

Psychosocial Experience of Parents of Children, Adolescents and Young Adults with Type 1 Diabetes in Brazzaville

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Abstract

Type 1 diabetes is one of the main chronic pathologies in children. Efficient care requires a good knowledge of the disease by the parents, and an exploration of psychosocial experience of the parents, who are on the front lines of the support. **Objectives:** Assess the impact of parents' level of knowledge, from their psychosocial experience and from the quality of life on the glycemic control of children, adolescents and young adults with type 1 (DT1) diabetes in Brazzaville. **Patients and Methods:** This was an analytical cross-sectional study with prospective data collection during 7 months at Brazzaville University Hospital CHU, involving 103 parents. We studied socio-demographic variables, the balance of children's diabetes by glycated hemoglobin, parents' knowledge of diabetes by questionnaire "Michigan Diabetes Research and Training Center's Revised Diabetes Knowledge Test". The assessment of anxiety and depression through the "Hospital Anxiety and Depression" (HAD) score. Parental stress was assessed by the "Pediatric Inventory for Parents" (PIP). **Results:** We reported certain anxiety symptomatology in 60 parents (58.3%). Certain depression was reported in 63 parents (61.2%), and a lesser degree of parental distress. These psychosocial disorders in the parents did not influence the glycemic balance of the children. Low socio-economic level of the family ($p = 0.001$), poor knowledge about diabetes ($p = 0.046$) and poorer quality of life ($p < 0.001$) are the causes of parental distress in our study. **Conclusion:** Psychosocial disorders were well observed in parents of DT1 children.

Keywords

Knowledge, Quality of Life, Psychosocial Experience, Parents,

Type 1 Diabetes

1. Introduction

Type 1 diabetes is one of the most common chronic conditions in children [1]. It represents approximately 6% to 10% of worldwide diabetes cases and its prevalence has been increasing by 3% to 4% per year for the past twenty years [2] [3]. About 50% of cases are reported before the age of 20. The few existing epidemiological data estimate the incidence of DT1 in Africa between 1.5 per 100,000 to 10.3 per 100,000 [4] [5]. The monitoring of type 1 diabetes in children often generates stress due to its unexpected onset [6]. Parents' concerns about long-term complications, management, diet and the constraints of the painful injection process lead to high levels of stress in families of young patients with diabetes [7]. Symptoms of anxiety and depression are also often reported in those parents. These psychosocial disorders influence not only the family itself, but also the therapeutic process, and ultimately, the glycemic control of those young patients [8]. It has been consistently shown that family functioning is a powerful determinant of the overall quality of life and well-being of young people with chronic pathologies [9]. Patients who experience high degrees of family conflict and, as a result, family stress, comply less well with therapy and poorly control the disease [10]. In Congo, no studies have been conducted on the psychosocial experience of parents of children, adolescents and young adults with type 1 diabetes.

It is in this perspective that the present study, which has set itself the objective of assessing the impact of parents' level of knowledge, psychosocial experience and quality of life on the glycemic control of children, adolescents and young adults with DT1 in Brazzaville, and to describe the psychosocial disorders observed in these parents with a view to integrating psychosocial aspects into the care package to people with diabetes.

2. Patients and Methods

This was a prospective analytical cross-sectional data collection study that ran from May 1st to November 30th, 2020 (7 months). The study was carried out at the University Hospital of Brazzaville (the departments of metabolic and endocrine diseases, pediatric intensive care, infant pediatrics and pediatrics for older children) and at the Maison Bleue diabetes institute. It concerned parents (father or mother) and/or guardians of children, adolescents (from 6 to 18 years old) and young adults (from 19 to 25 years old) with diabetes type 1 (the duration of disease assessment was ≥ 6 months). The sample size consisted of all parents or guardians of children, adolescents and young adults with DT1 received in consultation or hospitalization during the Inter-critical period in the two selected sites (CHU-B and the Maison Bleue Diabetes Institute), during scheduled checks

and over the study period. The parents included in the study were those who gave their consent to participate in the study (by written personal consent), and whose children had diabetes progressing for at least 6 months. Parents with a psychiatric history and those whose children left the parental home were not included in the study. The variables studied were sociodemographic and biological, for parents (age, sex, occupation, marital status, education level, socio-economic level) was assessed by the classification of Gayral-Taminh [11]. It was high when family resources came from the salary of a senior manager, a merchant or two middle managers; means when the resources came from a middle manager or an agent of the informal sector, and low when resources come from workers and the unenever; and for children (age, the number of hospitalizations in the last 12 months and glycated hemoglobin in the last 6 months by method “DCA 2000 advantage” optimal control if $\leq 7.5\%$; the high risk of complications if glycated hemoglobin greater than 9% ($\text{HbA1c} > 9\%$); Sub-optimal control: glycated hemoglobin between 7.5% and 9% ($7.5 < \text{HbA1c} \leq 9$). For variables related to parents’ knowledge of diabetes: the “Michigan Diabetes Research and Training Center’s Revised Diabetes Knowledge Test” questionnaire [12] was used. 14 items were considered (related to our subject of study) including general knowledge on hygienic-dietary rules, glycemic control, foot care, complications, hypoglycemia, hyperglycemia. Knowledge was rated good if more than 50% correct answers and bad if less than 50% correct answers. The study of variables on the quality of life of parents or guardians was done using the “PedsQL Family Impact Module” score [13] which includes 28 items for parental functioning (physical, emotional, social, cognitive functioning, communication and worries) and 8 items for family functioning (daily activities and family relationships). When there was never a problem (0) the score corresponded to 100, almost never a problem (1) score to 75, sometimes problems (2) score to 50, often problems (3) score to 25, almost always problems (4) score to 0 for variables related to the psychosocial experience of parents or guardians, parental stress was assessed using the “Pediatric Inventory for Parents (PIP) in its short-form contracted form”, through a score ranging from 13 (absent stress) to 65 (extreme or frequent stress); the assessment of anxiety and depression used the “Hospital Anxiety and Depression (HAD)” score [14], subdivided into two scores (7 items each), one for anxiety and the other for depression. In both psychological disorders this score varies from 0 (absence of anxiety or depression) to 21 (anxiety or severe depression). The analysis of the results was done on excel 2013 software for the creation of the database and R version 4.0.3 for statistical processing. The counts, means, standard deviations and percentages of the quantitative variables were calculated. The chi-square test of independence was used for the comparison of qualitative variables. The significance level was 0.05.

3. Results

Among the 103 parents surveyed there were 61 women (59.2%) and 42 men

(40.8%), either a sex ratio M/F of 0.7. The average age was 46 ± 8.9 , with the extremes of 28 and 68 years old. These were mostly mothers at 46.6%, fathers at 35.9% and guardians at 17.5%. The distribution according to the level of education of the parents, 69% had done secondary education, 15.5% had a primary level, 13.6% had a higher level and 1.9% had never been to school. The distribution of families according to socio-economic level, 40% of families were of low socio-economic level, 39% of families of medium socio-economic level and 21% of high socio-economic level. The parents' medical histories were high blood pressure (44%), diabetes (32%), no parent with a previous psychic history was included in the study. The children of the parents included in this study were 64 females (62.1%) and 39 males (37.9%); either a sex ratio M/F of 0.6. Their average age was 15 ± 4.9 years old, with extremes of 6 years old and 25 years old. Taking into account hospitalization, in the last 12 months prior to the survey, children whose parents are included in the study, 39.8% were included and 60.2% of children had not been hospitalized. In terms of children's glycemic control, the average glyated hemoglobin test was 11 ± 2.3 with extremes of 5.7 and 14. Among these children 68.7% had a high risk of developing complications, 20.4% had sub-optimal control and 10.7% had optimal control. For the assessment of parents' level of knowledge about diabetes, 60.2% had poor knowledge about diabetes and 39.8% had a good knowledge of diabetes. The distribution of parents according to psychosocial experience including the degree of anxiety (**Table 1**), 58.3% had certain anxiety, 22.3% had questionable symptoms of anxiety and 19.4% had no symptoms of anxiety. Depression (**Table 1**) was observed

Table 1. Distribution of the 103 parents by degree of anxiety, depression and distress.

	N	%			
Anxiety certain	60	58.3			
Questionable symptoms	23	22.3			
Absence of anxiety symptoms	20	19.4			
Total	103	100			
Depression certain	63	61.2			
Questionable symptoms	25	24.3			
Absence of symptoms of depression	15	14.5			
Total	103	100			
Distress	Minimum	Maximum	Average	Standard deviation	Median
PIP-F	25	45	37	4.8	38
PIP-D	15	48	34	6.7	33
Score global	52	86	71	7.9	73

with certainty in 61.2%, questionable symptoms observed in 24.3% of parents, and 14.5% of parents had no symptoms of depression. Parental stress was less with overall averages below the average of 39. Among the 62 parents with poor knowledge about diabetes, we noted 55 parents whose children had poor glycemic control, and 7 parents whose children were well controlled, however this difference was not significant $p=0.827$ (Table 2). In the group of parents with depression (15 parents), those with unbalanced children were 13, while 2 parents had balanced children. This difference had no statistical significance $p=0.699$ (Table 2). Parental distress was observed in 38 parents, influencing the glycemic balance of children in 32 parents compared to 6 parents with well-balanced children, with no statistical significance $p=0.225$ (Table 2). Poor quality of life was observed in 44 parents (score less than 50) of whom 39 had poorly balanced children and 5 parents had well-balanced children with a non-significant $p=0.846$ (Table 2).

Table 2. Influence of overall parental knowledge, depression, quality of life, and parental stress on the child's diabetes balance.

	Knowledge		OR [IC 95%]	p-value
	Good n (%)	Bad n (%)		
Glycemic control				
Optimal control	4 (9.76%)	7 (11.3%)	Ref.	Ref.
Poor control	37 (90.2%)	55 (88.7%)	1.18 [0.32; 4.31]	0.827
	Depressive symptomatology	No symptoms of depression		
Glycemic control				
Optimal control	9 (10.2%)	2 (13.3%)	Ref.	Ref.
Poor control	79 (89.8%)	13 (86.7%)	1.35 [0.26; 6.97]	0.699
	PedsQL Family Impact Module (quality of life)			
	<50	≥50		
Glycemic control				
Optimal control	5 (11.4%)	6 (10.2%)	Ref.	Ref.
Poor control	39 (61.4%)	53 (89.8%)	0.88 [0.25; 3.10]	0.846
	PIP-F(parental detresse)			
	<39	≥39		
Glycemic control				
Optimal control	5 (7.69%)	6 (15.8%)	Ref.	Ref.
Poor control	60 (92.3%)	32 (84.2%)	2.25 [0.64; 7.95]	0.225

4. Discussion

Our study looked at parents whose children had type 1 diabetes. The average age of parents was 46 ± 8.9 years old, with the extremes of 28 and 68 years old. The most represented age group is that of 40 - 49 years (42.7%). This result is close to the average age found in several studies on psychosocial aspects in parents of children with diabetes. This is the case for the mean of 44 ± 6.2 years found among fathers by Jönsson in Sweden [15]. This similarity in the average age of the parents could be explained by the fact that these are most often the samples selected on similar bases. In this study, the mother (46.6%) was the most represented parent, compared to the father's 35.9%, and to a lesser extent to the guardian (17.5%). In this study, the overall knowledge of parents of children with type 1 diabetes was rated poor in 62 (60.2%) cases, while in 41 (39.8%) cases it was good. This tendency for parents to have poor knowledge in this study may in part be explained by the fact that many parents did not attend therapy education sessions. This observation is in opposition to that one made by Moskovitz [16] which reported better levels of knowledge of parents of the order of 84%. However, no link was found between children's glycemic control and parents' level of knowledge (Table 1). On the other hand, Moskovitz [17] reported that a better level of knowledge was associated with better glycemic control, in particular when the knowledge related to nutrition and psychopathology, poor knowledge of diabetes was associated with a low socio-economic level. In our series, parents were in the majority from low socio-economic level (40%). We reported certain anxiety symptomatology (Table 2) in 60 parents (58.3%) and questionable symptomatology in 23 parents (22.3%). These results are similar to the 52% of certain anxiety symptomatology [17] of Aoun in Tunisia who used the same score as us, to the 47.4% of severe anxiety in Nakhaey's study [18]. In the present study, a certain depressive symptomatology (Table 2) was reported in 63 parents (61.2%), doubtful in 25 parents (24.3%). This finding is in line with what is often reported. In fact, the prevalence of depressive symptoms fluctuates between 10% and 74% [19]. However, Aoun found a prevalence well below ours of around 37.5%, using the same assessment score for depression [18]. No link was noted between depression and glycemic control (Table 1), which is however commonly reported in the literature (the existence of depressive symptoms negatively influencing glycemic control) [18], nor between depression and number of hospitalizations. Butwicka [20] reports the opposite (depressive symptoms would double the risk of hospitalization). In randomised controlled trials in children and adolescents with type 1 diabetes, psychological therapy, including counselling, cognitive behavioural therapy, family systems and psychodynamic therapy has been shown to improve glycemic control in children and adolescents [21]. Studies have identified profound emotional distress in parents of patients with diabetes [22]. We reported levels of parental distress with overall means (37 for the frequency subscale and 34 for the difficulty subscale) that were below the mean of 39, thus suggesting less parental distress (Table 1). One of the explana-

tions could be the age of the children involved in the present study. In fact, 50.5% of children were over 14 years old and only 17.5% were under 10 years old. Parental involvement has been shown time and again to be more pronounced in young children. This observation of less parental distress was also made by Mitchell [23]. The low socio-economic level of the family ($p = 0.001$), poor knowledge about diabetes ($p = 0.046$) and a poorer quality of life ($p < 0.001$) were found to be determinants of parental distress in our study (Table 3). On the other hand, no link was found between parental distress and glycemic control (Table 2), which is contrary to what the literature reports, in particular a poorer glycemic control produces parental distress, and parental distress in turn worsens glycemic control [24]. In the present study, an average overall quality of life score of around 50 was found, with better average scores (therefore a better quality of life in the “cognitive function” (62) and “daily activity” (61) components. On the other hand, a poorer quality of life was found with regard to “relationships with others” (48) and “emotional state” (48). Poor parental quality did not influence the glycemic control of children with type 1 diabetes in our study. This trend is contrary to that reported by Hoey [25] who asserts that an improvement in the glycemic control of children with diabetes requires good family cohesion. This difference can be explained by the impact of the supervised grouping of children through the Maison Bleue diabetes institute, where summer camps and therapeutic education sessions are organized, strengthening the family’s work with a view to better glycemic balance.

The limitations of our study were the assessment of the quality of life of parents of children with type 1 diabetes by the PedsQL scale in its Family Impact module which does not take into account certain aspects of the disease and the patient (religious aspects, financial expenses caused by the disease). In addition, as the study is carried out only in the capital, the results cannot be extrapolated to the national level.

Table 3. Determinants of parental distress.

	≥39 n (%)	<39 n (%)	OR (univariate)	OR (multivariate)
Socioeconomic level				
average/high	8 (12.9)	54 (87.1)	-	-
low	18 (43.9)	23 (56.1)	5.28 (2.07 - 14.53; $p = 0.001$)	4.40 (1.63 - 12.66; $p = 0.004$)
Quality of life				
≥50	7 (11.9)	52 (88.1)	-	-
<50	19 (43.2)	25 (56.8)	5.65 (2.18 - 16.11; $p = 0.001$)	4.73 (1.74 - 14.06; $p = 0.003$)
knowledge				
	≥78	<78		
bad	28 (45.2)	34 (54.8)	-	-
good	7 (17.1)	34 (82.9)	0.25 (0.09 - 0.62; $p = 0.004$)	0.31 (0.10 - 0.88; $p = 0.034$)

5. Conclusion

The consideration of parents in the follow-up of diabetic children is a significant component, as the overall knowledge of parents of children with type 1 diabetes was considered mostly bad in 62 (60.2%) cases, and a very high level of symptoms of anxiety and depression. However, parental distress was relatively less with regard to their child's illness. Optimizing the prognosis of these young patients requires improving the level of parents' knowledge of diabetes, integrating psychosocial aspects into the care offered.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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Appendix

Le Score PedsQL Family Impact Module

Parent Functioning	Items	General Content
Physical Functioning	6	Problems with physical functioning, including feeling tired, getting headaches, feeling weak, and stomach problems
Emotional Functioning	5	Problems with emotional functioning, including anxiety, sadness, anger, frustration, and feeling helpless or hopeless
Social Functioning	4	Problems with social functioning, including feeling isolated, difficulty getting support from others, and finding time or energy for social activities
Cognitive Functioning	5	Problems with cognitive functioning, including difficulty maintaining attention, remembering things, and thinking quickly
Communication	3	Problems with communication, including others not understanding the family's situation, difficulty talking about child's health condition, and communicating with health professionals
Worry	5	Problems with worrying, including worrying about child's treatments and side effects, about others reactions to child's condition, about the effect of the illness on the rest of the family, and about child's future
Family Functioning	Items	General Content
Daily Activities	3	Problems with daily activities, including activities taking more time and effort, difficulty finding time and energy to finish household tasks
Family Relationships	5	Problems with family relationships, including communication, stress, and conflicts between family members, and difficulty making decisions and solving problems as a family

Total score is computed by averaging all 36 items Parent HRQOL Summary Score in computed by averaging 20 items in Physical, Emotional, Social, and Cognitive Functioning, Family Summary score is computed by averaging 8 items in Daily Activities and Family Relationships.

Pediatric Inventory for Parents (PIP) dans sa forme contractée short-form

HOW OFTEN?	HOW DIFFICULT?									
	1 = Never					1 = Not at all				
	2 = Rarely					2 = A little				
	3 = Sometimes					3 = Somewhat				
	4 = Often					4 = Very much				
	5 = Very often					5 = Extremely				
EVENT	1	2	3	4	5	1	2	3	4	5
1. Difficulty Sleeping	1	2	3	4	5	1	2	3	4	5
2. Bringing my child to the clinic or hospital	1	2	3	4	5	1	2	3	4	5
3. Being unable to go work/job	1	2	3	4	5	1	2	3	4	5
4. Waiting for my child's test results	1	2	3	4	5	1	2	3	4	5
5. Trying not to think about my family's difficulties	1	2	3	4	5	1	2	3	4	5
6. Trying to attend to the needs of other family members	1	2	3	4	5	1	2	3	4	5
7. Seeing my child sad or scared	1	2	3	4	5	1	2	3	4	5
8. Talking with the nurse	1	2	3	4	5	1	2	3	4	5

Continued

9. Making décisions about medical care or medicines	1	2	3	4	5	1	2	3	4	5
10. Having little time to take care of my own needs	1	2	3	4	5	1	2	3	4	5
11. Thinking about other children who have been seriously ill	1	2	3	4	5	1	2	3	4	5
12. Speaking with my child about his/ her illness	1	2	3	4	5	1	2	3	4	5
13. Speaking with family members about my child's illness	1	2	3	4	5	1	2	3	4	5

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.

Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or wound up:			I feel as if I am slowed down:
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometime
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like "butterflies" in the stomach:
	0	Definitely as much	0		Not at all
	1	Not quite so much	1		Occasionally
	2	Only a little	2		Quite often
	3	Hardly at all	3		Very Often
		I get a sort of frightened feeling as it something awful is about to happen:			I have lost interest in my appearance:
	3	Very definitely and quite badly	3		Definitely
	2	Yes but not too badly	2		I don't take as much care as I should
	1	A little but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
	0	As much as I always could	3		Very much indeed
	1	Not quite so much now	2		Quite a lot
	2	Definitely not so much now	1		Not very very much
	3	Not at all	0		Not at all
		Worrying thoughts go though my mind:			I look forward with enjoyment to things
	3	A gret deal of the time	0		As much as I ever did
	2	A lot of the time	1		Racher less than I used to
	1	From time to time, but not too often	2		Defibitely less than I used to
	0	Only occasionally	3		Hardly at all

Continued

I feel cheerful:		I get sudden feelings of panic:	
3	Not at all	3	Very often indeed
2	Not often	2	Quite often
1	Sometimes	1	Not very often
0	Most of the time	0	Not at all
I can sit at ease and feel relaxed:		I can enjoy a good book or radio or TV program:	
0	Definitely	0	Often
1	Usually	1	Sometimes
2	Not often	2	Not often
3	Not at all	3	Very seldom

Please check you have answered all the questions Scoring:

Total score: Depression (D)----- Anxiety (A)-----;

0.7 = Normal;

8.10 = Borderline abnormal (borderline case) 11.21 = Abnormal (case).