

Diabetes, child care, and performance of family functions

Obciążenie opieką nad dzieckiem z cukrzycą a realizacja funkcji rodziny

Ewa Kobos, Jacek Imiela, Anna Leńczuk-Gruba

Department of Social Nursing, Warsaw Medical University, Warsaw, Poland
Head of the Department: Jacek Imiela MD, PhD

Medical Studies/Studia Medyczne 2017; 33 (1): 17–25
DOI: <https://doi.org/10.5114/ms.2017.66952>

Key words: burden of care, type 1 diabetes mellitus, caregiver, family functioning.

Słowa kluczowe: obciążenie opieką, cukrzyca typu 1, opiekun, funkcjonowanie rodziny.

Abstract

Introduction: Parents caring for a child with diabetes may experience a burden on both a practical and an emotional level.

Aim of the research: Analysis of the correlations between the care burden level and the perceived influence of type 1 diabetes in children on the performance of family functions.

Material and methods: The study included 112 caregivers of children with diabetes. The following inclusion criteria were taken into account: full family, direct caregiver of the child, the child's age 3–16 years, disease duration of at least 6 months, and no chronic diseases in siblings. The study material was collected using an interview questionnaire and the Caregiver Burden Scale. Correlation analysis was performed using the Spearman correlation coefficient. The significance level was defined as $p = 0.05$.

Results: A higher burden level of a caregiver in the individual subscales of the CB Scale was associated with a significant decrease in the intensity of performance of the cultural and social function as well as consumption function, the increased amount of time spent with a sick child, and an increase in parental disagreements. The overall burden level differentiated the performance of the religious function. An increase in the burden level on the overall effort subscale was accompanied by lower interest in sex and less frequent sexual intercourse. The higher level of caregiver burden occurs in families where permanent job income has fallen. The differences were shown in the performance of control-socialisation function due to the sense of burden on the environment subscale.

Conclusions: The burden level of a caregiver is important in the perceived influence of the child's illness on the functioning of the family. Stimulating a caregiver in dealing with the problems that are the consequence of the disease, as well as activating and preparing other family members to participate in the care of a sick child, and financial support may reduce the caregiver burden and thus facilitate the functioning of the family.

Streszczenie

Wprowadzenie: Rodzice, opiekując się dzieckiem chorym na cukrzycę, mogą doświadczać obciążenia zarówno na poziomie praktycznym, jak i emocjonalnym.

Cel pracy: Analiza korelacji między poziomem obciążenia opieką a dostrzeganym wpływem cukrzycy typu 1 u dziecka na realizację funkcji rodziny.

Materiał i metody: W badaniu wzięło udział 112 opiekunów dzieci chorych na cukrzycę. Uwzględniono następujące kryteria doboru do badania: pełna rodzina, bezpośredni opiekun dziecka, wiek dziecka 3–16 lat, czas trwania choroby co najmniej 6 miesięcy, brak chorób przewlekłych u rodzeństwa dziecka. Materiał badawczy zebrano za pomocą kwestionariusza wywiadu oraz Caregiver Burden Scale (CB Scale). Analizę zależności wykonywano za pomocą współczynnika korelacji Spearmana. Założono poziom istotności $p = 0,05$.

Wyniki: Wyższy poziom obciążenia opiekuna w poszczególnych podskalach CB Scale wiązał się istotnie ze zmniejszeniem natężenia realizacji czynności funkcji kulturalno-towarzyskiej, funkcji konsumpcyjnej, wzrostem ilości czasu poświęcanego choremu dziecku oraz wzrostem nieporozumień między rodzicami. Całkowity poziom obciążenia różnicował realizację funkcji religijnej. Wzrostowi poziomowi obciążenia w podskali wysiłek ogólny towarzyszyło mniejsze zainteresowanie seksem oraz rzadsze podejmowanie współżycia seksualnego. Stwierdzono różnicowanie realizacji funkcji kontrolno-socjalizacyjnej w związku z poczuciem obciążenia w podskali otoczenie.

Wnioski: Poziom obciążenia opiekuna ma znaczenie dla dostrzeganego wpływu choroby dziecka na funkcjonowanie rodziny. Stymulowanie aktywności opiekuna w radzeniu sobie z problemami będącymi następstwem choroby, aktywizowanie i przygotowanie innych członków rodziny do udziału w opiece nad dzieckiem chorym oraz wsparcie finansowe może redukować obciążenie opiekuna i tym samym ułatwić funkcjonowanie rodziny.

Introduction

According to the WHO definition, diabetes identifies “a group of metabolic diseases characterised by hyperglycaemia resulting from defective secretion and/or insulin action” [1]. Chronic hyperglycaemia leads to organ changes predominantly in the kidneys, eyes, blood vessels, and nervous system [2]. Type 1 diabetes is due to destruction of the pancreatic β cells, typically leading to the complete deficit of insulin [3]. Despite the average rate of incidence among European countries, Poland is characterised by the high growth rate of type 1 diabetes incidence. It is estimated that it is a level exceeding 9% per year [4, 5]. In Poland, the problem of type 1 diabetes applies to 20,000 children, and the current incidence rate is 17.1 per 100,000 children aged 0–14 years [6].

The literature dealing with the social consequences of the disease in the family not only focuses on the patient, his/her place in the family, attitudes of family members, and their emotional ties, but also tries to answer the question of which family functions change due to the disease [7]. Illness of a child fundamentally changes the situation of the family, relationships, and structure. It may disturb its functioning and result in the need to introduce a variety of adaptive mechanisms [7].

The study results show that families with chronically ill children may experience problems with adjusting to the disease, the relationship with the child, family conflicts can be enhanced, and problem solving skills may be decreased [8]. In connection with worse metabolic control of diabetes in the child, the quality of married life can be deteriorated [9], while prolonged care can exacerbate burnout syndrome in parents [10]. Diabetes is characterised by sharp and unexpected complications causing practical and emotional problems in the patient and his/her family. Parents may experience a sense of guilt for the lack of due care; families quarrel more often than those with healthy children [11]. The treatment of children with diabetes requires daily self-control in blood glucose monitoring, nutrition, physical activity, and insulin administration [12]. Treatment at home can foster misunderstandings between children and parents and is time-consuming. The study findings emphasise, among others, the following difficulties in caring for a child with diabetes: following dietary rules, making the child independent, the need for treatment, and learning difficulties [13].

Parents caring for the child may experience a burden on both a practical and an emotional level. The literature gives many different definitions of burden; Pearlin *et al.* defines it as problems of a physical, mental, emotional, social, and financial nature accompanying families who take care of the sick [14]. According to Sales, burden is a summary of all experiences and difficulties faced by family members as a result of

the illness of a loved one [15], it can “refer to the stress experienced by family, professional, and other providers when assisting others, especially individuals with disabling medical or psychiatric problems” [16]. Thus, the treatment of the disease cannot be limited only to medical intervention, but should also introduce social and mental actions in relation to the family.

In Poland we have not yet implemented research undertaking the issue of the burden experienced by a caregiver of a child suffering from diabetes and its importance in the performance of family functions. The world literature contains the results of studies relating to the impact of diabetes in a child on family functioning, but they are not considered in terms of changes in the intensity of the performance of family functions.

Aim of the research

The analysis of the correlations between the care burden level in a caregiver and the perceived influence of type 1 diabetes in a child on the performance of family functions.

Material and methods

Procedure

The implementation of the study was preceded by obtaining permission of the Bioethics Committee (KB/131) and the author of the Caregiver Burden Scale (CB-Scale) Elmståhl S. A previous study on reliability showed high internal consistency for the five factors with Cronbach's α values between 0.70 and 0.87. The studies were carried out in 4 out of 12 randomly selected centres in Poland (random sample without replacement). The following inclusion criteria were used: a child being treated in the clinical hospital, full family, direct caregiver of a child suffering from diabetes, the child's age 3–16 years, disease duration of at least 6 months, and no chronic diseases in siblings. Caregivers gave written, informed consent to participate in the study. Data for the analysis was collected during a follow-up visit of a caregiver with the child to the diabetic clinic. The data was obtained from the patient's history (performance of family functions) and CB Scale.

Measurement

Interview questionnaire

The interview questionnaire contained blocks of scalable questions for the assessment of the impact of diabetes in children on the intensity of performance of eight family functions: cultural and social, consumer, religious, material-economic, nursing care, emotional-expressive, control-socialisation, sexual and procreative. Characteristic activities (tasks) were distinguished within each function. Specific numeri-

cal values (from -3 to 3) were assigned to different values on the scale. This analysis allowed for calculation of the average for all activities within the analysed features.

Caregiver Burden Scale – CB Scale

The Caregiver Burden Scale (CB Scale) was used for the measurement of the burden level. It is a standardised and reliable tool developed by Elmståhl [17]. The scale contains 22 questions, which are answered on a scale of 1 to 4. The questions form five subscales: general effort, social isolation, disappointment, emotional involvement, and environment. The average score of the items included in the scale is the result of the total scale and subscales. The higher the number of points received by a respondent, the higher the burden.

Statistical analysis

Statistical analyses were performed using the program Statistica 9.0 PL. Normality of distribution for the study-dependent variables was tested using Shapiro-Wilk test. Correlation analysis was performed using the Spearman correlation coefficient. The significance level was defined as $p = 0.05$.

Results

In the study group, 30.4% of caregivers lived in cities of over 50,000 residents, 28.6% of respondents lived in cities up to 50,000 residents, and 41.0% in rural areas. The average age of the people involved in the study was 39.6 years (SD = 6.8). 45.5% of respondents had secondary and technical education, 24.1% vocational and gymnasium, and 26.8% higher. 21.4% of caregivers had 1 child, 51.8% had 2 children, and 26.8% had more than 2 children. 47.3% of direct caregivers were unemployed. 59.8% of families were in a good financial situation, 30.4% in the average financial situation. The average age of children with diabetes was 11.3 years (SD = 3.6), children aged 14–16 years accounted for 34.8%, and 7–10 years of age – 26.8%. 46.4% of children suffered for up to 3 years and 53.6% for over 3 years. Seventy-five percent of children were treated with insulin pump and 25% took insulin using a pen (Table 1).

The total level of burden in the studied group was 2.1 points. The highest levels of burden were observed in the “general strain” (2.41 points) and “disappointment” (2.31 points) subscales. For these subscales, 23.2% of caregivers declared a high level of burden. A low level of burden was observed among 59.8% of participants in the “isolation” and “environment” subscales (Table 2).

Data analysis shows that the burden level is important in the perceived impact of diabetes in a child on the performance of family functions. Higher val-

ues in the level of the caregiver burden are accompanied by a decrease of the intensity of activities within the cultural-social function (Table 3).

Statistically significant correlations were demonstrated between an increase in value of the total burden level and a decrease in the intensity of performance of the following activities: visiting friends and relatives ($R = -0.323$; $p < 0.001$), inviting friends and relatives ($R = -0.364$; $p < 0.001$), free relaxation ($R = -0.452$; $p < 0.001$), passive participation in culture ($R = -0.279$; $p = 0.002$), and active participation in culture ($R = -0.308$; $p < 0.001$). A relationship was shown between the burden level and performance of activities within the material-economic function. Higher values of the total burden level are accompanied by a decrease in permanent job income ($R = -0.280$; $p = 0.002$) and a decrease in spending on clothing ($R = -0.202$; $p = 0.032$). A higher level of burden in the environment subscale was significantly associated with a decrease of self-hygiene and care of appearance in adults ($R = -0.221$; $p = 0.018$) as well as less involvement of the spouse in the care of a sick child ($R = -0.192$; $p = 0.042$). The analysis of the relationship between the level of caregiver burden and the performance of consumer function reveals a downward trend in the individual subscales of the scale. The level of significance between the total burden level and a decrease in the intensity of housework was: cleaning ($R = -0.267$; $p = 0.004$), washing ($R = -0.281$; $p = 0.002$), ironing ($R = -0.307$; $p < 0.001$), and washing dishes ($R = -0.255$; $p = 0.006$). An increase in the total burden level is accompanied by an increase in the intensity of time spent with a sick child ($R = 0.329$; $p < 0.001$) as part of emotional-expressive family function and an increase in disputes between parents ($R = 0.408$; $p < 0.001$) (Table 4). The caregiver burden level did not substantially affect the performance of activities within the control-socialisation function. There was a significant correlation between an increase in the burden level on the environment subscale and an increase in the intensity of the control over a sick child ($R = 0.192$; $p = 0.041$). Other variables showed no relationship on the statistically significant level. The level of caregiver burden has little effect on the intensity of activities within the religious function. An increase in the total burden level is accompanied by a decrease in the frequency of confession ($R = -0.197$; $p = 0.036$) and receiving Holy Communion ($R = -0.197$; $p = 0.036$).

The reduced frequency of sexual intercourse ($R = -0.192$; $p = 0.042$) and lower interest in sex ($R = -0.209$; $p = 0.026$) were significantly associated with a higher sense of burden on the general effort subscale. No significant correlations were demonstrated between the caregiver burden level on the subscales of social isolation, disappointment, and environment, and within the changes in the intensity of the procreative and sexual function.

Table 1. Characteristics of the sample

Data on the caregivers		Number, <i>n</i>	Percentage (%)
Age [years] Mean = 39.6 SD = 6.8	< 35	39	34.8
	36–40	29	25.9
	41–45	22	19.6
	> 45	22	19.6
Education	Primary and lower	4	3.6
	Gymnasium and vocational	27	24.1
	General secondary and technical	51	45.5
	Higher	30	26.8
Professional activity	Working	59	52.7
	Not working	53	47.3
Place of residence of caregivers	Country	46	41.0
	City < 50,000	32	28.6
	City > 50,000	34	30.4
Material conditions of the family	Very good	8	7.1
	Good	67	59.8
	Standard	34	30.4
	Bad	3	2.7
Number of children in the family	1	24	21.4
	2	58	51.8
	3	19	17.0
	4–5	11	9.8
Data on the ill children		Number, <i>n</i>	Percentage (%)
Age [years] Mean = 11.3 SD = 3.6	3–6	18	16.1
	7–10	30	26.8
	11–13	25	22.3
	14–16	39	34.8
Duration of the disease [years]	≤ 1	13	11.6
	> 1 ≤ 3	39	34.8
	> 3 ≤ 6	36	32.2
	> 6	24	21.4
Method of administration of insulin	Pen	28	25.0
	Pump	84	75.0

Mean – average, SD – standard deviation, *n* – number of participants.

Table 2. Caregiver's burden according to CB Scale

CB subscales	Min.	Max.	Mean	SD	Level of burden (%)		
					Low	Average	High
General strain	1.1	3.8	2.41	0.67	27.7	49.1	23.2
Isolation	1.0	4.0	1.76	0.78	59.8	28.6	11.6
Disappointment	1.0	4.0	2.31	0.71	30.4	46.4	23.2
Emotional involvement	1.0	3.7	1.60	0.66	71.4	23.2	5.4
Environment	1.0	4.3	1.81	0.55	59.8	37.5	2.7
Total score	1.1	3.4	2.10	0.54	41.1	51.8	7.1

CB Scale – Caregiver Burden Scale, Min. – minimum, Max. – maximum, Mean – average, SD – standard deviation.

Table 3. The level of burden and realisation of functions of cultural and social, material and economic, care and nursing, and consumption – correlations

Kind of family function	CB subscales																	
	General strain			Isolation			Disappointment			Emotional involvement			Environment			Total		
	R	p		R	p		R	p		R	p		R	p		R	p	
Inviting relatives and friends	-0.239	0.011*	-0.417 < 0.001#	-0.246	0.008#	-0.155	0.102	-0.242	0.010#	-0.323	< 0.001#							
Visiting relatives and friends	-0.281	0.002#	-0.514 < 0.001#	-0.267	0.004#	-0.113	0.231	-0.282	0.002#	-0.364	< 0.001#							
Free time	-0.387	< 0.001#	-0.422 < 0.001#	-0.372	< 0.001#	-0.115	0.224	-0.428	< 0.001#	-0.452	< 0.001#							
Common ways of spending free time	0.078	0.408	-0.098	0.300	0.945	0.020	0.830	0.197	0.036*	0.053	0.575							
Organize travels	-0.169	0.073	-0.079	0.402	-0.114	0.227	0.777	-0.216	0.021*	-0.161	0.088							
Passive participation in culture	-0.230	0.014*	-0.296	0.001#	-0.339	< 0.001#	0.038	0.687	-0.207	0.027*	0.002#							
Active participation in culture	-0.286	0.002#	-0.273	0.003#	-0.252	0.007#	-0.104	0.272	-0.245	0.009#	< 0.001#							
Keeping/maintenance of telephone contacts	-0.094	0.323	-0.174	0.065	-0.094	0.322	-0.103	0.276	-0.066	0.488	0.199							
Income	-0.215	0.022*	-0.384 < 0.001#	-0.329	< 0.001#	-0.020	0.831	-0.168	0.076	-0.280	0.002#							
Spending on sick child's nutrition	0.121	0.200	0.060	0.525	0.075	0.427	0.073	0.440	0.122	0.198	0.200							
Spending on sick child's treatment	0.055	0.559	0.019	0.838	0.104	0.272	0.009	0.919	0.057	0.547	0.439							
Spending associated with sick child's care	0.063	0.504	0.085	0.372	0.035	0.709	-0.068	0.474	0.129	0.172	0.465							
Means spend on treatment of other family members	-0.120	0.204	-0.047	0.618	-0.142	0.134	-0.121	0.203	-0.039	0.682	0.203							
Spending on clothing	-0.164	0.082	-0.166	0.078	-0.266	0.004#	-0.043	0.647	-0.054	0.566	0.032*							
Spending on other family members nutrition	-0.005	0.956	0.013	0.885	-0.044	0.644	-0.048	0.612	-0.069	0.466	0.791							
Spending associated with education	-0.046	0.627	-0.012	0.894	-0.074	0.436	0.032	0.733	0.002	0.978	0.721							
Taking care of nutrition a sick child	0.079	0.405	-0.010	0.912	0.034	0.717	0.060	0.528	0.162	0.087	0.498							
Mutual help	-0.051	0.589	-0.031	0.739	-0.066	0.489	-0.040	0.671	-0.073	0.441	0.468							
Taking care of hygiene and appearance of adults	-0.135	0.153	-0.064	0.496	-0.179	0.058	0.019	0.834	-0.221	0.018*	0.109							
Taking care of family health	0.129	0.174	0.040	0.671	0.066	0.487	0.135	0.155	0.091	0.339	0.185							
Taking care of other children	-0.007	0.934	-0.048	0.608	-0.028	0.767	-0.029	0.753	-0.028	0.765	0.738							
Spouse's engagement in sick child's care	-0.042	0.659	-0.021	0.825	-0.034	0.716	-0.106	0.262	-0.192	0.042*	0.631							
Family member's engagement in sick child's care	-0.113	0.234	-0.064	0.501	-0.122	0.199	-0.011	0.907	-0.038	0.688	0.263							
Preparing meals at home	0.030	0.747	0.044	0.642	0.068	0.475	0.103	0.276	0.036	0.699	0.504							
Cleaning	-0.209	0.026*	-0.286	0.002#	-0.263	0.005#	-0.097	0.308	-0.228	0.015*	0.004#							
Washing	-0.228	0.015*	-0.297	0.001#	-0.223	0.017*	-0.183	0.052	-0.270	0.003#	0.002#							
Ironing	-0.253	0.006#	-0.327 < 0.001#	-0.250	0.007#	-0.202	0.032*	-0.280	0.002#	-0.307	< 0.001#							
Shopping	-0.124	0.189	-0.114	0.228	-0.164	0.083	-0.174	0.066	-0.162	0.087	0.066							
Washing the dishes	-0.255	0.006#	-0.199	0.034*	-0.219	0.020*	-0.043	0.646	-0.209	0.026*	0.006#							
Preparing meals at home	-0.057	0.545	-0.057	0.546	-0.086	0.365	-0.077	0.415	-0.070	0.462	0.436							

p – probability value, R – correlation coefficient, *0.01 < p < 0.05 – statistically significant correlation, #p ≤ 0.01 – statistically significant correlation, CB Scale – Caregiver Burden Scale.

Table 4. The level of burden and realisation of functions of emotional and expressive, control and socialisation, religious, sexual, and procreative – correlations

Kind of family function	CB subscale																			
	General strain			Isolation			Disappointment			Emotional involvement			Environment			Total				
	R	p	R	p	R	p	R	p	R	p	R	p	R	p	R	p	R	p		
Spending time with a sick child	0.315	< 0.001 [#]	0.355	< 0.001 [#]	0.281	0.002 [#]	0.053	0.572	0.211	0.025*	0.329	< 0.001 [#]	0.329	< 0.001 [#]	0.329	< 0.001 [#]	0.329	< 0.001 [#]	0.329	< 0.001 [#]
Spending time with other children	-0.004	0.963	-0.069	0.465	0.022	0.813	-0.037	0.691	-0.035	0.712	-0.018	0.848	-0.018	0.848	-0.018	0.848	-0.018	0.848	-0.018	0.848
Sense of community and family support	0.071	0.456	-0.108	0.253	-0.003	0.971	0.091	0.338	0.047	0.617	0.014	0.882	0.014	0.882	0.014	0.882	0.014	0.882	0.014	0.882
Efforts to bond and love within the family	0.043	0.648	-0.019	0.836	-0.039	0.676	0.101	0.285	-0.065	0.495	-0.004	0.962	-0.004	0.962	-0.004	0.962	-0.004	0.962	-0.004	0.962
Misunderstanding between children	0.001	0.989	0.017	0.854	-0.060	0.524	0.049	0.606	0.092	0.331	0.002	0.979	0.002	0.979	0.002	0.979	0.002	0.979	0.002	0.979
Misunderstanding between parents	0.369	< 0.001 [#]	0.231	0.013*	0.349	< 0.001 [#]	0.364	< 0.001 [#]	0.376	< 0.001 [#]	0.408	< 0.001 [#]	0.408	< 0.001 [#]	0.408	< 0.001 [#]	0.408	< 0.001 [#]	0.408	< 0.001 [#]
Mutual conversations	-0.031	0.739	-0.094	0.320	-0.040	0.669	-0.006	0.943	-0.072	0.449	-0.059	0.532	-0.059	0.532	-0.059	0.532	-0.059	0.532	-0.059	0.532
Control of sick child's behaviour	-0.013	0.887	0.058	0.541	0.081	0.393	-0.074	0.437	0.192	0.041*	0.042	0.653	0.042	0.653	0.042	0.653	0.042	0.653	0.042	0.653
Control of other child's behaviour	0.046	0.625	-0.017	0.855	0.047	0.619	-0.027	0.776	-0.019	0.837	0.021	0.819	0.021	0.819	0.021	0.819	0.021	0.819	0.021	0.819
Communication with children	0.147	0.121	0.033	0.727	0.071	0.451	0.080	0.400	0.103	0.277	0.115	0.225	0.115	0.225	0.115	0.225	0.115	0.225	0.115	0.225
Interest and checking school education	0.036	0.703	-0.081	0.392	-0.029	0.758	0.019	0.838	-0.085	0.370	-0.031	0.738	-0.031	0.738	-0.031	0.738	-0.031	0.738	-0.031	0.738
Engaging children in adults role	0.044	0.642	0.097	0.304	0.071	0.453	-0.041	0.660	-0.009	0.924	0.046	0.626	0.046	0.626	0.046	0.626	0.046	0.626	0.046	0.626
Enforcement of principles and rules	-0.103	0.277	-0.061	0.518	0.019	0.839	0.129	0.172	0.024	0.800	-0.028	0.764	-0.028	0.764	-0.028	0.764	-0.028	0.764	-0.028	0.764
Put demands of children	-0.148	0.118	-0.086	0.365	-0.021	0.818	0.085	0.370	0.000	0.998	-0.074	0.436	-0.074	0.436	-0.074	0.436	-0.074	0.436	-0.074	0.436
Daily prayer	-0.105	0.267	-0.088	0.356	-0.205	0.030*	0.003	0.973	-0.030	0.750	-0.128	0.178	-0.128	0.178	-0.128	0.178	-0.128	0.178	-0.128	0.178
Participation in church services	-0.135	0.155	-0.059	0.532	-0.251	0.007 [#]	-0.065	0.494	-0.050	0.594	-0.162	0.087	-0.162	0.087	-0.162	0.087	-0.162	0.087	-0.162	0.087
Interest in faith	-0.041	0.662	0.004	0.961	-0.039	0.680	0.032	0.735	-0.110	0.247	-0.040	0.675	-0.040	0.675	-0.040	0.675	-0.040	0.675	-0.040	0.675
Interest in religious education	-0.028	0.767	0.032	0.736	-0.011	0.904	0.051	0.589	-0.058	0.537	-0.021	0.818	-0.021	0.818	-0.021	0.818	-0.021	0.818	-0.021	0.818
Conversation concerning faith	-0.190	0.043*	-0.081	0.394	-0.205	0.029*	-0.122	0.199	-0.109	0.251	-0.197	0.036*	-0.197	0.036*	-0.197	0.036*	-0.197	0.036*	-0.197	0.036*
Confession	-0.190	0.043*	-0.081	0.394	-0.205	0.029*	-0.122	0.199	-0.109	0.251	-0.197	0.036*	-0.197	0.036*	-0.197	0.036*	-0.197	0.036*	-0.197	0.036*
Interest in sex	-0.209	0.026*	-0.144	0.128	-0.096	0.310	-0.032	0.733	-0.165	0.081	-0.165	0.081	-0.165	0.081	-0.165	0.081	-0.165	0.081	-0.165	0.081
Sexual activity	-0.192	0.042*	-0.151	0.111	-0.039	0.676	0.051	0.592	-0.158	0.095	-0.130	0.168	-0.130	0.168	-0.130	0.168	-0.130	0.168	-0.130	0.168
Practise contraception	-0.104	0.271	-0.158	0.095	-0.074	0.432	-0.198	0.035*	-0.110	0.247	-0.138	0.145	-0.138	0.145	-0.138	0.145	-0.138	0.145	-0.138	0.145

p – probability value, *R* – correlation coefficient, *0.01 < *p* < 0.05 – statistically significant correlation, [#]*p* ≤ 0.01 – statistically significant correlation, *CB Scale* – Caregiver Burden Scale.

Discussion

The study seems to be among the first determining the relationship between the caregiver burden level and the perceived influence of diabetes mellitus type I diagnosed in a child on family functioning.

It has been shown that the overall level of caregiver burden is on a medium level and is close to the overall burden level experienced by caregivers of stroke patients [18]. The high level of burden in the subscales of general effort and disappointment covers 25% of caregivers. The research conducted by Malerbi *et al.* shows that 63% of caregivers feel overwhelmed by caring for a child with diabetes [19]. Recommendations for the treatment of a child with type 1 diabetes impose a number of obligations on parents [3]. The intensive treatment can be tedious and stressful for direct caregivers. The huge involvement in child care and numerous sacrifices may in the long term lead to physical and emotional overload, and a feeling that everything is done badly. This can lead to so-called burnout syndrome [10, 20]. According to the study results, the above state in mothers is promoted, among others, by the lack of free time and financial problems [21]. The so-called financial stressors are situational elements associated with chronic disease in the family [22]. The research findings show that higher caregiver burden on the subscales of general overall, social isolation, and disappointment is related to the perceived impact of the disease in a child on a decrease of permanent job income in the family and limited possibility of free recreation. As was shown by the studies conducted by Lindley *et al.*, families with lower socioeconomic status experience higher financial burden, also at the lower levels of expense arising from the nature of the disease [23]. In the study group, only four fathers declared that they were direct caregivers of a sick child. A higher level of burden on the environment subscale was associated with a decrease in the perceived level of involvement of the spouse in the care of a sick child. The studies show that usually mothers are direct caregivers of children with diabetes. They take responsibility for the conduct of care to a greater extent than other members of the family [10, 19, 24–26]. The withdrawal of fathers from care may weaken the communication between spouses [27].

This means that fathers should be encouraged and trained to play a greater role in child care, thereby relieving mothers. The research conducted by Cyranka *et al.* showed that mothers of healthy children experience greater support and commitment of their spouses than those of children with diabetes [28]. Parents of young children are concerned that other people: nannies, teachers, family members will not be able to provide the proper care for a child [29]. This does not favour sharing responsibilities between different people, which may result in greater burden. Our findings confirmed that caregivers overwhelmed by

higher levels of burden on the CB subscales perceived limited participation of the family in maintaining cultural-social contacts and free leisure. According to the study conducted by Marshall *et al.*, parents indicate lack of freedom and liberty as losses resulting from diabetes in a child [30].

Our study confirmed that the higher overall caregiver burden level correlated with an increase in the number of family disagreements perceived in connection with the illness of a child. This is also reflected in the results of other authors [31]. It seems to be related to parents taking responsibility for treatment and beliefs about the feasibility of the treatment regimen, self-efficacy, and the fear of hypoglycaemia [32, 33]. The analysis of the burden level carried by Haugstvedt *et al.* using the Family Burden Scale showed that the highest burden was due to the exercise of medical care, followed by physical and mental problems, disturbances in the family, and social constraints of a child [34]. It was noted that a higher level of burden on the individual subscales was significantly associated with the amount of time spent with a sick child. The studies of Greek families with diabetic children indicated that caregivers adjusted their lifestyle to the illness of a child, which in turn did not improve relations between parents [35]. Burden on the emotional involvement subscale was on the middle level in 23.1% of caregivers, and in 5.4% it was high. Behavioural changes of a sick child perceived by parents are factors influencing the emotional condition of a caregiver [36]. In the states of hypoglycaemia patients may experience: irritability, tantrums, inappropriate behaviour, restlessness, aggression, and a jocular attitude. Caregivers can be impatient because of oversensitivity in a child [13]. Other results show that parents of children treated using pumps experience less stress [32], which may protect them against feelings of anger and rage. 71.4% of patients demonstrated low burden in the emotional involvement subscale. This may be related to the fact indicated in the literature that diabetes as a chronic stressor, whose potency decreases with duration of the disease, becomes one of the so-called nuisances of everyday life. It serves as a strong traumatic stressor during periods of acute and chronic complications [37].

The level of caregiver burden on the environment subscale in 37.5% of caregivers was on the medium level. Higher values of burden were accompanied by greater control of a sick child. The complexity of problems experienced by caregivers also stemming from the environment outside the family and the resulting anxiety may manifest itself in excessive control, which in the future may impede the child in taking responsibility for the control of the disease.

To sum up, a caregiver of a child suffering from diabetes type 1 experiences high and medium burden on the subscale of general strain and disappointment. The higher burden level correlates on a statistically significant level, mainly with changes in the intensity of per-

formance of the cultural-social, consumer, and emotional-expressive family function, perceived by a caregiver.

Our study proposes a range of studies conducted in families of children suffering from diabetes type 1. They have some limitations due to the impossibility to use an objective tool to measure the multi-dimensionality of changes that occur in the functioning of the family due to the illness of a child. Our study included only mothers.

The results suggest that future studies should seek to identify factors relevant to the caregiver burden level and realising that it may constitute an indirect threat to the functioning of the family of a child with diabetes mellitus type 1. Care providers should consider developing strategies to reduce the caregiver burden level, which can contribute to a better functioning of the family and indirectly achieve better therapeutic effects in children.

Conclusions

The burden of caring for a child with type 1 diabetes encourages social isolation of the family, neglecting everyday tasks, and increased disagreements between the parents. Deterioration of financial situation due to a child's sickness contributes to higher burden of care. Care disappointment experienced by caregivers is linked to reduced realisation of cultural, social, and consumptive family functions.

Recommendations

Preparing a family to care for a child with diabetes requires more education and stimulation of members of the family, other than the mother.

Families with a difficult financial circumstances created by a child's illness should receive financial support.

Support and encouragement of a caregiver's active ability to deal with a child's diabetes-related problems may reduce care disappointment and therefore make things easier for the family.

Acknowledgments

The authors would like to thank the caregivers who participated in the study and the author of the CB Scale for consent to use it.

The research was financed from the budget for science as research project No. 1940/B/P01/2010/39.

Conflict of interest

The authors declare no conflict of interest.

References

1. World Health Organization: Definition. Diagnosis and classification of diabetes mellitus and its complications. Report of a WHO consultation. Part 1. WHO Geneva 1999. Available from: whqlibdoc.who.int/.../1999/who_ncd_ncs_99.2.p
2. American Diabetes Association: Diagnosis and classification of diabetes mellitus. *Diabetes Care* 2015; 38 (Suppl. 1): S8-16.
3. Zalecenia kliniczne dotyczące postępowania z chorym na cukrzycę 2016. *Diabetol Klin* 2016; 5 (Supl. A): A1-70.
4. Jarosz-Chobot P, Polanska J, Szadkowska A, Kretowski A, Bandurska-Stankiewicz E, Ciechanowska M, Deja G, Mysliwiec M, Peczynska J, Rutkowska J, Sobel-Maruniak S, Fichna P, Chobot A, Rewers M. Rapid increase in the incidence of type 1 diabetes in Polish children from 1989 to 2004, and predictions for 2010 to 2025. *Diabetologia* 2011; 54: 508-15.
5. Patterson CC, Dahl uist GG, Gyürüs E, Green A, Soltész G; the EURODIAB Study Group. Incidence trends for childhood type 1 diabetes in Europe during 1989-2003 and predicted new cases 2005-20: a multicentre prospective registration study. *Lancet* 2009; 373: 2027-33.
6. International Diabetes Federation. IDF Diabetes Atlas update poster, 7th edn. Brussels, Belgium: International Diabetes Federation, 2015 <http://www.diabetesatlas.org/>
7. Bakun M, Szewczyk L. Sposoby funkcjonowania rodziców dzieci chorych na cukrzycę typu 1. *Pediatr Endocrinol* 2010; 3: 65-74.
8. McClellan CB, Cohen LL. Family functioning in children with chronic illness compared with healthy controls: a critical review. *J Pediatr* 2007; 150: 221-3.
9. Zegarlicka-Poręba M, Rembierz A, Jarosz-Chobot P. Jakość życia małżeńskiego rodziców dzieci z cukrzycą typu 1 w ocenie własnej. *Pediatr Endocrinol Diabetes Metab* 2008; 14 Supl. 1: 26 [U-32].
10. Nitka-Siemińska A, Mysliwiec M, Landowski J, Balcerska A, Wolnik W. Zespół wypalenia u rodziców osób chorych na cukrzycę typu 1. *Diabet Prakt* 2008; 9: 76-81.
11. Coffey JS. Parenting a child with chronic illness: a meta synthesis. *Paediatr Nurs* 2006; 32: 51-9.
12. Fichna P, Skowrońska B, Stankiewicz W. Leczenie cukrzycy w wieku rozwojowym. *Klin Pediatr* 2005; 13: 286-95.
13. Gawłowicz K, Krzyżaniak A. Wpływ cukrzycy typu 1 u dziecka na funkcjonowanie rodziny. *Probl Hig Epidemiol* 2009; 90: 72-77.
14. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990; 30: 583-94.
15. Sales E. Family burden and quality of life. *Qual Life Res* 2003; 12 Suppl 1: 33-41.
16. Kirch W. *Encyclopedia of Public Health*. Springer-Verlag 2008; 99.
17. Elmståhl S, Malmberg B, Annerstend L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Arch Phys Med Rehabil* 1996; 77: 177-82.
18. Jaracz K, Grabowska-Fudala B, Kozubski W. Obciążenie opiekuna po udarze. W kierunku modelu strukturalnego. *Neurol Neurochir Pol* 2012; 46: 224-32.
19. Malerbi FE, Negrato CA, Gomes MB; Brazilian Type 1 Diabetes Study Group (BrazDiab1SG). Assessment of psychosocial variables by parents of youth with type 1 diabetes mellitus. *Diabetol Metab Syndr* 2012; 4: 48.
20. Siemiński M, Nitka-Siemińska A, Nyka W. Zespół wypalenia. *Forum Medycyny Rodzinnej* 2007; 1: 45-9.
21. Lindström C, Aman J, Norberg AL. Parental burnout in relation to sociodemographic, psychosocial and personality factors as well as disease duration and glycaemic control

- in children with type 1 diabetes mellitus. *Acta Paediatr* 2011; 100: 1011-7.
22. Skórczyńska M. Przewlekła choroba dziecka w aspekcie realizacji zadań życiowych jednostki i rodziny. In: Dziecko chore. Zagadnienia biopsychiczne i pedagogiczne. Cytowska B, Winczura B (eds). Impuls, Krakow 2007; 39-51.
 23. Lindley LC, Mark BA. Children with special health care needs: impact of health care expenditures on family financial burden. *J Child Fam Stud* 2010; 19: 79-89.
 24. Rodrigues N, Patterson JM. Impact of severity of a child's chronic condition on the functioning of two-parent families. *J Pediatr Psychol* 2007; 34: 417-26.
 25. Seiffge-Krenke I. "Come on, say something, dad!": communication and coping in fathers of diabetic adolescents. *J Pediatr Psychol* 2002; 27: 439-50.
 26. Waizenhofer RN, Buchanan CM, Jackson-Newsom J. Mothers' and fathers' knowledge of adolescents' daily activities: its sources and its links with adolescent adjustment. *J Fam Psychol* 2004; 18: 348-60.
 27. Hamburg B, Gale A, Inoff GA. Coping with predictable crises of diabetes. *Diabet Care* 1983; 6: 409-16.
 28. Cyranka K, Rutkowski K, Król J, Krok D. Różnice w komunikacji małżeńskiej i postawach rodzicielskich między rodzicami dzieci zdrowych a rodzicami dzieci chorych na cukrzycę typu 1. *Psychiatr Pol* 2012; 46: 523-38.
 29. Sullivan-Bolyai S, Deatrick J, Gruppuso P, Tamborlane W, Grey M. Constant vigilance: mothers' work parenting young children with type 1 diabetes. *J Pediatr Nurs* 2003; 18: 21-9.
 30. Marshall M, Carter B, Rose K, Brotherton A. Living with type 1 diabetes: perceptions of children and their parents. *J Clin Nurs* 2009; 18: 1703-10.
 31. Leishman JM. Individual and family predictors of the caregiver burden of parents rearing a child with diabetes. *Electronic Theses and Dissertations*, 2010, p.41,44. Available from: <http://scholarsarchive.byu.edu/cgi/viewcontent.cgi?article=3407&context=etd>
 32. Streisand R, Mackey ER, Elliot BM, Mednick L, Slaughter IM, Turek J, Austin A. Parental anxiety and depression associated with caring for a child newly diagnosed with type 1 diabetes: opportunities for education and counseling. *Pat Educ Counsel* 2008; 73: 333-8.
 33. Streisand R, Swift E, Wickmark T, Chen R, Holmes CS. Pediatric parenting stress of parents with type 1 diabetes: the role of self-efficacy, responsibility and fear. *J Pediatr Psychol* 2005; 30: 513-21.
 34. Haugstvedt A, Wentzel-Larsen T, Rokne B, Graue M. Perceived family burden and emotional distress: similarities and differences between mothers and fathers of children with type 1 diabetes in a population-based study. *Pediatr Diabetes* 2011; 12: 107-14.
 35. Tsamparli A, Kounenou K. The Greek family system when a child has diabetes mellitus type 1. *Acta Paediatrica* 2004; 93: 1646-53.
 36. Twardowski A. Sytuacja rodzin dzieci niepełnosprawnych. In: Dziecko niepełnosprawne w rodzinie. Obuchowska I (ed.). WSiP, Warsaw 2008; 18-54.
 37. Cyranka K. Psychologiczne aspekty funkcjonowania rodziny dziecka chorego na cukrzycę typu 1. *Psychoterapia* 2012; 160: 51-63.

Address for correspondence:

Ewa Kobos MD
Department of Social Nursing
Warsaw Medical University
ul. Ciołka 27, 01-445 Warsaw, Poland
Phone: +48 503 307 136
E-mail: kobewa@interia.pl