Evaluating factors affecting diabetes management among teachers and parents of children living with type 1 diabetes

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Summary of the PhD Thesis

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List of publications providing the basis of the thesis:

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1. Introduction

Children with chronic illness and their families besides having to bring up, must manage their disease and its treatment. A long-term disease can affect the direction of a child's life and the development of a family in subtle and profound ways. Subjective factors (for example, what the patient and family perceive about the illness and its management) are generally more powerful predictors of disease outcomes than the "objective" measures of the patient's condition. Families, as well as other relevant developmental contexts (for example kindergartens and schools), are viewed as essential and inseparable from children living with a chronic disease in understanding illness and adaptation. The health-related concerns in addition to affecting the child, will also affect parents, siblings, extended family members, classmates, school personnel and the health care team. These groups or subsystems engage in mutual interactions with one another, and all of them both influence and are influenced by the child (Roberts & Steele, 2009).

As reported by Engel (1979) understanding illness requires an understanding of the interactions between biological psychological and social factors. The level of compatibility between people and their social context is an important predictor of physical and mental well-being (Stokols, 1996). The psychosocial research on the environment of people living with diabetes has shown that the social context is of great importance to clinical, behavioral and psychological outcomes (Wit et al., 2020). The International Society for Pediatric and Adolescent

Diabetes (ISPAD) stated that diabetes management could mostly be affected by psychosocial factors (Amiri et al., 2018; Delamater, 2009).

Diabetes management poses several unique challenges for parents concerning their everyday responsibilities, continuous supervision, and caregiving (Iversen et al., 2018), which is also psychologically challenging for parents (Helgeson et al., 2012). Having a child who lives with a chronic illness or a disability is related to psychological distress among parents (Patterson & Garwick, 1994). Diabetes management-related psychological factors, as fear of the child having hypoglycemia and distress about diabetes care affect the mental health and wellbeing of parents which will also affect the child's wellbeing and diabetes outcomes (such as HbA1c levels) (Eilander et al., 2017).

Teachers are also important contributors to the socio-ecology of the school (Farmer et al., 2011). Studies conducted with children have suggested that the quality of the teacher-student interaction may affect psychological adjustment and, more specifically, the lives of students who are marginalized or at risk (Troop-Gordon, 2015). Teachers play a crucial role in managing diabetes in schools and kindergartens, assisting with specific aspects of management for younger children and influencing the effectiveness of self-management through their approach and attitude for older, self-managed children (Pansier & Schulz, 2015; Tolbert, 2009). Holmström et al. (2018) found that school personnel experiences caring for youth with T1D with feelings of uncertainty and overwhelm and they must find their own way to cope with the difficulties of diabetes care. Furthermore, many teachers have

inadequate knowledge about diabetes and its' care (Bechara et al., 2018). Hence the American Diabetes Association (2011) recommends training school personnel in diabetes care and allowing students to monitor and treat blood glucose levels in the classroom.

2. Aims

We investigate diabetes care-related psychological factors among two types of stakeholders within the microenvironment of children living with T1D: parents and teachers. We present three studies: the first study was conducted among parents, while the second and third studies focused on teachers. The aims of each study are the following:

Study 1: We aim to identify profiles related to the behavioral and anxiety-related reactions to hypoglycemia. Furthermore, we analyze the differences the profiles show regarding additional diabetes-care related factors (diabetes distress, self-efficacy, perceived diabetes management problems, demographical and diabetes management related data) (Study 1).

Study 2: We explore teachers' attitudes towards diabetes care and their interpretations of their roles in supporting children living with T1D in schools and kindergartens using qualitative interview method. The following research questions guided the study:

1) How can teachers' attitudes towards diabetes care be described within the framework of the three components of attitude?
2) How do teachers perceive their own role in the support of children living with T1D? (Study 2)

Study 3: We investigate the effects of a short, standardized education program on teachers' diabetes knowledge and attitudes and their confidence in diabetes care. We measure the differences in the efficiency of the program in two forms: in-person and online. Our hypothesis is that a short diabetes education program increases diabetes knowledge and has positive effects on diabetes attitude and on confidence in diabetes care. Furthermore, we expect the effects to be stronger and more positive in person than online.

3. Methods

Study 1: A total of 403 parents (mean age: 41.5; SD=5.7; 22 males and 381 females) who primarily took care of diabetes management in their family completed the questionnaire. Which contained the Hypoglycemia Fear Survey-Parent version (HFS-P), measuring fear of hypoglycemia that parents of children living with T1D experience (Cox et al., 1987; Gonder-Frederick et al., 2006; Shepard et al., 2014; O'Donnel et al., 2022). It has three subscales. The Maintain High Blood Glucose subscale assesses the extent to which an individual engages in behaviors to prevent hypoglycemia by purposefully maintaining blood glucose levels higher than medically recommended. The Helplessness/ Worry About Low Blood Glucose subscale assesses worry about hypoglycemia and related feelings of helplessness such as having a low blood glucose while asleep. The Worry About Negative Social Consequences subscale assesses worry about social consequences of hypoglycemia such as the child doing something embarrassing. (Cox et al., 1987; Gonder-Frederick et al., 2006; Shepard et al., 2014; O'Donnel

et al., 2022). The Problem Area in Diabetes-Parent (PAID-P)**,** measuring diabetes-specific emotional distress related to the daily care demands parents with children living with T1D face (Evans et al., 2019) and a survey of diabetes care specific self-efficacy and perceived diabetes management problems which measures the parents' perceived competence in managing their child's diabetes and the extent of perceived diabetes management problems (Buzas et al., 2023).

Study 2: Teachers working in kindergartens and schools ($N = 30$, mean age: 42.9; $SD = 20$; 4 males and 26 females) participated in audio-recorded, semi-structured interviews (three focus groups and 20 individual interviews) that were transcribed and analyzed using thematic analysis (Braun & Clarke, 2006; Joffe, 2012) for narrative interviews (Riessman, 2008). We used the theory of the three components of attitude as theoretical framework for the coding templates (King, 2012), namely cognitive component, affective component and behavioral component (Allport, 1935; Fabrigar et al., 2005; Hovland & Rosenberg, 1960).

Study 3: A total of 60 teachers participated (mean age: 43.72 years (SD = 9.48), 56 female, 4 male) in our questionnaire survey. Diabetes education was offered in two formats: online (n=36) and in person (n=24). We administered questionnaires measuring diabetes knowledge (Diabetes Knowledge Test 2 (Fitzgerald et al., 2016; Papp-Zipernovszky et al., 2021), attitude (Diabetes Attitude Survey 3 (Anderson et al., 1998), School personnel diabetes attitude scale (Tannous et al., 2012), Semantic differential (Kivinemi et al., 2007) and Confidence in diabetes care (Van der Ven et al., 2003) before,

immediately after and one month after the diabetes education. We also compared the effects of online and in-person educations.

4. Results

Study 1: We conducted Latent Profile Analysis to identify subgroups with distinct profiles of parental fear of hypoglycemia. We applied 4 possible constraints provided by the tidyLPA package (Rosenberg et al., 2019) on the local distributions (variance) and covariances of the distinct latent profiles: equal variances and 0 covariances (Model 1), varying variances and 0 covariances (Model 2), equal variances and varying covariances (Model 3), and varying variances and varying covariances (Model 4). Comparing the results, we chose the five-profile solution of Model 1, since this was the first, most parsimonious solution (AIC = 2771; BIC = 2906; entropy = 0.84; BLRT/p= 83.0 (<.01)). We identified five distinct parental profiles, each with unique characteristics and levels of concern regarding diabetes management (see Figure 2).

The "Inactives" (13%) showed low engagement in maintaining high blood glucose levels and low anxiety about hypoglycemia. The "Worriers" (32.6%) exhibited the highest levels of worry and proactive behaviors in maintaining high blood glucose levels. The "Balanced" group (31.1%) had moderate levels of anxiety and proactive behaviors, balancing their concerns and actions. The "Confidents" (10%) demonstrated low anxiety and confidence in managing diabetes without excessive worry.

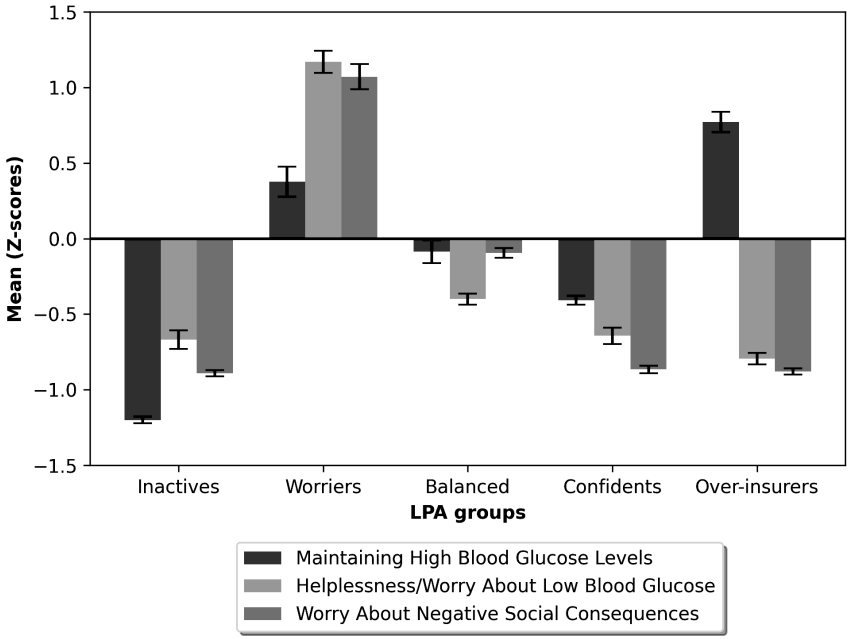

Figure 1. Profiles of the latent profile groups. Note: dimension scores are standardized factor scores with positive and negative SE Error bars

The "Over-Insurers" had the highest scores in maintaining high blood glucose levels but low anxiety. Further significant demographic and diabetes management-related differences were observed. The "Balanced" group (M = 42.4, SD = 4.87) had older parents than the “Over-insurers” group (M = 39.2, SD = 7.86) (F (4,391) = 2.70; p = 0.031). Whereas the "Worriers" (M = 9.22, SD = 2.94) had younger children than the “Balanced” (M = 10.30, SD = 2.48) (F (4,136) = 2.92; p = 0.023). The "Worriers" also showed the highest levels of diabetes distress (M = 62.9, SD = 18.1), among all of the groups (“Inactives” (M = 43.8, SD = 17.9); “Balanced” (M = 52.6, SD = 20.1); “Confidents” (M

= 44.3, *SD* = 18.5); “Over-insurers” (*M* = 52.2, *SD* = 17.5)) (*F* (4,394) = 14.1; *p* <0.001). Furthermore, the “Worriers” (*M* = 4.30, *SD* = 0.604) showed lower self-efficacy compared to the "Confidents" (*M* = 4.58, *SD* = 0.448) (*F* (4,394) = 3.31; *p* = 0.011). No significant differences were found among groups considering HbA1c levels (*F* (4,126) = 1.25; *p* = 0.292).

Study 2: The three components of attitude emerged during the analysis: knowledge, positive and negative emotions, approaches, and opinions toward diabetes and its management and behavior (see Figure 3).

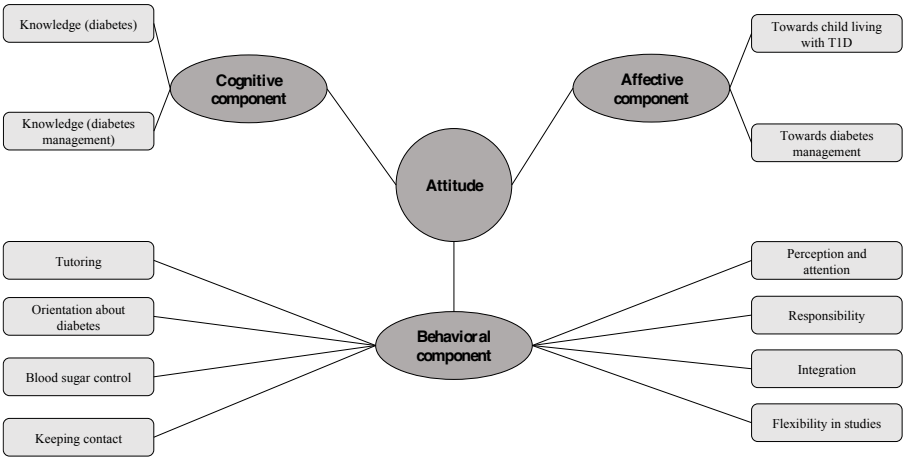

Figure 2. Overview of the subthemes of the components of attitude towards diabetes and its management. (circle: main themes, square: subthemes)

Themes	Subthemes	Quotations from focus group and individual interviews
Cognitive component	**Knowledge about diabetes**	'...the pancreas doesn't produce enough insulin, which is needed by the body, so blood sugar levels rise. Well...the symptoms...um...can be drinking a lot, going to the toilet a lot, mouth...breath changes, urine becomes acetous.' (II21)
	Knowledge about diabetes management	Considering type 1 [diabetes], I understand that insulin needs to be replaced. This can be done via a pen or a pump. .'(II11)
Affective component	**Towards child living with T1D**	'I can see her, poor thing, with the pump and the sensor. Her trousers slip down a little bit and I can see the little red dots on her, and it tugs at my heartstrings that God lets a little 5-year-old face these kind of obstacles.' (II4)
	Towards diabetes management	I'll tell you that it bothers us quite often. When we're here at work we're studying and concentrating, and P's (the child with T1D) device starts beeping... So, unfortunately we often feel that. 1: It's difficult 2: Tiring 1: A burden!' (FG2)
Behavioral component	**Perception and Attention**	'Here at school, if I see that R's eyes [the child with T1D] become a bit dizzy, I ask him immediately. (FG1)
	Responsibility	'This child is brought to the school, she spends her time between 8am till 5pm here, so during that time I'm responsible for her. And if I'm responsible for her, then my job is to learn the things that are necessary for her.' (FG2)
	Integration	'So that it's very important to talk about it with the other children. Using tales, puppets, we can strengthen the connection [between the child with T1D and his peers]' (II3)
	Flexibility in studies	'It turned out that he had diabetes and he 'slipped' [failed one academic year]. And the question was how we are going to manage to get him to graduation. So, in this case we handled it differently. There wasn't a date for the exam, he could take the exam when he was ready for it.' (FG1)
	Keeping contact	'We were in touch with the parents every single day. They told us how long the child sleeps, how we have to wake him/her up, what size of portions he should eat etc.' (FG1)
	Blood sugar control	'It happens that when their blood sugar level drops, we give them some cookies, some grape glucose tablets so that they don't start to fall into hypo [hypoglycemia].' (II4)
	Orientation about diabetes	When I found out that we were going to have [in the group] a little girl like that, I went to the XY [name of the foundation] Foundation's lecture before she joined the group, so that I could have some theoretical and practical experience of what it entailed.' (II4)
	Tutoring	'Let's think about the situation with glasses. Let's draw a parallel. If a child starts wearing glasses, a smart teacher says: "Wow, you've got such cool glasses" and "Wow it is so good!". And we prepare the child for this, right? We might even say that the glasses are very fragile, so we have to take good care of them...So, it won't draw too much attention if you introduce it properly.' (II5)

Table 1. Quotations of the subthemes (Abbreviations: focus groups 1,2,3 = FG1, FG2, FG3; individual interviews 1-20= II 1-20)

The main theme of knowledge included knowledge about diabetes in general and its management. Besides medical treatment, alternative treatment possibilities were mentioned by the participants. The affective component revealed empathy, integrating, and segregating approaches toward children living with diabetes. The behavior component revealed how teachers contribute to the care and integration of children with diabetes in schools. They support children with diabetes by the virtue of their profession. For example, they teach them health awareness and support their integration through peer education and sensitization. See quotations from the interviews regarding each subtheme in table 1.

Study 3: We conducted principal component analysis on two measures of diabetes attitude (DAS3, School Personnel Diabetes Attitude Scale) and named the emerging subscales according to the items they included. To examine the effect of the education, a mixed ANOVA test was performed for each scale. Post-hoc testing with Bonferroni correction was used to compare means across the three measurement occasions. The diabetes education program has led to a significant increase in diabetes knowledge following the education among all participants ($F(1,1.65) = 36.009$, $p < 0.001$). Participants scored higher in the test phase ($M = 20.315$, $SE = 0.494$) than in the pretest phase ($M = 16.641$, $SE = 0.538$) ($p < 0.001$). They also scored higher on the retest ($M = 20.138$, $SE = 0.449$) than on the pretest ($p < 0.001$). Considering diabetes attitudes, uniquely, the scores of the Semantic difference showed a significant rise after education ($F(1.773,102.85) = 13.345$, $p < 0.001$. The results of the tests showed significant increases from the pretest ($M = 3.277$, $SE = 0.98$) to the test

(M = 3.633, SE = 0.89) ($p < 0.001$), furthermore also from the pretest to the retest (M = 3.524, SE = 0.82) sessions among all participants (p = 0.004). The Emotional Effects (F(2,116) = 0.058, p = 0.943) and Social Support subscales (F(2,116) = 0.23, p = 0.795) of the DAS3 showed no significant improvement in scores after either in-person or online education. Similarly, the Integration (F(2,116) = 0.249, p = 0.78) and Distinction subscales (F(2,116) = 0.092, p = 0.912) of the School Personnel Diabetes Attitude Scale showed no significant post-education improvement. Confidence in diabetes management was increased by the education (F(2,116)= 131.441, $p < 0.001$). Participants scored higher on the test (M = 3.698, SE = 0.094) than on the pretest (M = 2.186, SE = 0.118) ($p < 0.001$). They also scored higher on the test, than on the retest (M = 3.398, SE = 0.098) (p = 0.005). Furthermore, they scored higher on the retest (M = 3.398, SE = 0.098) than on the pretest ($p <$ 0.001) However in the online group (M = 2.855, SE = 0.11) it showed a downward trend one month afterward compared to the in-person group (M =3.333, SE = 0.134) (F(1,58) = 7.597, p = 0.008).

5. Summary of the results and discussion

Study 1: The study identified five distinct parental profiles regarding diabetes management. Significant differences were observed among these profiles, including parental age, with the "Balanced" group having older parents and the "Worriers" having younger children, as well as differences in diabetes distress and self-efficacy levels.

Study 2: The findings indicated that, in addition to diabetes management tasks, teachers could help children with T1D by tutoring them and their peers about health awareness and T1D acceptance.

Study 3: We conclude that diabetes knowledge can be significantly increased by a short educational material and that knowledge is maintained in the longer term. However, this type of education has not been shown to be sufficient to change attitudes towards diabetes, using a more complex, perhaps interactive training is recommended for attitude change.

The care of children living with T1D necessitates a comprehensive approach that considers the interplay of biological, psychological, and social factors (Engel, 1979). Our findings emphasize the crucial role of the microenvironment, including parents and teachers, in supporting children with T1D (Roberts & Steele, 2009; Bronfenbrenner, 1979). The identification of distinct parental profiles of fear of hypoglycemia (FOH) and the significant differences in diabetes distress and self-efficacy underscore the need for tailored psychological support to enhance diabetes management and overall family well-being (Wit et al., 2020; Helgeson et al., 2012). Furthermore, teachers' attitudes towards diabetes care, characterized by empathy but also distress, highlights the importance of comprehensive diabetes education to alleviate fears and enhance their support for children's psychosocial development and integration (Runions et al., 2020; Farmer et al., 2011; National Association of School Nurses, 2016). Our intervention study demonstrates the effectiveness of in-person diabetes education in improving knowledge and confidence, underscoring the need for

interactive and comprehensive training programs to better equip school personnel in managing diabetes-related tasks just as it was recommended by the American Diabetes Association (2011). These results illustrate that addressing the support needs of both parents and teachers is vital for improving the diabetes management and the overall well-being of children with T1D, aligning with the systems-oriented framework that considers the mutual influence of children living with T1D and their social context (Kazak et al., 1995; Hobbs, 1966; Power, 2003).

6. Conclusions

Addressing the support needs of the microenvironment surrounding children with diabetes is just as important as supporting the children themselves. As practical implications of our work, we provide recommendations on how to effectively support two key groups of the microenvironment of children living with T1D. For parents, it is suggested to focus on handling anxiety-related symptoms linked to diabetes care and supporting their coping mechanisms for handling these challenges. For teachers, it is essential to enhance their diabetes-related knowledge and to clarify any fear-inducing phenomena they encounter related to diabetes and its management. Acknowledging that teachers play a significant role not only in managing diabetes-related tasks but also in helping children cope with the psychological difficulties associated with the condition. These forms of support could contribute to the mental health and well-being of the

microenvironment's members, thereby facilitating diabetes management and improving the health of children.

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