

Perspectives on diabetes-related social stigma: an interview study

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This study was the first to conduct an in-depth exploration of the perceptions and experiences of diabetes-related stigma from the perspective of adults with type 2 diabetes.

Background

- While the medical and psychological impact of living with diabetes is relatively well understood, the social impact is under-investigated
- Anecdotally, social stigma surrounding diabetes is an emerging problem, which has implications for individuals with diabetes and their families, as well as for public health campaigns and fundraising efforts
- Health-related social stigma is an adverse social judgement based on a feature of a condition or its management that may lead to perceived or experienced exclusion, rejection, blame, stereotyping and/or status loss^{1,2}
- Our recent review³ found evidence that people with type 1 diabetes (T1DM) and type 2 diabetes (T2DM) perceive and experience diabetes-related stigma, and that this stigma has negative consequences for their diabetes self-care, social and occupational functioning, and emotional wellbeing
- However, few studies have examined diabetes-related stigma specifically, with most referring to diabetes as being less stigmatised than other conditions, e.g. HIV/AIDS, epilepsy. Given its potential negative consequences, a systematic research program that seeks to first understand and then address diabetes-related social stigma is required urgently

Aim

- To explore the social experiences of adults living with T2DM, with a particular focus on the perception and experience of diabetes-related stigma

Method

Design and participants

- We conducted semi-structured interviews with 25 Australian adults with T2DM
 - 12 (48%) women
 - mean age: 59±14 years (range: 22–79 years)
 - diabetes duration: 7±7 years (range: 0-29 years)
- Participants were recruited primarily through the membership list of Diabetes Australia – Vic (the peak consumer body representing people affected by diabetes in the state of Victoria, Australia)
- Study advertisements purposefully did not refer to “stigma” in order to minimise the risk of attracting participants with extreme negative experiences, and to avoid biasing participants’ interview responses

Data collection and analysis

- Mean length of interview was 55 minutes (range: 25 – 103 minutes)
- All interviews were audio-recorded and transcribed verbatim, with transcripts imported into NVivo 10 to facilitate data coding and retrieval
- Data were subjected to thematic analysis using an inductive (data driven) approach
- Transcripts were read and re-read (by JB & AV) to develop an initial coding framework, which was reviewed by the full research team. Following some modifications, five transcripts were coded independently (by JB & AV) with inter-rater agreement rating of 99.5%, and minor discrepancies resolved through discussion
- Given high level of agreement, AV coded the remaining 17 transcripts independently
- The content of each code was then examined to determine whether some codes could be subsumed by others, and to explore relationships between codes

Results

- 15 (60%) participants indicated they believed there was social stigma surrounding T2DM
- 10 (40%) participants believed there was no stigma surrounding T2DM:
 - However, 6 of these described evidence of diabetes-related stigma throughout the interview
 - Four firmly believed there was no stigma and that they were surprised that this was a topic of interest
- Evidence of diabetes-related stigma was apparent in participants’ perceptions and/or experiences of:
 - being blamed and shamed for developing a (largely preventable) condition
 - negative stereotyping
 - discrimination and restricted opportunities in life
- Participants identified the following sources of stigmatising attitudes and practices:
 - the media
 - healthcare professionals
 - family, friends and colleagues
- As a consequence of stigma, participants reported:
 - becoming unwilling to disclose their condition to others, and as a result, compromising their safety and self-care activities
 - emotional distress, including feelings of shame, guilt, regret, and inadequacy
- There was a distinct feeling among participants that the stigma was specific to T2DM, and that those with T1DM were not judged so harshly
- Illustrative participant quotes are displayed in Table 1



Conclusions

- To our knowledge, this study is the first qualitative investigation of the experiences and perceptions of diabetes-related stigma from the perspective of people living with T2DM
 - Our findings indicate that stigmatisation is an issue of substantial concern for people with T2DM, and has harmful consequences for their willingness to disclose their diabetes, their self-care (especially in public places), their emotional well-being and life opportunities e.g. work, relationships
- ### Future research needs to focus on:
- quantifying perceptions of diabetes-related stigma among people with T2DM and its associations with self-care, emotional well-being and social functioning
 - how to dispel stigmatising attitudes and practices toward T2DM
 - how to minimise the impact of stigma (e.g. by enhancing resilience) amongst people with T2DM
 - exploring diabetes-related stigma in T1DM

Table 1. Themes and illustrative quotes from participants

Theme	Example quote
Evidence of stigma	
Blame and shame	“I find a lot of people, they like to think of you as being the culprit. In fact I actually had one person say ‘well you’ve dug your grave with your own teeth’.” (#12, man, aged 67)
Negative stereotyping	“I always worry that people must have thought I was some big fat pig gorging on cakes and lollies and was a shocking person and that’s why I developed it, I was lazy.” (#15, woman, aged 60)
Discrimination & restricted opportunities	“If I apply for a job that I would be discriminated against on the basis of that. That’s a fear. Now I don’t know if whether it’s well founded or not.” (#25, woman, 59yrs)
Sources of stigma	
Media	“think it’s wrong, the advertising. I feel like they probably look at you like ‘well you probably could have prevented it. Who knows what your eating’.” (#23, woman, 37yrs)
Healthcare professionals	“I went to see the dietician and I got treated a certain way... And that dietician, I tried to talk to her, my voice was all shaky but trying to stay calm and I was talking to her but she didn’t listen”(#16, woman, aged 35)
Family, friends, colleagues	“I just say to them ‘I know what I can put in my mouth and what I can’t, thanks all the same’... ‘I’d love it if you offer me what you’re handing around and I can say ‘yes’ or ‘no thanks’, that would be nice really’. That makes me feel excluded.” (#25, woman, aged 59)
Consequences of stigma	
Unwilling to disclose	“Apart from me, none of the people I know [who] have diabetes ever say they have diabetes, they never say it, they never speak up, they never say a word and I reckon it’s because the messages that are put out by [diabetes patient organisation] are shutting them up because they’re hurt and are mortified.” (#22, man, aged 56)
Emotional distress	“I think that people get blamed and shamed and I think that makes it worse... they feel hopeless.” (#11, woman, 61yrs)
Comparison with type 1	
Stigma is T2DM-specific	“‘Type 1 is ‘you poor thing’, type 2 is ‘you stupid thing’” (#4, man, aged 57)

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