

The degree of fathers' involvement in taking care of children with diabetes and its implications in family functioning in the assessment of diabetic children's mothers

Stopień zaangażowania ojców w opiekę nad ich dziećmi z cukrzycą i jego implikacje dla funkcjonowania rodziny w ocenie matek diabetyków

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Abstract

Introduction: Children's type 1 diabetes is one of the most mentally aggravating chronic diseases for the patient and his/her parents. The disease disturbs relationships in the family, disrupts communication, and enforces a change in the organisation of daily life.

The aim of the study was to gather opinions about fathers' involvement in taking care of children with type 1 diabetes. Opinions were stated by mothers of sick children regarding managing of diabetes and its impact on the functioning and relationships of the family.

Material and methods: The survey (conducted in 2017) was in the form of a questionnaire, which was filled in by 459 mothers. The average duration of the child's illness was 3.8 years, (SD 2.95, Me 3), the average age of the child was about 8.9 years (SD 3.96, Me 8.5).

Results: 83% of the respondents indicated that the child's disease was a huge psychological burden for them and that it was the mother who mostly took care of the sick child. 38.8% of mothers could count on the support of other family members. Because of the need to take care of the child, 58.8% of them were not professionally active, and 24.2%, despite their professional activity, were the only ones in the family who controlled the diabetes. In 15.3% of families, the father did not perform any activities related to the child's diabetes. 33.8% estimated that the child's disease worsened the situation of the family, and in 4.4% it caused its disintegration. Only 18.1% of mothers declared that the father was able to look after the child with diabetes by himself.

Conclusions: It is necessary to support families affected by diabetes. Their personal and social skills should be developed so that they can cope with chronic disease and the duties related to managing diabetes. The responsibility should be shared by both parents.

Key words:

type 1 diabetes, chronic disease, quality of life, family, mother.

Streszczenie

Wprowadzenie: Cukrzyca typu 1 u dziecka jest dla chorego i jego rodziców jedną z najbardziej obciążających psychicznie chorób przewlekłych. Wymóg ciągłej kontroli glikemii, konieczność insulinoterapii, obawa przed hipo- i hiperglikemią, a także lęk przed powikłaniami późnymi mają negatywny wpływ na kondycję psychiczną chorego i jego rodziny. Choroba zaburza relacje w rodzinie, pogarsza komunikację, wymusza zmianę organizacji życia, często prowadzi do rezygnacji z pracy matek, które przejmują wyłączną opiekę nad chorym dzieckiem i zostają obciążone odpowiedzialnością za samokontrolę cukrzycy.

Cel pracy: Poznanie opinii matek dzieci chorych na cukrzycę typu 1 na temat stopnia zaangażowania ojców lub opiekunów w sprawowanie opieki nad dziećmi w kwestii samokontroli i prowadzenia cukrzycy oraz jego wpływu na funkcjonowanie i relacje w rodzinie.

Materiał i metody: Badaniu poddano w 2017 r. w formie internetowego kwestionariusza ankiety 459 matek, o różnym czasie trwania choroby dziecka, średnia 3,8 roku (SD 2,95, Me 3), średni wiek dziecka 8,9 roku (SD 3,96, Me 8,5). Badane matki to podopieczne cukrzycowych organizacji pozarządowych i uczestniczki grup wsparcia w mediach społecznościowych.

Wyniki: 83% badanych wskazało, że choroba dziecka stanowi dla nich duże obciążenie psychiczne i że to głównie one opiekują się chorym dzieckiem, nie mogąc liczyć na wsparcie innych członków rodziny – 38,8%. Z powodu konieczności opieki nad dzieckiem

58,8% badanych nie jest aktywnych zawodowo, a 24,2% mimo aktywności zawodowej jako jedyne w rodzinie zajmują się kontrolą cukrzycy dziecka. W 15,3% rodzin ojców nie wykonuje żadnych czynności związanych z cukrzycą dziecka. 33,8% badanych ocenia, że choroba dziecka pogorszyła sytuację rodziny, a w 4,4% spowodowała jej rozpad. Tylko 18,1% matek deklaruje, że ojciec potrafi samodzielnie opiekować się dzieckiem z cukrzycą.

Wnioski: Konieczne jest wsparcie rodzin dotkniętych cukrzycą, rozwój ich osobistych i społecznych umiejętności, tak by radziły sobie z chorobą przewlekłą, a obowiązki związane z prowadzeniem i samokontrolą cukrzycy dziecka dzielone były przez oboje rodziców.

Słowa kluczowe:

cukrzyca typu 1, choroba przewlekła, jakość życia, rodzina, matka.

Introduction

Type 1 diabetes is one of the most common chronic diseases in the paediatric population. In Poland in the 1990s, the incidence rate of this type of diabetes was about 15 cases per 100,000 inhabitants per year [1, 2], and now it is 18-25 cases per 100,000 per year, depending on the region. According to data from the EURODIAB project, the growing dynamics of incidence in the last two decades contributes to a 300% increase in the number of cases. By 2025 the number of cases is estimated to quadruple, especially in the 5–9 and 0–4 age groups [3, 4]. Therefore, type 1 diabetes is becoming a social problem, affecting an increasing number of families, including those with small, dependent children. The disease imposes a number of duties on the child, requires constant self-control and discipline, is connected with the necessity of constant monitoring of glycaemia levels, observing the rules of insulin therapy, and meal counting. Diabetes type 1 is one of the most severe chronic diseases; it may cause lowering of self-esteem and emotional disorders [5–7]. Due to the difficulty and complexity of the matter, parents take over the management of the disease in children and, at least in the initial stage of the disease, also in teenagers. This requires additional duties and new regulation of life, often adjusting the daily schedule and professional commitments to the needs of self-control of diabetes in children [8]. The need for constant involvement in the care of the sick child and the need to control glycaemia, even at night, especially in small, dependent children, leads to a life of constant readiness, being “on guard”, and thus to significant stress, strain, and disruption of relations in relationships [9, 10]. The new situation and the burden of chronic disease may cause emotional problems in parents, especially mothers, such as guilt, anxiety disorders, or depressive states. While this is understandable in the initial stage of the disease, shortly after the diagnosis, when the process of acceptance from the shock phase to constructive adaptation [11], taking action, and coping with the disease must take place, such a condition, which persists for a longer time, has a negative impact on both the management of diabetes and the functioning of the family. In this context, it is important to organise family life in such a way that the care of a child with diabetes is shared between both parents in order to deal with new duties and take responsibility for the treatment process. In practice, however, it is usually the mothers who take over the care of the sick child. On the one hand, this often results from the necessity of a new or-

ganisation of family life, the resignation of one of the parents, usually the mother, from professional work, and on the other hand, from the natural, assigned in our culture, care function performed in relation to the child mainly by mothers. Studies prove that the emotional state of the mother, her ability to adapt to the new situation created by the chronic disease of the child, and the degree of coping with the disease influence the level of metabolic equilibrium of the child and his/her acceptance of the disease [12]. Coherent relations and good communication in the family also influence the child's metabolic equilibrium, and then the child's ability to take over the responsibility for independent diabetes management during adolescence [13–15]. Therefore, it seems necessary to take care of the quality of relations in the family and the psychological condition of the mother as the main carer in the disease.

Aim of the study

The aim of the study was to present the opinion of mothers of children with type 1 diabetes on the degree of involvement of fathers in the care of children in the self-control and management of diabetes and its influence on the functioning and relations in the family.

Material and methods

The study was conducted from 21.02.2017 to 20.03.2017 in the form of a questionnaire. The surveyed women (mothers) were: 1. members and charges of non-governmental organisations from all over Poland dealing with helping families with children with type 1 diabetes, and 2. members of support groups for mothers of children with type 1 diabetes in social media. The questionnaire was available at <https://profitest.pl/s/8687/stUJ93qxHEYtOmla> and consisted of 20 questions, usually allowing participants to choose one or more answers. In five questions, as well as the possibility to choose the proposed answers, open questions were provided, allowing for free statements and comments, requiring independent completion by the respondents. In the period from 21.02.2017 to 20.03.2017, 459 mothers with different length of illness of the child filled in the questionnaire correctly; the average length of the disease was 3.8 years (SD 2.95, Me 3), and the average age of the child was 8.9 years (SD 3.96, Me 8.5).

Results

The presented study started with a general question, in which mothers were asked to indicate the biggest problems related to the care of a child with type 1 diabetes mellitus. The respondents in the first place indicated psychological stress and stress related to the disease (83.0%), and while the second place was taken by two most important causes of this condition, i.e. high costs related to the disease (59.5%) and lack of support from other members of the family in child care (38.8%), the lack of support from the kindergarten/school in childcare was also highly rated (32.2%). The respondents who chose an answer 'other' (3.5%) in its development included an additional disease, most often coeliac disease, sleep deprivation, and lack of labour law and employment regulations that would support mothers of chronically ill children (Fig. 1).

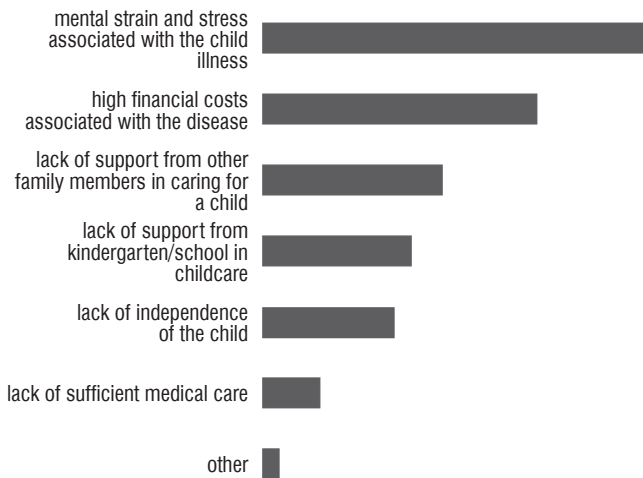


Figure 1. The biggest problems related to caring for a child with diabetes

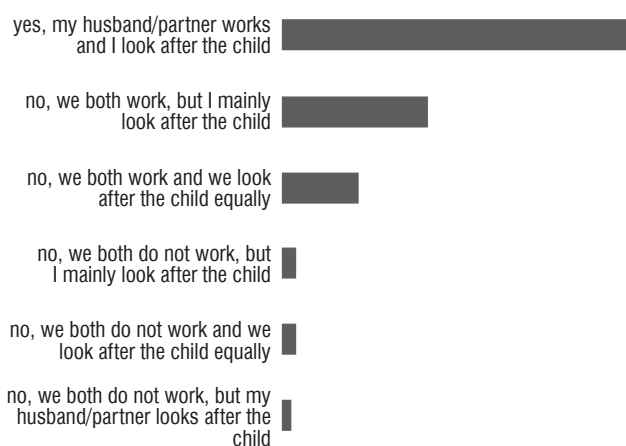


Figure 2. The division of duties in the family.

More than half of the respondents (58.8%) declared the division of duties into a working man and a woman mainly caring for a child, while some of the respondents (24.2%) combined professional work and exclusive childcare. It was rare for a child to be cared for mainly by the father (1.7% of respondents). Only 12.4% of the respondents declared that both parents worked and took equal care of the child (Fig. 2).

When asked about the assessment of the impact of the disease on the quality of family functioning, the respondents focused mainly on material and organisational factors – *one of the parents had to resign from work* (47.5%), *there was a new division of duties* (43.8%), and *our situation deteriorated* (33.8%). In their opinion, the disease affected the family in deeper, psychological areas causing the loss of the sense of stability – *it surprised us and we still cannot cope with it* (36.2%), *we moved away from each other* (25.9%) and even *broke up our family* (4.4%). A much smaller number of respondents indicated the good sides of the situation – *we came closer to each other* (16.8%), *we mobilised for a better life* (19.4%). The importance of the impact of the disease on the family is confirmed by the fact that only seven women (1.5%) stated that the disease had no impact on the family (Fig. 3).

In the next part of the questionnaire, the surveyed mothers were asked more directly about the assessment of fathers' or guardians' involvement in their care. They were asked to try to assess in which activities they see their least impact and to search for the causes of this condition. Although in the question on direct assessment of the degree of participation in childcare, the respondents almost equally divided their opinions: 56.6% assessed the involvement as insufficient and 43.4% as satisfactory, further results may indicate rather declarative character of the latter's assessment. Such a state of things may be related to the assessment of potential (not realistic) possibilities resulting from e.g. completing a training course on care of a child suffering from diabetes. The respondents declared a significant independent involvement in education (35.1%);

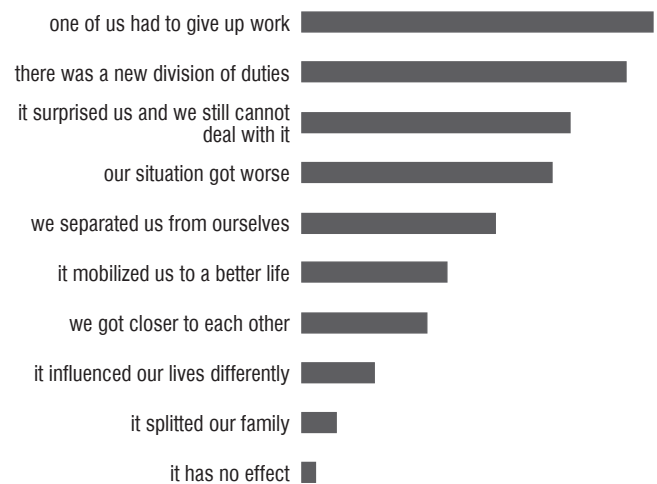


Figure 3. Evaluation of the impact of the child's disease on his/her family

however, it is also worth noting that more than half of them went through education with the father/guardian of the child (64.5%), and only four people indicated that it was only the man who participated in the education. When asked what kind of care activities are performed by the father/guardian of a child on their own, the surveyed women most frequently mentioned the measurement of sugars with a glucose meter (69.5%), insulin administration (57.3%), food weighting (47.9%), and night-time sugar measurements (44.2%). Their independence was least visible in the participation in educational and recreational meetings of the diabetic society (12.4%), the search for new technical solutions and self-education in the field of improvement in the care of a child suffering from diabetes (21.4%), and talking to a child about his or her illness (27.2%). In 70 examined families (15.3%) the father/guardian did not perform any of the above-mentioned activities (Fig. 4).

In the next question, in which the respondents were asked what activities they most expect from the father/guardian, the results were distributed quite proportionally, which may indi-



Figure 4. Activities in the field of looking after a sick child independently performed by fathers/guardians – in assessment by mothers

cate that mothers in all the areas mentioned above need help (or evaluate the existing help as insufficient). The most significant areas were in the field of night-time sugar measurements (63.4%), calculation of WW/WBT exchangers (38.6%), and exchange of punctures (36.8%), i.e. areas in the previous question considered as independent (potentially) areas of father/guardian interactions rather than real everyday activities. It is also interesting to note the relatively high number of mothers who marked the answer – I do not expect help (7.2%), indicating both resignation from seeking help and the fact that they were independent, without a sense of the need to support (excessively concentrated) the performance of all duties and to prevent fathers/guardians from assisting in their performance (Fig. 5).

In the next part of the questionnaire, the surveyed mothers were asked about the causes and costs of insufficient involvement of fathers/guardians in the help given and about the attention paid to taking actions aimed at changing this state of affairs.

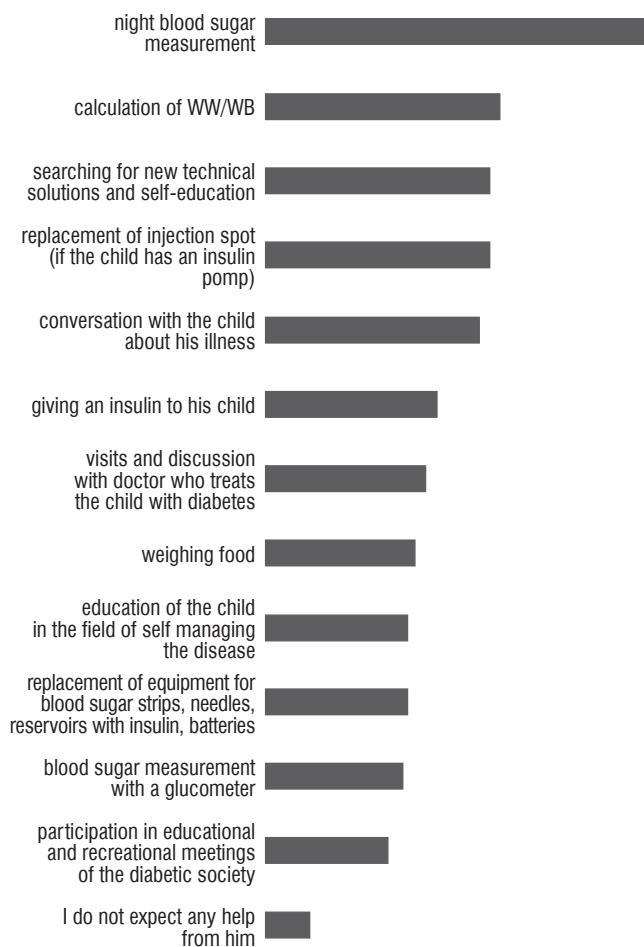


Figure 5. Activities in the field of looking after a sick child in which mothers expect help from fathers/guardians the most

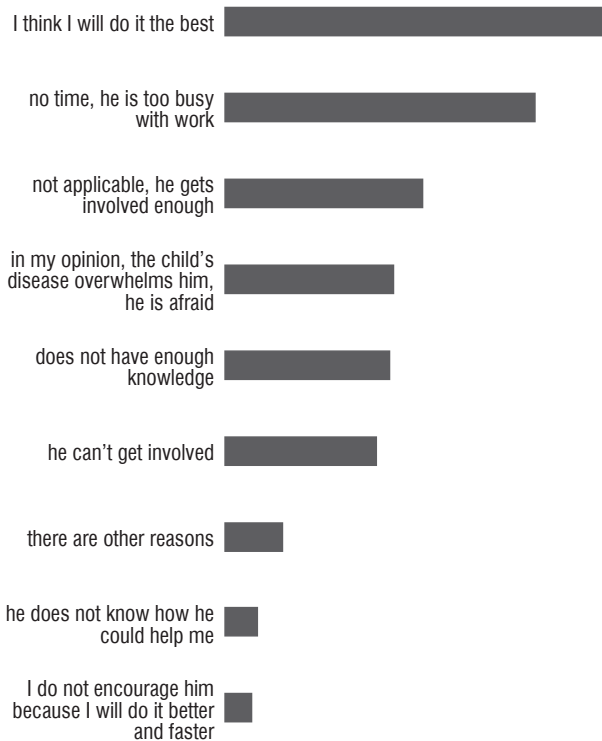


Figure 6. Causes of low level of involvement of fathers/guardians in managing diabetes

The respondents who were asked about the reasons for fathers'/guardians' lack of involvement in care to a sufficient degree indicated mainly the fact that fathers/guardians gave them responsibility: *he believes that I will do it better* (42.9%), *lack of time/concentration on professional work* (35%), emotional difficulties – *the child's disease defeats him* (18.9%), and *lack of knowledge* (18.4%). In response, other mothers pointed to the work of the child's father abroad, problems with alcohol dependence, and verbal aggression at the request for support in care (Fig. 6).

When asked about their own ways of changing this condition by, among others, encouraging fathers'/guardians' to be involved in care, the respondents declared these activities to a large extent (84.5%), and only 14.8% admitted not to encourage them to help for unspecified reasons. However, the analysis of activities undertaken in this area indicates that it is definitely mothers who take over the active responsibility for creating conditions for assistance by undertaking activities, i.e. *I tell him what to do* (47.9%), *I ask him* (39%), and *we talk about duties* (29.4%), and it seems that their role in creating conditions facilitating participation in the assistance of fathers/guardians is crucial. Some respondents indicated resignation and helplessness – *I resigned from it, I do everything by myself* (16.6%) and a low level of trust in the independence and knowledge of the caregiver. Only 83 mothers (18.1%) declared – *I leave him alone with the child, hoping that he will know what to do* (Fig. 7).

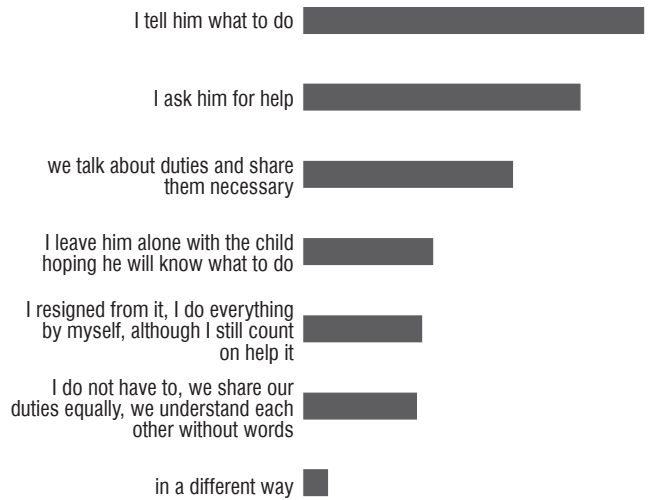


Figure 7. Methods of encouraging fathers by mothers of sick children

Finally, the question was asked, in which way greater involvement of fathers/guardians would help mothers of sick children. This question was aimed, on the one hand, at making women aware of the effects of the current state of affairs and, on the other hand, at awakening their motivation and power to take actions aimed at sharing responsibility and creating conditions for increasing the involvement of fathers and guardians in helping them. The respondents pointed to the following benefits resulting from the change for them – *I would feel more support* (57.3%), *I could rest* (57.3%), *I would not feel so lonely* (39.2%), *I could go out more often and have more time for myself* (31.4%), and *I would have someone to talk to about my doubts and difficulties* (30.1%). They also indicated a positive impact for the family – *we could spend more time together* (16.1%), *we would have more topics to talk in common* (12.4%) and for the child – *the child would see that the father/guardian is also involved in his/her care* (44.4%).

Discussion

The changing family model in Poland, from traditional to egalitarian, results in a new shaping of roles in the family, with fathers taking over or sharing the duties previously considered to be the domain of mothers [16]. Childcare, homework, and even parental leave for fathers are slowly but steadily becoming a fact. Comparative CBOS studies from 2006 (37%) and 2013 (46%) also show unequivocally that the number of couples preferring to share family responsibilities in a partnership is systematically growing in Poland, and thus the level of fathers' involvement in childcare, both at the declarative and actual level, is increasing [17]. Mothers, especially young mothers and urban dwellers, pursue their professional career, want to develop their interests, and expect the children's fathers to share

childcare responsibilities in a broader aspect than before, and fathers are more willing to fulfil this task [18]. Chronic disease disturbs this process and restores the traditional family model with the assumption that most of the care tasks are performed by mothers, who are often forced to resign from work in order to take care of the child.

The analysis of data obtained in the study confirms the existence of the problem of insufficient participation of fathers in undertaking activities supporting children in the treatment of diabetes and sharing responsibility for the treatment with mothers. This is a negative phenomenon, because life with diabetes is a heavy burden for all members of the family, and sharing the responsibilities would significantly improve the functioning of the family. Similar observations were made by Kobos *et al.* [19], who also point out that it is mothers who are responsible for providing care to a greater extent than other family members and postulate the need for greater involvement of fathers in the care of children with diabetes.

The analysis of the results also highlights the significant impact of a child's disease in the family on the division of professional and caring duties with a predominance of the assumption of childcare performed mainly by women, even if they are still professionally active. In the opinion of the respondents, the disproportionate division of duties has a significant negative impact on the mothers of ill children and on the quality of family relationships. Similarly, according to Szabata, the case of a child with diabetes in a family requires a division of responsibilities that equally involves both parents, in order to prevent a sense of lack of support, conflicts, and relationship breakdown. Parents should also take care of the quality of the relationship and seek support from professionals, self-help groups, or non-governmental organisations [20].

A study conducted by Cyranka *et al.* also showed that mothers of children with diabetes experience less support and involvement of fathers/guardians than mothers of healthy children. Fathers' withdrawal from care worsens and weakens even more the communication between the couple [21]. Lack of support from the partner may exacerbate the treatment burden and the mother's emotional problems. As many as 63.4% of respondents expected their partner to help them measure sugar at night, which is a physical burden associated with sleep deprivation and mental stress associated with fear of hypoglycaemia.

Similarly, in the study by Haugstvedt *et al.*, the influence of night-time measurements and fear connected with night-time hypoglycaemia on the emotional problems of parents, mainly mothers, was discussed. Night-time measurements of glycaemia were significantly associated with the perceived parental

burden, and experienced night-time hypoglycaemia was significantly associated with emotional pain [22].

Attention should also be paid to the high level of education of both parents in the field of knowledge and skills of independent childcare, with a relatively low level of real action taken in everyday life by fathers/guardians of sick children. On the one hand, it is probably related to low motivation, fear, involvement in work for earning purposes, and socio-cultural aspects determining the schematic roles and attitudes imposed on men in Poland on the side of fathers/guardians of sick children; on the other hand, it is probably related to the lack of effective encouragement on the part of mothers who largely monopolise child care and do not know how (and sometimes do not want) to change this situation.

The solution, or at least the mitigation of the problem posed by the chronic disease, is a supporting family, which should try to create a "new normality" regardless of the chronic disease [23]. The prerequisite for achieving this goal is a partnership and sharing the responsibility for the disease between both parents. Guthrie *et al.* [24] also stress the importance of the family in managing diabetes and the need for both parents to participate in the daily management of the disease, despite various difficulties resulting from cultural differences, lack of role models, and lack of therapeutic support. There is a huge demand from patients' families for support in the form of deliberate psychoeducation influencing a change in the level of knowledge, skills, and, most importantly, attitudes towards the undertaken roles and responsibilities carried out in the form of comprehensive interactions. It is also consistent with ISPAD recommendations, which emphasise that family factors are extremely important for the treatment of diabetes; family bonds, agreement on the duties related to the treatment of diabetes, supportive behaviours, and cooperative problem solving lead to better observance of the treatment scheme and better glycaemia control [25].

Conclusions

The complex nature of the problem indicates the necessity to undertake multifaceted and long-term educational, preventive, and activating actions aimed not only at diabetes "management", but also at developing personal and social skills of families affected by type 1 diabetes. All these actions should be a continuation and complement of training taking place immediately after the diagnosis of the disease in the hospital – usually organised one-time, focused on strict medical knowledge aimed at maintaining good physical health.

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