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## Disclosure of psychosocial stressors affecting diabetes care among uninsured young adults with Type 1 diabetes

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### Abstract

**Aims**—To determine the disclosure rates of psychosocial issues affecting routine diabetes care.

**Methods**—A total of 20 young adults were interviewed regarding the impact of psychosocial stressors on their diabetes care. The interviewer, endocrinologist and case manager reported the prevalence rates of psychosocial stressors. Disclosure rates were compared to determine the prevalence of psychosocial issues and the different patterns of disclosure.

**Results**—Participants reported a high number of psychosocial stressors, which were associated with poorer glycaemic control ( $r = 0.60$ ,  $P = 0.005$ ). Approximately half of all disclosed stressors (50.9%) were identified in routine care; other stressors were identified only through intensive case management and/or in-depth interviews.

**Conclusions**—Identifying psychosocial stressors in routine care, and providing referrals to psychological or social services, is a significant unmet need and may improve glycaemic control among certain populations with diabetes. Systematic mechanisms of capturing this information, such as by screening surveys, should be considered.

### Introduction

Young adults with Type 1 diabetes often have difficulty meeting targets for glycaemic control [1–3], and are at high risk for psychological distress [1, 4–6], diabetes complications [1, 2, 6], and loss to medical follow-up [1, 2, 7]. Underserved populations with diabetes, such as individuals with low socio-economic status or those from racial/ethnic minority groups, face additional challenges to maintaining health [8, 9]. Young adults with diabetes, as compared with older adults, also have more chronic stressors and negative life events [10]. Psychosocial stressors, such as mental health problems, a negative family climate and diabetes-related distress, are known to play a significant role in adherence to diabetes self-care and glycaemic control [4, 11–14], but may be under-reported in typical clinical settings. The purpose of the present paper was to report on the prevalence of psychosocial stressors and the rates of disclosure during routine clinic visits, as compared with during interviews or case management performed as part of a study of a diabetes transition programme within an urban public healthcare system.

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#### Competing interests

A.L.P. serves on advisory panels for the following corporations: Amylin Pharmaceuticals, Inc.; Boehringer Ingelheim Pharmaceuticals, Inc.; Cellnovo; Eli Lilly and Company; Novo Nordisk, Inc.; Sanofi-Aventis; and Takeda Pharmaceutical Company, Ltd. These corporations had no involvement in the current study.

## Methods

This project analysed data from a study investigating the efficacy of a structured transition programme on improving medical follow-up, glycaemic control and psychosocial outcomes among young adults with Type 1 diabetes (*Let's Empower and Prepare [LEAP] Program*, Leona M. and Harry B. Helmsley Charitable Trust #2010PG-T1D011; PI: A. Peters). That study was a three-arm trial in which two arms compared intervention and control groups enrolled in the study during continuous paediatric care in the year before transitioning to adult healthcare settings. A third group, termed 'rescue' participants, were enrolled in the study after having been discharged from paediatric care without an identified adult provider or lost to follow up for >3 months. The present report, henceforth, refers only to rescue participants. Participants were recruited through: urgent care centres, community clinics and emergency departments; paediatric providers' referrals of former patients; and snowball sampling among enrolled participants. The present study was approved by the University of Southern California Institutional Review Board; all participants completed an informed consent before participation.

All participants who enrolled in the study had access to comprehensive diabetes care overseen by an endocrinologist. In addition, they received intensive case management to support their transfer from paediatric to adult care, to ensure continuous medical follow-up and to provide diabetes education tailored to their developmental stage (e.g. how alcohol and substance use affects diabetes) and socio-economic circumstances (e.g. how to access services in the public healthcare system). Once enrolled, participants were invited to attend an interview regarding their experiences of managing diabetes without access to routine care, and how psychosocial issues had affected their diabetes self-management and clinical care. Interviews were conducted in participants' homes when possible ( $n=16$ ) or in the clinic or researcher's office when logistically necessary ( $n=4$ ). To enhance rapport and disclosure of potentially sensitive information, participants were assured before the interviews that information they shared would not be communicated to their care providers during the duration of the study. Interviews were conducted by the paper's lead author ( $n=17$ ) or by a trained research assistant ( $n=3$ ), audiotaped, and transcribed verbatim for analysis using NVIVO Version 9 ed software 2010 (QSR International Pty Ltd, Doncaster, Vic., Australia).

Through an iterative process of conducting and analysing interviews, 10 psychosocial stressors emerged from interview data as being potential barriers to diabetes care (Table 1). Interview transcripts were coded for each stressor by the lead author or trained research assistant. Independently, the endocrinologist overseeing the participants' care, and a case manager providing services to participants, were provided with definitions of each psychosocial stressor, and asked to categorize each participant as 'yes' or 'no/unknown' for each, based on their knowledge of patients' life circumstances from clinical encounters. The endocrinologist and case manager were blinded to each other's ratings of psychosocial stressors. The lead author/interviewer was not blinded to the endocrinologist or case manager's ratings, but substantiated all categorizations of psychosocial stressors with transcribed and coded interview data. Disclosure rates were compared with one another and with a criterion standard using Cohen's  $\kappa$  coefficient, calculated in Microsoft Excel 2011.

## Results

At the time of study enrolment, participants' ( $n=20$ ) mean ( $\pm$ SD) age was 21.1 ( $\pm$ 1.1) years old. Participants had been without routine diabetes care for a mean ( $\pm$ SD) of 11.3 ( $\pm$  9.8) months. The sample included 70% Hispanic/Latino participants, 15% 'other' (from Middle Eastern origins) and 15% white, Asian, or multiracial participants. Participants' mean ( $\pm$ SD) HbA<sub>1C</sub> concentration at study enrolment was 95 ( $\pm$ 1) mmol/mol [10.8 ( $\pm$  2.2)%].

## Prevalence of psychosocial stressors

Identified psychosocial stressors and their definitions are shown in Table 1. Overall, 80% of participants reported at least one psychosocial stressor in at least one setting (interview, case management and/or physician visit). The mean ( $\pm$ SD; range) number of stressors reported per participant was 2.65 ( $\pm$ 2.08; 0–6). The most common stressor reported was the absence of a parent or primary caregiver ( $n=16$ ). The least common stressors reported were incarceration ( $n=3$ ) and homelessness ( $n=2$ ). There was a significant positive correlation between the number of psychosocial stressors reported and participants' baseline HbA<sub>1C</sub> concentration (Spearman's rank correlation;  $r = 0.60$ ,  $P = 0.005$ ).

## Patterns of disclosure across settings

Table 1 shows the incidence of psychosocial stressors disclosed in clinic vs interview and case management settings, and patterns of disclosure across settings. Overall, interviews had the highest rate of disclosure, with 81.1% of known stressors identified in that setting, vs 50.9% by the physician and 43.4% by the case manager. Nearly half (49.1%) of disclosures were made in only one setting: 34% in interviews only (column 2), 9.4% in case management only (column 3) and 5.7% to the physician only (column 4). Of the remaining disclosures, 24.5% were made in all settings (column 6), while 26.4% were made in two of three settings (column 5), most commonly to the interviewer and physician.

Inter-rater  $\kappa$  coefficients were moderate, ranging from 0.38 to 0.58. In comparing each rater's disclosures to a criterion standard of all known disclosures made in any setting, the interviewer had the highest agreement to the criterion standard ( $\kappa = 0.86$ ). The physician ( $\kappa = 0.60$ ) and case manager ( $\kappa = 0.57$ ) had moderate agreement with the criterion standard. When the physician and case manager's ratings were combined, their ratings attained a  $\kappa$  of 0.74, indicating moderate to high agreement with the criterion standard.

The physician's awareness of stressors merits particular attention, as the physician was the only clinician involved in the present study who is routinely present in typical clinical settings, and is the source of referrals to psychological or social services. As noted above, overall, the physician was aware of 50.9% of all known stressors. As shown in Table 1, column 8, six stressors were disclosed to the physician at moderate to high rates (60–100%). By contrast, the physician had little or no knowledge (0–17% disclosure rates) of four stressors: participants having been in foster care or leaving home due to family conflict, history of abuse, learning disability and homelessness.

## Discussion

Young adults face significant obstacles to diabetes self-management, particularly young adults with low socio-economic status who have not had continual access to healthcare. This study identified a high prevalence of psychosocial stressors among this population, which was significantly associated with worsening glycaemic control. In many instances, participants themselves identified psychosocial challenges as contributing to poor diabetes self-management. In other cases, while participants did not link the two explicitly, it is likely that these factors contributed to suboptimum self-management through undermining participants' overall life stability and well-being.

The population sampled for this study, owing to their developmental stage and socioeconomic status, may have a higher overall prevalence of psychosocial stressors and face a somewhat different combination of stressors than other subgroups of patients with diabetes. Further research is needed to determine what types of psychosocial stressors are likely to influence diabetes care across different populations with diabetes, the magnitude of the impact of different stressors on diabetes self-care and glycaemic control, and effective

strategies to mitigate their impact on overall health. Additionally, further research is needed to determine whether our findings are representative of overall rates of disclosure of psychosocial stressors to physicians in the context of routine care, as well as how patient-provider communication can be optimized to facilitate disclosing and addressing such concerns in routine care. Once such challenges are identified, psychological or social services are also needed to provide patients with resources to cope with these stressors and mitigate their impact on overall health. Determining efficient and effective strategies to achieve these aims is an important next step toward enhancing clinical care.

The association between psychosocial stressors and glycaemic control demonstrated in the present study, and evidence that these stressors are frequently unidentified by care providers, reveals a significant need to address these issues in routine diabetes care, particularly in settings which provide care to underserved populations. In this study, only approximately half of all stressors were disclosed to the physician during typical clinic visits, and two-thirds to the physician or case manager. Optimizing routine care to elicit more information regarding psychosocial barriers interfering with diabetes self-care, and providing services to assist with these barriers, may improve glycaemic control in this population. Given the limited time and resources available in a typical clinic visit, developing strategies to screen for these issues efficiently and to facilitate referral to appropriate services has the potential to substantially improve health outcomes among patients who have difficulty maintaining self-care in the face of important psychosocial stressors.

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**What's new?**

- Psychosocial stressors among young adults with low socio-economic status with Type 1 diabetes in a public health system have a moderately strong correlation with glycaemic control ( $r= 0.60$ ) and are hypothesized to contribute to suboptimum diabetes self-care in this population.
- Approximately half of all known stressors are identified in routine medical care, and approximately two-thirds when a case manager is part of the diabetes care team.
- Improving strategies for identifying psychosocial stressors, and referring patients for appropriate psychological and social services, may contribute to improved glycaemic control in this population.

**Table 1**  
Concordance of disclosure of stressful psychosocial life circumstances in clinic and interview settings

Psychosocial life circumstance	Disclosure in interviews, case management and physician visits							
	2	3	4	5	6	7	8	
<b>1</b>	INT only, <i>n</i>	CM only, <i>n</i>	MD only, <i>n</i>	Disclosed in two of three settings, <i>n</i>	Disclosed in all settings, <i>n</i>	Total disclosures across settings, <i>n</i>	Known by MD, <i>n</i> (%)	
<b>Alcohol/drug abuse or dependence</b> Participant reports 'problem' drinking or substance use, addiction, or has sought treatment for above.				2 INT/MD	2	4	4 (100)	
<b>Parent, expectant parent or legal guardian</b> Participant is a parent or legal guardian to a minor child, or participant's partner is pregnant (pregnancy was exclusion criterion for present study).	1			2 INT/MD	1	4	3 (75)	
<b>Low education</b> Participant did not complete high school or earn a GED.				1 INT/CM 1 CM/MD	2	4	3 (75)	
<b>Absent parent</b> Departure of caregiver who was involved in participant's upbringing; due to death, divorce, migration, abuse or neglect.	3	1	1	4 INT/MD 1 INT/CM 1 CM/MD	5	16	11 (68.8)	
<b>Incarceration</b> Participant reports having served jail or prison sentence.	1		1		1	3	2 (66.7)	
<b>Mental illness/psychiatric comorbidity</b> Participant has mental health diagnosis or history of treatment with psychiatric medication.	1	1	1	1 INT/MD	1	5	3 (60)	
<b>Foster care/group home/left home</b> Participant removed from home by social service agency, or left home to escape significant family conflict.	3	1		1 INT/CM	1	6	1 (16.7)	
<b>Abuse by trusted adult</b> Participant reports abuse, assault, or physical violence perpetrated by parent, caregiver, or other trusted adult.	5					5	0 (0)	
<b>Learning disability/special education</b> Participant reports having learning disability or having been placed in special education classes in school.	2	2				4	0 (0)	
<b>Homelessness</b> Participant reports not having had a home at some point in life; was 'couch surfing', sleeping in car, temporary shelter, etc.	2					2	0 (0)	
<b>Total risk factor disclosures</b>	18	5	3	14	13	53	27	
<b>Percentage of total disclosures</b>	34	9.4	5.7	26.4	24.5	100	50.9	

INT, interviews; CM, case management; MD, physician.