN, South Africa (SA) was the site for the research. The hospital serves a population of over 1 million children under 15 years of age in the western inland half of the province. The clinic was led by a paediatrician with a special interest in paediatric DM with over 10 years of experience in caring for children with DM and consultative access and referral to a paediatric endocrinologist at the central provincial hospital.

Participants

Participants were caregivers of children with DM attending the clinic. An informed consent and assent process was followed. Participation was voluntary with no incentives or penalty.

Sampling

A purposive, maximum variation sample was selected.³⁷ The purposive aspect was necessary to ensure that inclusion criteria were able to secure rich content from caregivers who had a reasonable length of lived experience. Maximum variation was achieved using demographic characteristics of age of caregiver, differing durations of caring, relationship to patient, caregiver's employment status, and the child's DM type. While gender was considered, we were unable to secure variation on this characteristic due to the absence of male caregivers who met the inclusion criteria and attended the clinic during the study period. However, from the researchers' experience in the clinic, only a handful of male caregivers did attend. Data saturation, determined by the researchers during data analysis, was achieved when each item on the interview guide was adequately addressed with no new emerging themes that contributed to the findings arising from the latter interviews.⁴⁴ This was deemed to have been reached when 14 caregiver interviews were completed over six months. Care was taken that the interviews took place without affecting clinic flow or waiting times. No caregivers declined participation or exited.

Inclusion criteria

Interviewees had to be 18 years or older, with an established caregiving relationship with the child (not simply an accompanying adult), and attending the clinic for three or more visits.

Exclusion criteria

Interviewees must not have attended the clinic fewer than three times, not be simply an accompanying adult, under the age of 18 years, a caregiver of a child without DM or a caregiver of a child in severe medical crisis at the time (for example, diabetic ketoacidosis).

Data collection

Fourteen semi-structured interviews were conducted using an interview guide (see Appendix for interview guide) with open-ended questions focusing on three areas: (a) challenges experienced in caring for their child, (b) feelings around MDT consultations pertaining to helpfulness, support, and diabetes education, and (c) suggestions for clinic improvement. A further six respondent validation interviews were conducted after preliminary analysis of the data to verify accuracy of thematic analysis. Translations were verified with staff from the Department of African Languages Studies at UKZN. Interviews were performed by three postgraduate psychology students who were trained by the primary researchers in facilitating semi-structured interviews. All interviews were individual and conducted in a private office adjacent to the clinic. Debriefing meetings were held by the primary researchers with the interviewees as a reflexive practice to maintain consistency and to address interview biases. The debriefing process was also important for identifying if any participant was emotionally distressed or had reported social problems requiring assistance, in which case a plan was in place to offer referral to social work or psychology services at Grey's Hospital. This referral process was the usual practice in the MDT-based clinic functioning. Interviewees had been fully orientated to the clinic context and care framework as student observers before commencement of the interviews and were encouraged to share their ideas and insights. Interviews were conducted by participant preference in either isiZulu or English. QD methodology principles were used to guide data collection.^{35-37,44,45}

Data collation, analysis and quality

Interviews were digitally recorded, transcribed and anonymised to constitute primary data. IsiZulu data were translated into English by interviewees. Reliability was maintained by triangulation of interview field notes and debriefing discussion. The field notes included both a condensed account of the interview data (keywords, sentences or quotations from the interviews) and the interviewer's experience, ideas and insights.⁴⁶ Transcription methodology and procedures to maintain quality were in keeping with QD as a naturalistic, realist approach.⁴⁷⁻⁴⁹ These procedures included respondent validation, transparency, reflexivity and prolonged engagement. Respondent validation interviews (or member checks) allowed for the interviewees to verify the accuracy of the tentative ideas and themes emerging from the initial interview and provide further clarity on any points they had made. Transparency was maintained by keeping documentation sheets with demographic and diabetes-specific data for each interviewee. The debriefing discussions were the main way in which reflexivity was maintained. These reflexive discussions included considerations of (1) personal biases, (2) avoiding leading questions, (3) participants' assumptions and considerations and (4) using the interview guide in a way to maximise participant agency (such as asking

open-ended questions).⁵⁰ Prolonged engagement was maintained through triangulation of methods (multiple interviews; the transcripts as the primary data source with field notes; debriefing and data analysis discussions as further levels of engagement).

Transcripts and interviewer notes were analysed with thematic content analysis, a structured approach for identifying and categorising themes from text. The credibility of the data analysis was verified with analyses by two raters, triangulation (transcripts; interview notes), debriefing and other reflexivity processes (research team discussion).^{35,44,45,47,48,50–52} Demographic and diabetes-specific data were analysed using Microsoft Excel® (Microsoft Corp, Redmond WA, USA). In a recursive way, involving discussion and readjusting the thematic categories, the themes were adjusted until they best expressed the entire dataset comprising the transcripts triangulated with field notes as secondary sources.⁴⁴ Themes from the data were organised into three levels (global themes, organising themes and basic themes) and presented using tables and Thematic Network Diagrams, a tool for organising multilevel themes and their relationships.⁵¹

Results

Sample description

The sample statistics were a 'snapshot' of the clinic population. All the interviewees ($n = 14$) were female with a mean age of 38 (± 15) years, and a wide age range from 20 to 67 years. The mean duration of each caregiver's experience of caring for a child with DM was 3.4 (± 2.6) years, with a range between 5 months and 10 years. This range reflected likely differences based on the child's age at diagnosis. The primary caregiver was the biological mother in nine of the caregiver interviews. An aunt (3) or grandmother (2) were the other primary caregivers. Eleven families were 'not living together' with the child's biological father. That is, the family unit was separated with female caregivers bearing the care responsibilities in the home. The reasons for this were not elucidated in this study. Among the participants, 10 were unemployed and 2 were pensioners. These ratios were in keeping with the researchers' experiences of the profile of the users of this clinic (Table 1).

The children ranged from 3 to 15 years of age, with a mean age at time of caregiver interview of 10 (± 3.7) years. The age at diagnosis ranged from 3 months to 13 years 8 months, with a mean age at diagnosis of 6.7 (± 3.7) years. Thirteen children had Type 1 DM (T1DM) and were receiving insulin injections while 1

Table 1: Caregiver characteristics ($n = 14$)

Gender—female	14 (100%)
Age in years—mean (SD)	38 (± 15)
Primary caregiver—mother	9 (64%)
Primary caregiver—aunt	3 (22%)
Primary caregiver—grandmother	2 (14%)
Diabetes caregiving years (total)	47.4
Caregiver experience in years—mean (SD)	3.4 (± 2.6)
Caregiver employed	2 (14%)
Caregiver unemployed	10 (72%)
Caregiver pensioner	2 (14%)
Family living together	2 (14%)
Family not living together	11 (79%)

Table 2: Child characteristics ($n = 14$)

Gender—female	10 (71%)
Gender—male	3 (29%)
Age in years—mean (SD)	10 (± 3.7)
T1DM	13 (93%)
T2DM (no insulin)	1 (7%)
Age at diagnosis—mean (SD)	6.7 (± 3.7)

caregiver was caring for a child with Type 2 DM (T2DM) on oral medication. This was in keeping with expected proportions of T1DM and T2DM in a paediatric setting currently (Table 2).

Findings: thematic analysis

Themes were extracted from the data using analytic induction and were categorised into 'global themes', 'organising themes' and 'basic themes', presented in Thematic Network Diagrams (see Supplementary Material) and in Tables 3 and 4.

Caregivers' challenges of caring for their child with DM

The first global theme was identified as 'DM care is difficult' for caregivers (see Table 3 and Supplementary Figure 1), encompassing emotionally, practically, financially, behaviourally and socially challenging experiences. The second global theme identified was that a 'process of adjustment' was necessary in all these aspects of care (see Table 3 and Supplementary Figure 2). This dealt with caregivers' perceived experiences in adapting and moving forward from the challenges of DM care. This process appeared to be experienced differently according to the child's age and developmental stage. The caregivers identified that the adjustment process required them to be tenacious, resilient, resourceful, responsive and flexible.

Basic theme examples illustrating aspects from each organising theme are included below.

A. Emotionally for caregiver and child

DM care was experienced as emotionally difficult for both the caregiver and the child.

A mother of a 13-year-old who had lived with DM for 10 years described her experiences as destabilising at first and that she was scared and overwhelmed:

Caregiver A: 'you see I am going to be honest with you if I have to face when [child's name] was first diagnosed it was like I had lost my mind because I had always known it would happen in this family ... It was difficult and I didn't know where to begin helping her. I was scared but as time went on I accepted.'

There was the sense of additional and changing stresses as caregivers worked through their own emotions while continuing to support the child's treatment. A 34-year-old mother whose 12-year-old daughter had been living with DM for 17 months described her ongoing challenges of DM caregiving:

Caregiver B: 'it's quite difficult you've got to face new things with them every day. To see they don't get hurt, that kind of thing'

Table 3: Caregivers' challenges in caring for their child with DM

Global theme	Organising theme	Basic theme
DM care is difficult	A. Emotionally	
- Diagnosis	(a) Caregiver	1. Painful/sadness
- No cure, lifelong		- 'the pain'
- Injections		- 'heart sore'
- Many changes		- 'painful heart'
		2. Fear
		- 'scared'
		- 'see they don't get hurt'
		- 'something is gonna happen to her'
		3. Uncertainty/overwhelmed
		- 'don't know ... future ...'
		- 'face new things'
		- 'didn't know where to begin'
		- 'you never know if you doing enough or not'
		4. Loss
		- of normal child
		- of opportunities
		- of child's future 'lifelong'
		5. Grief
		- 'My God what did I do?'
		- 'What happened that caused my child to be diabetic?'
		- 'I cried and said it would have been better if I had it'
		6. Stress
		- 'lost my mind'
		- 'stressful'
		- 'stressed to the limit'
	(b) Child	1. Negative emotions
		'... crying with injections'
		'... he has doubts'
		'... he doesn't want to'
		'... he gets angry'
		'... very, very emotional and she gets depressed'
		'... she's hard-headed'
	B. Practically	
	(a) Diabetes-specific	1. Learning new tasks
		- SMBG* readings
		- Injecting insulin
		- Different insulins
		- 'Hypers' and 'hypos'
		- Corrections
		- Glucagon
		2. Accepting injections (most cases)
		3. Diet compliance
		- Many details
		- 'Carb counting'
		- 'Trial and error'
		4. Travel to consultations
		- Long distances
		- Overnight, long hours
		- '... very strenuous'
		- Siblings in care of 'neighbours'
		5. Unpredictable and erratic SMBGs
		- '... really confuses me a lot'

(Continued)

Table 3: Continued.

Global theme	Organising theme	Basic theme
		- Fear of severe hypo
	(b) Daily living	1. Tiring - 'I don't get enough sleep. I'm tired most of the times' - '... exhausting'
		2. Time-consuming - '... lot that happens'
		3. School - '... eats sweets, snacks' - Poor support - Educators lack understanding e.g. polyuria and hypes
		4. Play, sport, activities - '... long distances' - Caregiver 'must go too' or miss sport
		5. Others - Transport to hospital when acutely ill
	C. Financially	
	(a) Diabetes-specific	1. Specific diet - 'I can't follow the diet' 2. Insufficient glucose test strips - '... expensive'
	(b) Daily living	1. Social grant dependent, i.e. unemployed 2. Many dependents in family - '... there's a lot of us at home' - '... other child also needs money' 3. University fees 4. '... when kids grow up especially girls they want this and that'
	D. Behaviourally	
	(a) Child	1. Anger 2. Fear 3. Defiance
	(b) Siblings	1. Jealousy
	E. Socially	
	(a) Caregiver	1. No personal relationships 2. Leave or loss of job/work 3. Having a new baby/other children 4. Poor family support - Others are 'scared' - No partner support
	(b) Child	1. Stigma 2. Rejected by family
Process of adjustment	A. Emotionally	
- At each stage	(a) Caregiver	1. Negative to positive - Grieving process - '... as time went on I accepted' - 'I used to be terrible but I'm better now'
- Responsive		2. Stress - 'I got through it since I received counselling'
- Continual		3. Competence - 'I sleep most nights' - '... can live with' - '... it's just getting easier' - 'I now know I can do'
- Flexible	(b) Child	1. Improvement/accepting - '... does not cry anymore'

(Continued)

Table 3: Continued.

Global theme	Organising theme	Basic theme
	B. Practically	
	(a) DM-specific	1. Hyper and hypo symptoms - '... child is in trouble I can see'
		2. Finger pricks and injections - '... he is also used to it' - '... not a problem anymore'
	(b) Daily living	3. Improved diet compliance 1. Family support helpful (when available)
	C. Financially	1. Social grant income useful 2. Remained a problem for most
	D. Behaviourally	1. Care by psychologist
	E. Socially	1. Care by social worker

*SMBG—self-monitored blood glucose.

Table 4: Caregiver feelings of care consultations with the MDT

Global theme	Organising theme	Basic theme
Overall consultations	A. Positive feelings	1. Gratitude - 'I am very grateful' - '... to just thank them'
		2. Relief, sense of control - '... can live with this disease'
		3. Supportive/Friendly - '... can console you' - 'That makes me happy' - '... we are nothing without them' - '... they all very friendly'
		4. Helpful, competent - '... hospital helped me a lot' - '... doctors explain well' - '... they are very good' - '... if I'm confused ... make it quite clear for me'
		5. Satisfaction - '... we are well treated' - '... nurses treat us well' - '... hospital they fixed it' - 'I feel well taken care of' - '... do their jobs efficiently' - '... faster than before' - '... I am satisfied for now'
	B. Negative feelings	1. Boredom at visit - '... just sitting there waiting'
		2. Frustration - specific needs not met - group sessions repetitive
		3. Long waiting times
		4. Other hospitals to improve
		5. Medication available closer

(Continued)

Table 4: Continued.

Global theme	Organising theme	Basic theme	
MDT's helpfulness and support	A. Diabetes specific needs	1. DM knowledge and Information - '... helps increase my knowledge'	
		2. Practical care skills - '... dietitians ... teach us about food ... is helpful' - '... counselling helps'	
		3. Ongoing follow-up care - GM review downloads - adjusting regimens	
		B. Patient-centredness	1. Caring, loving, respectful - '... the way they treat the kids ... with respect-love'
			2. Inclusiveness
			3. Collaborative decision-making - '... they do not take decisions without you'
	4. Responsive - 'I have told them and they have fixed it' - '... been able to change the way they are working'		
	C. Problem-solving role	1. Resources - Grant application assistance - Food supplements	
		2. Advice - '... you will get what you can do' - '... try to find ways that help'	
	D. Access to group support	1. Not alone - '... not only your child ... can see other children' - 'We talk amongst each other and try to help one another'	
		E. Diabetes education	1. Relieves anxiety/empowering - '... was scared but now I'm brave'
	2. Self-efficacy & competence - '... can stand the diabetes' - 'I supervise the child'		
	3. Able to transfer to child - 'I have taught my child'		
	4. Satisfaction with education received - 'I was taught well' - '... taught me enough'		
	Clinic improvements	A. Waiting times	1. More doctors - '... add more doctors ... there's a lot of us'
			2. See the same doctor - '... different doctors ... things are moving slow'
		B. Continuity of care	1. See the same doctor - '... the doctors change a lot'
			2. Family consultations - '... families as a whole so they can all be taught'
		C. Care at other hospitals/clinics	1. Improve knowledge and skills - '... improve the hospitals close to us'
			2. Access to meds/consumables - '... transfer ... clinics closest to us'
			3. Troubleshooting skills
			4. Communication with clinic
		D. Insulin injections	1. Alternatives - '... another option ... besides having to inject'
2. Shorter needles (pharmacy) - 'Order enough' for children			

(Continued)

Table 4: Continued.

Global theme	Organising theme	Basic theme
	E. Other	1. '... assist us in offering discipline to the children'
		2. '... get recipes for the parents'
		3. More intensive dietetics advice

Caregivers also described the ongoing stress and anxieties associated with DM care and support. For example, a 29-year-old single mother of a recently diagnosed 3-year-old boy described the ongoing vigilance and self-doubt she experienced to be stressful:

Caregiver C: 'as the caregiver – ja – you have lots of choices to make and if you make the wrong decision you know and something happens then you're screwed [laughs] so ja I don't know – but other than that I think I used to be terrible but I'm better now – ja it's just getting easier ah I sleep most nights usually [laughs] but other than that ja I'm fine.'

The emotional stress and diabetes-related distress of the caregiver was very apparent in the above extract. The emotional process of the caregivers included fears, anxieties, losses, negative emotions and in some cases emotional pain. A 40-year-old mother of a 10-year-old boy who had been living with diabetes for 5 years described it as follows:

Caregiver D: '... first you have a problem that your child is sick and you can come here and find people that can help with what is in your mind about your painful heart – can console you and explain that it is not only your child that has this illness ... coming to the hospital is where you find relief actually – because you see other children and you see they are growing'

The clinic services included a support and diabetes education group facilitated by various health providers such as diabetes educator, psychologist, social worker and dietitian. It appeared to be in both the clinic consultations and the group interactions that caregivers experienced emotional validation, support and relief.

Emotional challenges among the children as experienced by the caregivers included denial or uncertainty, anger and frustration, bargaining and mistrust, low or depressed mood and a gradual process of acceptance in relation to loss and adjustment to living with diabetes. This grief response process seemed to also be the pattern of caregivers' own experiences. For example, a 67-year-old grandmother described her granddaughter's emotions as follows:

Caregiver E: 'the challenges maybe it's only one – it's that she sometimes has doubts – when she has to check – she has doubts and she doesn't want to check – she gets angry'

Here, it appeared that uncertainty and possibly mistrust of the self-recorded glucometer readings was very frustrating for the child. It was apparent that this can lead to feelings of discouragement and sadness, as described by a 26-year-old single mother talking about her 9-year-old daughter:

Caregiver F: 'I think the biggest problem is more of an emotional one with [child's name] because she is very dramatic [laughs] and she is a very loveable child so with the

other kids around her they keep eating stuff she can't eat ... and she gets very, very emotional and she gets depressed'

B. Practically

(a) *Diabetes-specific challenges and adjustments, including knowledge, skills and tasks.* Practical issues of DM care were experienced as challenging. Administering insulin was experienced as probably most challenging for caregiver and child, for example, as described by the mother of a 6-year-old who had been diagnosed at age 4 years:

Caregiver G: 'the hardship is just injecting the child part, it's not something that's easy—it's not easy – because sometimes you find that the child does not want to be injected ... when her sugars are high and you try to inject her – she says 'you're injecting me a lot!'

Other caregivers said day-to-day management like dietary management, continually checking blood sugar readings and correcting high and low sugar levels was also difficult and anxiety-provoking: 'difficult especially when she had to check her sugar ...', and 'I can't follow the diet'. The term 'sugar levels' was used by several of the caregivers to refer to glycaemic regulation. The administering of insulin by the other family members was perceived as stressful. This mother of a 4-year-old described these difficulties as follows:

Caregiver H: '... the family members you stay with do want to assist with injecting the child but they are scared – so sometimes you're the only one who's taking care of the child'

The practical DM-specific care tasks were perceived to be undeniably necessary but also burdensome and a constant source of worry to the concerned caregiver. Caregiver A described her challenges as an accumulation of stress and worry:

Caregiver A: 'I accepted it was difficult especially when she had to check her sugar levels – at other times she would leave me sitting in the room and take her machine and go and check herself in the dining room. When I asked her why she was going to another room she would tell me so that she can test herself – all of that is what ended up stressing me.'

Although the practical DM-specific care tasks were onerous, given time caregivers were able to improve care tasks with knowledge, skills and practice. They were able to build confidence, become comfortable and even troubleshoot problems as they gained competence. With this experience, caregivers adapted to the challenges and with a learning process the worry decreased. Caregiver C, the mother of a 3-year-old boy, indicated this with her words:

Caregiver C: 'I'm all right about the things I'm learning about sugar because a lot of things about sugar I know

them now – if I see that the child is in trouble I now know what I can do.'

Caregivers noted how they and the children adapted with time and became more accustomed to and accepting of the treatment as in the example below:

Caregiver C: '... when I inject him he doesn't cry anymore – because he used to cry – he also eats – when I call him to come and check he comes ... it's not a problem anymore.'

Caregiver E (the 67-year-old grandmother) expressed hope from her own learning that even the child could learn, improve and take on care tasks:

Caregiver E: 'I gain[ed] knowledge and she can also too maybe gain a bit on how to treat herself – what she must do and not do.'

(b) *Day-to-day living activities including in school.* Managing the child's daily living activities was reported to be difficult in many instances. A 28-year-old mother of an 8-year-old who had DM for 3 years listed symptoms which then impacted on the child's daily functioning:

Caregiver I: '... it becomes a problem when her sugar goes up – she loses weight – she urinates frequently ... yes it makes my heart sore when my child is sick.'

Other issues included managing DM at school, for example diet adherence and physical activities. For example, a caregiver noted that 'at school, he eats everything sweets, snacks, when he comes back his sugar is high'.

Employment was also an issue as stated by the following caregiver: 'you the only one who's taking care of the child, you can't even do anything. I was working, I eventually had to stop working.' It appeared that normal activities that often required little consideration without DM were experienced as significantly burdensome by the participants. They also felt that additional family support was especially helpful in managing daily living activities as these did not require DM-specific knowledge or skills.

C. Financially difficult with some adjustment

Finances were a constant difficulty and remained unresolved for most families, with many caregivers unemployed and/or subsisting on state pensions or social grants. For example, this caregiver mentioned that the child 'runs [out] of strip(s) quickly and I complained that three boxes are not enough and when they are finished I have to buy them and they are expensive'. Anxieties about future finances were noted: 'What I will do when the time comes and she needs to go to university since I am unemployed.'

An unemployed single mother described the financial challenges in a grant- and social pension-dependent household:

Caregiver C: 'I am faced with the fact that there's a lot of us at home, we are all dependent on our mothers that receive the elderly pension. None of us work, also I'm dependent on my children's government grant, and there are two of them. That's my livelihood, I cannot

afford to buy what my diabetic child needs, the things that he needs to eat. Whereas the other child also needs money at school to eat. In that sense I cannot afford.'

Financial challenges were a common theme in all the interviews, no matter the means within the family. The burdens of DM care were perceived to add disproportionately to the daily financial struggle of households and financial assistance was the area where caregivers felt that their families could be assisted most.

D. Behaviourally, including with siblings

Behavioural difficulties affecting the child and/or siblings were noted in several instances. For example, 'brother would get jealous that I'm paying more attention to her ...' and 'cause a lot of trouble at home ...'. The impact on others in the family was expressed in many ways: anger, disruptive behaviour, attention-seeking or discord in relationships, making for added care complexity and adjustment for caregivers and their families.

E. Socially

Caregivers noted a range of social difficulties impacting on themselves, the child or the family. Examples were: 'worries me is that her father and his family have rejected her since she has got diabetes', 'I don't know what her future holds', 'I haven't had a relationship in years', 'I'm tired most of the times' and 'it is exhausting as a grandmother'. This has had a great impact on caregivers' lives, as they each made committed efforts to care for their child with DM.

The interviewers observed that most caregivers' answers pertained specifically to their child's needs and rarely focused on themselves. The interviewers also noticed issues such as cultural differences, differing social registers among participants, and incongruent expectations between the MDT and family. These warrant further study.

Caregivers' feelings of care consultations with the clinic MDT

Caregivers' feelings of *overall consultations* with the MDT were grouped under two organising themes: positive and negative feelings. As shown in Table 4 (Supplementary Figure 3), the positive feelings were of satisfaction and gratitude. Most important from the MDT perspective was the feeling of self-efficacy, control and competence that caregivers were able to articulate.

One stated: 'I have the ability to live with a child that is diabetic.' Another: 'for a person who found out and was scared but now I'm brave, I can stand the diabetes'. This indicated that with time the caregiver and the MDT were able to meet care needs to satisfaction level. Negative feelings of boredom, frustration, long waiting times and poorer care at other hospitals, including lack of medication, were noted.

MDT helpfulness and support is shown in Table 4 (Supplementary Figure 4). Patient-centred communication during consultations was expressed as 'caring', 'respectful', 'loving' and 'informative'. Decision-making was collaborative involving parents/caregivers: 'What's important is that the doctors talk with you first as the parent and then you make the decision about your child.' Advice was helpful, as one caregiver reported: 'you will get what you can do' and another said 'try to find ways that can help'. MDT knowledge, skills and care were well received and were reported to have met caregiver needs. This was especially important with regard to diabetes education and training, as the

caregivers were able to express competence in daily tasks as described earlier.

Caregivers' suggestions on clinic improvement

Clinic improvements suggested are shown in Table 4 (Supplementary Figure 5) and included shorter waiting times, more doctors, improved continuity of care and family consultations. These made absolute sense and indicated caregivers were in tune with child's DM care needs such as continuity and consistency of care in a relationship with a knowledgeable and understanding healthcare team. Examples: 'doctors change a lot. This month you find a different doctor next month you find a different doctor', 'It's the waiting but maybe it is because they want to evaluate the patients properly' and 'have meetings with the families as a whole so they can all be taught'.

Another improvement request was to make medication and appropriate consumables reliably available at closer proximity to home: 'transfer our medication to the clinics closest to us because when we go to those clinics they do not give us any medications even if the child has run out of strips'. This was with reference to the multilevel healthcare system in KZN comprising primary health clinics/community health centres; district and regional hospitals; and tertiary and central hospital. While quality care close to home is the goal of this health system organisation, caregiver experiences suggest obstacles and barriers to care delivery still need attention. Finally, caregivers asked for more help with the practical aspects of dietary management, assistance with discipline and this caregiver's plea to find 'another option ... besides having to inject' insulin.

Discussion

In this qualitative study, we report a description of the challenges experienced by caregivers of children with DM, their perspectives on care consultations with the MDT and their suggestions for clinic improvement at a public sector, tertiary hospital in South Africa. In the care of children with DM and other LTHCs, more focus is being placed on the interactions between and experiences of the child, caregivers and MDTs to achieve therapeutic goals.^{3,34,36,39,41,43} Several strategies can add value towards patient engagement and help improve communication to positively influence behaviour patterns for better DM and QoL outcomes.^{50,52-56} Exploring and understanding experiences and how to use the information to achieve this is the key.^{34,36,43,54}

Caregivers' challenges in caring for their child with DM

Caregivers were able to paint a rich picture of their challenges in caring for their children with DM in this setting. The first global theme that 'DM care is difficult' emotionally, practically, financially, behaviourally and socially for the caregivers and children is consistent with experiences reported from studies across the world. This is an indication of a shared, almost universal experience with caring for this LTHC, irrespective of the context.⁴⁻²² The occurrence of general stress, diabetes distress, anxiety, fear, anger and even depressed mood among caregivers is evident around a diabetes diagnosis and ongoing practical day-to-day diabetes care tasks. Caregivers' experiences seem to be alike irrespective of the age of the child at diagnosis. It is also evident from their experiences that the child is initially fully care dependent and the caregiver has to shoulder a large care burden as described elsewhere.⁵⁷⁻⁵⁹ This impacts on all aspects of the caregivers' well-being, with changing

employment and relationship status too. The significant financial burden, linked especially to diabetic diet and glucose monitoring sticks, was seemingly weighing heavily on all participants interviewed.

The dependence on social and financial support was apparent from the results and was consistent with the public sector context as experienced by the researchers. Therefore, caregivers expressed gratitude for assisting with grant applications to improve finances. While financial issues are similar to other sub-Saharan and LMIC, the clinic had the following features not common to African contexts: the patients received insulin that was not determined by out-of-pocket payments; they also receive diaries, sponsored glucometers, limited glucose test strips, urine ketone test strips, and frequent consultations with regular HbA_{1c} testing. The service was free for under-sixes, and followed a 'scale of benefits' income-based approach for the rest. Other similarities to LMIC include the lack of adequate expertise at all levels of care, poor access to consumables and medication at hospitals closer to home and costly, long-distance travel for tertiary consultations. These access issues do not usually affect care to the same extent in better resourced HIC. These barriers make diabetes care life-threatening and possibly influence negative outcomes like poor control and increased frequency of complications.^{3,18-21,29-32}

Female primary caregivers, including some who are not the mother, are common in our setting and get little caregiving support or respite from care duties from male caregivers. This phenomenon is similar among other LMICs, especially in families living in poverty. These social determinants may have an influence or serve as further barriers to good outcomes for children in these communities. The negative effects of these difficulties are likely to be associated with poor metabolic control and QoL for the child with DM. Therefore, these factors warrant review during selection of diabetes care regimens for each child. Our caregivers experienced collaborative, patient-centred decision-making around care options that could serve as facilitators to improved adherence and outcomes.⁵⁸⁻⁶⁰ It is important to realise that the impact on the caregiver was onerous. Therefore, caregiver-based strategies to assist in identifying, managing and mitigating the challenges, including social determinants, need to be incorporated into routine MDT care in order to improve outcomes for the child. Research into specific interventions in this area may prove beneficial.

In this sample, the second global theme identified a 'process of adjustment' by caregivers being necessary to overcome the initial trauma of diagnosis, learning life-saving diabetes-specific skills, developing competence and hence confidence to face life with DM. This adaptation heralds an acceptance or triumph that is apparent in caregivers akin to a sigh of relief with the realisation that this LTHC is manageable. The findings show the resilience of families, who eventually accept the challenges of care and attempt to meet them. The themes described are consistent with experiences of caring for children with other LTHC including DM from HIC as reported in a systematic review where caregivers are attempting to balance daily living with disease-specific demands.^{61,62} Our caregivers expressed gratitude and satisfaction to the MDT for their role in supporting, educating and providing advice and therapeutic options when needed.

A difference in the reported care experiences and challenges to HIC, including the South African private healthcare sector, is the absence of experiences involving newer technologies that

would provide injection alternatives as requested by one of the caregivers. This would include insulin pumps and injection substitute devices used to reduce the number of injections experienced by the child. For the caregivers, the anxiety around not being able to check glucose values at school or when the child is asleep can be alleviated by continuous glucose monitoring sensors with remote alerts on caregivers' smartphones for abnormal values.⁶³ The main reason for this difference would be that the grant-dependent, poor financial status in this setting makes the available technologies out of reach.⁶⁴ If available, these technologies could assist in alleviating stress and anxiety experienced, make outcomes better, and probably have the potential for improving QoL for caregivers and children with DM. Internet-based monitoring, cloud downloads and computer-based education or support were also likely not to be possible.^{3,26,65}

Caregivers' feelings of care consultations with the clinic MDT

Caregiver perceptions of care consultations were perceived with both positive and negative feelings. The support, education and care offered by the 'knowledgeable', patient-centred and 'caring' MDT was perceived appreciatively with trust by the participants. The caregivers' satisfaction with care, evidence of self-efficacy and empowerment was encouraging.^{56,60,61} Similarities to sub-Saharan countries that were articulated by the caregivers included a lack of adequate expertise at all levels of care, poor access to consumables and medication at hospitals closer to home and costly, long-distance travel for tertiary consultations.^{3,18–21,30–32}

In gauging QoC, in line with the six aims of improvement from among the perspectives of the caregivers, care consultations with the MDT were mainly perceived as patient-centred. However, they were not timely (long waiting times), or equitable (quality varied between the tertiary site and hospitals closer to home). The efficiency, safety and effectiveness will need to be measured against norms and standards.⁶⁶ Overall, some degree of quality was expressed, as needs were being met, and satisfaction with care was noted.^{34,40,43} However, deficiencies identified by caregivers in the health system and clinical management were in line with care expectations for DM and need to be addressed adequately.^{67–69}

Interviewers' observation of caregivers focusing on the child rather than themselves warrants further exploration. Does it reflect selfless, positive acceptance or negative, reluctant resignation to the burden of care? This may have impact on sustainability of caregiving and provide areas of focus for future MDT interventions.

Caregivers' suggestions for clinic improvement

Clinic improvements suggested by caregivers were congruent with DM care needs worldwide.^{2–4} Continuity of care with knowledgeable, consistent, trusting family-MDT relationships is the expectation. The challenge for the MDT is to find innovative interventions and creative partnerships within available limited resources to meet valid expectations. The observation by caregivers of under-resourcing of medical staff, benefits of continuity of care by known providers, inadequate expertise or troubleshooting skills of staff, inconsistent medication and consumables supply at primary care facilities points to health system strengthening opportunities.^{26,29,31}

The system and infrastructure are mostly in place in the primary healthcare prioritised district health system adopted in South Africa. The staffing numbers and expertise need a boost. Possible solution strategies include promoting evidence-based guidelines and tool use such as 'Standard Treatment Guidelines'

and ISPAD/International Diabetes Federation *Pocketbook for the Management of Diabetes in Childhood and Adolescence in Under-resourced Countries*.⁷⁰ Training from tertiary sites with expertise to primary care facilities through outreach visits, experiential learning clinic visits, telemedicine and online activities should be among the priorities. These activities will also enhance relationships between tertiary and referral hospital doctors through shared expectations.²⁶ Better communication through telephone consultations, clear bi-directional referral letters and technology-based methods such as an email of glucometer downloads would possibly also offer a better service. Reliable medication supply of insulins and adequate consumables (pen-sets, needles, glucometers, glucose test strips, batteries for glucometers, computers and software for downloads) at sites close to home is possible with programmes currently in place in KZN. This would require committed planning, better prioritisation of resources and efficient implementation to reap the value of better control.^{60,61,69}

The knowledge obtained in this study remains in line with the PCCM-DM and the CAMCI-DM models reported earlier. In addition, the findings are consistent with the theoretical framework reported as 'The Logic of Care'.^{71,72} The child with DM is dependent and needs a caregiver. The caregiver requires to be supported by family. The clinical care is carried out by an MDT playing a role in educating, caring for and then supporting the caregiver and patient with long-term care. The MDT must learn what the challenges and experiences are for the patient and family, in order to understand the issues better so that we can educate, care and support better, to be more directed towards the needs of the children both as individuals and as a population of children with DM attending our clinic. The families must be an active part of a collaborative, patient-centred care effort, with an adjustment of care plans in accordance with experiences and perceptions that are described in order to achieve control and QoL.

Limitations of this study

Sampling fell short of maximum variation as no male participants presented to the clinic during the study period. While this is not unusual for the clinic, there are some male caregivers whose experiences have not been captured. Based on the pure description inherent in using QD design, any described themes or phenomena will have to be screened for in each patient-caregiver dyad as generalisation to all clinic users is inappropriate. Thereafter, changes or improvements will need to be tailored to each dyad's responses rather than making major organisational, design or other changes in the clinic.

Conclusion

With an increasing prevalence of NCDs internationally and as part of South Africa's 'quadruple burden', caregivers' experiences of caring for children with DM and perceptions of consultations have provided a valuable insight into their 'lived experience' and presented opportunities to improve care.^{2–4,36,40,61,66,71}

Caregivers' challenges in caring for their child with DM highlighted that 'DM care is difficult' and needs a 'process of adjustment' as care added further complexity to pre-existing hardships. Many studies have reported similar experiences worldwide.^{4–22} The findings painted the local picture well, and showed the tenacity and resilience required in meeting care, support and supervision responsibilities. Caregivers' views of their interactions with the MDT in care consultations were mainly positive and reflected that many stated aims of current paediatric DM care were being achieved in our clinic.^{2,3,26,34,43}

Negative feelings will become improvement targets. Based on the findings we conclude that some degree of quality care has been perceived to have been delivered with the resources available in the context presented. The challenge remains to use the knowledge gained to eliminate astute caregiver-identified barriers to care and direct relevant clinic improvement to increase quality, satisfaction and outcomes.^{26,40,43,53}

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Appendices

Appendix 1



GREY'S HOSPITAL

201 Townbush Road, Northern Park, Pietermaritzburg, 3201
Private Bag X9001
Tel: 033-897-3775 Fax:033-345-5278 Email: david.blackbeard@kznhealth.gov.za
www.kznhealth.gov.za

CLINICAL PSYCHOLOGY
DEPARTMENT

Information Sheet and Consent to Participate in Research

Date:

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Dear Caregiver

My name is _____. You are invited to consider participating in a study that involves researching **caregivers’ perceptions of child diabetes consultations**. The aim and purpose of this research is to **understand the challenges of caregivers of children with diabetes, especially caregivers’ experiences of diabetes consultations at the clinic**.

The study is expected to enroll about 20 caregivers from this clinic at this hospital only (Grey’s Hospital). It will involve the following procedures:

- (1) An interview with the researcher or the researcher and a psychology student. The interview questions will be about your experiences of diabetes consultations and any challenges you have as a caregiver.
- (2) A brief follow-up interview to check that we have accurately understood your views and perspectives.
- (3) The interviews will be audio-recorded and transcribed.

An aim of the study is to improve services by understanding the experiences of caregivers.

The study may involve the following risks and/or discomforts: emotional or social issues may be discussed. If required, you can be referred for Clinical Psychology or Social Work services by the researcher or any member of the diabetes treatment team. We hope that the study will create the following benefits: improved services through a better understanding of caregivers of children with diabetes in our local context to improve our health services. The study does not involve any additional treatment.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number_____).

Participation in this research is voluntary and participants may withdraw participation at any point. In the event of refusal/withdrawal of participation the participants will not incur penalty or loss of treatment or other benefit to which they are normally entitled. The participant may indicate in person or in writing at any time that they wish to withdraw from the study. If the researcher becomes aware for any reason that further participation in the study is not in the interests of the patient or the caregiver, this will be discussed with the consultant doctor and the participation of the caregiver will be terminated with reasons fully discussed with the caregiver.

The study will take place in the course of the usual running of the clinic without affecting the patient flow. No costs will be incurred by participants as a result of participation in the study. Information gathered through the interviews will be confidentially and securely kept in the Clinical Psychology Department for the proscribed period of time after which the information will be destroyed.

CONSENT TO PARTICIPATE IN THE RESEARCH

I, _____ have been informed about the study entitled **Caregivers of children with diabetes: experiences and perceptions of consultations**.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care to which I would usually be entitled.

I have been informed about any available compensation or medical treatment if injury occurs to me as a result of study-related procedures.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher **David Blackbeard** at (Clinical Psychology Department 033-8973775).

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BRECA@ukzn.ac.za

Signature of Participant

Date

**Signature of Witness
(Where applicable)**

Date

**Signature of Translator
(Where applicable)**

Date

Appendix 2



GREY'S HOSPITAL

201 Townbush Road, Northern Park, Pietermaritzburg, 3201
Private Bag X9001
Tel: 033-897-3775 Fax:033-345-5278 Email: david.blackbeard@kznhealth.gov.za
www.kznhealth.gov.za

CLINICAL PSYCHOLOGY
DEPARTMENT

Interviewer Topic Guide and Notes
Umhlahandlela wokuxoxisana kanye namanothi

Date of Interview/ Usuku lokuxoxisana: _____

Time of interview/Isikhathi sokuxoxisana _____

Interviewer names/Igama lomcwaningi: _____

Patient number/ Inombolo yesiguli: _____

1. Demographic characteristics

1.1 Caregiver/Umnakekeli

1.1.1 Gender/Ubulili:

Owesilisa Owesifazane

1.1.2 Age/Iminyaka _____ Iminyaka/years

1.1.3 Biological parents living together/Abazali abakuzalayo bahlala ndawonye

Yebo Cha

Okunye okwengezayo: _____

1.1.4 Caregiver's current employment status/Isimo somnakekeli sokusebenza:

Usebenza ngokugcwele Usebenza ngokungagcwele Ungumnakekeli ngokugcwele Akasebenzi Umfundi

Okunye okwengezayo: _____

1.1.5 Caregiver's occupation/ Indawo lapho kusebenza khona umnakekeli

:
Umsebenzi oqeqeshelwe Oqeqeshelwe kancane Ongaqeqeshelwe
ngumnakekeli ngokugcwele Akasebenzi

Okunye okwengezayo: _____

1.1.6 Ubudlelwane bomnakekeli nomntwana:

Umzali oyizalayo Ugogowayo Okunye (Balula)

Okunye okwengezayo: _____

1.2 Child/Umntwana

1.2.1 Gender/Ubulili:

Owesilisa Owesifazane

1.2.2 Age/Iminyaka:

_____ years/iminyaka _____ months/nezinyanga

1.2.3 Age at diagnosis/iminyaka yayimingaki ethola isigulo:

_____ years/iminyaka _____ months/nezinyanga

1.2.4 Diabetes duration/Ubude besigulo sikashukela

_____ years/iminyaka _____ months/nezinyanga

1.2.5. Uthembele kwi-Insulin

Yebo Cha

2. Umhlahlandlela ngesihloko:

What are your challenges as a caregiver of a child with diabetes?
Iziphi izinselelo obhekana nazo njengomnakekeli womntwana onoshukela?

How do you feel about your consultations with the team members?
Uzizwa kanjani mayelana nokubonisana namalungu asizayo esibhedlela

What has been helpful about consultations with team members?
Yini ekusizile ngokubonisana namalungu asizayo esibhedlela?

What has been less helpful about consultations with team members?
Yini ebe nosizo oluyincane ekuboniseni namalungu asizayo esibhedlela

How do you feel about the support offered at the clinic?
Uzizwa kanjani ngokwesekeleka okuthola eMtholampilo?

How do you feel about the education offered at the clinic?
Uzizwa kanjani ngemfundiso oyithola eMtholampilo?

What can be done to improve the clinic?
Yini engenziwa ukwenza ngcono uMtholampilo?

Bonga umnakekeli. Bhala ngezansi uma kukhona eminye imibuzo noma okukukhathazayo:

Kusayina oqoqa ulwazi: _____

Igama loqoqa ulwazi: _____

Usuku: _____