

# Psychological Support for Children with Diabetes: Are the Guidelines Being Met?

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**Abstract** The significant role of psychosocial factors in the management of type 1 diabetes in youth has been well documented. The International Society for Pediatric and Adolescent Diabetes (ISPAD) therefore published the Clinical Practice Consensus Guidelines for psychological care of young patients. However, it is unclear if and how these guidelines are being implemented. A questionnaire was created to assess implementation of the guidelines and directed to physicians through the ISPAD listserv via a web-based survey. One hundred fifty-five participants from 47 countries completed the survey. Ninety-six percent of respondents reported that they work in a team with other professionals, and 95 % of teams discuss psychological difficulties associated with diabetes management. Seventy-two percent of respondents reported having “easy access” to a mental health specialist (MHS). In 56 % of practice settings, the MHS is considered to be part of the team; 43 % participate in routine clinic visits and 26 % see all patients. Seventy percent screen for psychological problems and 57 % assess family functioning. Psychosocial or behavioral interventions addressing psychosocial and regimen adherence difficulties are offered by 79 % of teams. Psychological care is available for many children with diabetes worldwide. Yet, nearly 30 % of teams do not have access to a MHS. More training in the recognition of

psychosocial problems and counseling skills is warranted. More advocacy is needed to increase availability and utilization of psychological services in routine diabetes care.

**Keywords** Pediatric diabetes · Psychology · Health care · Practice guidelines

## Introduction

There is substantial evidence for the significant role of psychosocial factors in the management of type 1 diabetes (T1D) in youth. For example, research has shown that psychological problems such as depression and disturbed eating behavior are elevated in children with T1D and associated with adherence problems and suboptimal glycemic control (Colton, Olmsted, Daneman, Rydall, & Rodin, 2004; Colton, Olmsted, Daneman, & Rodin, 2013; Reynolds & Helgeson, 2011). In addition, family conflict has consistently been associated with lower levels of adherence and worse glycemic control in youth with T1D (Butler et al., 2008; Drotar et al., 2013; Lewin et al., 2006). Insulin omission (Burdick et al., 2004; Weissberg-Benchell et al., 1995), failure to bolus correctly (Danne et al., 2008; Mehta, Quinn, Volkening, & Laffel, 2009) and decreased self-monitoring of blood glucose (Levine et al., 2001; Weissberg-Benchell et al., 1995) are common in adolescent patients, and often associated with psychosocial problems.

The International Society for Pediatric and Adolescent Diabetes (ISPAD) therefore published the Clinical Practice Consensus Guidelines in 2009 for psychological care of young patients with T1D (Delamater, 2009), with the general recommendation that: “Resources should be made available to include professionals with expertise in the mental and behavioral health of children and adolescents

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within the interdisciplinary diabetes health care team. These mental health specialists (MHSs) should include psychologists and social workers.” Regarding the tasks and skills of the MHS, the guidelines state: “The MHS should be available to interact not only with patients and families at clinic visits to conduct screening and more complete assessments of psychosocial functioning but also to support the diabetes team in the recognition and management of mental health and behavior problems. All mental and behavioral health specialists should have training in diabetes and its management.”

Psychological support does not only mean access to a MHS. It also involves routine assessments, screening, and delivery of effective interventions. Routine assessment of the developmental progress on all domains of quality of life, as well as the adjustment to and understanding of diabetes management should be conducted. In addition, the interdisciplinary diabetes team should assess general and diabetes-related family functioning. Identification of psychiatric disorders, depression, eating disorders and psychosocial adjustment problems should be conducted by the MHS at planned intervals. The ISPAD guidelines also recommend that preventive interventions should be delivered at key developmental times (e.g., at diagnosis, prior to adolescence, and in late adolescence), and that patients should be evaluated and provided interventions when they exhibit psychosocial, behavioral or psychiatric difficulties, regimen adherence problems, and chronically poor glycemic control. Given the significant role of psychosocial factors in pediatric diabetes management, the purpose of the present study was to determine if and how these guidelines are being implemented in routine care in pediatric diabetes clinics around the world.

## Methods

Based on the ISPAD psychological care guidelines, a questionnaire was developed to assess implementation of the guidelines. The questionnaire was directed to physicians through the ISPAD listserv via a web-based survey. The instruction was that only one survey should be completed per clinical center; ideally, this would be completed by the lead physician. If the person who wanted to complete the survey was not the lead physician, or the lead physician was not a member of ISPAD, it was suggested they consult with him or her as they completed the survey.

At the time of the study in spring 2011, the ISPAD listserv reached 883 members of ISPAD. Of those members, 84 % ( $N = 741$ ) were physicians (6 % nurses, 3 % psychologists, 3 % dietitians and 4 % other health care professionals). One hundred and fifty-five participants from 47 countries completed the survey. Considering the total

number of physicians on the listserv, the response rate was 21.1 %. However, since there typically are several physicians per diabetes center or clinic, and only one physician per center was requested to participate in the survey, a physician’s responses could reflect the views of more than one medical doctor at that site. Responses were screened for duplicates based on hospital name and none were found.

## Questionnaire

All 30 items of the survey are shown in Table 1. The questions were designed to match the guideline recommendations as closely as possible. This included use of concepts, terminology and order of questions. The survey included background questions on country, setting (university hospital, children’s hospital, general hospital, or other), center size defined by number of children treated with T1D and type 2 diabetes (T2D), and whether the center or clinic participated in research. Additional questions considered the interdisciplinary treatment team, the MHS, and screening and interventions for psychological problems.

## Statistical Analysis

Descriptive analyses and Chi square tests were used to analyze the quantitative data. A median split was used to convert Center size to a binary variable with smaller centers defined as those having  $\leq 200$  T1D patients, and larger centers as those having  $>200$  pediatric T1D patients. The latter category includes all centers treating  $>50$  patients with T2D. Regarding the number of different disciplines on teams, a median split was used to generate a binary variable with smaller teams defined as those having 4 or less disciplines, and larger teams defined as those having 5 or more disciplines. Frequencies were analyzed. To examine whether clinic characteristics were associated with provision of mental health care, differences by continent, setting, number of children treated (less or more than 200) and research participation were examined using Chi square tests. SPSS version 20 was used to execute all analyses. Content analysis was performed on written comments to open ended question #30, the last item in Table 1. The text was coded and the codes were then grouped into categories and ultimately meaningful clusters (Hsieh & Shannon, 2005). All coding was done by the first author. Comments were read word by word by first highlighting the exact words from the text that appeared to capture key thoughts or concepts. Next, labels for codes were noted that were reflective of more than one key thought. Codes were then sorted into categories. These emergent categories were used to organize and group codes into meaningful clusters.

**Table 1** Survey questions and frequencies of responses

Question	N	%
<i>Background (N = 155)</i>		
1. In what country do you work?		
Europe	72	46.5
Northern Americas	35	22.6
Oceania	19	12.3
Southern Americas	10	6.5
Azia	10	6.5
Africa	9	5.8
2. In what setting do you work?		
University hospital	60	38.7
Children's hospital	40	25.8
General hospital	35	22.6
Other	20	12.9
3. How many children with type 1 diabetes are treated in your clinic in a given year?		
1–50	15	9.7
51–100	12	7.7
101–150	22	14.2
151–200	18	11.6
201–250	13	8.4
251–300	6	3.9
More than 300	69	44.5
4. How many children with type 2 diabetes are treated in your clinic in a given year?		
0	11	7.1
1–50	118	76.1
51–100	13	8.4
101–150	4	2.6
151–200	2	1.3
201–250	1	0.6
251–300	3	1.9
More than 300	3	1.9
5. Does your team participate/initiate research?		
Initiate research studies	65	41.9
Take part in research studies	75	48.4
Not take part in research studies	15	9.7
<i>Treatment teams: composition and training</i>		
6. Do you work in an interdisciplinary diabetes team?		
No/yes	7/148	4.5/ 95.5
7. Who are members of your diabetes team (on-site, within your clinic setting)? <sup>a</sup>		
Pediatrician/pediatric endocrinologist	145	98.0
Diabetes nurse	119	80.4
Diabetes educator	80	54.1
Dietician	131	88.5
Psychologist	86	58.1
Psychiatrist	18	12.2
Social worker	80	54.1

**Table 1** continued

Question	N	%
Pedagogue	10	6.8
Other	9	6.1
8. Does your team have regular interdisciplinary meetings?		
9. How often?		
No	34	21.9
1× per week	60	38.7
2–3× per month	16	10.3
1× per month	31	20.0
Less than 1× per month	14	9.0
10. Do you or does a member of your team discuss the psychological difficulties associated with diabetes management with children and families?		
No/yes	8/147	5.2/ 94.8
11. Did your team receive training by a MHS in the recognition and management of mental health and behavior problems?		
No/yes	107/48	69.0/ 31.0
12. Did your team receive training by a MHS in the recognition of severe psychopathology and how to refer to a psychiatrist?		
No/yes	114/41	73.5/ 26.5
13. Did your team, other than the MHS, receive training in counseling techniques to change behavioral functioning?		
No/yes	93/62	60.0/ 40.0
14. Who determines if a patient needs to be seen by the MHS? <sup>a</sup>		
Physician	110	71.0
Nurse	73	47.1
Dietician	42	27.1
Other team	24	15.5
Parent	68	43.9
<i>Mental health specialist (MHS): access, reimbursement, training and service</i>		
15. Do you have easy access to a MHS?		
No/yes	44/111	28.4/ 71.6
If yes (N = 111):		
16. Is the MHS part of the diabetes team?		
Yes	62	55.9
No, but affiliated with the team within the hospital/clinic	41	36.9
No, outside the hospital or practice setting	8	7.2
17. Please indicate what type of MHS		
Psychologist	91	82.0
Psychiatrist	36	32.4
Social worker	45	40.5
Other	2	1.8
18. How is the MHS funded/reimbursed?		
Government health system	69	62.2
Grant	5	4.5

**Table 1** continued

Question	N	%
Contract	16	14.4
Fee for service	18	16.2
19. Did the MHS receive training in pediatric diabetes?		
No/yes	51/60	46.0/ 54.0
20. Does the MHS participate in routine clinic visits?		
No/yes	63/48	56.8/ 43.2
21. Does the MHS see all patients?		
No/yes	82/29	73.9/ 26.1
<i>Screening &amp; interventions</i>		
22. Does the MHS screen for psychological problems? <sup>a</sup> ( <i>N</i> = 111)		
No	33	29.7
Yes, on overall psychological functioning/quality of life	59	53.2
Yes, on depressive symptoms	2	1.8
Yes, on family functioning	1	.9
Yes, on behavioral problems	6	5.4
Yes, all of the above	10	9.0
23. When is this done? <sup>a</sup> ( <i>N</i> = 78)		
Specific time intervals	21	26.9
Referral	65	83.3
Diagnosis	4	5.1
Other	11	14.1
24. How is this done? <sup>a</sup> ( <i>N</i> = 78)		
Rating scales	21	26.9
Clinical interview	32	41.0
Unstructured interview	29	37.2
Not sure	19	24.4
25. Does some member of your team routinely assess family functioning? ( <i>N</i> = 155)		
No/yes	66/89	42.6/ 57.4
If yes ( <i>N</i> = 89):		
26. How is this done?		
MHS interview	25	28.1
Other team member	49	55.1
Questionnaires	8	9.0
All	3	3.4
Other	4	4.5
27. Does your team provide psychosocial or behavioral interventions for patients and families?		
No/yes	32/ 123	20.6/ 79.4
If yes ( <i>N</i> = 123):		
28. At what point(s) in the child's life? <sup>a</sup>		
Diagnosis	85	69.1
Poor control	100	81.3
Pre-adolescence	27	22.0

**Table 1** continued

Question	N	%
Adolescence	48	39.0
Other	22	17.9
29. Who provides the intervention? <sup>a</sup>		
Nurse	40	32.5
Dietician	13	10.6
MHS	93	75.6
Social worker	50	40.7
30. Could you discuss issues in your setting related to integration of psychosocial services in clinical care? <i>open question</i>		

<sup>a</sup> Multiple answers possible

The co-authors (AD and EP) were consulted on the veracity of the categories and clusters, in particular for their labeling. This process was repeated until a final number of clusters were agreed upon and nothing further emerged from the data. Next, definitions for each category, subcategory, and code were developed.

## Results

Table 1 shows the frequencies of responses to all individual questions of the survey.

### Region and Work Setting

Almost half of the respondents came from Europe (46.5 %). Regional differences are presented in more detail in Table 2. The number of ISPAD members differs per continent, with implications for the relative response rate per region. There was representation in the survey from respondents in all six continents; however, there were significant differences between continents, with respondents from Oceania and North-America more likely to respond and respondents from Asia, South America, and Africa less likely to respond,  $\chi^2(5) = 117.92$ ,  $p < .001$ . Overall, more respondents (39 %) worked in a university hospital (Table 1, item 2), but that pattern varied across continents and actually prevailed in only three of them,  $\chi^2(15) = 38.93$ ,  $p = .001$ .

### Patient Population Served

Overall, 44.5 % of respondents treated more than 300 T1D patients in their clinic and 76.1 % treated 50 or less patients with T2D (Table 1, items 3 and 4). The last two columns of Table 2 show that the pattern of these measures differ across the continents,  $\chi^2(5) = 34.17$ ,  $p < .001$ : specifically, the reported percentages of patients seen in

**Table 2** Characteristics of survey respondents per region

Continents (number of ISPAD members)	Relative response rate per region <i>N</i> (%)	Setting (%)				Center size <i>N</i> (%)	
		University hospital	Children's hospital	General Hospital	Other setting <sup>a</sup>	Type 1 > 200 pts	Type 2 > 50 pts
Europe (403)	72 (17.9)	44.4	11.1	33.3	11.1	34 (47.2)	1 (1.4)
North America (148)	35 (23.6)	31.4	42.9	5.7	20	33 (94.3)	21 (60.0)
Oceania (53)	19 (35.8)	10.5	47.4	31.6	10.5	12 (63.2)	3 (15.8)
South America (85)	10 (11.8)	30.0	50.0	10.0	10.0	1 (10.0)	1 (10.0)
Africa (78)	10 (12.8)	77.8	11.1	0	11.1	3 (50.0)	0
Asia (112)	9 (8.0)	50.0	20.0	20.0	10.0	3 (33.3)	0

<sup>a</sup> Respondents did not have the option of providing a write-in answer to specify what “Other” meant

**Table 3** Center size and MHS service by setting

Setting	Center size ( <i>N</i> = 155) <i>N</i> (%)				MHS sees all patients ( <i>N</i> = 111) <i>N</i> (%)	
	Type 1		Type 2		Yes	No
	≤200 pts	>200 pts	≤50 pts	>50 pts		
University hospital	22 (36.7)	38 (63.3)	53 (88.3)	7 (11.7)	8 (18.2)	36 (81.1)
Children's hospital	8 (20)	32 (80.0)	25 (62.5)	15 (37.5)	10 (29.4)	24 (70.6)
General hospital	27 (77.1)	8 (22.9)	35 (100.0)	0 (0.0)	11 (55.0)	9 (45.0)
Other setting <sup>a</sup>	10 (50.0)	10 (50.0)	16 (80.0)	4 (20.0)	0 (0.0)	13 (100.0)

<sup>a</sup> Respondents did not have the option of providing a write-in answer to specify what “Other” meant

high volume clinics, i.e., clinics with >200 T1D patients, and clinics with >50 T2D patients, is notably higher in North American treatment centers than in treatment centers on other continents. Additionally, as shown in Table 3, center size was strongly related to setting; university and children's hospitals treated more children with T1D compared to general hospitals,  $\chi^2(3) = 32.01$ ,  $p < 0.001$ .

#### Treatment Teams: Composition and Training

As can be seen from items 6 and 7 in Table 1, almost all of the respondents (95.5 %) reported that they work on a team. Overall, these teams consisted of a pediatrician and diabetes nurse and/or educator, who were complemented by the addition of one or two other disciplines. However children's hospitals were more likely to have a broader range of disciplines represented on a treatment team (75.0 % had five or more disciplines). In addition, 70.5 % of the teams that treat >200 T1D patients had five or more disciplines available on the team. Table 1 (items 8 and 9) shows that 69.0 % of the teams meet at least once per month. Psychological difficulties associated with diabetes management were discussed by 94.8 % of the teams (item 10). However, only a minority of teams received training in the recognition and management of mental health and behavioral problems (31.0 %) or the recognition of severe psychopathology (26.5 %), and only 40.0 % of non MHS

**Table 4** MHS participation on treatment team by continent

Continent	MHS part of the diabetes team <i>N</i> (%)			
	Yes	No, affiliated within hospital	No, outside hospital	No, not at all
Europe	37 (51.4)	17 (23.6)	1 (1.4)	17 (23.6)
North-America	18 (51.4)	4 (11.4)	4 (11.4)	9 (25.7)
Oceania	6 (31.6)	6 (31.6)	1 (5.3)	6 (31.6)
South-America	1 (10.0)	4 (40.0)	1 (10.0)	4 (40.0)
Africa	0 (0)	6 (66.7)	1 (11.1)	2 (22.2)
Asia	0 (0)	4 (40)	0 (0)	6 (60)
Total	62 (40.0)	41 (26.5)	8 (5.2)	44 (28.4)

members of the teams received training in counseling techniques (items 11–13).

#### Mental Health Specialist: Access, Reimbursement, Training and Service

Easy access to a MHS was reported by 71.6 % of the respondents (Table 1, item 15). Table 3 shows that center size was related to having easy access,  $\chi^2(1) = 6.30$ ,  $p = 0.01$  for T1D patients and  $\chi^2(1) = 4.36$ ,  $p = 0.04$  for T2D patients. Fifty-six percent of respondents reported that the MHS was considered part of the treatment team

**Table 5** MHS access, training and service by center size

Center size	Easy access to MHS (%)		MHS received training in diabetes (%)		Participation MHS in routine clinic visits (%)	
	Yes	No	Yes	No	Yes	No
Type 1						
≤200 pts	61.2	29.8	39.0	61.0	29.3	70.7
>200 pts	79.5	20.5	62.9	37.1	51.4	48.6
Type 2						
≤50 pts	68.2	31.8	47.7	52.3	37.5	62.4
>50 pts	88.5	11.5	78.3	21.7	65.2	34.8

(Table 1, item 16). As is shown in Table 4, there were differences between the continents,  $\chi^2(10) = 30.64$ ,  $p = .001$ . Psychologists were the MHS referred to most frequently (82.0 %; Table 1, item 17). Table 1 (item 18) shows that most MHSs (62.2 %) were reported to be reimbursed for their services by the government. Overall, 54.0 % of MHSs were reported to have received training in pediatric diabetes (Table 1, item 19). However, this differed by center size as can be seen from the third column in Table 5. MHSs in teams that treated over 200 children with T1D or over 50 children with T2D were more likely to have received training in pediatric diabetes,  $\chi^2(1) = 5.19$ ,  $p = 0.02$  and  $\chi^2(1) = 6.85$ ,  $p = 0.01$ , respectively.

Less than half (43.2 %) of the MHSs were reported to participate in routine clinic visits (Table 1, item 20). As shown in the last two columns of Table 5, in teams that treat more than 200 children with T1D or over 50 children with T2D, MHSs were reported to participate in routine clinic visits more often,  $\chi^2(1) = 5.17$ ,  $p = 0.02$  and  $\chi^2(1) = 5.71$ ,  $p = 0.02$ , respectively. Item 21 in Table 1 show that 26.1 % of MHSs see all children, however there were differences in setting and the number of children treated. As shown in right-hand columns of Table 3, in 55.0 % of general hospitals, all children with diabetes were seen by a MHS, versus 18.2 % in an university hospital or 29.4 % in a children's hospital, with MHSs not being involved at all (0 %) in other settings,  $\chi^2(3) = 14.86$ ,  $p = 0.002$ . As center size is closely related to setting, post hoc analyses revealed that this finding only remained significant for teams who treat <200 children with T1D,  $\chi^2(3) = 12.17$ ,  $p = 0.007$ .

### Screening and Interventions

Screening for psychological problems was reported for 70.3 % of the MHSs (Table 1, item 22). The most common type of screening procedure was either a structured

(41.0 %) or unstructured (37.2 %) clinical interview, with rating scales used by 26.9 % of MHSs (item 24).

**Family Assessment** The majority of teams (57.4 %) reported they assessed family functioning. This was done by the MHS conducting a clinical interview in 28.1 % of the teams. Questionnaires to assess family functioning were used in only 9 % of teams and formal observations conducted in just 1 % of teams (Table 1, items 25 and 26). As shown in Table 6, there were differences between continents, with family functioning being more likely to be assessed by teams in North America and Oceania,  $\chi^2(7) = 13.98$ ,  $p = 0.01$ .

**Psychosocial and Behavioral Interventions** As can be seen from Table 1, item 27, most teams (79.4 %) reported providing psychosocial and/or behavioral interventions to their patients. As shown in item 28, such intervention was mainly offered at diagnosis (69.1 %) and/or when the child had poor glycemic control (81.3 %). Item 29 shows that in most teams, the MHS provided the intervention to patients (75.6 %). Teams with a large center size were more likely to offer psychosocial and/or behavioral interventions to their patients, 85.2 % versus 71.6 %,  $\chi^2(1) = 4.26$ ,  $p = 0.04$ .

### Issues Related to Integration of Psychosocial Services

In the open ended question #30, respondents were asked to discuss issues in their setting related to the integration of psychosocial services in clinical care. Two main clusters were derived from the 109 comments: barriers and facilitative issues. With regard to the barriers, most respondents ( $n = 61$ ) indicated lack of staff to be a problem. Twenty-four specifically mentioned funding to be a major issue. The following two quotes illustrate this issue:

Funding for these important services has become an issue as grants have dried up and insurance reimbursement has faltered. In addition, the necessity of shortening clinical visits to physicians and nurses has

**Table 6** Assessment of family functioning by continent

Continent	Routine assessment of family functioning N (%)	
	Yes	No
Europe	31 (43 %)	41 (57 %)
North-America	26 (74 %)	9 (26 %)
Oceania	14 (74 %)	5 (26 %)
South-America	5 (50 %)	5 (50 %)
Africa	6 (60 %)	4 (40 %)
Asia	7 (78 %)	2 (22 %)
Total	89 (57.4 %)	66 (42.6 %)



limited our ability to screen for diabetes/life issues which would benefit from intervention.

Lack of psychologist; Inadequate social work time available; Insufficient staff to provide groups regularly; Lack of capacity to provide real time intervention in clinic - done using an appointment system with only limited direct interventions; interventions tend to be more crisis management rather than pre-emptive support/management

The lack of skills of the MHS in diabetes ( $n = 8$ ) or the teams' psychological skills ( $n = 7$ ) were also addressed in comments. For eight respondents, referrals were identified as a barrier in providing adequate mental health care to their patients, due to long waiting lists and lack of diabetes expertise. Seven respondents also identified reluctant parents and/or children as a barrier to treatment. As one respondent stated, there were:

very few [MHSs] available, and if available, unreliable and not properly trained. [There is] also resistance on part of the family to access the service

Twenty-four respondents commented on facilitative experiences. These experiences were in reference to good relationships with social workers and/or psychologists ( $n = 10$ ) and smooth referrals ( $n = 4$ ) as illustrated by the following:

I believe that [addressing] psychological issues is very important, even when (...) psychopathology is present and [this] has to be a routine practice in diabetes management of all children. We are lucky to have this in our Service.

[We have a] good working relationship with psychology and psychiatry with an understanding that we refer only when absolutely necessary - the result is that the response time is fairly short. Any crises are dealt with very promptly.

Four respondents addressed the importance of psychosocial interventions and four others expressed their gratitude with the integration of psychosocial services in their routine care. Six additional respondents cited the routine assessments by a MHS at diagnosis.

At diagnosis our social worker meets [with] the parents and scores a family stress rating. Each year children > 10 years old fill in a computerized list about quality of life, family stress, eating behavior and weight, and friends.

Our psychologist works part- time so this can limit their involvement, particularly with newly diagnosed patients. We find that patients are more likely to

engage in the long term with MHS if they are introduced at diagnosis as a routine part of the interdisciplinary team.

## Discussion

This survey sought to determine whether psychological services are being provided to children with diabetes in clinics throughout the world in accordance with recommended ISPAD guidelines (Delamater, 2009). There were a number of positive findings from this survey. First, the findings indicate that team care for children and adolescent diabetes is clearly the norm, with several disciplines represented on the team; 96 % of respondents reported that they work in a team setting in which psychological issues are commonly discussed in regular team meetings. Second, this study shows that psychological care is available for many children with diabetes worldwide. Yet, nearly 30 % of teams do not have access to a MHS, especially in the smaller clinics. Further, a MHS is not considered to be part of the treatment team by 44 % of the centers represented, with referrals made outside of the team in these centers. This finding suggests that integrated psychological care of children with diabetes, with MHS as part of an interdisciplinary team, is occurring in less than half of centers sampled in this survey. It should be noted that the data of our study do not indicate what proportion of children in need of a MHS actually have access to and/or receive the services. Only a minority of MHSs were reported to see all children with diabetes, and in just 43 % of centers, a MHS participated in routine clinic visits. In a recent survey in the UK, only 21 % of the teams had a psychologist or psychiatrist as an integrated part of the team (Gosden et al., 2010). In the current study, looking only at the UK centers, the percentage was 25 %, consistent with the previous report (Gosden et al., 2010).

Center characteristics were associated with the level of available psychosocial support. These findings have implications for the design and organization of facilities that provide specialty services for children with diabetes. Children treated in larger centers had more psychological support services available than smaller centers. Not surprisingly, larger centers were more likely to have easy access to a MHS, to have the MHS participate in routine clinic visits, and to offer psychosocial or behavioral interventions. Larger centers clearly have more resources available for comprehensive care of children with diabetes, including psychological support services. A somewhat surprising finding was that MHSs working in general hospitals were more likely to see all patients with diabetes. However, this result must be interpreted with caution due to limitations of the response format for the item.

Respondents could choose only one category of work setting, and there was no allowance for possible overlap between settings. This should be considered in future research.

Routine screening for psychological difficulties was reported to be done by 70 % of treatment teams. Most commonly, screening occurred after referral by the physician, other team member, or parent, and not necessarily at any specific time interval or according to developmental milestones. Psychological screening was conducted at diagnosis only by 4 % of teams. In light of recent research indicating the importance of psychological functioning at diagnosis for predicting later diabetes outcomes, this is an issue that should receive more attention in clinical practice (Schwartz, Cline, Axelrad, & Anderson, 2011). Interestingly, screening was implemented most commonly by clinical interviews, with only a minority of centers (19 %) using standardized rating scales, despite there being a number of reliable and valid tools available. In a stepped care approach, treatment team members can assess and discuss the quality of life of youth with diabetes, while at the same time, using rating scales to screen for psychosocial functioning, and then refer to MHSs when a more comprehensive psychosocial assessment is needed (de Wit et al., 2008; de Wit & Snoek, 2009).

The importance of family factors in diabetes management has been documented consistently in the research literature (Anderson, 2004). However, only half of treatment teams in this study reported that they assess family functioning in routine practice, and teams in North America and Oceania were more likely to do so compared with Europe and other parts of the world. Again, standardized rating scales were infrequently utilized as a method of assessment (9 % of teams), relying most commonly on clinical interviews conducted by various team members, with MHSs doing this in only 28 % of teams. MHSs are often confronted with having to manage adherence problems in children with diabetes, which involves working with parents as well as children. However, MHSs have often not been trained in diabetes management and assessment in the context of the family. Use of diabetes specific standardized rating scales would be helpful to the MHSs.

The Diabetes Family Conflict Scale (DFSC) and Responsibility Questionnaire (DFRQ) are widely used to assess conflict and sharing of responsibility for diabetes treatment within a family (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Hood, Butler, Anderson, & Laffel, 2007). Both questionnaires give a good impression of the areas of diabetes treatment families struggle with and are related to glycemic control. The Blood Glucose Monitoring Communication questionnaire assesses the quality of communication between child and parent around blood

glucose monitoring, a vital part of diabetes management (Hood, Butler, Volkeneing, Anderson, & Laffel, 2004).

Following psychological screening and family assessments, more comprehensive assessment and interventions may be indicated. The guidelines recommend offering psychosocial or behavioral interventions at key developmental periods. There are a number of evidence-based interventions available with positive effects on regimen adherence, glycemic control, and psychological distress (Harris, Freeman, & Duke, 2010; Hood, Rohan, Peterson, & Drotar, 2010; Winkley, Landau, Eisler, & Ismail, 2006). Most well established and researched are Coping Skills Training, Motivational Interviewing, and Family Behavior Therapy, targeting the patient and/or family (Channon et al., 2007; Grey et al., 2013; Wysocki et al., 2008). Although the guidelines do not specify *who* should deliver the intervention, it should be realized that the MHS is trained to deliver such interventions, whether or not together with other team members. Unfortunately it is unclear whether the physicians, nurses and dieticians who are reported to deliver such interventions do this alone, or received specialized training. Other providers may be delivering psychological interventions because there is no access to a MHS as part of their treatment team. Future research should address this issue more thoroughly.

According to the findings from this survey, most teams provide psychosocial interventions when patients are in poor control, rather than as preventive interventions provided at key developmental times such as late childhood or early adolescence. Given the increased risk of psychosocial difficulties in children with diabetes (Delamater, 2009), prevention programs could be very valuable in terms of improved adaptation and coping skills, better glycemic control, and reduced economic burden (Fogel & Weissberg-Benchell, 2010). According to the results of the current survey, few teams offer psychosocial interventions at diagnosis. However, given the expected worsening of glycemic control in adolescence, more intervention is needed during the early adolescent years to promote effective family teamwork in diabetes management (Anderson, Brackett, Ho, & Laffel, 1999).

It has been shown that better adherence to guidelines regarding diabetes care (e.g., achieving HbA1c goals, and managing hypoglycemia effectively) is associated with better glycemic outcomes on the center level (Hanberger, Samuelsson, Bertero, & Ludvigsson, 2012). It is likely that better adherence to psychosocial support services at the center level may result in better psychological as well as regimen adherence and glycemic control outcomes, but this remains to be determined and is an area for further research. However, it has been shown that systematic monitoring of the quality of life of adolescents with diabetes has a positive effect on their psychosocial well-being



(de Wit et al., 2008). In addition, psychological and behavioral interventions, including motivational interviewing, problem-solving and coping skills training, and interventions to promote family teamwork, have improved both psychological distress and glycemic control (Delamater, 2009; Winkley et al., 2006).

Despite the importance of understanding the medical management of diabetes, only 54 % of MHSs reportedly received such training, with those in larger centers more likely to have been trained. The role of the MHS is in screening, assessment and providing interventions for mental health problems such as depression, and as well as providing interventions for regimen adherence problems which almost always involves family interventions. Respondents to the survey also reported the lack of skills as a barrier in relation to the integration of mental health care in routine care. Conversely, just 40 % of non MHS members of diabetes teams had training in counseling techniques, and even less received training in the recognition of mental health problems or more severe psychiatric disorders. For successful team management of pediatric diabetes, it is important that all team members receive additional training in collaborative patient-centered care. It is also necessary for MHSs to know more about diabetes and its management, and for physicians, nurses, and dietitians to know more about recognizing mental health problems, family dysfunction, and effective counseling approaches (Delamater, 2012).

A major barrier to overcome is the difficulties for funding of psychological services in diabetes care. Shortage of staff and funding resources were mentioned as the main barriers to offer psychosocial support to children with diabetes. Those teams who have MHSs available report positive experiences with their participation in routine care and patient outcomes achieved.

A limitation of the current survey results is the fact that the respondents who completed the survey were self-selected participants who are members of a professional organization. We recognize that there are physicians who treat children with diabetes that are not members of ISPAD and therefore were not able to participate. As the survey was in English, this could have been a barrier for professionals from non-English speaking countries to complete the survey. Indeed, the response rates from North America and Oceania were highest; however, it should be noted that English is the accepted language of international societies such as ISPAD, which may have ameliorated to some extent the potentially negative impact of language as a factor. Uncertainty about representativeness and the generalizability of the findings is a clear limitation of the current study. Nevertheless, the present findings may well be the best available overview of worldwide trends in integrating MHS services into

pediatric diabetes treatment. Further research needs to be done to confirm our results by future surveys making an effort to include non-ISPAD members from a wide range of countries by providing surveys in different languages.

Although we used the terminology of the guidelines, some phrases are open for discussion. Most prominent is the use of *interdisciplinary* team. In the guidelines, there is no further definition. In this survey, we asked which disciplines were members of the team, on-site, within the clinic setting. However, some respondents may have interpreted *interdisciplinary* to mean *multidisciplinary*, a term with a meaning different from that which we meant to convey. Because we did not provide a definition of *interdisciplinary*, the interpretation was left to the respondent. Interdisciplinary implies an integration of MHSs with other disciplines in the collective care of children with diabetes. Multidisciplinary refers to multiple disciplines caring for a patient, but not necessarily integrated care. For the purpose of this survey, integration of mental health care would suggest at a minimum that the team has team meetings and the MHS is considered to be part of or affiliated with the team within the hospital. Using that definition, 87 teams (56 %) were reported to include a MHS. However, in just 43 % of teams the MHS was reported to see patients routinely at clinic visits, which suggests that interdisciplinary integrated psychological care is not being implemented in the majority of centers participating in this survey. The initial purpose of this study was to identify how many teams had access to and involved MHSs; further research on the effectiveness of *multidisciplinary* versus *interdisciplinary* teams is warranted.

In conclusion, the main findings from this survey of ISPAD members were that psychological care for children with diabetes seems to be available for many children worldwide, but is less likely to be offered in smaller centers and centers outside of Europe and North America. Furthermore, only 56 % of teams were reported to have a MHS as part of the team, and only 43 % of teams reportedly have a MHS participating in routine clinic visits. Although only a minority of MHSs see all children with diabetes or are part of routine clinic visits, nearly 30 % of teams do not have access to a MHS. More advocacy is needed to increase availability and utilization of psychological services in routine diabetes care. Additional training for physicians, nurses, and dietitians in the recognition of mental health problems and counseling skills is warranted and MHSs should be trained in pediatric diabetes to optimize their support.

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