

ORIGINAL ARTICLE

The diabetes family social consequences survey: predicting diabetes quality-of-life in the context of insulin-treated multigenerational legacy of diabetes

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Abstract

Background: Stigma is an important construct that can be shared and recalled by family members affected by diabetes. Stigma and disclosure beliefs are formed and passed down by families in the multigenerational context of diabetes. Insulin is an object of stigma in diabetes treatment, influencing health behavior and quality of life.

Methods: Hospitalized adults in a Northeast Coast Metropolitan area in the United States of America with diabetes who were newly initiated onto insulin were surveyed to assess the validity and reliability of the family social consequences of diabetes treated with insulin. The survey items were factor analyzed and tested for internal consistency reliability. The predictive ability of the survey to assess diabetes-specific health-related quality-of-life was assessed.

Results: The survey identified two highly valid and reliable components that measure recollections of family stigma and family disclosure within the context of insulin use in the multigenerational legacy of diabetes. Family stigma explained 59% variance, and family disclosure explained 70% variance. The survey significantly predicted diabetes-related health quality of life ($R^2 = 0.35$, $P = 0.02$) with family stigma contributing uniquely to explaining variance in quality-of-life scores.

Conclusion: Family stigma and disclosure are measurable constructs capable of predicting quality of life. In the presence of recollections of family stigma and disclosure of insulin use, individuals experience sub-optimal health-related quality of life. Nurses and diabetes educators can assess the impact of family experiences on health outcomes.

Keywords: *diabetes; family stigma; family disclosure; multigenerational legacy of diabetes; quality of life*

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Individuals with a family history of diabetes are three times more likely to develop the condition than those without a family history,¹ independent of race, body mass index, age, or income.² Diabetes is a condition that can have invisible or visible complications, self-care behavior, perceptions, emotions, and experiences that are narrated and passed down, like legends that family members can later recall, known as a multigenerational legacy of diabetes.³ Disclosure of diabetes, with openness, has been found to increase with subsequent generations.⁴ Nonetheless, fear of social judgment and stigma of diabetes remains prevalent globally.⁵ When there is a multigenerational legacy of diabetes, the stigma from diabetes is conceptually the family's stigma. The International Diabetes Federation (IDF) has emphasized the need to study the stigma of diabetes globally.⁶ This report outlines the development of a survey designed to assess the social

consequences of diabetes, both as a family concept and in terms of its impact on health-related quality of life.

Diabetes stigma as a family systems experience

Stigma is defined by international consensus as the experience of exclusion, rejection, social judgment, blame, stereotypes, and prejudice.⁷ Diabetes stigma refers to feelings of being treated differently, labeling, stereotyping, and separation, and may result in discrimination.⁸ The prevalence of individual stigma due to diabetes is reported to be as high as 78% in type 1 diabetes, with 98% being adolescent-reported and 70% in type 2 diabetes.⁹ According to family systems theory, families operate as emotional units with behavioral expectations, and individual behavior cannot be fully understood without consideration of the family context.⁵ Presumably, when there

is a multigenerational occurrence of diabetes, it may be viewed as a family attribute that can further formulate stigma and behavioral expectations that impact how one copes with diabetes. Diabetes has been described as a family systems experience of multiple intergenerational relationships where communication of familial risk influences prevention behavior.¹⁰ Family interactions, communication patterns, and intergenerational openness can be identified by healthcare providers in practice.⁴

Disclosure in the family context of stigma

Disclosure of a diabetes diagnosis is usually decided on the basis of motivational factors such as seeking information or social support, ending the succession of diabetes in families, preparation for emergencies, maintaining an image of health, and protecting employment.¹¹ Disclosure may increase perceptions of stigma in some contexts and be protective of health in others. For example, disclosure of illness or familial illness risk in the context of the family can influence the trajectory of illness. For example, Cafferty et al. studied women's disclosure of their prediabetes diagnosis to their children to prevent the multigenerational legacy of diabetes through lifestyle changes.¹⁰ Some complications due to diabetes may be obvious, prompting disclosure, such as a lower extremity amputation and acanthosis nigricans.⁵ Disclosure risks may include more social distance in those who had family members and close relatives with diabetes¹² and disease concealment.⁸

A consequence of stigma in the family context may include being excluded from events or choices involving food and perceiving judgment regarding food choices, consistent with the findings of Taher et al.¹³ Generally, stigma is associated with lower levels of psychosocial functioning, decreased self-care behaviors, higher HbA1c levels, and higher levels of complications across types and generations.⁵ Diabetes-related shame in type 2 diabetes is known to be higher in those with low self-efficacy, financial burdens, and external pressures. It is associated with emotional distress and low levels of psychological well-being.¹⁴ Discriminatory processes in families¹⁵ may lead to low confidence, self-esteem, and self-blame that can influence self-care and mental health,^{16,17,18} an important quality of life indicator.¹⁹ Generally, individuals disclose less if they fear being treated differently and more if they feel they need support for emergency preparations.²⁰ More information is needed on how stigma and disclosure are associated with health-related quality of life. Gredig and Bartelsen-Raemy studied the association between stigma and health-related quality of life and found that perceived stigma was associated with psychological distress, depression, and low quality of life scores.¹⁹ In a study by Tuncay and Koçyiğit, those with higher levels of stigma experienced less self-care of diabetes.²¹

The common lived experience of diabetes in the context of a multigenerational legacy of diabetes could create a sense of normalization, which is protective against stigma.⁵ Scollan-Koliopoulos et al. found that stigma is prevalent in those who are diagnosed with diabetes who also have recollections of perceived stigma of family members with diabetes and is associated with lower levels of medication adherence.^{22,23,24} For some people, it is feasible that, if multiple family members have diabetes, disclosure could function as a form of peer support, potentially resulting in reduced feelings of isolation and loneliness in coping with the condition, in young adults.²⁵

Insulin as an object of stigma in diabetes care

In diabetes care, insulin treatment can become an object of stigma. In the family context, the use of insulin poses some perceived restrictions, such as the need to alter lifestyles, routines, and perhaps even role changes or loss due to the need to use insulin. Much attention has been drawn to the need for insulin as a defining characteristic of diabetes severity. Insulin treatment can represent an actual sense of loss or fear of losing a sense of effectiveness, health loss, or relationship loss if roles change in the family due to the need for insulin. With each added daily insulin injection, perceptions of stigma rise according to the findings of Aslan et al.²⁶ Similarly, in some studies, stigma is higher in those with insulin-requiring type 1 diabetes compared to type 2 diabetes¹⁸ accounting for social judgments associated with obesity.²⁷

Family members and close relatives have the potential to stigmatize the individual with diabetes.^{22,23,24} Gredig and Bartelsen-Raemy studied the association between stigma and health-related quality of life and found that perceived stigma was related to psychological distress, depression, and low quality of life scores.¹⁹

Theoretical assumptions of the multigenerational legacy of diabetes

The multigenerational legacy of diabetes (MGLDM) is defined by Scollan-Koliopoulos as recollections of a family member affected by diabetes by an individual who also has diabetes. MGLDM comprises salient recollections of illness perceptions, complications, and self-care behaviors that shape an individual's illness perceptions, anticipation of complications, and self-care behaviors.³ For this study, we assume that family stigma and disclosure predominate around the recollections of insulin use, which is the object of anxiety regarding the diagnosis of diabetes. The overarching proposition tested is as follows (depicted in Figure 1):

- (1) Suppose an individual's family member with diabetes experienced stigma and inhibited disclosure regarding diabetes and or its treatment with insulin. In that case, they will recall the family member's

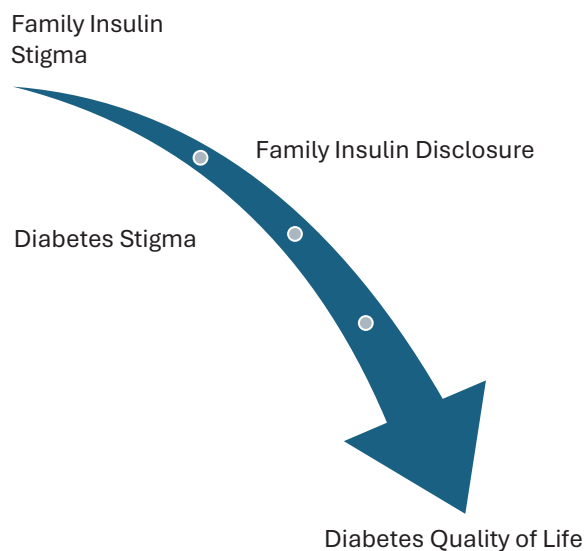


Fig. 1. The multigenerational legacy of stigma and disclosure.

experience with the stigma of insulin use and inhibited disclosure of diabetes and/or insulin use in a measurable way.

- (2) If an individual's recollections of family stigma of diabetes and its treatment with insulin and disclosure are measurable, the measure can be used to predict diabetes-related quality of life.

Methods

After ethics approval by the institutional review boards of the sponsoring University (UMDNJ-0120070087) and the three Northeast coast Metropolitan area hospitals (UMDNJ-0120070087; AHS-R07-08-004; HUMC 07.01.066) where subjects were recruited, the Social Consequences of the Multigenerational Legacy of Diabetes Survey was piloted. The convenience sample consisted of $n = 92$ hospitalized participants who reported both a family history of diabetes and were newly initiated onto insulin use during the hospital stay. Participants were recruited during hospitalization, increasing the likelihood of unplanned insulin initiation. It was felt that we could more accurately capture the emotions associated with unplanned insulin initiation, thereby heightening memories of their family member's experiences. All the participants were new to using insulin and were hospitalized for their acute care condition and not primarily for diabetes. This criterion was used because it was assumed that recollections of family members' experiences would be heightened under the circumstances of being faced with insulin use on oneself. Inclusion criteria were age over 18 years, fluency in English, and absence of severe pain or sedating medication. Participants were left the self-report paper-and-pencil surveys to complete on

their own throughout a full day. Participants were incentivized with a \$40 token of appreciation and a gift card to a food store. Participants were approached after their staff nurse asked if they could be approached, and ensured they were not from a vulnerable population (i.e. prisoners) or in extreme pain or unable to provide consent.

Measures

Participants were administered paper-and-pencil surveys that they completed independently. They were provided with a characteristics survey, the Diabetes Quality of Life Survey, and the social consequences of diabetes individual and new family version.

Survey validity and reliability

Diabetes quality of life

The original survey by Burroughs et al. is a health-related quality of life survey that predicts diabetes self-care and satisfaction.²⁸ The survey consists of 15 items with an internal consistency reliability of Cronbach's alpha = 0.85, with self-care ($R^2 = 0.360$) and satisfaction with diabetes control being well-predicted ($R^2 = 0.56$) in type 1 diabetes, and satisfaction with diabetes control ($R^2 = 0.513$) being well-predicted in type 2 diabetes.²⁸

Individual and family social consequences of diabetes survey

The original social consequences of diabetes measures^{22,23} encompassed two domains: stigma and inhibited disclosure of diabetes, and these were modified for this study to include additional family recollections, including stigma and inhibited disclosure within the family. The original survey, developed by Scollan-Koliopoulos et al.,²² included a preliminary series of interviews with patients using the think-aloud method of cognitive interviewing²⁹ to understand the narrative perceptions of the consequences of the multigenerational legacy of diabetes. For this study, the survey items were developed to emphasize insulin by family members who had diabetes, as recalled by the target subjects. The terms and framing in the questions are consistent with the labeling of trigger stigma words identified in the current preceding literature review regarding diabetes stigma, including judgment terms, such as 'bad', 'disgusted', and 'ashamed'. The eight original items of the social consequences survey by Scollan-Koliopoulos et al. were validated using exploratory factor analysis, with an internal consistency reliability of Cronbach's alpha = 0.80 for the combined two constructs of social consequences.^{22,23} For this study, additional items were added to differentiate between recollections of stigma and disclosure of family members with diabetes and one's stigma and disclosure. The items are measured on a 5-point Likert scale with strongly disagree and strongly

agree parallels. The family recollection items were ranked on a 5-point Likert scale ranging from 'no recall' to 'strong recall'. For each subscale, high scores on stigma items indicated greater stigma, while high scores on the disclosure items indicated more inhibited disclosure (i.e. less talking). The items are presented in Tables 1 and 2.

Statistical analysis

The new Family Social Consequences Survey underwent an exploratory and confirmatory factor analysis using SPSS version 29.0, employing principal components analysis with orthogonal rotation on the current sample.³⁰ Data were excluded listwise for missing data management, with Kaiser eigenvalues over one accepted for factor extraction. Following the exploratory factor analysis, a confirmatory analysis was conducted, forcing each component to determine if the items maintained the exploratory structure. Thereafter, an internal consistency reliability coefficient using Cronbach's alpha was calculated for each element and the two components together as one comprehensive survey. The survey was then used in bivariate correlational

and regression analysis to assess the prediction of diabetes specific health-related quality of life.

Findings

The sample consisted of $n = 92$ participants. The descriptive statistics describing the sample characteristics are depicted in Table 3. Recollections of family members are included in Table 4. Missing data were handled by listwise deletion. The iterative principal components factor analysis resulted in two reliable components consistent with the theoretical domain, namely (1) Family diabetes stigma and (2) Family diabetes disclosure. The complete initial exploratory factor analysis showed 67.31% of the variance with the combined items. Two components that measured the individual's perception of whether the family had stigma had a very low reliability ($\alpha < 4.0$), despite showing 64 and 52.5% variance on their own, and these items were discarded.

The confirmatory process resulted in the two subscales: the 8-item family diabetes stigma scale, which explained 59% of the variance with a Cronbach's alpha of 0.89, and

Table 1. Exploratory factor analysis

| Item (factor loading) |
|---|
| Component 1 (26.44% variance [eigen 5.3]) |
| My family member believed that insulin use meant you had bad diabetes (0.80). |
| My family member believed that needing insulin meant they did not take care of themselves (0.71). |
| My family member believed others would look at them in a bad way if they were on insulin (0.80). |
| My family member believed insulin use was something to be ashamed of (0.84). |
| My family member thought others were disgusted by them for needing insulin (0.84). |
| My family member felt giving oneself shots was bodily mutilation (0.65). |
| My family member felt their doctor blamed them for needing insulin (0.65). |
| My family member was embarrassed to be taking insulin (0.67). |
| Component 2 (14.17 [eigen 2.8]) |
| My family member acted more seriously about their diabetes after going on insulin (0.53). |
| I am blamed for having diabetes (0.50). |
| My family should not talk about diabetes (0.66). |
| Having diabetes embarrasses the family (0.52). |
| My family member let family and friends know he/she were on insulin (0.65). |
| Component 3 (12.34% variance [eigen 2.5]) |
| People look at me in a bad way if they know I have diabetes (0.65). |
| My Family member talked about being on insulin in public (-0.61). |
| My Family member talked about needing insulin with family and friends (-0.58). |
| Component 4 (8.47% variance [eigen 1.7]) |
| I should not talk about diabetes in public (0.78). |
| I should not openly talk about diabetes with family (0.63). |
| Component 5 (5.57% variance [eigen 1.1]) |
| My family member felt giving oneself shots was bodily mutilation (0.43). |
| My family member felt their doctor blamed them for needing insulin (0.45). |
| Component 6 (5.14% variance [eigen 1.0]) |
| Having diabetes is something to be ashamed of (-0.59). |
| Low scores = less recall (very strong recall [4], strong recall [3], some recall [2], very little recall [1], no recall [0]). |

Table 2. Confirmatory factor analysis

| Item (factor loading) |
|---|
| Component I- Family stigma (58.47% variance [eigen 4.67]). |
| My family member believed that insulin use meant you had bad diabetes (0.74). |
| My family member believed that needing insulin meant they did not take care of themselves (0.72). |
| My family member believed others would look at them in a bad way if they were on insulin (0.88). |
| My family member believed insulin use was something to be ashamed of (0.88). |
| My family member thought others were disgusted by them for needing insulin (0.88). |
| My family member felt giving oneself shots was bodily mutilation (0.61). |
| My family member felt their doctor blamed them for needing insulin (0.67). |
| My family member was embarrassed to be taking insulin (0.67). |
| Subscale II- Recollections of Family Disclosure (69.75% variance [eigen 2.79]) |
| My family member talked about being on insulin in public (0.81). |
| My family member let family and friends know he/she was on insulin (0.84). |
| My family member talked about needing insulin with family and friends (0.88). |
| My family member acted more seriously about their diabetes after going on insulin (0.79). |

Low scores = less recall (very strong recall [4], strong recall [3], some recall [2], very little recall [1], no recall [0]).

the four-item family diabetes disclosure subscale, which explained 70% of the variance and held a Cronbach's alpha of 0.85. When the subscales are combined into one considerable measure, internal consistency reliability is maintained with a Cronbach's alpha of 0.87 for 12 items.

The predictive ability of the survey to assess diabetes-specific health-related quality of life was evaluated. In this regression model, each subscale was added as an independent variable with health-related quality of life as the dependent variable. The multigenerational legacy of diabetes social consequences constructs significantly predicted health-related quality of life ($F = 4.0$, $df = 2$, $P = 0.02$, $R^2 = 0.35$) with recollections of family stigma of insulin contributing unique variance ($B = -0.39$, $P = 0.007$), meaning for every one unit increase in recollections of family insulin stigma, one's quality of life declines by -0.60 . This indicates that more stigma results in reduced quality of life. In the model, recollections of family disclosure did not significantly contribute unique variance above and beyond the recollections of family insulin stigma. To further understand how recollections of insulin may contribute to variance in the health-related quality of life of individuals with diabetes, we added the participants' strength of recollections of insulin. We found a continued trend toward significant associations with quality of life ($F = 2.7$, $df = 3$, $P = 0.056$, $R^2 = 0.37$). This suggests that the family member's recollections of insulin use, and stigma may be particularly salient during insulin initiation.

The final prediction tested was whether family stigma or disclosure of insulin would be associated with one's stigma and disclosure of diabetes. Surprisingly, the recollections of family stigma, despite having a negative influence on one's quality of life, did not contribute to predicting one's stigma ($F = 1.12$, $df = 3$, $P = 0.34$,

$R^2 = 0.21$). Pearson's correlations were estimated among the variables presented in Table 5. Table 6 has the subscale scores for the surveys.

Discussion

Recollections of insulin treatment especially shape the family context of stigma. Consistent with the findings of Aslan et al., the cognitions surrounding insulin stigma were more reliable than those of diabetes in a more general sense.²⁶ In accordance with the study by Park and Park, family stigma is a definable concept whereby an individual's stigma becomes the family's stigma and can be assessed by nurses.³¹ This makes theoretical sense as the authors hypothesize insulin to be the object of stigma and social anxiety in diabetes management. Generational differences are evident in explaining the association of stigma and disclosure with disease duration.²³ Also notable are different patterns of stigma and disclosure. The sample was recruited during hospitalization and was new to needing insulin, likely heightening family members' recollections of their insulin use. Highly salient, prominent recollections were associated with family diabetes stigma and disclosure. The final survey should be utilized as either one extensive comprehensive survey or two subscales, each with the ability to be used separately: (1) Family insulin stigma and (2) Family insulin disclosure. This survey will offer the flexibility to predict important health constructs more accurately.

Limitations of this study included a small convenience sample of participants hospitalized and requiring initial insulin use. The sample was a convenience sample, allowing recruitment of many people initiating insulin under unplanned circumstances. The results are likely applicable in primary care when someone is told they need to start

Table 3. Sample demographic characteristics

| Characteristic | N (%) |
|---|-----------|
| Age | |
| 26–29 | 3 (3.3) |
| 30–39 | 7 (7.6) |
| 40–49 | 17 (18.5) |
| 50–59 | 26 (28.3) |
| 60–69 | 20 (21.7) |
| 70–79 | 12 (13.0) |
| 80–99 | 4 (4.3) |
| Income (USD) | |
| <\$20,000 | 31 (33.7) |
| \$21–29,000 | 7 (7.6) |
| \$30–39,000 | 5 (5.4) |
| \$40–49,000 | 4 (4.3) |
| \$50–59,000 | 8 (8.7) |
| \$60–69,000 | 4 (4.3) |
| >\$70,000 | 10 (10.9) |
| Do not wish to answer | 19 (20.7) |
| Gender | |
| Male | 45 (48.9) |
| Female | 44 (47.8) |
| Do not wish to answer | 3 (3.3) |
| Education | |
| <8 th grade | 13 (14.1) |
| 9–12 Grade | 13 (14.1) |
| 12 th grade completed | 27 (29.3) |
| Some College/Trade | 13 (14.1) |
| College Graduate | 18 (19.6) |
| Trade Graduate | 5 (5.4) |
| Ethnicity | |
| Hispanic | 16 (17.4) |
| Non-Hispanic | 62 (67.4) |
| Do not wish to answer | 4 (4.3) |
| Race | |
| Black | 39 (42.4) |
| White | 38 (41.3) |
| > 1 race | 4 (4.3) |
| Asian | 2 (2.2) |
| Do not wish to answer/unsure | 6 (6.6) |
| Duration of diabetes | |
| 0–5 years | 7 (6.3) |
| 6–10 years | 8 (8.8) |
| 11–25 years | 12 (13.2) |
| >25 years. | 6 (6.6) |
| Diabetes self-management education | 40 (43.5) |

insulin under unplanned circumstances. The survey should be replicated and validated in other samples across settings. Future studies should compare individuals with and without a family history of insulin use to better understand the motivators behind their decisions to

Table 4. Family recollections of diabetes

| Relative remembered | N (9%) |
|--|-----------|
| Mother | 41 (44.6) |
| Father | 29 (31.5) |
| Grandmother | 17 (18.5) |
| Grandfather | 6 (6.5) |
| Brother | 20 (21.7) |
| Sister | 19 (20.7) |
| Aunt | 14 (15.2) |
| Uncle | 12 (13.0) |
| Cousin | 13 (14.1) |
| Lived with family member | 51 (55.4) |
| <5 years | 16 (17.4) |
| 6–10 years | 19 (20.7) |
| 11–25 years | 18 (19.5) |
| >25 years | 3 (3.3) |
| Family Insulin treatment | 32 (34.8) |
| Family pill treatment | 28 (30.4) |
| Family pill & insulin treatment | 22 (23.9) |
| Type of diabetes | |
| Type 1 | 21 (22.8) |
| Type 2 | 51 (55.4) |
| Other | 2 (2.2) |
| Do not know | 13 (14.1) |

Table 5. Pearson's correlations

| |
|--|
| Diabetes quality of life |
| Family Stigma of insulin ($r = -0.33, P = 0.006^*$) |
| Family disclosure of insulin ($r = -0.023, P = 0.43$) |
| Strength of recollections of a family member's treatment with insulin |
| Family disclosure of insulin ($r = 0.67, P = 0.006^*$) |
| Family stigma of insulin ($r = 0.47, P = 0.07$) |

*Statistically significant.

disclose diabetes, treatment, or coping aspects of the diagnosis. Because some studies show that stigma is at its lowest levels when one is first diagnosed with diabetes, the same may not hold for insulin initiation. For example, in youth diagnosed with type 1 diabetes, stigma is notably higher early on.⁵ Those with type 2 diabetes may have more salient memories later in the diagnosis regarding family recollections of insulin. To understand best how family stigma recollections influence one's perception of stigma, it would be essential to look at not just duration of insulin use or diabetes since diagnosis, but whether the trajectory of approaching insulin use followed a similar timeline. Future studies should test this measure in a general setting with a mix of people not on insulin. This will be important for future generations with type 2 diabetes who may use diet and exercise alone or pills, or newer

Table 6. Social consequences survey scores

| Construct | Mean (SD) | Range (min-max) |
|-------------------|--------------|------------------|
| Family Stigma | 9.09 (4.4) | 13 (4–17) |
| Family Disclosure | 13.96 (7.2) | 32 (0–32) |
| Quality of Life | 49.61 (10.6) | 61.86 (17.14–79) |

glucagon-like peptide injections that have reduced or eliminated the need for insulin in some populations.³² There is a need for a family stigma and disclosure survey that is not focused on insulin.

Conclusion

The clinical implications of this study are that the social consequences survey will assist nurses and diabetes educators in understanding preconceived notions of insulin and stigma that may need to be addressed when someone is initiated on the treatment. This is especially true if their insulin needs are out-of-context for the acute care condition being treated. In the context of a multigenerational legacy of diabetes, there is also the formation of stigma that is carried forward when someone is diagnosed with diabetes or faced with transitions in their treatment trajectory, such as insulin initiation. Insulin treatment is a salient recollection of others' treatment and serves as an object of stigma. The social consequences of family diabetes currently include two predictive subscales: family insulin stigma and family insulin disclosure. The measure can be used in conjunction with the original social consequences of diabetes that measure stigma and disclosure in the family context of diabetes from one's perspective, without accounting for specific family recollections. This study contributes to the step of understanding how stigma and expectations of disclosure are formed in the multigenerational legacy of diabetes.

Conflict and interests and funding

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