



Contents lists available at ScienceDirect

## Journal of Pediatric Nursing

journal homepage: [www.pediatricnursing.org](http://www.pediatricnursing.org)

# Can the group effect dominate the influence of the child on the parent's decision to care for type 1 diabetes?

Zsanett Tesch<sup>a</sup>, Szabolcs Prónay<sup>b</sup>, Norbert Buzás<sup>a,c,\*</sup>

<sup>a</sup> Department of Health Economics, Albert Szent-Györgyi Medical School, University of Szeged, Hungary

<sup>b</sup> Institute of Business Studies, Faculty of Economics and Business Administration, University of Szeged, Hungary

<sup>c</sup> Department of Theoretical Health Sciences and Health Management, Faculty of Health Sciences and Social Studies, University of Szeged, Hungary

## ARTICLE INFO

### Article history:

Received 25 August 2023

Revised 12 January 2024

Accepted 13 January 2024

### Keywords:

Group effect

Netnography

Peer support

Social media

Type 1 diabetes

## ABSTRACT

**Aim:** To understand how the interaction of peer parents in disease-specific social media groups influences their daily treatment decisions.

**Design and methods:** We examined the content of the largest Hungarian Facebook group for parents of children with type 1 diabetes mellitus, analyzing 28 days of activity using netnography. In addition, we undertook an on-line quantitative questionnaire to identify group members' ( $n = 267$ ) attitudes.

**Results:** In exploring the influence of the community on the decisions of peer-parents, we found that the respondents could be divided into two clusters. The main difference between the clusters was that committed parents sought the online community for advice and asked questions more frequently, and the peer-support community was a more important part of their self-image. Comparing the influence of online communities and children on the parents' decisions, we observed that the community had the most significant impact on attending diabetes-specific events, while children had the greatest influence on meals and leisure time and were often in conflict with parents.

**Conclusions:** Social media strongly support the integration of prescribed therapy into daily routine. The influence of the child with diabetes on parental decisions shows that diabetes education needs to become child-centered and that the parent-child relationship should be considered as a crucial element for therapy effectiveness.

**Practice implications:** Online parenting groups provide mental support in coping with diabetes and would serve as a primary non-medical information source; the healthcare staff must be supportive or even encouraging when parents join such groups.

© 2024 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

## Introduction

### Peer-facilitated decision-making in diabetes

Peers, as individuals with similar health conditions or experiences, can help each other navigate between complex healthcare choices (Farnham et al., 2002; Preece & Maloney-Krichmar, 2005). Through emotional support, sharing knowledge or coaching, peer support helps reduce depression (Dennis, 2003) and may contribute to improved chronic conditions, such as diabetes management (Joseph et al., 2001). Peer support is especially beneficial when patients with chronic diseases are tackling challenging new medical tasks, such as

glucose monitoring or insulin administration (Wilson & Pratt, 1987). Peers can frequently offer unique insights and practical advice that healthcare professionals may not provide; therefore, peer support is increasingly recognized as a valuable component of informed decisions-making processes (Buzás et al., 2023).

There may be several cases in which people are unable to access peer support in-person (Titoria et al., 2022). Location of the residence, lack of adequate transport or a special work schedule may all be obstacles to meeting in-person. In such cases, non-face-to-face assistance, such as telephone-based, web-based, or email-based peer support, will be given priority (Heisler, 2007). Hence, immediate information needs for parents of the society might be required, that is, time-sensitive demand for specific information that the individuals would require to make informed decisions (Zhang et al., 2013). It would also lead to a change in face-to-face peer support in many ways, and it could be replaced by online communication (Warshaw & Edelman, 2019).

\* Corresponding author at: Department of Health Economics, Albert Szent-Györgyi Medical School, University of Szeged, Hungary.

E-mail address: [buzas.norbert@med.u-szeged.hu](mailto:buzas.norbert@med.u-szeged.hu) (N. Buzás).

### Peer support from online diabetes communities

For more than a decade, the availability of social media has enabled a new kind of forum among people with chronic diseases, such as diabetes, and their caregivers (Balkhi et al., 2014). The volume of peer support has increased exponentially through social networks (Warshaw & Edelman, 2019) and has given rise to a number of virtual diabetes-focused groups, which are referred to as diabetes online communities (Hilliard et al., 2015). Such communities provide tailored care, disease information, peer support and information about the accessibility of healthcare professionals (Boogerd et al., 2015). While active participation and engagement in such diabetes-specific social media groups are associated with mostly positive effects, very little is known about what content is shared via these channels or what features of posts engage users the most (Gabarron et al., 2020).

Groups for children with type 1 diabetes mellitus (T1DM) occupy a special place within the online diabetic patient population. Younger children are not in a position to make direct decisions about their treatment and lifestyle because of their age, however, their compliance to the treatment is crucial for the effectiveness of the therapy (AlBuhairan et al., 2016). Young children must rely on their parents and families for instruction, support, and daily help in coping with such a complex set of demands (Nardi et al., 2008). Rafferty and Sullivan (2017) have interviewed 35 parents of children diagnosed with complex, chronic diseases and found that social networking and informativeness are behaviors that may help parents engage with their child's care team and advocate effectively. Thus, understanding how parents advocate for their sick children is critical in providing high quality pediatric care. Content analysis of the counseling has shown that online parent-peer support focuses on four major topics: navigating care with medical professionals, communicating the need for social support from others, enduring positivity amidst hardships, and advocating for the child (Balkhi et al., 2014; Rafferty & Beck, 2020). Our previous results also showed that peer-support groups on social media platforms could serve as sources for necessary information, social support, and feedback on parental diabetes management competence (Buzás, Horváth, Tesch, & Hallgató, 2023).

Beyond the challenges of daily care and monitoring, young patients face emotional and psychological difficulties that reflect on their own coping abilities as well as their families' (Zysberg & Lang, 2015). The management of T1DM is particularly overwhelming and stressful for parents, who have to adapt to the psychological tasks associated with the child's development and to the expectations of the new situation (Nardi et al., 2008). Little is known about the types of uncertainty associated with T1DM diagnosis and subsequent treatment, and how this uncertainty is managed; nonetheless, negative consequences on the health of the affected patients might occur. An evaluation of 29 in-depth interviews with parents of children with T1DM, by Perez et al. (2019) has found that most parents sought to reduce uncertainty by seeking information or joining support groups. Therefore, it can be concluded that parents of children with T1DM might be more inclined to join online communities that welcome those with similar problems and provide support in issues of everyday life, without discussing the disease. Through the direct involvement of parents, juvenile-onset T1DM can also be seen as a family disease (AlBuhairan et al., 2016).

Parent interviews in a study by Gavrila et al. (2019) have revealed that parents received little personal support when their child was first diagnosed with the disease, other than that provided by the medical team, since there were few parents within the local area facing a similar situation, and therefore, nobody seemed to understand their anxiety and struggles. The "CGM (Continuous Glucose Monitoring) in the Cloud" Facebook group (The Nightscout Foundation, 2014) has almost 40,000 members, offers a virtual network for these parents and families. Some parents have revealed that although they now have another family in their neighborhood with a child living with T1DM, they still get most of their support from members in the Facebook group. This may

lead us to believe that emotional support can be provided virtually, especially when these connections may not exist as a result of the sparse number of parents with T1DM children in the area. Emotional support is also crucial for the longer-term mental health of the mother because maternal adjustment, shortly after the establishment of the diagnosis, is a predictor of the mother's own long-term emotional well-being (Channon et al., 2016). A comparative study of support options for 120 parents of children with diabetes discusses that groups who have received diabetes-specific care messages reported higher levels of disease management and were more satisfied than those who received general parenting messages, whether via SMS or Facebook (Holtz & Mitchell, 2023).

By analyzing three blogs of parents caring for a child with T1DM, Oser et al. (2017) have assessed, among other parameters, the burden of intensive self-management experienced when caring for a child with T1DM and have found that support was received via peer-to-peer blogging. Blogs provide a unique avenue for support, where misinformation is rarely identified, and they may be a resource that diabetes caregivers can consider to offer to families as support.

The role of online social support is controversial in increasing the diabetes self-efficacy of parents of children with T1DM (Marchante et al., 2014). Measuring the impact of a web-based platform on the self-efficacy of parents of children with type 1 diabetes, Merkel and Wright (2012) describe that parents take advantage of online social support, and as a result, their self-efficacy scores on both the Diabetes Empowerment Scale and the Self-Efficacy for Diabetes Scale increase significantly. Their data support a positive relationship between social support and self-efficacy in raising a child with T1DM. In contrast, an 8-week pilot study of the MyT1DHope website by Holtz et al. (2020) revealed that while there were significant improvements in diabetes knowledge and caregiver satisfaction, no change in self-efficacy or quality of life could be identified. Using an online questionnaire survey of 198 parents of children with diabetes, Uhm and Kim (2022) have recently found that online social support alone has a limited role in chronic disease management self-efficacy. Using the modified Maternal Self-efficacy for Diabetes Management Scale, Uhm & Kim could identify only an indirect relationship between diabetes-related burden and diabetes self-efficacy.

### Our study

Previous studies have outlined the impact diabetes online communities may have on parents' diabetes management (Boogerd et al., 2015; Gabarron et al., 2020; Gavrila et al., 2019). However, much of the research on interaction focuses mainly on the interplay within the community (Oser et al., 2017; Sahiti et al., 2020; Zhang et al., 2013) and with little consideration to the role of healthcare professionals. There is a paucity of in-depth research about the extent of group influence on the range of diabetes management tasks, such as Meals, Exercise, Insulin therapy, Use of equipment, Choice of school, Leisure time, and Attending events, and the interplay between peer groups on parental decision-making. Our study aims to gain a deeper understanding of the influence within a diabetes online forum, across diabetes management tasks, and the influence of the opinions of peer parents on parents' decisions when managing their child's diabetes. In addition, we wished to identify how and who joined the online community, the information exchanged, and what actions occurred outside the virtual space, either with private peer encounters or health professionals.

### Methods

#### Participants

Currently, in Hungary, more than 5000 families raise a child living with T1DM. Since its starting in 2012, nearly 4000 people have joined the largest Hungarian social network of its kind (a Facebook group for

parents of children with T1DM). This group was investigated in our study, as it provided the broadest convenience sample of parents. Subjects were informed that participation in the study was anonymous and no information would be collected based on which participants could be identified.

#### Data collection

To understand parents' views on certain issues and to study their interactions, we used netnography (Tenderich, 2019) within this Facebook group in February 2022 for 28 days. Based on the activity parameters of the group, during the period studied members created 294 posts, and 3416 comments were posted and 7113 emojis were received.

We also conducted an online survey to analyze the group members' attitudes towards the group and its influence on the parents' behavior. The self-administered questionnaire was pre-tested with parents of children with diabetes. The questions were answered in a self-filling manner using Google Forms. Recruitment stopped at the end of the day when the number of participants exceeded the recruitment target of 250 ( $n = 267$ ). Respondents answered the questions according to their individual perceptions; therefore, no health data was collected in the research.

#### Data analysis

Using netnography, we analyzed the posts by grouping them according to their topic, the creator's status, and the commenter's attitude.

By exploring the impact on commitment, we differentiated between parents with T1DM children according to their attitude towards the online community studied. Then, by examining the differences between the group of parents with various commitments to the group, we were able to identify areas where the community's influence was more pronounced and others where it had a lesser effect on altering the parents' behavior. Based on questions about commitment to the group, cluster analysis was used, to identify patterns in the participants' interaction with the forum. These variables were first merged into factors using principal component analysis by SPSS 26 software. The applicability of factor analysis was tested by the Kaiser-Meyer-Olkin (KMO) Measure and Bartlett's Test of Sphericity. The ANOVA test was used to examine the main differences between the groups. The independence of the influence of the group's opinion and the opinion of the diabetic child was tested by the Pearson's correlation test.

#### Ethical considerations

Permission to conduct the study was obtained from the Ethics Committee of the National Medical Research Council (IV/9901–1/2021/EKU). The questionnaire was posted in the Facebook group with permission from the administrators. Parents who participated in the research were informed about the purpose of the research and the study process through the survey form. No personal data was collected in the study.

## Results

#### Netnography

In our experience, once members join the T1DM Parent Group, they usually stay and participate in the community until their children become adolescents or until parents no longer have an influence on the management of their condition. As a result, the group has a limited number of participants who are caring for children capable of self-managing their diabetes. The number of members continued to increase

during the period under review, with 87 applications approved in 28 days. 92.1% of the group members have an active status, i.e., they have joined the group at least once in the past 30 days during the study period.

The content composition of the posts are varied but mostly relate to the topic of diabetes.

Communication in the group was dominated by posts about the professional care of the disease, with nearly half of the posts (48.64%) discussing insulin use, devices related to blood glucose measurement (glucose sensor, blood glucose meter) and insulin dosing (pen, insulin pump). Posts concerning the devices needed to manage the disease on an ongoing basis were focused on how to use them or how parents might help each other when something was missing.

Diet ranked as the second most popular topic (25.17%), emphasizing the importance of meals in diabetes care. In this category, post primarily centered around sharing information regarding food, ingredients and cooking techniques.

Several social activity posts (20.07%) discussed important days in the life of children with diabetes (e.g., birthdays), with cakes, popcorn, and sugary drinks being a common topic. As this disease requires constant preparedness and careful planning on the side of parents, it is also necessary to be prepared for situations that extend beyond the typical daily routine. These situations included holidays, going to the beach with a Continuous Glucose Monitor (CGM) and insulin pump, as well as arrangements for air travel, all of which were repeatedly mentioned in the posts.

Posts related to public education institutions were placed in the social care category. The care of children with diabetes during the day requires supervision and active assistance, especially in the case of children under 14 years of age. Parents were interested in the experiences and advice of peer parents and how they tried to prepare for events at the institutions. Subsidies related to the healthcare system were also listed here. Regarding the classification in Hungary, type 1 diabetes falls under the category of "permanently ill or severely disabled"; therefore, the parents of these children are entitled to health and social benefits (e.g., home care allowance, or tax relief). However, it is difficult to navigate in the maze of official procedures; thus parents often asked for help in this regard.

#### Questionnaire survey: demographics

The majority of the respondents (94.8%) are female, in line with the experience that mothers are the primary caregivers of children with diabetes (Sullivan-Bolyai et al., 2003). 54.3% of the parents were between the ages of 35 and 44 years, while 33.7% of them were between 45 and 54 years. The average age of the children was 10 years and 4 months (range 1–18, because in Hungary, decisions related to health for children under the age of 18 years are the responsibility of the parents;  $SD = 3.89$ ). The average number of years since the establishment of the diagnosis of T1DM was 4 years and 2 months (range 0–18,  $SD = 4.3$ ). Only two participants reported having more than one child with T1DM.

The geographical composition of the group shows that 90.5% of the members live in Hungary. As the language of the forum is Hungarian, other members are assumed to be Hungarian-speaking minorities living in other countries.

The attendance pattern of the social community is given in Table 1. The majority of participants visit Facebook every day (47.2% of them several times a day and 24.3%, once a day). One third of the parents used more than one device to connect to the internet, and a large percentage of the participants was communicating via smartphone (73.2%), while the rest of them connected via laptop (16.3%), computer (7.4%), or tablet (3.1%).

**Table 1**  
Attendance pattern.

Group analytics	%
Visit frequency	
Many times a day	47.2
Once a day	24.3
Several times a week	22.1
Once a week	3.8
Every two weeks	0.4
Once a month	0.0
Less often	2.2
Location of visit/connection	
Home	53.7
Workplace	16.7
On the way	10.2
While waiting	19.4
Device	
Computer	7.4
Laptop	16.3
Tablet	3.1
Smart phone	73.2

### Questionnaire survey: relationship

The responses to questions about joining the T1DM online parenting group and interactions outside the group are summarized in Table 2. The largest proportion of parents who joined the group (44.8%) did so as a result of the suggestion/encouragement of peer parents. More than a quarter (27.1%) of the parents found the online community as a result of their own search, while a similar proportion (25.8%) indicated healthcare professionals (doctors, specialist nurses, or dietitians) as the initiator of joining the group.

The question about the membership of the group by the respondent's family members and acquaintances was designed to see to what extent the respondent's environment accepted and valued the

**Table 2**

Conditions for joining the group and interactions apart from the group. (*M* = multiple answers could be chosen).

Who told you about the Facebook group? (M)	%
Recommended by another peer-parent	44.8%
I found it myself	27.1%
From a healthcare professional	25.8%
Other	2.3%
Are other family members or acquaintances of the respondent also members of the Facebook group?	
No	57.3%
Yes (M)	42.7%
Spouse, partner	22.7%
Grandparents	8.5%
Own child with T1DM	7.0%
Brother or sister of the child with T1DM	1.3%
Brother or sister of parent	1.3%
Other	1.9%
Has the respondent established a relationship within the group that was followed by a private online conversation?	
Yes	64.4%
No	35.6%
Has the respondent established a relationship within the group that was followed by a personal meeting?	
Yes	34.5%
No	65.5%
Who do you talk about what you read in the Facebook? (M)	
Spouse, partner	26.4%
Own child with T1DM	26.2%
Healthcare professional	20.6%
Grandparents	9.0%
Friend not affected by diabetes	8.4%
Teacher in kindergarten or school	5.1%
Brother or sister of the child with T1DM	4.3%

group membership, and possibly, how much this membership was involved indirectly in the care of the child with diabetes. 42.7% of the respondents indicated that other family members or friends were the members of the group. More than half of them were the spouse or partner and one-fifth were the grandparents. A smaller proportion included the child with diabetes himself/herself and a minority consisted of the sibling or uncle/aunt of the child with diabetes.

The impact of the forum interactions on the relationships outside the virtual space was examined, i.e., whether the exchange of information within the group was followed by a private conversation or a face-to-face encounter with another group member. Almost two-thirds of the respondents (64.4%) had an in-group relationship which was followed by a private online conversation and 34.5% had a relationship that was followed by a planned face-to-face meeting.

To find out how much of the conversations and information within the group was shared beyond the virtual space, respondents were asked whether they discussed what they had read in the group with others. Out of the 267 respondents, 720 answers were marked (an average of 2.7 per respondent), indicating that on average respondents shared and discussed what they had read in the group with 2 to 3 people. More than a quarter of the respondents discussed what they had read with their spouse/partner, and the same proportion with their child with diabetes. When including grandparents (9%) and the siblings of the child with diabetes (4.3%), it was found that communication within the immediate family accounted for almost two-thirds of the discussion of what was happening within the group. Out of the 20.6% of healthcare professionals involved in the management of the disease, the treating doctor accounted for 13.2%, specialist nurses for 3%, the dietitian for 2.3%, and the general practitioner for 2.1%. 8.4% of the parents discussed these issues with their own friends who were not affected by diabetes, and 5.1% with the teachers of the child with diabetes.

### Questionnaire survey: commitments

To assess the influence of the group on the decisions and actions of its members, we initially examined whether there was a difference in the commitment level of group members to the group. Subsequently, we investigated whether the influence of the group differed across the seven areas of diabetes life mentioned earlier, considering different commitment segments.

Cluster analysis was used to separate the groups based on questions about commitment to the group. First, these questions were grouped into factors by using principal component analysis. The analysis identified two factors into which all the variables studied could be classified with a proportion of variance of 59.37% ( $KMO = 0.800$ ; Bartlett's Test of Sphericity sig = 0.000). Based on these two factors K-means cluster analysis was performed using SPSS 26. The 267 items were classified into 2 clusters: 96 items and 171 items, which we called "Not Committed" and "Committed", respectively. It should be highlighted that this commitment did not indicate the overall commitment of the parents to their child or childcare, but rather the strength of the attachment to the online group. Members of the "Committed" group were considered truly hardcore with a strong emotional attachment to the online group, while "Not Committed" members were not completely ignorant but rather more loosely attached to the community than the "Committed" ones and cared less about the group in general. Although one segment was labeled as "Not Committed", it should be noted that these individuals were still members of the study's online community and therefore, they could be considered relatively more committed compared to the parents outside the group.

To characterize the clusters by the commitment to the group, we compared the mean values of the variables in each factor by cluster. The ANOVA test showed that there were significant differences between the clusters for all variables. Table 3 presents the differences between the "Committed" and the "Not Committed" clusters based on the variables used for the cluster analysis.

**Table 3**

Difference in the means (M) of the two segments along the cluster affiliation questions (Scale was 4 items, where 1 = Strongly disagree; 4 = Strongly Agree; N = 267).

	Not Committed N = 96 Mean (M)	Committed Mean (M) N = 171	Total Mean (M) N = 267	Difference of means (DM)
Being part of a group helps me a lot in my mental coping with living with diabetes	2.90	<b>3.73</b>	3.43	0.84
Being part of a group makes it easier to follow a diabetes management routine	2.81	<b>3.70</b>	3.38	0.89
I am more likely to seek advice from the community than to look for information on the Internet	2.39	3.44	3.06	1.05
I enjoy asking questions to group members	2.17	3.15	2.79	0.98
I find this community more reliable than a web doctor	2.46	3.26	2.97	0.80
I am happy to share my experiences with group members	2.44	3.06	2.84	0.63
This community is an important part of who I am	2.15	3.20	2.82	1.05

Our results show that the online community was more of an emotional support. This assumption was based particularly on findings in the “Committed” cluster (M = 3.73). The “Not Committed” cluster also had the highest mean value for this variable (M = 2.90), indicating that the mental aspect of belonging to a group was also important for them, but to a lesser extent than for the “Committed” ones (DM = 0.84). The role of the community in following the diabetes routine was similarly important for both the “Committed” (M = 3.70), and the “Not Committed” (M = 2.81) members, despite a slightly larger difference (DM = 0.89). The most significant difference between the “Committed” and the “Not Committed” members was in the extent to which they were willing to turn to the community for advice (DM = 1.05) or for answers to their questions (DM = 0.98), and in the importance of the community in how they thought of themselves (DM = 1.05).

We examined how these two groups differed in other aspects than the variables used for clustering. The ANOVA test results showed that there were no differences between the groups by gender, financial status, education level, or the age of the child. We were able to identify significant differences based on the length of experience with the disease. In the “Not Committed” group, parents had an average of 5.15 years of experience of having a child with diabetes, while the same proportion was significantly lower among the “Committed”, with an average of 3.15 years. This finding may suggest that parents with less routine and habituation tend to be more engaged and are more in need of support.

As the decisions of a parent caring for a child with diabetes were often influenced by the child, we also considered whether some areas of diabetes life were more influenced by the online community than the opinion of the parent's child. As a first step, we used Pearson's correlation to test whether the degree of group influence was related to the degree of influence from children in each domain. We found that the children's influence and group influence were significantly, but not strongly, correlated in all the domains examined as follows: Meals: 0.221, Exercise: 0.178, Insulin therapy: 0.259, Use of equipment: 0.253, Choice of school: 0.259, Leisure time: 0.217, and Attending events: 0.231). Sig. (2-tailed) was 0.000 for all areas except for Exercise, which was 0.003.

We then identified whether the relationship between the online community and the influence of the child differed between the “Committed” and the “Not Committed” segments. Using the ANOVA test, we found that the two segments did not differ in terms of the child's influence on any of the topics tested, with one exception (“Attending events”). In other words, children's influence was only minimally related to the commitment to the online community; partly explaining the low correlation values presented above.

We also explored the differences in the influences of the group and the children in more detail. We examined the degree of influence of the group and the child separately for the seven areas of the “Committed” and “Not Committed” segments (Table 4).

In all the areas of diabetes life examined, the influence of the group is more significant in the “Committed” segment than in the “Not

Committed” one, confirming that the separation of the two segments was appropriate.

In the whole sample, the influence of children was greater than the influence of the online community in all but one of the topics (Insulin therapy). Compared to the online peer parents, the influence of children was particularly significant in Meals, Exercise, and Leisure time. However, we also observed that in these areas, the differences in the influence of the child's and the group's opinion were much larger in the “Not Committed” segment than in the “Committed” one (0.84, 0.74, and 0.83 vs. 0.36, 0.30, and 0.58, respectively).

The influence of the online community was explicitly significant, i.e., reaching the level of the children's influence in Attending events and Use of equipment, respectively. For the former, the degree of the group's influence was relevant even in the “Not Committed” participants (M = 2.10).

The most significant difference in the degree of group influence was observed for Insulin therapy and Use of equipment. For the “Committed” segment, there was a significant group influence in areas such as Insulin therapy (M = 2.17) and Use of equipment (M = 2.27), and this influence was similar to the degree of children's influence (M = 2.02 and M = 2.30, respectively). Conversely, in the “Not Committed” segment (Insulin therapy M = 1.69; Use of equipment M = 1.84), this similarity was not observed.

In terms of Choice of school, the Facebook group had only a minor role in absolute terms and in comparison to the influence of children.

## Discussion

The flow of online health information without professional control raises the possibility that such information may be inaccurate, misleading or anxiety-provoking (Swee-Lin & Goonawardene, 2017). Several healthcare professionals are found to be hesitant to refer patients to online blogs for support because of concern about the spread of

**Table 4**

Differences in means (M) between the Committed and Not Committed clusters along the questions on group influence and child influence (Scale was 4 items, where 1 = Strongly disagree strongly; 4 = Strongly Agree; N = 267).

	Influence of	Not Committed	Committed	Total
Meals	Group	2.05	2.48	2.33
	Child	<b>2.89</b>	<b>2.84</b>	<b>2.86</b>
Exercise	Group	1.93	2.30	2.16
	Child	<b>2.67</b>	<b>2.60</b>	<b>2.62</b>
Insulin therapy	Group	1.69	2.17	2.00
	Child	1.83	2.02	1.96
Use of equipment	Group	1.84	2.27	2.12
	Child	2.10	2.30	2.23
Choice of school	Group	1.40	1.66	1.57
	Child	2.10	2.01	2.04
Leisure time	Group	1.95	2.30	2.18
	Child	<b>2.77</b>	<b>2.88</b>	<b>2.84</b>
Attending events	Group	2.10	<b>2.54</b>	2.38
	Child	2.19	<b>2.53</b>	2.40

misinformation and the lack of clinical moderation of the content (Ventola, 2014). These concerns and an unsupportive attitude about these resources may result in people either not utilizing peer support groups or not sharing the use of these resources with their healthcare professionals (Litchman et al., 2018). However, research in recent years has confirmed that groups are overwhelmingly engaged in precise, useful and supportive communication (Gavrila et al., 2019), and only very little evidence of risky or misleading information is supported by the social media (Greene et al., 2011) with minimal clinical impact (Oser et al., 2017). For this reason, despite the fact that all parents had access to healthcare professionals 24 h a day, parents might rather ask for advice from other parents and try to find an individual solution based on shared experience. The importance of peer support has also been acknowledged by professional organizations, leading to strengthened cooperation with these groups (Warshaw & Edelman, 2019). Our research may further confirm this trend, with healthcare professionals not only embracing the joining of such groups but also, by recognizing their importance, may actively endorse and support these groups. This is evident, as a quarter of the respondents specifically joined the group based on their suggestions.

Our study also tried to shed light on the effects of communication within the group on the relations outside the group. We found that online social spaces also involved active one-to-one communication, followed by a personal meeting for one in three participants, suggesting that the group also actively contributes to the development of human relationships. Online and offline peer support could complement each other, and combining them is mainly described as beneficial by the group members (Strand et al., 2020).

Several parents also discuss what they had read in the forum with their children's teachers, because parents (and children as well) desire that teachers be more knowledgeable about T1DM (Gutzweiler et al., 2020). It has been previously shown that teachers do not have adequate knowledge about diabetes (Jarrett et al., 1993). Nevertheless, it has also been observed that despite their fears, teachers are willing to participate in diabetes care, even though less than 1% of them have received education on how to support children with diabetes in a professional way (Carral San Laureano et al., 2018). Thus, parents sharing and discussing their knowledge with teachers in the group would have a major role to play in enhancing the knowledge about diabetes of teachers working with children living with diabetes. This is particularly important because teachers are the most supportive of all school staff when it comes to children with diabetes (Amillategui et al., 2009).

In exploring the influence of the online community on decisions of the peer-parents, we found that the respondents could be divided into two segments: the "Committed" and the "Not Committed". These groups differed along demographic factors only in that parents with children diagnosed long ago were less committed to the online community than parents whose children have been recently diagnosed with diabetes (3.15 years on average). The latter group was likely to be less experienced in caring for a child with diabetes and likely to feel more vulnerable and thus more in need of peer support. This is not only true for online peer support in diabetes, because those who are newly diagnosed with Multiple Sclerosis are also more likely to turn to peers for emotional support than those who have suffered from the disease for longer (Morris-Bankole & Ho, 2022).

In terms of the impact of the online community, the main difference between the "Committed" and the "Not Committed" clusters was that the "Committed" parents sought the online community for advice and asked questions more frequently, and the peer-support community was a more important part of their self-image compared to the "Not Committed" ones. Noteworthy, 67.42% of the whole sample agreed or strongly agreed with the statement that the community was part of their positive self-image. In a study of 15 Facebook groups of diabetes management, Greene et al. (2011) had similarly found that users can develop a positive but realistic self-image through the groups.

Looking at the nature of the support received from the group, it could generally be said that online groups may mainly provide emotional support. For the statement "Being part of a group helps me a lot in my mental coping with living with diabetes", the mean of the responses indicating agreement was highest among the Committed group (3.73) and the total sample (3.43) as well. As illustrated by the number of responses, a total of 240 out of 267 responses were marked "Agree" and "Strongly agree", which is nearly 92%. This may contradict the findings of Rupert et al. (2016), who, in their interviews with 89 online health community members, found that respondents primarily valued such groups as an alternative source of information about treatment options and self-care, rather than a source of emotional support.

We compared the influence of online communities and children with diabetes on the parents' decisions. While these two effects seemed to be related, we could only find a weak correlation between them (Pearson's correlation was lower than 0.26 for all diabetes life areas). Table 4 shows that neither the online groups, nor the children have a meaningful influence on insulin therapy (for a mean of 2.00 or below, the vast majority of the respondents marked the "Strongly Disagree" and "Disagree options"), which may be explained by the fact that this is an area where the doctor obviously sets the agenda. It confirms that peer support should be considered as a complementary treatment for patients with diabetes, and members of such groups provide psychological support rather than influence each other in therapy (Gilbert et al., 2012). Only in the Committed cluster could we observe a minor peer influence on insulin therapy ( $M = 2.17$ ), suggesting that they rarely take the group's opinion into account on this issue. It should not be a matter of essential dosage adjustments but rather adjusting the temporary base (e.g., for exercises) or the dosage of specific boluses (e.g., for eating pizza). Neither the group, nor the children's impact on school choice was identified, which also was to be expected, as it typically depends on a parental choice and the availability of local opportunities.

The largest influence of the online community in the Attending event was identified in the "Committed" group (2.54), showing that many of the recommendations for events came from this specialized group. Nonetheless, attendance itself also depended on the opinion of children, because the influence of the two groups were balanced in this area.

Children had the greatest influence in the areas of Meals and Leisure time. These were the two areas with the most conflicts, where children sometimes did not fully understand (or some young adults even directly resisted) parental expectations regarding adherence to testing and care protocols (Zysberg et al., 2013). The clear predominance of children's influence on Meals was particularly an unexpected result in light of that diet was the second most popular topic for seeking peer support.

### Limitation

In evaluating the limitations of our study, it is important to recognize the constraints inherent in netnography and survey methods. Netnography, while effective in capturing group-level interactions within online communities, may not fully represent the diversity of experiences and opinions of all group members, particularly those less active or vocal online. We should also not forget about patients and their parents who are still not members of such Facebook groups. In the future, it would be worthwhile to reach out to parents who are indeed not committed, and this could be done by offline sampling as they are not members of any online community. Moreover, this method relies on the interpretive skills of the researchers, introducing potential biases in understanding the context and meaning of online interactions.

The survey approach generally has the limitation of self-selection bias, as it predominantly captures the perspectives of those motivated to respond. Additionally, the survey's reliance on self-reported data can lead to inaccuracies due to respondents' subjective interpretations or memory recall biases, and this can be even more typical in case of such an emotionally sensitive topic. Furthermore, the study's focus on

a specific Hungarian Facebook group limits its generalizability to other online communities or cultural contexts.

### Nursing implications

T1DM online parenting groups might be a very important mental support in coping mechanism for parents with a diabetic child and can serve as a primary non-medical source of information; moreover, it is important that the healthcare staff should be supportive or even encouraging when parents join such groups. Fears among health professionals that the advice parents obtained from the online group would lead them in the wrong direction in nursing for their children were unfounded. Only in very rare, but very useful cases, do members of these groups deal with insulin therapy issues and only in areas where parents have a lot of practical experience (e.g., temporary base adjustment or specific boluses). Thus, participation in such groups can be a very useful complement to the advice of healthcare professionals. The strongest influencing effect of these groups should be participation in professional events; therefore they can also be seen as a primary source of information for such events. Additionally, it may also be important due to the fact that meeting peers face-to-face can help parents in coping with all the associated difficulties, and a parent in a better mental state can support a child with diabetes more effectively.

### Conclusion

We may conclude that social media strongly supports the integration of prescribed therapy into daily life. Despite the fact that parents are constantly asking for and seeking information about the care of children living with diabetes, parents themselves admitted that children still had a greater influence on the decisions about their meals, doing physical exercise, and leisure activities than the group of peers. The increased influence of the child with diabetes on parental decisions would show that diabetes education needs to become child-centered in the future, and that the parent-child relationship should be considered a crucial element of therapy effectiveness.

Our study highlighted the importance for a deeper investigation of T1DM online communities. It may provide a methodological basis for isolating committed group members, and explore how the impact of online communities in key areas of diabetes life may compare to the impact on parents of children with diabetes. We demonstrated that the exchange of information in the online community may continue outside the group, and thus, it could have an impact on the whole peer support community. From a practical point of view, our work highlights that the discourses in online communities might have a major impact on the daily lives of the families concerned; parents should also be able to openly discuss with the healthcare professionals the information they learn.

### Funding

The authors reported that there was no funding associated with the work featured in this article.

### CRediT authorship contribution statement

**Zsanett Tesch:** Writing – review & editing, Writing – original draft, Formal analysis, Data curation, Conceptualization. **Szabolcs Prónay:** Writing – original draft, Methodology, Formal analysis. **Norbert Buzás:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Formal analysis, Conceptualization.

### Declaration of competing interest

No potential conflict of interest was reported by the authors.

### References

- AlBuhairan, F., Nasim, M., Al Otaibi, A., Shaheen, N. A., Al Jaser, S., & Al Alwan, I. (2016). Health related quality of life and family impact of type 1 diabetes among adolescents in Saudi Arabia. *Diabetes Research and Clinical Practice*, 114, 173–179.
- Amillategui, B., Mora, E., Calle, J. R., & Giral, P. (2009). Special needs of children with type 1 diabetes at primary school: Perceptions from parents, children, and teachers. *Pediatric Diabetes*, 10, 67–73.
- Balkhi, A. M., Reid, A. M., McNamara, J. P. H., & Geffken, G. R. (2014). The diabetes online community: The importance of forum use in parents of children with type 1 diabetes. *Pediatric Diabetes*, 15, 408–415.
- Booger, E. A., Maas-vanSchaaijk, N. M., Noordam, C., Marks, H. J., & Verhaak, C. M. (2015). Parents' experiences, needs, and preferences in pediatric diabetes care: Suggestions for improvement of care and the possible role of the internet. A qualitative study. *Journal for Specialists in Pediatric Nursing*, 20(3), 218–229.
- Buzás, N., Horváth, M. D., Tesch, Z., & Hallgató, E. (2023). How online peer support affects management efficacy and mitigates difficulties of parents caring for children with type 1 diabetes. *Primary Care Diabetes*, 17, 607–611.
- Carral San Laureano, F., Gutiérrez Manzanedo, J. V., Moreno Vides, P., de Castro Maqueda, G., Fernández Santos, J. R., Ponce González, J. G., & Ayala Ortega, M. D. C. (2018). Teachers' attitudes and perceptions about preparation of public schools to assist students with type 1 diabetes. *Endocrinología, Diabetes Y Nutrición*, 65(4), 213–219.
- Channon, S., Lowes, L., Gregory, J. W., Grey, L., & Sullivan-Bolyai, S. (2016). Feasibility of parent-to-parent support in recently diagnosed childhood diabetes - the PLUS study. *The Diabetes Educator*, 42(4), 462–469.
- Dennis, C. -L. (2003). Peer support within a health care context: A concept analysis. *International Journal of Nursing Studies*, 40(3), 321–332.
- Farnham, S., Cheng, L., Stone, L., Zaner-Godsey, M., Hibbeln, C., Syrjala, K., ... Abrams, J. (2002). HutchWorld: Clinical study of computer-mediated social support for cancer patients and their caregivers. *CHI '02: Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 375–382).
- Gabarron, E., Larbi, D., Dorronzoro, E., Hasvold, P. E., Wynne, R., & Årsand, E. (2020). Factors engaging users of diabetes social media channels on Facebook, Twitter, and Instagram: Observational study. *Journal of Medical Internet Research*, 22(9), Article e21204.
- Gavrila, V., Garrity, A., Hirschfeld, E., Edwards, B., & Lee, J. M. (2019). Peer support through a diabetes social media community. *Journal of Diabetes Science and Technology*, 13(3), 493–497.
- Gilbert, K., Dodson, S., Gill, M., & McKenzie, R. (2012). Online communities are valued by people with type 1 diabetes for peer support: How well do health professionals understand this? *Diabetes Spectrum: A Publication of the American Diabetes Association*, 25(3), 180–191.
- Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2011). Online social networking by patients with diabetes: A qualitative evaluation of communication with Facebook. *Journal of General Internal Medicine*, 26(3), 287–292.
- Gutzweiler, R., Neese, M., & In-Albon, T. (2020). Teachers' perspectives on children with type 1 diabetes in German kindergartens and schools. *Diabetes Spectrum: A Publication of the American Diabetes Association*, 33(2), 201–209.
- Heisler, M. (2007). Overview of peer support models to improve diabetes self-management and clinical outcomes. *Diabetes Spectrum: A Publication of the American Diabetes Association*, 20, 214–221.
- Hilliard, M. E., Sparling, K. M., Hitchcock, J., Oser, T. K., & Hood, K. K. (2015). The emerging diabetes online community. *Current Diabetes Reviews*, 11(4), 261–272.
- Holtz, B., & Mitchell, K. (2023). Supporting parents of children with type 1 diabetes: Experiment comparing message and delivery types. *JMIR Formative Research*, 7, Article e41193.
- Holtz, B. E., Mitchell, K. M., Nuttall, A. K., Cotten, S. R., Hershey, D. D., Dunneback, J. K., & Wood, M. A. (2020). Using user-feedback to develop a website: MyT1DHope, for parents of children with T1D. *Health Communication*, 35(3), 281–288.
- Jarrett, L., Hillam, K., Bartsch, C., & Lindsay, R. (1993). The effectiveness of parents teaching elementary school teachers about diabetes mellitus. *The Diabetes Educator*, 19(3), 193–197.
- Joseph, D. H., Griffin, M., Hall, R. F., & Sullivan, E. D. (2001). Peer coaching: An intervention for individuals struggling with diabetes. *The Diabetes Educator*, 7(5), 703–710.
- Litchman, M. L., Edelman, L. S., & Donaldson, G. W. (2018). Effect of diabetes online community engagement on health indicators: Cross-sectional study. *JMIR Diabetes*, 3, Article e8.
- Marchante, A. N., Pulgaron, E. R., Daigne, A., Patiño-Fernandez, A., Sanchez, M., Sanders, L. M., & Delamater, A. M. (2014). Measurement of parental self-efficacy for diabetes management in young children. *Children's Health Care*, 43(2), 110–119.
- Merkel, R. M., & Wright, T. (2012). Parental self-efficacy and online support among parents of children diagnosed with type 1 diabetes mellitus. *Pediatric Nursing*, 38(6), 303–308.
- Morris-Bankole, H., & Ho, A. K. (2022). Uncovering patterns of real-world psychological support seeking and the patient experience in multiple sclerosis. *Multiple Sclerosis and Related Disorders*, 59, Article 103666.
- Nardi, L., Zucchini, S., D'Alberon, F., Salardi, S., Maltoni, G., Bisacchi, N., ... Cicognani, A. (2008). Quality of life, psychological adjustment and metabolic control in youths with type 1 diabetes: A study with self-and parent-report questionnaires. *Pediatric Diabetes*, 9(5), 496–503.
- Oser, T. K., Oser, S. M., McGinley, E. L., & Stuckey, H. L. (2017). A novel approach to identifying barriers and facilitators in raising a child with type 1 diabetes: Qualitative analysis of caregiver blogs. *JMIR Diabetes*, 2(2), Article e27.
- Perez, L., Romo, L. K., & Bell, T. (2019). Communicatively exploring uncertainty Management of Parents of children with type 1 diabetes. *Health Communication*, 34(9), 949–957.

- Preece, J., & Maloney-Krichmar, D. (2005). Online communities: Design, theory, and practice. *Journal of Computer-Mediated Communication*, 10(4), JCMC10410.
- Rafferty, K. A., & Beck, G. A. (2020). "You are not alone": Advice giving for parents of children living with complex chronic conditions. *Health Communication*, 35(11), 1386–1395.
- Rafferty, K. A., & Sullivan, S. L. (2017). "You know the medicine, I know my kid": How parents advocate for their children living with complex chronic conditions. *Health Communication*, 32(9), 1151–1160.
- Rupert, D. J., Read, J. G., Amoozegar, J. B., Moultrie, R. R., Taylor, O. M., O'Donoghue, A. C., & Sullivan, H. W. (2016). Peer-generated health information: The role of online communities in patient and caregiver health decisions. *Journal of Health Communication*, 21(11), 1187–1197.
- Sahiti, M., Lewis, B., Singh, T., Paiva, K., Kim, S. M., Cebula, A. V., ... Wang, J. (2020). Diabetes self-Management in the age of social media: Large-scale analysis of peer interactions using semiautomated methods. *JMIR Medical Informatics*, 8(6), Article e18441.
- Strand, M., Eng, L. S., & Gammon, D. (2020). Combining online and offline peer support groups in community mental health care settings: A qualitative study of service users' experiences. *International Journal of Mental Health Systems*, 14 Article 39.
- Sullivan-Bolyai, S., Deatrick, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with type 1 diabetes. *Journal of Pediatric Nursing*, 18, 21–29.
- Swee-Lin, T. S., & Goonawardene, N. (2017). Internet health information seeking and the patient-physician relationship: A systematic review. *Journal of Medical Internet Research*, 19, Article e9.
- Tenderich, A. (2019). What are people with diabetes doing online? A netnographic analysis. *Journal of Diabetes Science and Technology*, 13(2), 187–197.
- The Nightscout Foundation (April 28, 2014). CGM in the Cloud. <https://www.facebook.com/groups/cgminthecloud/>.
- Titoria, R., Amed, S., & Tang, T. S. (2022). Peer support interventions on digital platforms for children with type 1 diabetes and their caregivers. *Diabetes Spectrum: A Publication of the American Diabetes Association*, 35(1), 26–32.
- Uhm, J. -Y., & Kim, M. S. (2022). Online social support and collective empowerment: Serial mediation effect on self-efficacy among mothers of children with type 1 diabetes. *Journal of Advance Nursing*, 78, 3225–3234.
- Ventola, C. L. (2014). Social media and health care professionals: Benefits, risks, and best practices. P&T: A peer-reviewed. *Journal for Formulary Management*, 39(7), 491–520.
- Warshaw, H., & Edelman, D. (2019). Building bridges through collaboration and consensus: Expanding awareness and use of peer support and peer support communities among people with diabetes, caregivers, and health care providers. *Journal of Diabetes Science and Technology*, 13(2), 206–212.
- Wilson, W., & Pratt, C. (1987). The impact of diabetes education and peer support upon weight and glycemic control of elderly persons with noninsulin dependent diabetes mellitus (NIDDM). *American Journal of Public Health*, 77(5), 634–635.
- Zhang, Y., He, D., & Sang, Y. (2013). Facebook as a platform for health information and communication: A case study of a diabetes group. *Journal of Medical Systems*, 37, 9942.
- Zysberg, L., & Lang, T. (2015). Supporting parents of children with type 1 diabetes mellitus: A literature review. *Patient Intelligence*, 7, 21–31.
- Zysberg, L., Lang, T., & Zisberg, A. (2013). Parents' emotional intelligence and children's type 1 diabetes management. *Journal of Health Psychology*, 18(9), 1121–1128.